OBTAINING RESPONDENT
COOPERATION ON NHANES III

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1. PURPOSE OF THIS MANUAL

The Home Study Package and Interviewer's Manual reviewed during the first week of training provided you with the basic information you need to understand the study and perform your work. We want to emphasize again that it is very important to know the study. So be familiar with the following sections and components of the Interviewer's Manual:

- The history and goals of the NHANES program (1.1)
- NHANES III (1.2); and
- The survey forms, documents, and procedures discussed throughout the manual.

In this handbook we want to focus on you, the interviewer, because you are the backbone of this very important survey. How well we do is going to depend on how well you do. Out in the field, you are the primary contact point between respondents and the survey. So we want to focus here on some particular aspects of interviewing that are essential to obtaining the highest degree of respondent cooperation possible. Our discussion will be divided into two basic sections:

1. Your introduction at the door prior to conducting the Screener; and
2. Completing the interview and making the MEC exam appointment.

These sections each represent a "stage" in the interview process, and for each stage, we will discuss the following kinds of issues:

- Techniques and methods of successfully obtaining respondent cooperation. We have compiled these guidelines from our own experience and the advice of experts in sales and public relations, and we think that they represent a powerful inventory of approaches that have a record of success.

- Your own attitude and appearance. This is so important because respondents take their cue about how to view the study from how they view you. In fact, even if all your explanations and assurances about the study don't convince someone to participate, they might do it anyway just on the strength of how you come across.

- Materials. These include your ID badge, brochures, fact sheets, business cards, and other materials that play an important role in creating a positive attitude towards participating in the survey.

- Detailed information about why each component of the MEC exam has been included. You need to be well-informed about the MEC exam in order to answer respondent questions, allay their fears, and in general come across as a professional, competent member of the study team.

- Responses to questions. Here we'll go through examples of questions you might be asked about the survey, and some ways you can answer them. Although you should be familiar with these responses, one of the keys to successful interviewing is to be flexible and aware. Don't respond to questions with memorized answers, but talk to your respondents as people who have real concerns.

- Special target groups. For certain respondent groups, you will want to gear your approach to accommodate their particular needs or just to communicate in a relevant way. For example, older persons might have more trouble in terms of transportation to and from the MEC, and might require more time to answer the questionnaire or go through the exam.

2. INTRODUCTION AT THE DOOR

Your first task is to introduce yourself, the survey, and convince the respondent to cooperate in answering the Screener Questionnaire -- all at once. Because you have a number of purposes entwined in this initial introduction, it is very important that you are prepared, know your role, and know the resources you have at your disposal to help you successfully fulfill that role.

On the Screener there is a printed introductory statement:

INTRODUCTION: Hello, I'm __________ and we are conducting a survey for the U.S. Public Health Service (SHOW ID CARD). A letter was sent to you recently explaining the survey, which is called the Health and Nutrition Examination Survey and is about your family's health. (IF RESIDENT DOES NOT REMEMBER LETTER, HAND NEW COPY.) All the information that you give us will be kept in the strictest confidence. Your name will not be attached to any of your answers without your specific permission.

Use this to start your presentation. Learn it well enough so that you are not reading it mechanically. In some cases the introduction in conjunction with the advance letter received by the household will be enough to convince the respondent to participate. In other cases, you must be prepared to go further. This is where the techniques and resources we will discuss in this manual come into play.

2.1 The Interviewer (YOU) as Focal Point

You have undoubtedly seen commercials where a celebrity is speaking for a product. Advertisers do that because if the potential customer doesn't know the product, they will at least identify it with the spokesperson, and if they admire or like that spokesperson they're more likely to buy the product.

We're working on the same principle. The concept of "a study" or "a survey" is often too abstract for people to have any feeling about it which would motivate them to participate. So, this is where you step in. You become the spokesperson, the personification of the study, and if respondents get a good feeling about you, they're likely to have one about the study.

RULE OF THUMB: You are the study -- IN PERSON. If you remember this you'll see why it is important for you to:

- Be enthusiastic about the study.
- Make it clear that you are committed to the project, and that you think it is worthwhile and important.
- Present a neat, clean, professional appearance. This is important not only for the respondent, but because even in walking around the neighborhood you present an image that will be picked up and possibly talked about among neighbors. You're a public person.
- Know the study. If you come across as confident and knowledgeable, respondents will be inclined to trust you, including your answers to their questions and your assurances about their fears.
- Be organized, and have all the materials you need. Again, this helps you to appear competent and knowledgeable.

- BE ON TIME. If you have scheduled an appointment, be there when you say you're going to be there. Doing so conveys the impression that you are "on top of things" and trustworthy, and also that your respondent is important.

SECOND RULE OF THUMB: Your respondents are people with lives, concerns, goals, values and fears just like you. So:

- Be sensitive to the respondent as an individual, as a person. Try to get a sense for who they are by paying attention to their particular living situation, their response to you, any physical limitations you notice (e.g., among the elderly), and so on.

- Show your concern in the way you answer respondent questions, conduct the interview, or even carry on small-talk.

- Be friendly, courteous, and helpful.

