

**April 1, 2009**

# **Report of the NHANES Review Panel to the NCHS Board of Scientific Counselors**

## **Executive Summary**

The Board of Scientific Counselors (BSC) of the National Center for Health Statistics (NCHS) commissioned a panel to review the National Health and Nutrition Examination Survey (NHANES) as part of an ongoing program review process and to report its findings to the BSC. This report summarizes that review process, describes NHANES and its accomplishments and challenges, and presents a series of recommendations.

### **Description, Accomplishments and Value of NHANES**

NHANES is a program of studies designed to assess the health and nutritional status of adults and children in the United States. The survey is unique in that it combines interview, standardized physical examinations and laboratory testing to produce data on a wide array of measures. As the Review Panel began its evaluation of NHANES, they reviewed the accomplishments of the survey and its impact—both direct and indirect—on the health of the American people and the nation’s public health system. The panel addressed the program’s strengths, weaknesses, and future threats and opportunities with emphasis on scientific quality and the program’s responsiveness to the user community. The Panel concluded that NHANES simply must continue, and in a form that will fully sustain its historical importance as a key source of health information. NHANES is universally considered to be at the foundation of the nation’s health information system, with the reliance on NHANES data for policy, programmatic and basic research purposes. There are numerous examples of the direct and indirect impact of NHANES data. NHANES data are used as a benchmark, producing prevalence estimates and standards and reference populations. NHANES data support public health recommendations and guidelines and are used in nutrition and environmental monitoring.

### **Current Status and Issues Affecting NHANES**

From its start almost 50 years ago, NHANES has evolved to meet the health data needs of the nation. The survey rigorously evaluates new components and additions to the survey to determine if they meet public health data needs and have the scientific quality and precision to be incorporated into a finite interview and examination schedule. The current NHANES is widely viewed as having the best and most practical collection of individual tests and measures creating the most effective overall survey. NHANES now faces a number of challenges: budget, lack of long-range planning resources, and an upcoming survey redesign. The current NHANES budget is inadequate to maintain the current survey, adapt to meet future data needs, and support its aging physical infrastructure. NHANES obtains advice, guidance and feedback through a number of channels and mechanisms. Decision-making for NHANES is somewhat ad hoc and

reactive. The staff seeks to develop more long-range strategic plans but lacks sufficient staff to dedicate the level of resources needed for this effort. Much of the on-going planning is directed to immediate survey plans on content and operational changes required for each two-year phase of the survey. There is an interest in adding a longitudinal component to the survey and conducting the survey in a way to produce data at the state and local level. These and other issues will need to be addressed in the near future.

## **Recommendations**

As a basic principle underlying its recommendations, the Panel concluded that the NHANES program must continue. Its role is so vital and so central to the health information needs of the nation, that it should be maintained, strengthened, and supported so that it may continue to fulfill its mission. Based on the issues raised above and other observations concerning the current operation of the NHANES program, the panel makes the following specific recommendations to NCHS:

### **1. *Create a Standing External Committee to Broadly Advise the Program on Methods, Content and Long-Term Strategic Planning***

NHANES would benefit extensively and in many ways by having a standing external committee to provide advice on the survey, including development and prioritization of content, survey methodology, and analysis and dissemination of findings. An overall strategic planning process for the survey would benefit from the informed advice and guidance from individuals and organizations which have the depth and breadth of experience to speak broadly of public health data needs and advances and applications of survey and statistical methodology. An advisory body could consider in depth some of the pressing questions and issues which the survey faces, such as whether to have a longitudinal component and how it could be implemented and possible integration with the National Health Interview Survey. In addition, issues unique to NHANES, such as maintenance of its infrastructure, as well as the possibility of instituting user fees might also benefit from external review and advice. An advisory body would not only advise but could also advocate. Members of an advisory body would be leaders in public health and have opportunities to speak on behalf of the survey and/or promote the survey to various audiences, programs, or organizations.

### **2. *The NCHS Director's Office Should Continue to Aggressively Market the Expertise and Products of the NHANES Program to Current and Future Data Users and Potential Funders***

NCHS and DHANES need to develop a systematic and high-level marketing initiative to bring NHANES to the attention of both current and potential data users and funders. While not requiring a "Madison Avenue" approach, the marketing initiative needs professional marketing expertise to develop the overall marketing strategy, assist in seeking out and planning specific marketing opportunities, design effective marketing materials, translate materials for selected audiences, and transmit and communicate appropriately with various

audiences for measurable and effective results. A theme of a marketing campaign could be “imagine the world without NHANES” and it should have a level of urgency befitting that possibility. Further, there needs to be a direct link from data to support for data. NHANES data are not a public good which exist without a complex organizational structure and resources to support that structure. Without continuing and substantial support, NHANES cannot continue to provide the information that it alone can produce. As a marketing tool, DHANES should create a categorized bibliography of publications resulting from the use of NHANES data to illustrate the many and varied uses of the data and the vast array of applications of NHANES findings in policy development, public health and medical research, prevention and education

**3. *Conduct a Thorough Retrospective Review of the Realized Statistical Benefits of Oversampling Population Subgroups for NHANES Samples Since 1999***

The survey should undertake a retrospective evaluation of oversampling and an assessment of whether the current oversampling scheme meets established statistical quality needs for data in terms of the oversampled subpopulations, as well as for detecting geographic patterns, and monitoring current and emerging health issues. DHANES should also evaluate oversampling vs. targeted special surveys to reach specific groups or address specific topics. It is appropriate for NHANES to view oversampling not as an integral aspect of the survey but as a design decision which needs to be periodically evaluated in light of not only the survey’s current role but its future obligations.

**4. *In Collaboration with the American Statistical Association and Other Scientific Organizations, Create a Workshop to Examine the Relative Statistical and Operational Utility of USPS Delivery Sequence Files for Household Enumerations for NHANES***

DHANES should consider co-sponsoring a workshop on potential ways to improve the cost efficiency and screening efficiency for area probability sample recruitment by utilizing commercial data bases for household enumeration. The enumeration of households for the NHANES sample is a costly and time-consuming process and other surveys are successfully using commercial data bases for the entire sample or to supplement enumeration processes. The workshop could be held in collaboration with other statistical and survey organizations and this could be a centralized research activity.

**5. *Continue to Explore the Possibilities of NHIS-NHANES Design Integration in a Way That Will be Beneficial to Both Programs***

NCHS should initiate a process to determine if the integration of the NHANES with the National Health Interview Survey (NHIS) would be beneficial to NHANES—and NHIS—in terms of efficiencies in conducting the surveys and potential to improve the analytical power of each. The integration of the two surveys needs to be looked at from the point of view of the goals and objectives of NHIS and NHANES to determine whether the goals of both surveys can be

achieved in an integrated survey, and if not, what goals can be compromised. An integration plan also needs to address administrative issues and the feasibility or advantages of administration integration. Planned redesigns for both NHIS and NHANES are to be implemented at about the same time (2012/2013) and thus timing is optimal for an in-depth evaluation of survey integration to input into the design process for each survey. For both surveys it is mandatory that the scientific integrity be maintained and that the integrated resulting survey (if recommended) be an enhanced survey program that can build upon the strengths of each survey without diminishing the current utility of these two important data gathering systems.

**6. *Continue Pursuing Opportunities with Larger States and Municipalities to Utilize Portions of the NHANES Sample to Also Meet Local Health Information Needs***

DHANES should continue to explore the use of NHANES data for certain large states and municipalities. There is an essential and well-recognized need for state and local health data for policy development, program planning and administration, monitoring progress and measuring disparities at the local level where many policies are set, decisions made and resources allocated. There is a need for more information and better information in terms of quality, depth and breadth, at the state and local level than is produced at the present. While some work has already taken place, DHANES should increase its efforts to explore the efficiencies of utilizing a portion of the NHANES sample in major state and local jurisdictions to supply information needs at both levels. There may also be possibilities to share revenue sources and identify new and creative revenue sources that may not be available to a Federal government agency operating without a local partner.

**7. *Continue to Seek Mechanisms to Add Longitudinal Follow-up of NHANES Cross-Sectional Respondents***

The scientific merit of a longitudinal program commands the continued pursuit of a possible mechanism for mounting a longitudinal survey while preserving the essential elements of a cross-sectional survey. There is continuing interest--both internal and external--in conducting a NHANES longitudinal survey. While the analytical value of such a longitudinal component is generally considered a given, DHANES should document the relative benefits of a longitudinal component vs. cross sectional surveys. It must be clear what the main objectives of the longitudinal survey will be and the sample size requirements to obtain measurements that help achieve the goals. The desirability of the longitudinal component should be weighed against the impact that conducting this additional component would have on the on-going survey. DHANES could explore mechanisms for shared funding with NIH, for example, adding value to the type of epidemiologic researched funded by NIH.

## **Conclusion**

NHANES is a critical component of the nation's health information systems. NHANES is a survey that is essential and it must not be allowed to be eliminated, diminished or in any way recede from its enormously important mission. This is a critical time for reviewing and rethinking NHANES. DHANES and NCHS have an opportunity--driven by necessity, but nevertheless a real opportunity--to help NHANES achieve new accomplishments that can even surpass its past contributions.

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### **I. Overview**

The Board of Scientific Counselors (BSC) of the National Center for Health Statistics (NCHS) commissioned a panel to review the National Health and Nutrition Examination Survey (NHANES) as part of an ongoing program review process and to report its findings to the BSC. This report summarizes that review process; describes NHANES, its accomplishments and value, the current status of the survey, and the issues affecting the survey; and presents a series of recommendations.

#### Charge

The NHANES Review Panel was charged to examine the current status, scientific quality and responsiveness of NHANES within the context of its mission. The review procedures require that the review take into account future availability of financial and staffing resources, emphasize forward thinking and future plans, as well as assess current operations. The process should be an interactive review that obtains information from written materials, presentations, and discussion with program staff.

#### Accomplishments and Value of NHANES

As the Review Panel began its work, they reviewed the accomplishments of the survey and its impact—both direct and indirect—on the health of the American people and the nation's public health system. The panel addressed the program's strengths, weaknesses, and future threats and opportunities with emphasis on scientific quality and the program's responsiveness to the user community. The contributions of NHANES, both far-ranging and fundamental, would rank it among the top two or three programs in the Federal health statistics system, thus leading the Panel--after its deliberations--to conclude that NHANES simply must continue, and in a form that will fully sustain its historical importance as a key source of health information.

NHANES is universally considered to be at the foundation of the nation's health information system, with the reliance on NHANES data for policy, programmatic and basic research purposes. There are numerous examples of the direct and indirect impact of NHANES data. A relatively small staff of dedicated workers enables NHANES to produce its consistently high-quality data. In conducting the survey, they work closely with numerous collaborators and address the data needs of federal and state governments, industry, and research institutions. One of the reasons the survey is so effective is its ability to adapt its content and design to meet data needs.