2.2 General Approaches and Techniques

Here are some "techniques" and approaches that will be helpful to use during your introduction:

1. IDENTIFY YOURSELF CLEARLY: Make sure your respondent knows exactly who you are, whom you represent, and why you are there (i.e., ID card, business card, Screener brochure).

2. SELL YOURSELF: As we mentioned in the last section, and as sales professionals teach, a buyer must be sold on the seller as much as the product. Honesty, integrity, sincerity, empathy, concern, knowledge, professionalism and a positive image motivate people to respond.

3. GOOD RAPPORT: Sometimes, offering compliments about the person's house, children, etc., is a good way to establish rapport. But remember to make your contact with the respondent friendly, while at the same time professional. Also, be sensitive to the person's living situation, and show concern for any special needs or questions they might have.

4. YES-ANSWER QUESTIONS: Try to ask questions of your respondent that will elicit a "YES" response. If a person agrees with you at various points during your presentation, it will be harder for them to say "NO" at the end. Examples of YES-answer questions could be:

   - "Would you agree that improving the nation's health care is an important goal?"
   - "Would you agree that to improve health care, we need to know what kinds of problems people are having?"
   - "In order to really understand the kinds of health problems people are having, we need the most complete and accurate information possible, wouldn't you agree?"

5. LET RESPONDENT SET PACE: Don't use first names unless the respondent tells you to; let the respondent be the guide as to how informal you are, or how fast you go.

6. BE "ON YOUR TOES": Be confident, reassuring, and ready to react promptly to a respondent's cues. Don't get into a "set interviewing routine" that keeps you from dealing with each respondent's individual concerns.

7. FOCUSING ON THE RESPONDENT: Don't be self-conscious, rather, focus attention on the respondent. Use good eye contact and ask questions to draw out respondent's concerns, then translate survey in terms of how it will meet those concerns. Be sincere, listen intently, and watch body language. When someone expresses lack of interest don't be frightened away. This person is usually the easiest to convince once you uncover their primary objection. Pretend you don't hear negative comments; generally people are only using this as a tactic to delay making a

decision. You might nod and say "I understand" and continue your presentation. Be kind, not defensive. Be complimentary, not hostile.

8. THE RESPONDENT IS NEEDED: Make the respondent feel as if they are a needed, valuable part of the study; that the study is a cooperative effort towards the attainment of shared goals and mutual benefits .... "We can work together to help improve the kind of health care available for your family as well as others across the country."

9. "JOINING WITH THE NEIGHBORS", OR, THE CIVIC PRIDE APPROACH: People often decide what is right to do based on what others do. So, it can be helpful to mention that other families in the neighborhood are participating, or if you know that any important local leaders ("the mayor", etc.) are doing so .... "You can join (many of your neighbors, Mayor Jones, etc.) in helping with this important work." This can be especially useful in neighborhoods with a strong sense of community.

   You can also point out that studying people in the stand location (e.g. Silver Spring, McAllen, Los Angeles, etc.) contributes important information that will become part of the national health picture.

   And, mention that over the last 25 years, more than 70,000 people have participated in NHANES surveys.

10. START QUESTIONNAIRE AS QUICKLY AS POSSIBLE: Try to get started with the questionnaire as quickly as possible; once you begin asking the questions, the respondent may see that his/her fears about the interview are unfounded.

11. KNOW THE STUDY: Above all, be thoroughly familiar with all study materials so that you can readily answer a respondent's questions about the survey.

2.3 Materials

Your Interviewer's Manual (Section 2.1) generally describes all the materials you will be using. Here we want to focus on those that are specifically intended to help in obtaining respondent cooperation by introducing yourself and the survey to respondents.

Make sure you are familiar with all these materials so that you can use them when most helpful to your presentation.

- Advance Letter (in English and Spanish) -- This letter introduces the survey and requests the respondent's participation. In most situations, the home office will send a letter to each address just before you are assigned the case. In some areas, however, the addresses will not be adequate to mail the letter. In those cases, you will present the letter during the first contact with a household member. Make sure that each household has received an advance letter either in the mail or directly from you during your introduction.

- Screener Brochure (in English and Spanish) -- This brochure contains a brief description of the study and provides answers to questions respondents may have about the study. It emphasizes that eligible respondents may be asked further questions related to health and nutrition. It does not include information relevant to the specifics of NHANES III Sample Person participation. You should have this brochure available to hand out to an eligible Screener respondent.

- Call-Back Card (in English and Spanish) -- The call-back card is left when no one is at home at a sampled address. It briefly describes the study and tells the respondent that you will return.

- Identification Badge (English only) -- This photo ID verifies that you are an employee working on the study.

- Business Cards (English) -- Each interviewer will have personal business cards with your name, title (Health Representative), and the name of the study preprinted on each.

These materials are useful in establishing the legitimacy of the study (and you as a representative), providing information to help the respondent realize the importance of his/her participation, and notifying the respondent of your return in the case that s/he is not home.

The Advance Letter, for example, which is on official NCHS stationery, not only provides information about the survey, but also helps in creating a sense of legitimacy, since it shows that you are part of a planned study conducted by a government agency. The respondent will have received this letter before you arrive, or if not, you can present it to him/her at the door.