- Examples of direct impact
  - Use as a benchmark -- NHANES produces objective, standardized data on the prevalence of a wide range of diseases, conditions, and risk factors in the population. The data can be analyzed by race/ethnicity, age, sex and other variables. These findings are used as benchmarks for the overall population and specific demographic groups.
    - **Prevalence estimates** -- The NHANES data provide estimates of the prevalence of heart disease, diabetes, arthritis, hypertension and many other chronic diseases. The same is true for a full range of infectious diseases from HIV/AIDS to herpes, hepatitis B and C, HPV, and many others.
    - **Standards and reference populations** -- In addition, NHANES sets the standards for a large number of physiological measurements, including body measurements such as height and weight; blood pressure; cholesterol; triglycerides; immunization levels and many other measures. NHANES data indicate the average and the distribution of these measures in the population thus creating reference populations used for comparison with the results of many other studies in this and other countries. The NHANES data have been particularly important in documenting the extent and timing of the obesity epidemic.
  - Supporting public health recommendations and guidelines – NHANES data have been and are essential for developing public health and dietary recommendations and guidelines and evaluating the extent to which they are followed, as well as the results and impact of those recommendations and guidelines. NHANES data have been used in these diverse applications:
    - **Immunization** -- One example of the use of NHANES data is the setting of immunization policies, to allow programs to target groups at greatest risk and protect the public as a whole. NHANES data showed antibody levels for tetanus, pertussis, diphtheria, HPV and other infectious disease were low and risk greater for certain subgroups in the population. These data provided the scientific foundation for immunization awareness campaigns and recommendations for immunization schedules.
    - **Cholesterol** -- The campaign to reduce cholesterol levels in the population owes much to NHANES data. The National



- Growth charts – The pediatric growth charts consist of a series of percentile curves that illustrate the distribution of selected body measurements in U.S. children. Since 1977, pediatricians, nurses and parents have used these growth charts to track the growth of infants, children and adolescents in the United States. The 1977 growth charts were developed by NCHS as a clinical tool for health professionals to determine if the growth of a child is adequate. The 1977 growth charts were also adopted by the World Health Organization for international use. With later and better data, NHANES revised the growth charts and produced a new edition in 2000. The revised growth charts provide an improved tool for evaluating the growth of children in clinical and research settings. The revised charts contain two new body mass index-for-age charts for boys and girls. The new BMI growth charts can be used clinically beginning at 2 years of age and can indicate children at risk for overweight. The growth charts appear in most pediatricians' offices and are familiar to parents who can track their child's progress and discuss any concerns with the doctor. Easy-to-use growth charts are on the CDC website and an individual child's measurements can be entered and measured against the values on the chart. The growth charts have become not only a clinical and research tool but are also used in health education.
- Blood lead levels -- NHANES data on blood lead levels in the 1970's showed high levels in U.S. adults and children. High blood lead levels among children can lead to mental retardation and other serious health problems. Using these findings, Congress and others took action to ban lead in gasoline and in paint. Subsequent NHANES surveys showed a steady drop in blood lead levels over the next two decades.
- Metrics for Healthy People 2010 and other Federal initiatives -- NHANES data are the only source of information for many of the Healthy People 2010 objectives in areas such as heart disease, diabetes, arthritis, immunization, oral health, infectious disease control, diet and nutrition, and environmental exposures. The NHANES data helped set objectives for Healthy People 2010 and for the Healthy People initiatives that preceded the current effort. NHANES data are used to track progress, to adjust objectives at midcourse reviews and to measure the final progress in reaching the objectives. NHANES data are also key indicators of the success of efforts of the Department of Health and Human Services over several decades to reduce or eliminate disparities in health.
- Example of Indirect Impact

Tutorial for teaching; data for teaching -- The large nationally representative data sets produced by NHANES have long been a major resource for teaching. Medical schools, schools of public health, programs in health administration, epidemiology, statistics, and countless other university programs use NHANES data for teaching and research purposes. A large number of master's thesis and doctoral dissertations based on NHANES are produced each year. NHANES staff

works with some of these researchers directly and has knowledge of specific projects, but many researchers access the data independently. The NHANES data allow faculty and students to address health issues and problems utilizing high-quality objective health data. A canvass of ongoing research at schools of public health and other academic institutions would undoubtedly elicit a long list of research projects and publications. Another way to quantify the research output—a recent search of citations in PubMed for NHANES data shows almost 16,000 citations.

## **II. Description of NHANES**

The National Health and Nutrition Examination Survey is a program of studies designed to assess the health and nutritional status of adults and children in the United States. The survey is unique in that it combines interviews, standardized physical examinations and laboratory testing to produce data on a wide array of measures. The NHANES program began in 1959 (then known as the National Health Examination Surveys) and was conducted as a series of surveys focusing on different population groups or health topics. In 1999, it became a continuous survey that has a changing focus on a variety of health and nutrition measurements to meet current and emerging data needs. The survey examines a nationally representative sample of about 5,000 persons located in 15 counties across the country each year. The survey includes interviews in the home to collect demographic, socioeconomic, dietary and health-related information and a standardized physical examination and laboratory tests administered in mobile health examination centers that travel to each survey location. The mobile examination centers consist of four tractor-trailer units. The trailers are interconnected and provide a standardized environment for the health examination components of the survey. Standardized equipment is required for all survey components. The exam component sets NHANES apart from the health surveys based on interviews or health records which can collect data only on diagnosed conditions. With such important diseases such as diabetes, for example, not diagnosed in a significant portion of the population which has the disease, the key role of the examination component of NHANES is readily apparent.

### Survey Objectives

The overall objective of NHANES, as it is currently conducted, is to assess the health and nutritional status of adults and children in the United States. The major goals of the program are to:

1. estimate the number and percent of persons in the U.S. population and designated subgroups with selected disease and risk factors
2. monitor trends in the prevalence, awareness, treatment and control of selected diseases
3. monitor trends in risk behaviors and environmental exposures
4. analyze risk factors for selected diseases
5. study the relationship between diet, nutrition and health
6. explore emerging public health issues and new technologies
7. establish a national probability sample of genetic materials for future genetic research

8. establish and maintain a national probability sample of baseline information on health and nutritional status

Although all of the objectives are important and related, objectives 1-4 and number 8 are considered the most fundamental to the mission and operation of NHANES.

### Sample design

NHANES uses a complex, multi-stage probability sample design. The NHANES sample represents the total non-institutionalized civilian population of the United States. Active military and institutionalized persons are not part of the sample population. A four-stage sample design is used for NHANES. The primary sampling units (PSUs) are selected from a frame of all U.S. counties. Fifteen PSUs are selected each year to reach a sample of about 5,000 individuals. The PSUs are mostly single counties, but in a few cases, several counties are grouped to keep PSUs above a certain minimum size. Secondary sampling units are area segments, which are Census blocks or combinations of blocks. Segments consist of about 150 households. Following the selection of segments, all dwelling units in the segment are listed and a sample is selected for screening in each segment. The final stage of selection occurs in the household, where a subsample of individuals is selected for the survey.

The NHANES sample design starts with a large self-weighting, equal probability design but then uses household screening based on pre-determined sampling fractions to get an expected sample size for each demographic domain. Sampling domains are defined by race/ethnicity, sex and age. Sampling fractions are then set to get the expected sample sizes for the each of the survey's 76 domains. NHANES employs oversampling—the selection of individuals based on demographic, socioeconomic, or other characteristics in greater numbers than would occur in a sample that is a simple proportionate demographic representation of the population. Oversampling takes place to obtain sufficient numbers of respondents with certain characteristics. The current NHANES program oversamples Mexican Americans (and Hispanics beginning in the 2007 and beyond samples), black Americans, low-income white/other Americans, persons below age 20, and persons above age 60. In earlier surveys, pregnant women were oversampled.

The following table summarizes the extent of oversampling (based on 2001-2002 data).

	Percent in sample	Percent in population
Mexican American	25	9
Black	24	12
Low income other	12	15
Remainder	39	65
Less than 20	51	29
20-59	32	57
60+	17	14

The oversampling has usually taken place to ensure that sufficient numbers of individuals relevant to specific content would be included in the survey. Thus, when the nutrition monitoring component was added in the 1970's, the survey began to oversample low-income Americans who would be at risk of certain nutrient deficiencies and suboptimal calorie intake. Another reason for oversampling was to examine health disparities between and among race/ethnic groups in the population. Once a group is oversampled in the survey, it usually continues to be oversampled in future phases of the survey. NHANES has a highly clustered sample, partially as a result of an efficient method of oversampling and partially to ensure sufficient numbers in each survey location for efficient operation of the mobile examination center. The use of subgroup oversampling and the selection of a relatively small number of relatively large sample clusters have important statistical and operational implications for NHANES estimates. For example, the relatively large number of sample respondents from a relatively few PSUs can adversely impact the precision of overall and subgroup estimates.

NHANES includes 18 self-representing PSUs. The sampled respondents from each of these areas form a representative sample for certain survey measures in a single year or with an accumulation of data over two or more years. For overall national estimates for most of the measurements in the survey, NHANES data are released in two-year increments. This is considered the shortest period of data collection for accurate and appropriate analysis of the findings. Some measurements may require longer periods of data collection to produce reliable data. The two-year framework for data release may result in relatively large confidence intervals for some measures and thus impact period as well as trend analysis.

### Survey content

The survey consists of interviews administered in the home that gather demographic information, including information on income, occupation, and family/household relationships. With some variations over time, the interviews also include questions about physical activity and functioning, medical conditions, health insurance, health care utilization, prescription drug use, and food security and dietary supplement use. More sensitive questions, such as those on risk factors (tobacco, alcohol and illicit drug use, for example) are asked in interviews that take place in the mobile examination center.

The examination component of the survey is administered by a physician and medical and health technicians. The exam component consists of the physician's general exam, including the multiple taking of blood pressure readings. Some anthropometric measures such as height and weight have always been on the exam while a number of other tests have moved on and off the exam depending upon the current focus and design. The survey has included an oral health examination, vision and hearing tests, spirometry measures of respiratory health, various tests of physical functioning including balance, dual x-ray to measure body component and bone density, and various measures of mental health and mental well-being. The survey includes a venipuncture and blood tests vary from year to year but virtually always have included cholesterol, basic hematology, a basic biochemistry panel, and fasting glucose. In addition to these "core" tests, the laboratory tests of blood and urine in any given year are very extensive. The numerous

urine tests include tests for environmental exposure. A complete listing of survey content from 2000-2008 appears on the website at [www.cdc.gov/nchs/nhanes](http://www.cdc.gov/nchs/nhanes).