Now suppose the respondent expresses some hesitancy about who you are. Your Identification Badge, which you should have clipped to your lapel, will help here. At this point, you can also hand the respondent a Business Card, which has your name, the name of the study, and your title of Health Representative printed on it.

If the respondent expresses concern about the nature of the survey, hand him/her a Screener Brochure, which briefly describes the study, and gives them something to look at while you describe it verbally (also briefly). Remember that the Screener Brochure is different than the Sample Person Brochure which we will discuss in Section 3. The Screener Brochure does not include information about the extended interview and medical examination.

If no one is at home, leave a Call-Back card, which notifies the household that you will return and briefly describes the study.

2.4 Answering Questions

Although in most cases the introduction is all you'll need to gain the respondent's cooperation, there will be times when you will have to answer questions before you begin (or during) the interview. But keep this in mind: A respondent's questions means they are interested and concerned. So, you need to be prepared to answer in ways that respond to that interest and concern. Questions are not obstacles but opportunities.

Listen to the respondent's questions and answer by providing only the information needed to handle the respondent's doubts about you or the survey. In otherwords, make your answers brief and to the point. Don't volunteer extra information or unnecessarily lengthy explanations, because unasked for information may be misunderstood and confuse the respondent.

As we have said many times, it is extremely important that you be thoroughly familiar with the purpose and general operation of the survey so that you can answer questions accurately. You should also be familiar with the contents of the advance letter and brochures so that, when appropriate, you can point out the written answers as you respond to questions.

If you don't know the answer to a question, admit that you don't know it. Continue with the interview, but volunteer to have your supervisor call to talk with the respondent if the respondent wants you to. That's one way to project integrity. Bluffing is not.

Here are some questions respondents will frequently ask about the survey when you first introduce it, and suggested answers. REMEMBER, don't memorize the answers. These are just guidelines. In an actual interview situation you want to be flexible and personal -- that is, direct your answers to the respondent's concern instead of providing a "canned" answer ...

1. WHAT IS THE U.S. PUBLIC HEALTH SERVICE? "The U.S. Public Health Service is part of the Department of Health and Human Services. The Public Health Service contains many branches some of which are responsible for research about the health of the U.S. population."

2. WHAT'S THIS STUDY ABOUT? "This study is being conducted nationwide for the U.S. Public Health Service to find out about people's health."

   - "The results will be used to evaluate health and nutrition programs and determine the needs for health care."

   - "Over the last 25 years, more than 70,000 people have participated in the National Health and Nutrition Examination Survey."

3. WHAT ARE YOU GOING TO ASK? [SCREENER] "I am just going to ask a few questions about your family and household, so that we can determine whether anyone is eligible to participate in the survey."

4. HOW LONG WILL IT TAKE? IF ASKED BEFORE SCREENER: "The interview should take less than ten minutes -- just long enough for me to find out if I need to talk to you and your family in more detail."

5. DO I HAVE TO ANSWER THE QUESTIONS? "Your participation in this survey is voluntary. However, unless everyone participates in the survey, our information will not be as accurate. The answers you or members of your household may give, however, will be used to help develop national health policies and programs, so we hope that you will take the time to participate."

6. WILL ANYONE KNOW WHAT MY FAMILY OR I HAVE TOLD YOU? "Answers will be kept confidential and will be seen only by researchers involved with this study. All the information you give us is protected under the Privacy Act of 1974." READ CONFIDENTIALITY STATEMENT ON THE COVER OF THE SCREENER/QUESTIONNAIRE.

7. WHAT WILL BE DONE WITH THIS INFORMATION?

   - "The information you give us is put together with similar information from other respondents throughout the United States to produce totals, averages, and statistics about national health in general. The U.S. Public Health Service will then use this information to help them understand and respond to health problems and needs."

   - "Previous health studies have allowed the Public Health Service to develop growth charts. Physicians use these charts to identify health and developmental problems among children."

   - REFER TO NHANES DATA USES CARD. Example: The information will help determine the number of persons in the U.S. with iron deficiency anemia.

   - SHOW RESPONDENTS THE CATALOG OF VARIOUS ARTICLES THAT NCHS PUBLISHES.

8. HOW WAS I SELECTED? "Your address was randomly selected. By selecting households for interviews in this way, everyone has an equal opportunity of being interviewed and we are ensured of gaining a good understanding of the health conditions in (LOCAL AREA)."

9. WHY DON'T YOU GO NEXT DOOR? "Each chosen household represents many others that were not chosen, and it is very important that we get your answers so that others like you will be represented. Once your household is chosen, we are not permitted to substitute another household for yours, so only you may answer for all those other households you represent."

10. WHY IS IT IMPORTANT FOR OLDER AMERICANS TO PARTICIPATE IN THIS HEALTH SURVEY? There is little information on the health of older Americans. We need to know more about such important things as how many people have high blood pressure, or arthritis. In fact, one of the special things about NHANES III is that persons age 75 or older will be participating for the first time. We are hoping to be able to learn more about the health needs of older Americans.