NHANES is a keystone in the nation's health information system, collecting data that can best or only be obtained through direct physical examinations, clinical and laboratory tests, personal interviews and related measurement procedures. Because of this unique combination of data collection tools, NHANES is viewed as a national resource and has come to be one of the Federal government's principal health surveys collecting the data needed for many of the government's health programs and initiatives. In order to meet those needs the content of the survey has vastly expanded, new tests and examinations incorporated, and many innovative technologies and cutting edge assessments developed and fielded as part of NHANES. The dynamic nature of NHANES--its ability to add and change components while keeping a uniform core—has resulted in a survey which has and continues to meet the needs of many public and private programs, while responding to an evolving research agenda driven by current and emerging health issues. One of the most fundamental changes took place in 1970 when a large nutrition component was added to the basic design and the survey changed from the National Health Examination Surveys to the current National Health and Nutrition Examination Survey. With that change, the survey added dietary interviews, food frequency and adequacy measures, and many tests to assess the nutrition status of the population as well as the prevalence of nutrition-related diseases and conditions.

NHANES responds not only to changing data needs, but also to operational changes brought about by advances in methods of laboratory testing, improvements in health measurement technology and refinements and updates in survey questionnaires. These changes can make the measurement of temporal changes more difficult and the analysis of trend data more complex. In order to understand the potential impact of these changes on the data, NHANES carefully documents the methodological changes and alerts data users to those changes in the data documentation available on the website. Where possible, NHANES staff will conduct cross-over studies to compare results using both the old and the new methodology. For example, laboratory processing for a certain blood test may be repeated using old and new methodology. Body measurements, such as blood pressure, have been duplicated for a small portion of the sample when the methodology changed. Regression analysis is performed and the results incorporated into the data documentation. Cross-over studies on all changes aren't feasible. Excess sera are needed to perform dual blood tests and that is limited. Sample respondents can't be asked for the same information using different forms of the same question. Collecting data for cross-over studies requires careful advance planning and prioritizing to cover the most significant changes on the most significant measures.

Environmental monitoring is another major responsibility folded into the on-going NHANES. The survey's biomonitoring component documents exposure to environmental toxicants by direct measure of chemicals in blood or other biological specimens from individuals. The collection of blood and urine specimens in NHANES provides a unique opportunity for monitoring environmental exposure in the U.S. population. Biomonitoring in NHANES began with the measurement of blood lead levels in 1976 and has moved on to encompass testing for blood mercury levels and other environmental pollutants added to the survey in 1999. Now a full range of

environmental toxins from pesticides to phthalates are measured by the survey. These environmental exposure measurements are widely used by the EPA in its risk assessment models for the U.S. exposures to pesticides and other potentially toxic compounds.

When the AIDS epidemic emerged, NHANES incorporated a blood test for HIV and produced the first estimates of HIV/AIDS in the general population. Prior to the NHANES measurements, the only data available were from specialized populations, such as patients at clinics for the treatment of drug abuse and sexually transmitted diseases. NHANES provided the data to measure overall prevalence in the general population and ascertain the groups at greatest risk as well as monitor the trends over time. There are numerous other examples of the evolution of the survey to meet the expressed information needs of a vast array of health officials, researchers, policymakers, program sponsors and other data users.

DHANES conducts a very active and dynamic process to solicit proposals to change or add content to the interview, examination or laboratory testing components of the survey. Proposal solicitation announcements and research proposal guidelines for new survey content are posted on the NHANES website and presented at a wide array of professional meetings and meetings with many other government agencies, including virtually all DHHS agencies. Notices are sent to professional journals and other media. Members of the NHANES user community receive letters inviting them to submit research proposals. At various times, DHANES has held forums and workshops with invited experts to provide advice on content. The planning process is conducted in stages and currently begins two to four years prior to the implementation in the field. In 2001, a decision was made to solicit content, plan the survey, collect the data and release findings in two-year cycles.

The process of developing content for the survey begins with a formal research proposal solicitation phase. Interested researchers submit a brief letter of intent that outlines the topic, the public health significance and the proposed methodology. The letters of intent are evaluated to determine if the proposed topic is safe, feasible, and of sufficient public health significance to include in NHANES. If the letter of intent is acceptable, the proposer is asked to submit a comprehensive research proposal. The proposal evaluations are discussed during formal meetings and a decision made to approve or disapprove. There is a good deal of communication with the proposers who are usually subject area experts. Some agencies have advisory groups that advise them on the proposal. At times the DHANES planning staff meets with these advisory groups. If approved, the protocol is fully developed and prepared for field testing prior to use in NHANES. If required, cognitive testing and translation activities are completed prior to field implementation. Similarly, laboratory methods must have been tested and deemed reliable and validated prior to their inclusion in NHANES. All survey protocols, consent forms, and information materials must be approved by the NCHS Ethics Review Board (Institutional Review Board) prior to use. Finally DHANES submits the survey content to the Office of Management and Budget for annual review and approval. After new survey content has been formally approved, work begins in protocol development and training and in the design of any structural changes in the mobile examination center. Additionally the software and systems groups begin work on the software specifications, design and development of software and testing in preparation for the pilot test.

The science behind a component remains the primary consideration for inclusion in the survey, but funding for a proposed component is important, if it is not a part of the core funded by DHANES. About a third of the survey content is funded by collaborators who work with the DHANES staff in developing and testing the component for inclusion into the survey. The most common reason for rejection of proposed content is lack of feasibility of performing the specific element in the mobile examination center. This includes taking too long, not being safe to perform in a survey/trailer setting or having a poorly standardized protocol. Sometimes examination content requires further consideration and extensive developmental work to get to a final proposal. An example of this effort is the Total Body Dual X-ray component to test for body composition and bone density. DHANES staff worked diligently with university researchers to successfully move this type of test from a clinical environment for assessment of individual patients to use in a large-scale survey process with numerous test subjects. Not all new tests require the level of developmental work that the bone density test required to successfully integrate it into the survey environment but a number of new tests have required a significant level of effort, especially when new technology or innovative approaches are involved.

NHANES survey core-- both interview and examination-- is not precisely defined. There is an operational definition of core which consists of the components which have generally remained in the survey over time. These include some type of physician's examination, body measurements, basic blood tests and urine analyses. Also core would include a dietary interview and interview in the mobile examination center, focusing on risky health behaviors. The core components of the survey are those for which there is strong and constant involvement by survey sponsors, such as the nutrition component, since only some of the core is supported by NHANES funding. The NHANES core provides a basic assessment of the population's health and addresses some public health data needs but does not allow the broad assessment of the range of public health issues covered in the current NHANES.

### Data collection

The NHANES survey data collection in each of the 15 annual locations begins with a community outreach campaign to ensure that county health officials, community groups, media and citizens are aware of the survey, its purpose, and the way it will operate in the community. Field staff holds meetings and solicits support to promote a favorable reception for the survey by the community and potential survey respondents. In a series of visits, NHANES field staff asks for help in identifying a central, safe and convenient location for the mobile examination centers and seek information about the community that could affect the successful operation of the survey.

Potential respondents receive an introductory letter about the survey. Households are then visited and screened to determine if there is someone in the household who meets the survey sampling requirements. If so, and the selected eligible individuals consent to participate through a thorough and informative consent process, the respondents receive an extensive health interview. Upon completion of the household interview, participants are asked to schedule an appointment for a physical examination at the mobile

examination center. In the mobile examination center respondents provide blood and urine samples, have a physician's examination and answer additional questionnaires both guided by an interviewer and via self-administered computer-assisted mode. The latter method is used for the most sensitive questions. The precise set of tests and questions vary depending upon age and sex of the survey participant. Additional questionnaires or tests may be completed in the household and via the telephone some time after the exam. Some of the laboratory tests are completed in the MEC, but most of the specimens are sent out to laboratories around the country with which DHANES has agreements in place for standardized processing. NCHS works with CDC's National Center for Environment Health to conduct a number of the laboratory tests.

Data collection for NHANES is managed currently by Westat, a large multi-faceted survey and data organization. Westat trains and supervises the interviewers; recruits, trains and supervises field staff both in the mobile examination center and in the field office; and is responsible for maintenance of the information technology system for the collection and transmission of data. DHANES staff and Westat work closely on many aspects of survey design and with the complex and multi-layered structure for field operations. The current multi-year contract (approximately \$28 million annually) for fieldwork will end in 2012. An RFP will be developed and competed to have a contractor in place at that time.

### Dissemination

NHANES data are widely disseminated and widely used. Data are available in multiple formats and are provided with many aids to assist users in analyzing the data accurately and applying the findings effectively to various research and policy questions. The NHANES data preparation and dissemination process is a multi-step process, consisting of data review, editing and production of data sets and related documentation, collaborator review and disclosure review. The survey contractor, Westat, is involved in the preliminary stages of processing and provides the sample weights for the data. The DHANES Informatics Branch performs more complex editing and processing of the data, and subject-matter specialists within DHANES are also involved in the process of editing and cleaning the data for data release. Organizational collaborators are the subject-matter experts and receive preliminary data products for scientific review and evaluation of data quality. This is a limited period of time (two months), after which the data sets are completed and released to all data users. Additionally, the data are reviewed by the NCHS Disclosure Review Board to ensure that the data will not pose a risk of inadvertent disclosure of the identity of a survey participant. Data that for some reason pose a disclosure risk are not released to the public and instead are available through the NCHS Research Data Center (RDC). The NCHS RDC provides on- and off-site secure access to the full range of NCHS data sets, including those with detailed geocoding, while continuing to protect the confidentiality of the respondents and records. The RDC provides a dataset created for the user, based on user analytical requirements but specially designed and formatted to maintain the complete confidentiality of the data.

DHANES has focused on improving the schedule for data release and has greatly reduced the processing time to provide data on a timelier basis. Currently many of the data files are released within a year of the end of data collection and most others within a year and

a half. This speed-up of data release is due to improved use of information technology throughout all phases of data collection, data management and data release. In addition to improving the timeliness of the data, DHANES has improved the data products with innovative approaches and creative use of electronic dissemination. Virtually all of the NHANES data are available on the NCHS website. Web-based tutorials provide the users with extensive information needed for analyzing continuous NHANES data (from 1999 forward) and earlier NHANES surveys. The NHANES Tutorials are designed to help users navigate through the dataset. Users can browse through different modules to gain insight into NHANES data. From each round of the survey, users can expect that public use data files on the range of components and topics will be released with full documentation. There may also be journal articles, NCHS publications both electronic and printed, and presentations.