11. HOW WILL MY PARTICIPATION IN THIS SURVEY HELP ME AND OTHER OLDER AMERICANS? Lawmakers, other public officials and physicians need this information in order to design better healthcare programs for older persons. Organizations for older Americans need this information to improve the quality of life for older Americans and to help them live better independently.

2.5 Refusals and Other Problems

2.5.1 Contacting a Respondent

Sometimes you will encounter problems in making contact with a respondent to administer the Screener. These problems and what to do about them are covered in Section 10.1 of your Interviewer's Manual, but here we want to reiterate just a few points:

1. If no one is home, leave a Call-Back Card (under the door, not in the mailbox). You can also leave a business card.

2. Contact a neighbor. Probe to find out when an adult household member (or, later, a selected SP) will be home. Return at that time.

3. If possible, try and complete as much of the Screener as you can from information provided by a neighbor.

4. Remember that any adult household member can respond to the Screener.

2.5.2 Refusals

Occasionally even the best interviewers receive refusals to participate in a survey. Most respondents do not refuse outright; rather, they express some hesitancy, reservation, or initial hostility. In a short time, you will become sensitive to the firmness of the "NO" conveyed by the tone and wording of the respondent's comments. You will also learn to sense the reasons behind a respondent's hesitancy and develop ways of dealing with those "hidden" concerns.

Always listen very carefully to what the respondent has to say, and then address your remarks to the respondent's concerns. Some of the most common reasons respondents give for refusing are:

- Too busy; don't have the time;
- Not interested in the study;
- Don't want to be bothered or involved;
- Waste of time and money;
- Government interference;
- "Nothing in it for me;" and
- Too ill, don't feel well enough.

These reasons reflect two broad types of concerns respondents may have: Concerns about the time you are asking them to give and concerns about the study itself or about surveys in general. You can respond to the first concern by emphasizing the importance of the study, and by persuading respondents that we <u>do</u> appreciate their contribution to the project. You can respond to the second type of concern by explaining how the

project is worthwhile, by pointing out that people making decisions on government programs need good information to guide them, or that for a survey's results to be useful, they must include information from a representative sample. Use the approaches that you learned in Section 2.2.

If you find that you are not getting anywhere with a respondent, try to end the contact before you get a final "No." However gruff or rude a respondent may be, always maintain a pleasant, courteous manner. Above all, do not antagonize or alienate the respondent. Try to keep the door open for future contacts. In most situations, your supervisor will assign another interviewer to attempt the interview. If you can leave on a pleasant note, the respondent may be more receptive to the efforts of another interviewer. After leaving the respondent, record the situation completely as noted in Section 10.1 of the Interviewer's Manual, and return the case to your supervisor.

3. COMPLETING THE INTERVIEW AND MAKING THE EXAM APPOINTMENT

Once you have completed the Screener and are either attempting to interview SP's, in the process of interviewing, or setting up examination appointments, the tasks you face will be somewhat different. The emphasis will move from creating a first impression to building confidence in the survey, fielding questions, encouraging respondents to participate with more "in-depth" techniques, and handling special SP concerns or problems.

At this stage, "your foot is already in the door". Your job now is to make sure that you obtain a quality interview (or interviews) and build up enough confidence and motivation so that the SP will follow through with the exam.

3.1 General Approaches and Techniques

As in Section 2.2, here are some general approaches that you can use when you are at this stage of the interviewing process. Although some of the approaches mentioned here are like those in Section 2.2, they are important throughout the interview, and especially when convincing SP's (other than Screener respondent) to participate who will be forming a first impression of you, and to whom you will be introducing the survey for the first time.

1. THE RESPONDENT IS NEEDED: Continue to let the respondent, and now any SP's in the household, know that they are a vital part of the study; that the study is a cooperative effort towards the attainment of shared goals and mutual benefits .... "We can work together to help improve the kind of health care available for your family as well as others across the country." .... "And by helping, you'll also receive a free medical exam and a compensation fee in appreciation for your time." (When was the last time you were paid to go to the doctor? Usually works the other way, right?) So, everyone wins!"

2. FOCUSING ON THE RESPONDENT: This approach is as useful in this stage of your interview as it was in the initial phase (see description in Section 2.2).

3. YES-ANSWER QUESTIONS: As in your initial approach, continue to ask smaller questions that get a "YES" answer, instead of a big question at the end ("Will you or will you not participate?"). The idea here is that several minor decisions are easier to make then one major decision, and that if a person agrees with you at various points during your presentation, it will be harder for them to say "NO" at the end. Examples of YES-answer questions could be:

   - "Would you agree that improving the nation's health care is an important goal?"
   - "Would you agree that to improve health care, we need to know what kinds of problems people are having?"
   - "In order to really understand the kinds of health problems people are having, we need the most complete and accurate information possible, wouldn't you agree?

4. SELL YOURSELF: Continue to sell yourself throughout the interview. This is very important, not only with respect to the Screener respondent, but to SP's and any member of the household (see description of technique in Section 2.2).

5. GOOD RAPPORT: Maintain the good rapport you started with the respondent, again remaining professional but friendly (see description in Section 2.2).

6. PARTICIPATION AS AN OPPORTUNITY: Talk about participation in the survey as an <u>opportunity</u> to help toward an important social goal (i.e., goals listed at item 3 -- YES-answer questions). Without going overboard, you can even phrase it as a "gift" -- something we are giving respondents

the chance to do. "It's a chance you don't often get to contribute directly to improving our health care."

If the Sample Person feels that his/her participation does not matter or is a personal imposition, presenting NHANES as a contribution to valuable research can be a basis for cooperation. Most people consider health research a necessity and NHANES can be beneficial not only to his/her general health but to that of his/her children and grandchildren as well as the general population of the United States. Conversely, non-cooperation can be interpreted, in effect, as a "vote" against medical research.

To assist you we have prepared a "NHANES DATA USES" fact sheet which lists a few examples of information collected in earlier NHANES and how it has been used (to be discussed in Section 3.3, Materials).

7. PERSONAL BENEFIT: Although examinees do not receive a complete physical, the personal benefit approach has been used successfully in the past. This approach is valid in that respondents do receive many of the tests performed during a regular physical examination and some that are not always included in a regular physical exam. The results of these examinations are sent to the respondent's physician and dentist and the potential value to the examinee can be stressed. It may also prove helpful to mention that such an examination at a private medical facility could cost $500 or more.

   And don't forget that examinees are given a cash payment to complete the exam.

8. SAMPLING: One of the most common objections to participation is "Why me?" Until the sampling procedure is in some way explained, the respondent may suggest "picking someone else" or "getting someone who needs it." A brief description of how s/he was selected for NHANES can be an effective persuasion tool. (See the Sample Person Brochure.)

Also, telling the Sample Person that s/he represents a number of other people sometimes puts the importance of their participation into a different perspective. The Sample Person Brochure discusses this issue. For example, you might say something like: "Since it is impossible for us to examine everyone, we use strict, scientific sampling methods - rather like a lottery - to select a 'sample group'. Once selected these people represent all the other people in different geographical areas and of different backgrounds whom we could not examine."

9. "JOINING WITH THE NEIGHBORS", OR, THE CIVIC PRIDE APPROACH: As we suggested in Section 2.2, people often decide what is right to do based on what others do. So, it can be helpful to mention that other families in the neighborhood are participating, or if you know that any important local leaders ("the mayor", etc.) are doing so .... "You can join (many of your neighbors, Mayor Jones, etc.) in helping with this important work." This can be especially useful in neighborhoods with a strong sense of community.

   You can also point out that studying people in the stand location (e.g. Silver Spring, McAllen, Los Angeles, etc.) contributes important information that will become part of the national health picture.

   And, mention that over the last 25 years, more than 70,000 people have participated in NHANES surveys.

10. FRIENDS AND FAMILY: Friends, neighbors and other relatives can be especially effective motivators, particularly if they have been successfully examined previously. Encourage the SP to contact previously examined friends and relatives who have participated as "satisfied examinees."

11. CONTACTING PHYSICIAN: If the respondent mentions that s/he would like to consult with his/her personal physician before making a commitment, do not discourage the Sample Person from doing so; rather agree that it is a good idea and then ask the SP if s/he would be agreeable to having a survey representative contact the physician to

provide him/her with further information about the program. The interviewer should then obtain the name, address and telephone number of the physician and inform the SP that the site office will contact his/her physician as soon as possible.

12. GIVING DETAILED INFORMATION ABOUT THE EXAMINATION: Try to answer all of the Sample Person's questions about the MEC exam yourself if you are sure of the answers [DURING THE DRESS REHEARSAL, YOU NEED TO GO THOUGH THE EXAM YOURSELF.] Allow yourself plenty of time for this process. If the respondent feels you are in too much of a hurry to complete the interview and get their consent to the exam, they may simply refuse to take part.

    Use your Exam Component Hand Card to show each MEC Exam component and to what age groups they will be administered. Respondents who ask for more detailed information about the examination than you can provide or that is provided in the Sample Person Brochure can be referred to the stand office staff. Respondents can discuss the examination with the MEC Manager directly from their home. If more detail is required, the stand office can also ask a MEC staff member to contact the respondent. Remember that respondents can also get very detailed information during their actual visit to the MEC.

13. QUALITY EXAM STAFF: Stress that all the exam staff are professionals chosen only after a careful review process. For Spanish-speaking respondents, mention that some of the MEC staff are Spanish-speaking.

14. LET RESPONDENTS DECIDE: Give respondents the feeling that (despite your attempts at persuasion) they are in control of their decision to participate or not, that they are not being cajoled or manipulated. Appeal to their sense of social value, civic pride and so on. Again, this works much better if you have asked YES-answer questions in which respondents assert their own views. Once they have verbalized these views, participating will feel like a personal decision (assuming, of course, that in the YES-answer

questions they agree). People are more likely to be committed to personal decisions for which they take responsibility.