### Reporting of Findings

An operational issue that only NHANES, of all NCHS surveys, faces is the reporting of clinical results to survey participants. In recruiting participants, NHANES promises to send results to those who participate in the survey. This is a major recruiting tactic that is effective in gaining cooperation. Despite the effectiveness of this practice in improving survey response rates and the value of the information to the respondent, there are concerns about how to provide the individual test results to those respondents. In earlier days, NHANES sent findings to the respondent's physician to assist the respondent in interpreting the results. After some concerns were voiced by the medical community about receiving information for which they were unprepared to process and which could result in medical liability, NHANES changed the procedure and began sending findings directly to participants beginning in 1988. However, DHANES remains, concerned about finding the best way to provide information that is meaningful and useful to the respondent who is unlikely to have the medical background and knowledge to interpret the information.

NHANES views the provision of findings to respondents as an ethical issue and is committed to providing the findings on tests for which there is a known clinical intervention. Based on NHANES data, respondents can take action which could be beneficial to them. There is a well-designed, recently modified and extensive protocol for reporting results to survey participants. The survey uses a tiered approach, with life-threatening and potential emergencies reported immediately to patients by the survey's medical doctor. Another set of measurements that meet certain criteria are also fast-tracked, and finally the remaining results are provided to respondents. This whole process may take several months. Results are provided with a reference range for some interpretation by respondents who are advised to take the results to their health care providers for more interpretation in their individual situations. The survey's medical advisor is available to discuss the tests in general but does not interpret the meaning of individual findings. In each survey location the field staff identifies free or low-cost health care services to which survey respondents can be referred. There is a separate and confidential system for the reporting of HIV test results.

### Methodological research

Despite limited resources and time, DHANES staff has done a remarkable amount of methodological research and maintained methodological research as a core function. Projects have spanned many diverse areas with the goals of increasing response rates, improving the quality of the data, collecting more diverse data and providing estimates at the sub-national level. Often the research agenda developed from issues raised by staff or users. NHANES staff often conducts collaborative methodological research with staff in NCHS's Office of Research and Methodology (ORM) or with collaborators in other organizations and agencies, including the overall contractor for the survey, Westat. ORM supplements a DHANES capacity for methodological research with other methodological research done on contract.

Recent methodological research in the area of survey design and analytical research (see attachment 1 for illustrative list of recent examples) include research on:

- optimum selection of primary sampling units
- variance estimation and design effects
- multiple imputation and
- matrix sampling

In the area of survey operations, research projects focused on:

- remuneration studies
- multiple evaluations of response rates and nonresponse
- small area estimation
- use of fixed sites versus mobile examination centers

Many of the research efforts focus on specific measurements used in or being considered for NHANES, such as the evaluation of an automated soluble transferring receptor assay on the Roche Hitachi Analyzer and its comparison to two ELISA assays for the calibration of serum creatinine.<sup>1</sup> DHANES research often contributes not only to more precise measurements collected during the survey but to advances which can be applied to other population surveys and in some instances to clinical practice. One example is a number of research projects related to improving the measurement of blood pressure during the exam. One study analyzed the selection of correct blood pressure cuff-size based on self-reported height and weight and estimating equations for mid-arm circumference.<sup>2</sup> In examining trend data from NHANES, the study documented an increase in mid-arm circumference among children and adolescents which would require the use of an adult blood pressure cuff to produce an accurate reading in 40 percent of girls 13-17 and more than half of all boys that age. Another study evaluated the effect of observed training and protocol standardization on reducing blood pressure measurement error.<sup>3</sup> Looking at other measurements used in the survey, staff evaluated various folate and other laboratory methods, as well as additional utilization of previously collected x-rays and ultrasound tapes for alternative research proposals.

In addition, other research focused on the content and presentation of the complex consent process used in the survey and its effects on survey participation and data quality. Still other methodological research is conducted to support the protection of the confidentiality and security of the data through the entire survey process including data dissemination. Finally, all the content of NHANES goes through pilot testing and/or cognitive lab testing before implementation in the full survey.

Staff has been active in presenting at scientific meetings, interagency forums, and various other settings to share research results and promote methodological work on topics relevant to the survey's data collection and analysis. Staff members publish frequently in peer-reviewed journals, though these articles are more likely to be dealing with substantive health research and subject-matter analyses than methods research. Various bibliographies exist but there is no central repository of methodological research that could stimulate complementary research building upon past research initiatives. An even greater lost opportunity to share and promote research is that a good deal of the research remains unpublished and exists in the form of internal memoranda, staff notes, and other informal documentation. Some of these studies are not available on the DHANES website and the NCHS website, in general, can be hard to search for this type of information.

#### CHANES and other technical support

While NHANES serves the need for national data, no comparable program is available to provide the data needed at the state and local level. Similarly there is a need for a program to assess the health status of targeted populations, such as the medically underserved, low-income populations, or specific race/ethnic populations such as tribal groups. DHANES developed the Community Health and Nutrition Examination Survey (CHANES) to provide capacity for health and biomonitoring at the community level. CHANES uses the expertise, experience, methods, protocols, information technology and equipment of DHANES to conduct community surveys and produce the specific data needed at the local level as well as information comparable to national NHANES results. CHANES was designed to operate in a 3-year cycle from initial planning through data collection and release. DHANES has worked on this initiative for several years, built several community-based trailers, developed a conceptual framework and had discussion or consulted with over 30 different communities.

In 2003-2004, NCHS helped the New York City Department of Health and Mental Hygiene successfully conduct the first NYC HANES. DHANES produced the study design, developed the information technology, planned the data collection methodology, adapted NHANES protocols, conducted pilot testing and dress rehearsals, and consulted during the field operations. By using comparable methods, NYC identified how the health of the city's population compared to that of the nation, thus highlighting the city's most significant health issues. Objective health estimates of selected conditions such as diabetes, high blood pressure, high cholesterol and depression were produced allowing NYC to direct resources to the health needs of New Yorkers. Similarly DHANES is currently working with the California Department of Public Health in planning a State biomonitoring program, using the NHANES methods and procedures.

Other CHANES projects include discussions with health officials in state and local areas: Baltimore, Maryland; District of Columbia; Connecticut; Denver; Hawaii; Illinois; Marin County, California; Milwaukee, Wisconsin; Ohio; Oregon; Philadelphia; Puerto Rico; Seat Pleasant, Maryland; Washington State; West Virginia and Wisconsin. Still other projects have focused on areas with specific health issues: Border States and the communities of Brownsville and Matamoros, Texas; Delta area of Mississippi; the areas

affected by Hurricane Katrina in cooperation with FEMA; and the World Trade Center Rescue Effort. DHANES staff has also consulted on projects directed to specific population groups, such as American Indian/Alaska Native populations in several locations and projects related to specific diseases or conditions or exposures: contaminant biomonitoring, heart disease, dengue fever and stroke. A few of the projects have been completed, some others are still active, and others still in the discussion stage or on hold.

Many DHANES staff members have been involved in these projects, but most of the work has been done by senior staff including the DHANES director and key staff members in the Office of the Director, including the senior computer scientist, mathematical statistician, infectious disease officer and DHANES branch chiefs. There are many positive aspects of this consultation. Staff finds a great deal of personal and professional satisfaction in being able to translate NHANES policies and procedures to local health problems and produce data for important public health goals. The recipients of this consultation benefit enormously by having experts in all phases of the survey provide extensive consultation directed at specific local projects. The exchange of information on statistical and scientific processes raises the level of knowledge of all and it is a rewarding professional encounter. However, Staff resources are diverted from the national survey and there is little or no remuneration for staff time and consultation.

On the international level, DHANES staff has consulted with health officials in a number of other countries. The desire to collect data through direct health examinations has increased, especially in the last 10 years. In the late 1990's DHANES staff actively participated in the planning of nutrition surveys in New Zealand and Australia. In both countries, many of the nutrition measures included in NHANES were successfully adopted for use in the surveys in each of those countries. DHANES has also been involved in the planning and execution of health examination surveys in Korea and even more extensively in Canada. The efforts in Canada culminated in the successful implementation of the Canadian Health Measures Survey. These international collaborative efforts have provided the opportunity to make international comparisons of a variety of critical public health issues as well as survey methods where there are differences. The most recent collaboration is with the European Union (EU). The EU is proposing to conduct health examination surveys in all of the countries in the EU during the next decade. DHANES staff is advising public health experts in the EU on the best practices to follow in the conduct of such surveys. International consultation continues to be an important activity for DHANES staff and presents the same opportunities and concerns as consultation on projects within the United States. Staff values these opportunities to gain international research experience and learn from the comparable and unique situations they face in designing and international study. However, these consultation efforts are time-consuming and offer no monetary return to DHANES.

### DHANES Staffing

The DHANES program staff consists of many diverse disciplines, including epidemiologists, biologists, biomedical engineers, nutritionists and dieticians, physicians, a dentist, nurses, mathematical and biostatisticians, public health and budget analysts, computer scientists and administrative and clerical staff. As of October 2008, the staff of

DHANES consisted of 56 federal employees and 17 contractors (both full and part-time in each category), 5 visiting scientists, and 1 Epidemic Intelligence Service Officer. There are also 3 vacancies for external hires for which the Division is not authorized to recruit and hire at this point. The staff is organized into the Office of the Director and 4 branches that cover the primary functions in the Division. They are:

- Analysis Branch – the Analysis Branch provides statistical and scientific input for the analysis of NHANES data. Staff prepares scientific papers on the prevalence of disease or health-related characteristics and on the relationships of these variables as observed in the United States population. The staff provides expert scientific consultation in public health research and analytic oversight for DHANES data collection programs. Staff also assists in the development, application and dissemination of analytical guidelines and methods of estimation for the DHANES data collection programs.
- Informatics Branch – the Informatics Branch is responsible for overseeing the design and development of the survey information technology architecture to support NHANES field data collection. The Branch is also responsible for the data review, production and dissemination operation and for maintaining and improving the DHANES website. The Branch takes the lead in managing the security risk management project and financial performance responsibilities and requirements.
- Operations Branch – The Operations Branch is responsible for overseeing the full lifecycle of field data collection to ensure a continuous, unbiased and ethically performed study. A portion of this effort is done under contract requiring staff to develop and administer the contractual work for data collection, engineering, acquisition and maintenance of the mobile examination centers. Branch staff also represents NHANES before the NCHS Ethics Review Board and handles outreach to county health officials and survey participants, as well as providing exam results and interpretation to survey participants. The Branch oversees all aspects of quality assurance for the NHANES data collection processes and designs methodological studies as well as contributing to the design and planning for CHANES studies.
- Planning Branch – The Planning Branch is responsible for the planning, design, implementation and oversight of new questionnaire, examination and laboratory content. This includes soliciting and reviewing new content proposals, working with collaborators to review the science and refine, test and implement proposals; preparing OMB documentation, performing quality control on fielded content; observing field operations in households and in the mobile examination center; and preparing and reviewing data for public release.