3.2 Accommodating the Respondent

Sometimes the respondent may agree with all you have said about the survey, but particular problems or circumstances (such as a fear about one part of the examination, inability to take off work, etc.) lead him/her to be reluctant to participate. Here are some approaches for that kind of situation:

1. OVERCOME FEAR OR MODESTY: In many cases reluctance will be a result of fear or modesty. Most of the time, these reasons will not be admitted by the respondent. In these situations you should explain to the respondent that the examination is neither painful nor embarrassing. Women should be assured that a woman assistant is always present while the physician is performing the examinations, that garments cover the SP completely during the entire examination and that there is no gynecological exam. [There is also a woman doctor who will be on staff at half the stands. IF YOU ARE AT ONE OF THESE STANDS, MENTION THIS TO FEMALE SP'S.] Local newspaper publicity and other outreach activities may also help to alleviate anxieties in the minds of Sample Persons.

   For SP's who feel uncomfortable or fearful about coming in for the exam, mention that they can bring other family members along for support if they would like. If an older SP is coming alone, mention that s/he can bring a friend.

2. EXAMINATION CONCESSIONS: Most people cooperate fully once they are in the examination center, so you should try to avoid making non-participation in a particular test (e.g., drawing blood) a condition for being examined.

Occasionally, in the past, examination response has been obtained by making certain concessions or promises about the examination ~~or its~~ results to ~~the Sample Person~~. For example:

Surpluses

- Sample Persons who have indicated a fear of a particular procedure (e.g., blood drawing), have been assured that the procedure would not be performed if they came for the examination;

- Conversely, in other cases certain procedures have been promised to others who would not normally receive such procedures (e.g., an examinee under 60 years old receiving an X-ray);

- Results of the examination have also been mailed for the purpose of providing medical information relative to qualifying for a job; and

- Arrangements have been made for non-SP's to be examined at the request of a related SP (surplus SP's).

While there are no objections to using any of the above, they should only be used as a LAST RESORT to obtain response and not offered immediately. Whenever a concession has been made as agreement to participate in the examination, it is imperative that it be communicated to the stand office staff and the examination staff. It is the responsibility of the interviewer making the concession to verbally notify the stand office and to make a note of any concessions on the front of the SP questionnaire, the consent form, and the appointment slip; it is the responsibility of the office to make any required scheduling arrangements and inform the exam staff both verbally and in writing on the daily schedule what concessions are to be made.

When an SP requests certain concessions, it is important that the interviewer be able to explain any limitations in granting the SP's request. ~~For example, examination findings normally are not provided directly to the SP but only to his/her personal physician or health care provider;~~ that our physicians cannot prescribe medication or treatment; that our examination is not a certification of health, etc.

NOTE: Since all concessions must be discussed during the call to the field office to schedule and confirm the appointment, any problems can be determined at this time. Any concessions agreed upon should be noted on the appointment slip and the consent form copy left with the respondent.

3. FLEXIBILITY IN MAKING APPOINTMENTS: For SP's with busy schedules, either at home or work, remember that there are evening and weekend appointments available, SUBJECT TO NHANES III APPOINTMENT GUIDELINES ASSOCIATED WITH FASTING RULES (I.E., STANDARD OR MODIFIED).

   In addition, to ensure privacy for disabled SP's, they can be scheduled for exams at times when the MEC is least busy.

4. NOTIFYING EMPLOYERS: A Sample Person may be reluctant to miss work either because of loss of pay or because work absence may be a mark against him/her. A visit or telephone call to the employer, with the SP's permission, might solve this problem.

   Inform the SP that _if_ (and _only_ if) s/he would like, the office can contact his/her employer to explain the nature of the survey and the need to examine this individual. If the respondent is willing to let us make the contact, you should obtain from him/her the name, address, and telephone number of his/her employer and the name of his/her immediate superior or anyone else s/he so designates for us to contact.

5. NOTIFYING SCHOOLS: A youth or his/her parents or guardians may be genuinely concerned about missing classes either because of the difficulty involved in making up assignments or because of school regulations. If Saturday or evening scheduling is not feasible, the principal, a teacher or a counselor may be able to excuse the youth from certain tasks and/or persuade the youth to make up an assignment at a later date.

Inform the SP that the office can provide him/her with a letter, to be presented to the school, explaining the nature of the survey and the need to examine this individual. If the respondent or his/her parent or guardian is willing, explain to him/her that a school excuse letter (see Exhibit 3-1) will be sent along with the reminder letter. This form should be completed by the parent or guardian and sent to the school. If further contact with the school is required, the site office can make arrangements to do so upon notification.

6. CHILD CARE: If the respondent indicates that s/he could go to the examination center but has child care problems, point out that s/he will be reimbursed at the examination center for baby-sitting expenses incurred during the visit to the MEC.

7. TRANSPORTATION: Emphasize that transportation is either free or reimbursed. For SP's that are concerned about coming to the MEC by taxi, mention the name of the taxi service to assure the SP that it is a "known company". If you <u>still</u> sense some reluctance by the SP, then tell them that you or another staff member can drive them. If a staff member other than yourself will be driving the SP, give the staff member's name ("Donna Jones will be picking you up at...").

3.3 Materials

During this stage of the process, the following materials are helpful, in addition to those described in Section 2.3 of this Manual:

- <u>Sample Person Brochure</u> (English and Spanish versions) -- The Sample Person brochure contains the following:
  - Description of the study and why it is special.
  - Explanation of how NHANES has made a difference in health care policy.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Center for Health Statistics
3700 East-West Highway
Hyattsville MD 20782

Exhibit 3-1. School Excuse Letter

Dear Principal:

Please excuse the below named student from class to participate in the National Health and Nutrition Examination Survey of the U.S. Public Health Service. The date and arrangements we have made for transportation are indicated below.

NAME ______________________________

DATE ______________________________

☐ Parent will pick up.

☐ Taxi will pick up.

☐ One of our representatives will pick up.

☐ Student will leave from home.

Thank you for your cooperation and your appreciation of the valuable contribution this student is making to our study. If you need to contact us, please call __________________.

Sincerely,

____
Stand Manager

As parent/guardian of the above named child, I consent to the arrangements indicated.

____
Signed (parent/guardian)

PHS 6227-1
12/87

- Endorsements.
- Questions and answers about the study.
- The MEC Examination Consent Form, on the last page of the brochure. Remember that no exam can be given without the SP's consent, so you need to be sure SP's fill out this form and sign it (or have proxy sign it). If an SP will not do so during the interview, they can also sign a consent form at the MEC.

Interviewers should have this brochure available to hand to an eligible respondent upon completion of the ~~Screener.~~ questionnaire

Whenever home exams are to be offered, you will also have a Home Exam Fact Sheet in the Sample Person Brochure, which explains what the home exam includes, and the amount of compensation to be paid ($15).

- Diabetes Fact Sheet (English and Spanish version) -- USE FOR AGES 40-74 ONLY. This fact sheet provides you with diabetes data. It is intended to help you persuade respondents to follow their fasting instructions and take the GTT at their appointed time.
- HANES Data Uses Sheet (English and Spanish version) -- This fact sheet provides you with examples of information collected on previous HANES surveys and how the information has been used to the benefit of the U.S. population.
- MEC Exam Component Card (English and Spanish version) -- Lists all MEC Exam components, and what age groups will receive them.
- AIDS Card (English and Spanish version) -- A card assuring respondents that the AIDS test is completely anonymous, and that there is no risk of AIDS from any procedure in the MEC exam.
- Certificate of Appreciation (English and Spanish version) -- This certificate is given to each SP at the household after s/he has scheduled an examination appointment. It is signed by the Assistant Secretary of Health and the Surgeon General.

- Materials for the Elderly (English) -- These include booklets and other publications of the National Institute on Aging which discuss the health concerns of older persons, how older persons can actively maintain and improve the quality of their health, and listings of resources for more information about these topics.

- Selected Pages from the American Journal of Public Health (English) -- Includes an editorial describing NCHS health surveys as the "very core of public health", and an article on diabetes that discusses the significance of findings from NHANES II.

- Catalog of Publications of the National Center for Health Statistics (English) -- Lists NCHS publications, including those based on past NHANES studies, and shows how any of these can be ordered.

The brochures, fact sheets, and data use sheets contain information that helps the respondent understand how s/he fits into the public health process, and how important his or her participation is. Printed material of this nature also helps reinforce legitimacy.

At this stage of your interview, you will be turning to the SP's in the household, who may also (if different from the Screener respondent) want to know what the study is about. As you verbally describe the study, hand the SP the Sample Person Brochure, which provides a description of the study, what they will be asked in the interview, and information about the MEC exam. You can also show the SP the MEC Exam Component Card, which lists all MEC exam components and what age groups will receive them. Now suppose on seeing all this, the SP shakes his/her head and says "Oh, I don't know. I don't really see why I need to go through all this." You could then hand the SP the NHANES Data Uses Sheet and (IF 40-74 YEARS OLD) the Diabetes Fact Sheet, explaining how important the study has been in the past to

public health programs, and, for example, the surprising fact that so many people have "hidden conditions" like diabetes without even knowing it.

You also have, as additional materials to be handed out, a selection of pages from the American Journal of Public Health which contain a discussion of how NCHS health statistics are so vital to the development of public health programs, and how past NHANES data has been useful in evaluating how much of a national health problem diabetes is. And if respondents are interested in how the data from NHANES III will be used, or in more specific uses of past NHANES data, the Catalog of Publications of the National Center for Health Statistics shows them how to order reports and other publications based on this data. Again, these materials serve as "evidence" that the study in which they are being asked to participate is an important one.

For older SP's you will have available several pamphlets and booklets, published by the National Institute on Aging, on health problems of older persons. These are not specifically about NHANES, but can be used to emphasize that NHANES III is especially concerned with the health of older Americans, and in this way make an older SP feel that s/he has more of a personal stake in participating. For example, if you sense some reluctance by an older SP, either before completing the Household Adult Questionnaire or when setting up an exam appointment, stress that one of the most important goals of the study is to obtain more and better information about the health of older Americans, and then give the SP one of the publications, explaining that "already we are beginning to be more aware of ways in which older persons can improve their health, as this pamphlet shows. The current study will do a lot to improve that awareness." You can also refer the SP back to the SP Brochure for more general statements abut the importance of the survey.