FTE's by category are distributed across DHANES as shown in the table below. Analytical functions crosscut the branches as staff in each analyze and publish data; to some extent planning and operations activities are performed throughout the Division as well.

DHANES Staffing as of 1/9/09														
Branch	Total # of staff	Type	Number	Epidemiologists	Computer scientists	Statisticians	Medical officers	Dentist	Nurses	Medical Tech.	Public Health Analysts	Admin. Support	Engineers	Other
OD	13*	FTEs	8	2	1	2					1	2		
		Contractors	5		3	2								
AB	11	FTEs	11	6		3	1	1						
		Contractors	0											
IB	17	FTEs	10		10									
		Contractors	7		5	1						1		
OB	13	FTEs	10		1	1	1		1		3	2	1	
		Contractors	3									1	1	1
PB	19	FTEs	16	10		2	2		1	1				
		Contractors	3	1							1			1
<b>Totals</b>	<b>73</b>		<b>73</b>											
FTEs =55, Contractors =18														

\*Includes Admin Officer who is officially in another NCHS office

### Organizational Collaborators

NHANES is a highly collaborative undertaking, with many Federal agencies supporting various components, tests and questions on the survey. Working with many collaborators on each NHANES has provided scientific insight and consultation on complex, specialized components of the survey and financial support for those components. The support has enabled the survey to expand the content to meet emerging public health data needs and to maintain a constant data collection effort on major public health topics. In addition, the collaborators' financial contribution is approximately one-third of the overall NHANES budget. By utilizing the NHANES infrastructure, the Federal government operates a very efficient data collection mechanism and by having access to the full range of NHANES data not just the supported components, the collaborators have a data resource far exceeding their specific contributions. Collaborators have included programs within four government agencies: Department of Health and Human Services, Environmental Protection Agency, Department of Agriculture, and Department of Housing and Urban Development. Frequent collaborators have come from the various programs in the National Institutes of Health and the Centers for Disease Control and Prevention.

### **III. Review Process**

The Chair of the NHANES Review Panel (membership list in Attachment 2) first met with the members of the BSC in its regular meeting on April 25, 2008. The purpose of this meeting was to hear the Board's sense of the issues that the Panel might consider in its review. The Chair of the Panel later met separately with staff in the NCHS Director's Office and with NHANES program staff to hear their perspectives on issues for the panel to consider. The results of these two sets of meetings were passed on to Panel members prior to a conference call on September 2, 2008 and formed the basis for the agenda for the Panel's only in-person meeting on November 11 (off-site) and November 12 (at NCHS), following an established agenda (attachment 3).

In its in-person deliberations, the Panel followed the “Procedures for Reviewing NCHS programs” established by the BSC (attachment 4). In advance, the Panel received a number of documents listed in attachment 5, which provided detailed information on the background and history of the survey, program structure and operations, survey data products, and issues and challenges the survey faces. The survey staff provided answers in writing to initial and subsequent questions from panel members. During the two-day meeting, the Panel heard presentations from NCHS Director, Dr. Edward J. Sondik and NCHS Associate Director for Science, Dr. Jennifer Madans. DHANES Director Clifford Johnson gave a presentation that focused on the issues for which the survey sought advice and counsel and then he and DHANES staff responded to questions from panel members. Staff present or available on the phone included: Susan Schober, Deputy Director; Kathryn Porter, Medical Officer; Lisa Broitman, Public Health/Budget Analyst; Jerry Del Rosso, Informatics Branch Chief; Vicki Burt, Planning Branch Chief; Gerry McQuillan, Senior Infectious Disease Officer; and Randy Curtin, Mathematical Statistician. The panel deliberated on the current and future status of the NHANES and developed a set of recommendations to be included in a final report. A draft of the report was prepared, circulated among panel members, revised and presented to the BSC at its January 23 meeting.

#### **IV. Current Status of NHANES**

##### Function and Role

NHANES is a survey of major importance to public health in the United States. It has achieved and maintained this position because of the breadth and depth of its data and because of the quality and objectivity of its findings. From its start over 50 years ago, NHANES has evolved to meet the health data needs of the nation. It has added major components in nutrition and environmental monitoring. Its data are used for policy development and to establish, monitor and evaluate national health programs and policies. It is a cornerstone of prevention efforts and is a survey that is greatly admired and emulated by communities in this country and abroad. The survey rigorously evaluates new components and additions to the survey to determine if they meet public health data needs and have the scientific quality and precision to be incorporated into a finite interview and examination schedule. The current NHANES is widely viewed as having the best and most practical collection of individual tests and measures creating the most effective overall survey.

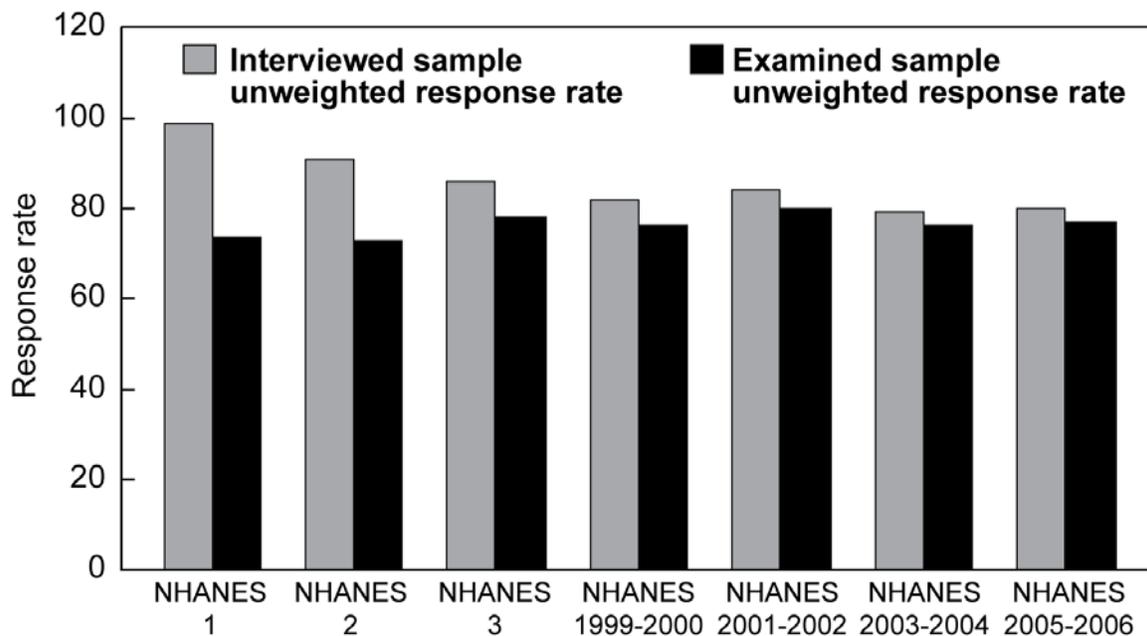
##### Data Quality

While the NHANES sample size is relatively large for a national survey, its principal statistical liability has been its relatively small PSU sample size and large average sample cluster size, necessitated by the substantial average unit costs of its PSUs. The result has been a highly clustered sample and thus somewhat less statistically efficient estimates than most comparable surveys. Despite this limitation, however, its considerable content breadth and acclaimed quality of survey measurements have made NHANES one of the top health surveys in the world.

Data quality in NHANES is derived from an effective survey design and planning process, including stringent evaluation and pre-testing of survey components; sound data collection methods, including the achievement of high response rates; and sophisticated statistical and analytical processes used to prepare and release data. All new interview questions and examination components are pre-tested prior to final inclusion in the survey. After additions are vetted in a series of internal steps, a formal pretest is conducted to ensure that the test will produce quality data and can be successfully integrated into the existing survey structure. When needed, interview questions are evaluated in the NCHS Cognitive Laboratory utilizing a study population similar to the population that will be participating in the survey.

NHANES has been able to maintain high levels of cooperation and participation in a demanding health interview and examination survey, even as other surveys have been affected by diminishing response rates. From NHANES I through NHANES 2005-2006, the survey has maintained an overall response rate of 73 percent or better. The chart below shows response rates from NHANES I, 1970-74; NHANES II, 1976-80; NHANES III, 1988-94; and continuous NHANES from 1999 through the 2005-2006 cycle.

## NHANES Response rates



Well-trained and motivated interviewing staff receives a good deal of the credit for this achievement as well as overall supervisory oversight and attention to survey outreach to both communities and respondents. High response rates certainly contribute to the quality of the data as do the completeness of interviews and examinations, with a relatively low rate of missing items on either portion of the survey. Respondents have the ability to opt out of specific questions and exams but relatively few do as they are encouraged by interviewing and mobile examination staff to take part in the full survey. Once in the mobile examination center, survey respondents report a high level of

satisfaction with the survey as evidenced in exit surveys conducted periodically through the survey's history. However, there are definitely patterns in the overall response rate or in item response. Older individuals are less likely to participate in the survey as a whole; younger children to opt out of the venipuncture during the exam, for example. NHANES carefully tracks item non-response which varies by type of survey participant and specific question or test. The survey tracks, monitors, documents and adjusts for item non-response.

The process of preparing data sets for release is no less rigorous than all other aspects of the survey. The contractor, Westat, performs some basic data cleanup and then the DHANES staff involved in the development of specific survey components, along with appropriate collaborators, are responsible for editing and cleaning the data prior to release. DHANES devotes at least a full year after data collection ends for data preparation. Collaborators receive a data set for a two-month period to review for data quality. NHANES data are published in a wide array of peer-reviewed professional journals. Many articles are authored by DHANES staff but the vast majority of articles are authored by researchers who access NHANES data in public use data sets and analyze and publish data independently of DHANES. With the full and easy access to NHANES data, subject-matter experts in many diverse fields analyze and publish data in national and international journals.

### Funding

Funding for NHANES comes from two primary sources: direct funding through the NCHS base budget and reimbursable funding from collaborating agencies. Additional support is provided as "in kind" services such as scientific and technical support, laboratory and data processing, and consultation. In the 2007 and 2008 DHANES budgets, NCHS provided \$18 million per year, and an additional \$12 million per year came from the reimbursable agreements with DHANES collaborators. These numbers exclude staff costs and in kind contributions both from NCHS and collaborators. However, between field costs, support services, contracts, laboratory and reading costs, building new trailers and DHANES operating expenses, the expenses totaled approximately \$32 million. The shortfall was funded with carry-over funding from previous years. NCHS has special legislative authority to carry reimbursable funding from outside CDC across fiscal years.

The budget chart below shows estimated funding and expenses for DHANES through 2012. NCHS budget contributions and reimbursable funds for collaborators are expected to be flat over the next few years, expenses will increase due to rising field costs and other operating charges, and there are no carryover funds to offset the difference. NHANES relies heavily on collaborators, who fund 30-40 percent of the survey through reimbursable agreements. As NCHS faces budget problems, so do the other Federal agencies that support NHANES. DHANES cannot count on a steady and sure flow of funding from collaborators as those collaborators adjust their programs to match their funding levels. If collaborators drop out they affect not only the portion of the survey they fund, but also the entire enterprise. NHANES is marketed as a high-quality, secure data collection mechanism which offers a diversity of data through its various collaborators and core components. In addition to the actual funding or lack of funding is

the timing. DHANES must be assured of funds for each component in advance to continue the complex and lengthy planning process. Delays in funding decisions at any level within CDC or by external sources adversely impact the planning, pre-testing and fielding of the survey. It should be noted that there is considerable overhead on reimbursable agreements, including a 9 percent CDC charge and a 15 percent charge by NCHS.

#### **DHANES Budget and Projections as of April 2008**

	2007	2008	2009	2010	2011	2012
NCHS Funds	\$18.00	\$18.00	\$18.00	\$18.00	\$18.00	\$18.00
Reimbursable Funds	\$12.30	\$10.10	\$11.80	\$11.20	\$11.20	\$11.20
Carryover Remaining	\$7.10	\$5.85	\$1.65	\$0.00	\$0.00	\$0.00
Income	\$37.40	\$33.95	\$31.45	\$29.20	\$29.20	\$29.20
Field Costs	\$27.80	\$28.63	\$29.49	\$29.98	\$30.18	\$30.38
Lab Readings Costs	\$1.50	\$1.70	\$1.80	\$1.85	\$1.91	\$1.97
Support Contracts	\$1.70	\$1.77	\$1.82	\$1.88	\$1.93	\$1.99
Trailers	\$0.35		\$0.70			
IT Infrastructure Upgrade			\$1.00			
Division Operations	\$0.20	\$0.20	\$0.21	\$0.22	\$0.22	\$0.23
Expenses	\$31.55	\$32.30	\$35.02	\$33.92	\$34.24	\$34.57
Cumulative Balance / Deficit	\$5.85	\$1.65	-\$3.57	-\$4.72	-\$5.04	-\$5.37
Additional Funds to Make Whole	\$0.00	\$0.00	\$3.57	\$4.72	\$5.04	\$5.37
Cumulative Total Additional Funds Needed			\$3.57	\$8.30	\$13.34	\$18.71

Note: All figures in millions; \* NHANES field operations end in 2012 by current contract terms

Assumptions:

- \* No changes made to operations, sample size, or over-sampling.
- \* NCHS OD provides \$18M from 2007 - 2012
- \* Reimbursables constant at \$11.2M from 2010 and beyond
- \* Field costs increase 3% / year for 2008 and beyond
- \* Lab costs increase by 3% a year from 2009 forward
- \* New support contracts with initial increase of 8% (1/2 year) and then 3% a year beyond 2009
- \* New trailers built in in 2007(1), 2009(2)
- \* IT infrastructure upgrade costs \$1M in 2009, and then produces \$400K (2010) and ~\$700k savings each year thereafter. Savings are subtracted from the field costs.
- \* Division operations increase by 4% a year from 2009 forward
- \* Additional funds added each year to make study whole

In addition to the financial aspects of reimbursable agreements, there are many other aspects that impact the program significantly. Considerable staff time is involved in initiating, negotiating and managing these agreements. Staff works with external agencies throughout the entire process, from the first discussions on a possible survey component through the development, testing, fielding, and data processing and release. Even when the component is in the field, unexpected situations may arise which require consultation and adjudication. Reimbursable agreements bring necessary funds and scientific expertise, but they also require the survey to make many decisions “by committee,” and allow sufficient time for discussion and finding solutions to sometimes competing interests.

## **V. Issues Affecting NHANES**

### Program advisory mechanism

DHANES obtains advice, guidance and feedback through a number of channels and mechanisms. These generally tend to be episodic, topic-driven, and narrowly focused. The lack of an on-going advisory body with extensive programmatic knowledge and experience and broad public health perspective can be felt as the DHANES seeks to direct NHANES through difficult times. Decision-making is somewhat ad hoc and reactive. The staff seeks to develop more long-range strategic plans but lacks sufficient staff to dedicate the level of resources needed for this effort. Much of the on-going planning is directed to immediate survey plans on content and operational changes required for each two-year phase of the survey. There is no clear mechanism for determining that the most important public health issues are being addressed as many decisions about including or eliminating content depend on the availability of funding from collaborators.

### Survey design

Several features of the NHANES design offer possibilities for reduced data collection costs without compromising the statistical integrity of survey estimates. One is oversampling of certain population subgroups (e.g. Hispanic). NHANES has a complex sample design with a high level of oversampling of various population subgroups. Oversampling creates a mandatory large-scale screening process that adds substantially to survey costs in each of the 15 survey locations each year. Another factor in survey costs is household enumeration, and the use of postal listings offers a potential method of complementing or supplementing the current, ongoing process. The use of postal listings also has the potential to at least partially replace the more expensive household enumeration process that has been used in the past. A recent Westat study<sup>4</sup> concluded that forming dwelling unit sampling frames in the traditional manner is approximately four times the costs of using address lists. However, the study also pointed out that there are some problems for certain geographic areas so some traditional listing would still be needed. Finally, the study concluded that eliminating the need for listers in certain areas would mean a net savings of about 20 percent in the cost of listing housing units. There needs to be further evaluation to determine if this would be a useful cost-savings measure.

Extending the mission of NHANES to meet both national and local health information needs is another potential source of revenue for the continuing operations of the survey. The existence of 18 self-representing (or certainty) PSUs in the first stage of the current NHANES sample design opens up another potential for NCHS to promote the use of findings from these 18 PSUs to local communities. NHANES could also design ways to add onto the NHANES sample or add additional content for these areas. CHANES offers still another approach to producing local area estimates.

Since 1999 the survey has been in continuous data collection. Earlier the survey was conducted periodically, allowing separate time for planning, data collection, and data analysis. Now all of those functions must be done simultaneously by the same size staff. There is some consideration of alternating cross-sectional data collection with a longitudinal component. This might increase the analytical potential and power of the survey but wouldn't necessarily reduce the burden of simultaneous survey operations,

since survey staff would still be planning, conducting and analyzing data from either the cross-sectional component or the longitudinal NHANES at the same time.

Another potential approach to dealing with an overall budget deficit and limited staff resources is to consider an integration of NHANES with another NCHS population-based survey, the National Health Interview Survey, a large-scale household interview survey. There are some potential savings if PSUs overlapped for the two surveys and one interview operation could service both programs. These issues will be evaluated prior to the 2012/2013 redesign of both surveys.

### Staffing

A key to the continuing viability of a successful organization is a continuity of strong and creative leadership. The NHANES program has benefited from having had such leadership through most of its history, starting with Art McDowell who served for 20 years, then Robert Murphy who led the program for another 20 years, and most recently Cliff Johnson who has directed or served as deputy or acting director for about 10 years. To ensure that a strong leadership after Cliff chooses to step down, a succession plan must be in place. The Panel's concern is that it is not clear what planning is underway or efforts are in place to build, recruit, train, or groom the next director or generation of DHANES senior staff. With such a complex program to maintain and advance and such a high level of expertise required in so many subject areas, planning for leadership is essential. A number of personnel approaches and methods of drawing technical and management resources could be considered. For example, the IPA program, which allows senior researchers and managers in state or local government agencies or academic programs to take assignments in Federal agencies, offers possibilities.

Another personnel issue that affects the operation and costs of NHANES is the composition and roles of examination staff. Each exam team has a physician who seems to perform relatively low-tech, repetitive measurements that could possibly be performed equally well, or even more effectively, by technicians on the team. Part of the reason for the placement of a physician on each team is related to malpractice insurance and the handling of potential emergencies in the mobile examination center. The survey field team also includes other highly-trained personnel, such as a dentist and nurse practitioner. While the tightly standardized, carefully conducted tests in the mobile examination center are central to the accuracy of results and the quality of data, further assessment of the level of training and education of staff might prove useful in lowering staff costs.

An overriding staffing issue affecting DHANES is the stress placed on staff by conducting a continuous survey with no down time. With continuous operations there is no separate time for planning, data collection and data analysis. Essentially, most of the staff is involved in each of these areas and work non-stop to keep the survey going and get the data out. Staff lacks the time for reflective thinking and strategic planning, since day-to-day operational decisions and immediate crises take priority. Funding levels preclude hiring additional staff to share the burden and actually require staff to do more with less.

### Longitudinal HANES

The current NHANES is designed as a cross-sectional study and longitudinal follow-up is limited to linkages of survey participants with the National Death Index, Medicare enrollment and claims data, and Social Security Administration records. The last longitudinal study conducted on NHANES participants was a follow-up of NHANES I participants who were examined in 1971-75. Conducted by the NCHS Office of Analysis and Epidemiology, four waves of the NHANES I Epidemiologic Follow-up Survey were conducted between 1982 and 1992. There was a serious effort to develop a longitudinal component for NHANES III (1988-1994). The longitudinal survey was to begin as NHANES III ended and to be completed before the next cross-sectional survey. There was a great deal of interest by potential collaborators at NIH, meetings were held, but ultimately NCHS had no funding to start the project. A later effort to follow-up the respondents to NHANES III ended similarly due to lack of funding. Options of follow-up through full examinations, re-interviews or telephone contacts have been explored and costed out.

At this point, NCHS has not identified a mechanism to fund a longitudinal study. Interspersing a cross-sectional and longitudinal component might be possible but that approach would seem to be problematic if it causes a delay in releasing current data to survey sponsors and data users. Data are now provided in two-year cycles and users, especially those formulating national policies, have come to depend upon this schedule and on having current estimates on an array of key indicators. However, there is certainly strong scientific value in a longitudinal component and a great deal to be gained in the study of disease progression, the impact of risk factors and exposures and the effects of various forms of intervention and treatment on health outcomes.

### Funding

Funding for NHANES is uncertain in upcoming years. There is a shortfall between revenue and expenses that for 2007 and 2008 was covered by reimbursable funds carried over from previous years. Needed IT improvements and other expenses were moved to the budget for 2010 thus avoiding a shortfall in 2009, but without a new infusion of money the survey will be under-funded beginning in 2010. More specifically, it looks like no new funds will be forthcoming from the NCHS budget and reimbursable funding, while steady to date, cannot be counted on to add new resources nor necessarily maintain the current pace. Expenses are increasing due to rising travel and hotel costs as the field office staff, survey interviewers and examination staff move from location to location for most of the year. Without a significant funding increase, fielding NHANES beyond 2010 will be very difficult and it will be impossible to consider IT re-engineering or replacing the fleet of aging trailers. There are financial as well as operational benefits to be gained from the application of the latest technologies in data collection systems. The underlying information system used for NHANES data collection systems has been in use for ten years, greatly exceeding the "life" of today's evolving computer technologies. IT infrastructure upgrade costs are estimated at \$1 million in 2009, and would then produce an estimated \$400,000 in savings in 2010 and \$700,000 savings each year thereafter.

Likewise, some of the trailers that make up the mobile exam center were purchased over 20 years ago prior to the start of NHANES III in 1988. Despite the efforts to maintain them, areas of rust are developing on the trailers which could eventually compromise the structural soundness of the trailers. In FY 2007 DHANES awarded a contract for the construction of one new laboratory trailer and took delivery of it late last year. The cost was approximately \$300,000. The contract includes an option to purchase two more trailers. That option expires later this year. DHANES staff feels that it is extremely important to exercise that option; however, efforts to purchase new trailers or making improvements to data collection infrastructure are hampered by budgetary constraints.

DHANES staff has looked at four cost-savings options for NHANES and the concerns raised by each:

- Eliminate over-sampling -- This option could reduce costs by about \$1-2 million over two years but cost savings wouldn't be sufficient to cover shortfall and could result in the loss of collaborator funding. This option would also decrease the minority participation in the survey and make the data less useful for policy purposes.
- Reduce the number of PSUs -- Reducing the number of PSUs by 6 over the two year period would save about \$1 million, an amount with little impact on the overall budget. It would also result in larger variance estimates
- Flexible sample size -- Reducing sample size, operating only two mobile exam centers and having only one field team in year two of the two-year survey cycle would save approximately \$4-6 million. It would also delay the loss of highly-trained field staff and buy some time to gain additional funding in later years. If that funding materializes it would be difficult to come back up to full operations.
- Reduction in sample size -- Covering the current one-year sample of 5,000 over a two-year period generates considerable cost savings estimated at \$8-12 million over two years. However, that option also has a number of drawbacks, including limited 2 year estimates with larger variance estimates. The survey is also likely to lose significant reimbursable funding and lose trained field staff. In addition it will be more challenging to ramp-up in 2011-2012 if full funding returns.

The uncertainty of the 2009 budget is another problem. The survey could begin with one survey design and if funding doesn't materialize, the leadership could make major changes such as eliminating an exam team and taking longer to collect the data. This poses scientific and ethical problems in dealing with collaborators who expect a certain product delivered in a certain time frame.

## **VI. Recommendations**

As a basic principle underlying its recommendations, the Panel concluded that the NHANES program must continue. Its role is so vital and so central to the health information needs of the nation, that it should be maintained, strengthened, and supported so that it may continue to fulfill its mission. Based on the issues raised above and other observations concerning the current operation of the NHANES program, the panel makes the following specific recommendations to NCHS:

**8. *Create a Standing External Committee to Broadly Advise the Program on Methods, Content and Long-Term Strategic Planning***

NHANES would benefit extensively and in many ways by having a standing external committee to provide advice on the conduct of the survey, from development of content to survey methodology to analysis and dissemination of findings. NHANES currently has a variety of feedback mechanisms and approaches to gaining advice and guidance on the survey. These mechanisms have included topical workshops, convening of expert panels, data users' conferences, individual user feedback, and extensive consultation and interaction with collaborators who fund components of the survey. These methods have been valuable and served the program well in many ways. However, this focused, practical approach lacks a consistent, across-the-board, transparent process that could provide the strategic, forward-thinking planning that the survey needs. A truly effective overall strategic planning process for the survey would benefit from the informed advice and guidance not only from individuals and organizations supporting a specific data collection technology but those who have the depth and breadth of experience to speak broadly of public health data needs and advances and applications of survey and statistical methodology.

This external advisory group would not be focused on current operations or planning but on future requirements and opportunities. It could help the survey set a course which could enable it to better choose among competing priorities for content, all of which may be sound individually, but some contribute more to overall goals in public health and health statistics. A standing advisory group would have an advantage over ad hoc advisory bodies by having extensive knowledge of the complex survey in order for its recommendations to be both innovative and practical. With a rotating membership that includes the top survey methodologists and practitioners, this advisory group would contribute to keeping NHANES scientifically strong and dynamic.

An advisory body could consider in depth some of the pressing questions and issues which the survey faces. Among the topics that an active advisory board could address would be long-term planning for content and systems for deciding and prioritizing content areas. The advisory group could also consider the possible modes for a longitudinal component and how that might be instituted from simple systems of linkages to on-going follow-up of survey respondents. The advisory body could also give guidance on the possible integration of NHANES with NHIS and how to set the parameters and priorities for such an integration.

In addition, issues unique to NHANES such as maintenance of its infrastructure could also benefit from external review and advice. An issue which deserves more deliberate review is the possibility of instituting some form of users' fees for NHANES data. An analysis of the potential market for NHANES data would be a first step in exploring the advisability of providing the NHANES data products on some type of user fee basis. Consideration should also be given to whether a user fee structure would inhibit the wide use of the NHANES data sets. With

NHANES data used extensively by industry in everything from product development and testing to marketing, a possibility of generating income from the data used by profit-making entities should at least be considered. NHANES as well as other NCHS data are viewed as in the public domain and wide use of the data by all types of data users is encouraged. However, other agencies have adopted a hybrid approach which allows free distribution to some users and a fee basis for others. In times of severe budget limitations, this idea is worthy of further study.

An advisory body would not only advise but could also advocate. It is expected that members of an advisory body would be leaders in public health and have opportunities to speak on behalf of the survey and/or promote the survey to various audiences, programs, or organizations outside of or in addition to the survey's usual contacts. The advisory body could advise NCHS and DHANES on methods to increase support from the unique perspective of the individual members of the body and the body as a whole. The advisory body could increase the knowledge of the survey among key decision-makers and could provide its knowledge and awareness to sharpen and improve the survey's own marketing efforts. To assemble the best advisory group, DHANES could seek recommendations from a variety of professional associations, as well as key leaders in the health community. The advisory body would be an effective networking tool, putting NHANES in touch with others in the field and expanding NHANES's already broad knowledge of who's who in health statistics and public health.

9. ***The NCHS Director's Office Should Continue to Aggressively Market the Expertise and Products of the NHANES Program to Current and Future Data Users and Potential Funders***

NHANES is a unique information resource that is under-appreciated and undervalued. Most current users recognize the worth of the data from NHANES, however, other potential users are not aware of the high-quality data resources that are available from NHANES. NCHS and DHANES need to develop a systematic and high-level marketing initiative to bring NHANES to the attention of both current and potential data users and funders. While not requiring a "Madison Avenue" approach, the marketing initiative needs professional marketing expertise to develop the overall marketing strategy, assist in seeking out and planning specific marketing opportunities, design effective marketing materials, translate materials for selected audiences, and transmit and communicate appropriately with various audiences for measurable and effective results. DHANES staff can provide extensive information for this marketing effort. For example, the numerous examples of the use of NHANES data for public health policies in prevention and intervention could alone make the case that NHANES data are essential. On the reverse side, NCHS should be able to easily demonstrate what information would not be available without NHANES data and therefore what policies and programs could not have been designed, developed, implemented and managed without those data. A theme of the

marketing campaign could be “imagine the world without NHANES” and it should have a level of urgency befitting that possibility.

Further, there needs to be a direct link from data to support for data. NHANES data are not a public good which exist without a complex organizational structure and resources to support that structure. Without continuing and substantial support, NHANES cannot continue to provide the information that it alone can produce. No other Federal survey (and certainly no private endeavor) currently produces the range, type and quality of information that NHANES has generated and continues to generate even under severe financial pressures. NHANES has done some outreach to potential funders, but has stopped short of having a full-scale marketing endeavor utilizing all of the types of funding mechanisms including indirect support such as that through the CDC or other foundations. The audiences for a marketing initiative are both internal and external. NCHS needs to make sure that CDC and HHS are among the organizations fully supporting NHANES and willing to make that support known and visible. NCHS must also identify sources of external support, working with stakeholders to expand their interest in narrow components of the survey to a more generalized support of the survey in its entirety. The survey will not thrive in the future as just a collection of separate components.

As a marketing tool, DHANES should create a categorized bibliography of publications resulting from the use of NHANES data to illustrate the many and varied uses of the data and the vast array of applications of NHANES findings in policy development, public health and medical research, prevention and education. NHANES can be credited with a plethora of landmark findings, just the simple listing of which is impressive. A NHANES bibliography would be extensive and somewhat daunting. Alternatively, DHANES might consider maintaining links on the website to articles published in the past 5 years or so. Another possibility is to create a statistical summary of articles by publication year, general content area, and journal. The marketing effort could also be boosted by information which quantifies the impact of NHANES, for example, a count of grant applications which utilize NHANES data.

Efforts are underway to celebrate the 50<sup>th</sup> anniversary of NHANES later in 2009 and this should offer the opportunity to showcase the survey and its findings to old and new audiences. The participation of health VIPs in anniversary events can enhance the visibility of the survey. NCHS must take advantage of naturally occurring opportunities to promote the survey and, in places or times when none exist, create the opportunities to advance the survey and its contributions. Promote NHANES not on the basis of what the survey needs to survive, but on the basis of public health’s need for NHANES. The direct users of NHANES data and those who indirectly benefit by having good data available for sound public health policy must be energized to act on behalf of NHANES. NCHS must enlist the public health community, professional associations, industry and others to support and “lobby” for the sustainability of NHANES. The Friends of NCHS, an active group advocating for a strong national vital and health statistics program, would certainly be an important source of support.

**10. *Conduct a Thorough Retrospective Review of the Realized Statistical Benefits of Oversampling Population Subgroups for NHANES Samples Since 1999***

NHANES has a long history of oversampling subgroups in the population, identified by age, race/ethnicity, gender and income. The oversampled populations have varied over the survey but once in the sampling frame they have tended to remain there. The primary objective of the oversampling is to reach sufficient numbers to produce data on specific topics. Oversampling has been subject-driven and designed to produce reliable results for specific survey components. Another reason for oversampling has been to meet the need for data on specific minority populations for several high-priority government programs, including the various phases of the Healthy People initiative and the programs and policies to eliminate or reduce disparities developed by the Department of Health and Human Services. Oversampling to produce reliable data on specific topics for specific groups does not come without some detrimental effect on the representative quality of the findings for the NHANES national sample as a whole. Specifically, nominal gains in subgroup sample sizes may be offset by losses in precision due to sample disproportionality.

DHANES has not undertaken an overall assessment of the oversampling process and the impact of oversampling on the survey's statistical effectiveness as well as the competing benefits and costs in terms of survey design, operations and data analysis. Certainly oversampling adds to the complexity of the survey in its operations, for example in screening the correct mix of survey respondents in each of the geographic areas. Oversampling also requires complex weighting formula to be applied in the analysis of findings. On the other side, many data users support the oversampling and the data the survey can then produce on selected groups at risk or targeted for special policy and program initiatives.

The survey is overdue for a retrospective evaluation of oversampling and an assessment of whether the current oversampling scheme meets current needs for data in terms of appropriate subpopulations, geographic patterns, and current and emerging health issues. DHANES is often asked to include race/ethnic groups not currently oversampled nor for which the survey can produce a reliable estimate. These groups include Asian/Pacific Islanders and American Indian/Native American as a total group or specific tribal entities. In the past, when NHANES addressed the data needs for Hispanics (Mexican Americans, Cuban Americans and Puerto Rican Americans) the survey developed a targeted survey of these groups and conducted the survey in three areas of the United States. DHANES should also evaluate oversampling vs. targeted special surveys to reach specific groups or address specific topics. It is appropriate for NHANES to view oversampling not as an integral aspect of the survey but as a design decision which needs to be evaluated anew in light of not only the survey's current role but its future obligations.

**11. *In Collaboration with the American Statistical Association and Other Scientific Organizations, Create a Workshop to Examine the Relative Statistical and***

***Operational Utility of USPS Delivery Sequence Files for Household Enumerations for NHANES***

The enumeration of households for the NHANES sample is a costly and time-consuming process. There are now other sources available for household listings including USPS Delivery Sequence files and other commercial databases, some of which various surveys are using either for the entire sample or to supplement enumeration processes. To explore the use of these alternative sources, DHANES should consider co-sponsoring a workshop on potential ways to utilize these other sources. The Panel does not recommend that DHANES take the lead in creating this workshop. Instead, the workshop could be held in collaboration with Survey Research Methods and Government Statistics Sections of the American Statistical Association, the Census Bureau, as well as other large survey research organizations to find ways to improve the cost efficiency and screening efficiency for area probability sample recruitment. NCHS may want to consider having this be a centralized research activity and its Office of Research Methodology could coordinate the workshop and related research.

***12. Continue to Explore the Possibilities of NHIS-NHANES Design Integration in a Way That Will be Beneficial to Both Programs***

NHANES and NHIS are conducted by NCHS, both began about 50 years ago and both measure the health of the U.S. population. They have produced a broad array of widely used data throughout that time, but both now face severe budget limitations. The household sample has been cut repeatedly for NHIS, training postponed and other economies instituted. NHANES faces similar budget challenges. Integrating the surveys could be helpful in reducing survey operational costs and a well-designed integration could enhance the analytical potential. One approach is for the larger NHIS sample of households in overlapping PSUs to supplant the need to sample and screen households as currently required by NHANES. The integration of the two surveys needed to be looked at from the point of view of the goals and objectives of NHIS and NHANES to determine whether the goals of both surveys can be achieved in an integrated survey, and if not, what goals can be compromised.

At this time, NCHS has established three groups: one each to study conducting the NHIS and NHANES separately and one to study the potential, benefits, costs, difficulties and issues in combining the surveys. It is recognized that survey integration may require some structural design modification to either or both samples; organizational cooperation/coordination between Census (for NHIS) and Westat (for NHANES) would also be required. Planned redesigns for both NHIS and NHANES are to be implemented at about the same time (2012/2013) and thus timing is optimal for an in-depth evaluation of survey integration to input into the design process for each survey. For both surveys it is mandatory that the scientific integrity be maintained and that the integrated resulting survey (if recommended) be an enhanced survey program that can build upon the strengths of each survey. An integration plan also needs to address administrative issues and the feasibility or advantages of administration integration. Could both

surveys benefit from combining administrative functions as well as scientific programs? Some years earlier NHIS and the Medical Expenditures Panel Survey (MEPS) conducted by the Agency for Healthcare Research and Quality were integrated (the NHIS sampling frame was used for the MEPS) but the analytical potential of the integration was never achieved and NHIS has not benefited particularly from this move. Thus, it is imperative that an integrated NIHS/NHANES would benefit both programs and achieve a cost savings of sufficient magnitude to make the efforts to integrate worthwhile.

**13. *Continue Pursuing Opportunities with Larger States and Municipalities to Utilize Portions of the NHANES Sample to Also Meet Local Health Information Needs***

There is an essential and well-recognized need for state and local health data for policy development, program planning and administration, monitoring progress and measuring disparities at the local level where many policies are set, decisions made and resources allocated. Some of the data needed at the local level are collected and analyzed by State and local governmental entities or private sector organizations, foundations, and academic institutions. National data collection efforts such as the Center for Disease Control's Behavioral Risk Factor Surveillance System produces state and local data based on telephone interviews with state-based samples. However, there is a need for more information and better information in terms of quality, depth and breadth, at the state and local level than is produced at the present. NHANES has a nationally representative sample and was not designed initially to generate findings for State and local areas. With its clustered sample design, NHANES is not conducted in each state but does return to some selected areas—states and cities—frequently and over time can produce reliable estimates on certain health measures. For example, NHANES is conducted in Los Angeles each year and may have several survey locations throughout California in a year or two. Data can be grouped over a multiple-year period to increase the sample size and improve the precision of estimates. NHANES is now working with health officials in Los Angeles to explore that potential. At least initially, conditions with relatively high prevalence and of major importance, such as hypertension, diabetes, and heart disease are likely candidates for analysis at the local level.

DHANES should continue to explore the use of NHANES data for certain large states and municipalities. This may require occasional sample size supplementation or use of a sample design where PSUs are self-representing areas. Currently there are a number of self-representing PSU's in the NHANES sample. The NHANES sample design has the flexibility to adapt to local needs. With limited resources both at the national level and in local communities for the production of health information, local areas may be able to efficiently and effectively "buy" NHANES data thus generating resources for the overall survey while providing local estimates at a greatly reduced cost compared to independent locally-based survey operations. While some work has already taken place, DHANES should increase its efforts to explore the efficiencies of utilizing a portion of the NHANES sample in major state and local jurisdictions to supply

information needs at both levels. There may also be possibilities to share revenue sources and identify new and creative revenue sources that may not be available to a Federal government agency operating without a local partner.

#### **14. *Continue to Seek Mechanisms to Add Longitudinal Follow-up of NHANES Cross-Sectional Respondents***

There is continuing interest--both internal and external--in conducting a NHANES longitudinal survey. While the analytical value of such a longitudinal component is generally considered a given, DHANES should document the relative benefits of a longitudinal component vs. cross sectional surveys. It must be clear what the main objectives of the longitudinal survey will be and the sample size requirements to obtain measurements that help achieve the goals. The desirability of the longitudinal component should be weighed against the impact that conducting this additional component would have on the on-going survey. The resources, both staff and funding, for a longitudinal survey are substantial and should be considered carefully in light of the current demands to keep the cross-sectional survey in the field with sufficient staff to manage the operational and analytical aspects. The statement of benefits could lead to the identification of logical mechanisms to add a longitudinal component and ways to support that mechanism. DHANES could explore mechanisms for shared funding with NIH, for example, adding value to the type of epidemiologic research funded by NIH. On another point, care needs to be taken in defining a process where longitudinal surveys are interspersed with cross-section studies. NHANES sponsors, collaborators, and data users both in the policy arena and scientific community have come to depend upon the early and regular release of findings from the survey. The continuous form of survey operations and the continuous and frequent release of data have proven to be very critical for policymakers and researchers and it is possible that survey supporters could withdraw support if they could not count on a constant flow of findings. However, additional survey staff might make it possible to operate both a cross-sectional survey and longitudinal components simultaneously. The scientific merit of a longitudinal program commands the continued pursuit of a possible mechanism for mounting a longitudinal survey while preserving the essential elements of a cross-sectional survey.

## **VII. Conclusion**

NHANES is a critical component of the nation's health information systems. NHANES is a survey that is essential and it must not be allowed to be eliminated, diminished or in any way recede from its enormously important mission. For nearly 50 years, it has produced data that have directed national health policies and programs and resulted in improved health for all Americans. Now the survey faces challenges in funding, survey design and operations. How it gains the resources necessary for updating its aging physical infrastructure, marshals its user community and sponsors, considers innovative designs, and responds to new and emerging data needs will determine how well the survey's legacy will be carried into the future. This is a critical time for reviewing and

rethinking NHANES. DHANES and NCHS have an opportunity--driven by necessity, but nevertheless a real opportunity--to help NHANES achieve new accomplishments that can even surpass its past contributions. With the nation facing escalating chronic disease rates driven by modern life styles of poor health habits, NHANES data will be even more useful in finding the intervention points and directing prevention strategies. The nation's health care system, struggling under the burden of providing care in tough economic times, will need the best information possible to deliver health care for millions. A global health environment means that NHANES data will be more important than ever before in monitoring existing and emerging infectious diseases. NHANES has the scientific capacity to do this and more but the survey needs to be supported at the level commensurate with its important mission.

#### Attachments

1. Examples of Recent Unpublished Methodological Reports by NHANES Staff
2. NHANES Review Panel Membership
3. NHANES Review Panel November 11-12 Meeting Agenda
4. Procedures for Reviewing NCHS Programs
5. Documents received by NHANES Review Panel

#### References

1. Pfeiffer DM, Cook JD, Mei Z, Cogswell ME, Looker AC, Lacher DA, Evaluation of an Automated Soluble Transferrin Reception Assay on the Roche Hitachi Analyzer and its Comparison to Two ELISA Assays *Clin. Chim. Acta* 2007; 382:112-116
2. Prineas RJ, Ostchega Y, Carroll M, Dillon C, McDowell M. US demographic trends in mid-arm circumferences and recommended blood pressure cuffs for children and adolescents: data from the National Health and Nutrition Examination Survey 1988-2004. *Blood Press Monit.* 2007; 12:75-80.
3. Ostchega Y, Prineas RJ, Paulose-Ram R, Grim CM, Willard G, Collins D, National Health and Nutrition Examination Survey 1999-2000: effect of observed training and protocol standardization on reducing blood pressure measurement error. *J Clin Epidemiol.* 2003 Aug; 56(8): 768-74
4. WESTAT report: Dohrmann, S, Han, D., and Mohadjer, L "Using Purchased Address lists for use in area samples: research for the NHANES" January 6, 2009