Something to remember when giving out brochures, fact sheets, pamphlets, or other materials: Giving something to the respondent is one way of showing sincerity and good will, and can help motivate the respondent to "return the favor" by participating fully.

If respondents are concerned either about exposure to AIDS during one of the MEC exam procedures, or about access to their AIDS test results, read and hand the AIDS Card to the SP, which explains the need to test for AIDS, and that blood tested for AIDS will not be personally identified in any way -- even to researchers -- so that no one, including the SP, will know the results of any individual's test. The card also assures the SP that s/he cannot get AIDS from any procedure done in the MEC. Refer to your Interviewer's Manual Section 8.4, for more specifics on how to handle questions on AIDS.

When an SP has set up a MEC exam appointment, present him or her with a Certificate of Appreciation, which is both a message of thanks and an acknowledgement of the respondent's importance to the survey. Because it is signed by the Assistant Secretary of Health and the Surgeon General, it is also a tangible reminder of the importance of participation and the official nature of the survey, and will help encourage the SP to follow through with his/her exam.

All the materials we have discussed in this section and in Section 2 work together with your own presentation to strengthen your case for respondent participation. To remind yourself how these materials can be an integral part of your "persuasive repertoire", refer back to Sections 2.1, 2.2, 3.1 and 3.2 of this manual, which discuss your role as an interviewer, and techniques, approaches, and strategies you can use.

3.4 MEC Exam Components

You will need to be knowledgeable about the exam components so that you are able to answer questions. If the questions are too technical, refer the SP to the field office. We will cover some essential facts here, but your Interviewer's Manual (Section 8) has more details.

The exam has the following general components, but the particular tests will vary depending on the person's age (see Exhibit 3-2):

- Physician Exam - A physical exam which includes blood pressure measurement, examination of the skin, heart, lungs, and joints. It does not include a gynecological exam.

- Blood Test - A number of analyses are done on blood samples. These include hemotology, hepatitis test, a test for the AIDS virus (not in Dress Rehearsal), and analysis of vitamins, glucose, cholesterol and selected hormones.

  The blood test will include what is called Glucose Tolerance Test (GTT). This is the most important test for diabetes, a major national health problem. It is a fairly involved test, and will be administered to all adults between 40 and 74 years old. Before taking this test, sample persons will have to fast -- either for 6 hours or 10-16 hours depending on which version of the test they are assigned. But, for both versions, when they come into the MEC, a blood sample will be taken, then they will drink a sweet, juice-like drink. Two hours later another blood sample will be taken. Because of the nature of the test, sample persons will be asked to make their exam appointments at particular times.

- Body Measurements - Height, and weight, and arm girth and skinfold measurements.

Replace

Exhibit 3-2

NHANES III
MEC EXAM COMPONENTS BY AGE GROUP

EXAM COMPONENT	AGES					
	2 months-5	6-19	20-39	40-59	60-74	75+
Physician's Exam	X	X	X	X	X	X
Blood Test	X	X	X	X	X	X
Body Measurements	X	X	X	X	X	X
Dietary Interview	X	X	X	X	X	X
Fundus Photograph	-	-	-	X	X	X
ECG	-	-	-	X	X	X
Bioelectrical Impedance	-	X*	X	X	X	X
Spirometry	-	X**	X	X	X	
Dental	X	X	X	X	X	
Bone Density	-	-	X	X	X	X
Hand, Knee X-ray	-	-	-	-	X	X
Gallbladder Ultrasound	-	-	X	X	X	-
Allergy	-	X	X(½)	X(½)	-	-
Audiometry/Tympanometry	-	X	-	-	-	-
Physical Function-Measures	-	-	-	-	X	X
Health Interview	-	X	X	X	X	X
Neurological Tests	-	-	X(½)	X(½)	-	-
Cognitive Test	-	X***	-	-	-	-
TOTAL COMPONENTS	5	11	11	14	14	[illegible]

*Ages 12+

**Ages 8+

***Ages 6-16

(½) Denotes that procedure is for half-sample only.

- Dietary Interview - Assessment of eating habits of adults and children including a 24-hour recall for all ages and a food frequency questionnaire of foods eaten in the past month for ages 12-16.

- Fundus Photograph - A photograph of the back (fundus) of the eye which shows the condition of the blood vessels and is helpful in diagnosing complications of diabetes and hypertension.

- ECG (EKG) - Check heart rhythm and screen for possible heart disease.

- Bioelectrical Impedance - Measurement of body fat. (No sensation is felt by SP.)

- Spirometry - Measurement of lung capacity to screen for obstructive or restrictive problems such as asthma. It does not diagnose lung disease.

- Dental - Limited dental exam which checks for cavities, periodontal problems, tooth loss and soft tissue lesions.

- Bone Density - Examination of bones in the hip to estimate mineral content. Results will be used to study osteoporosis. Not a diagnostic test for osteoporosis.

- X-Ray - X-ray of hands and knees for people over 60 (knees to check for arthritis).

- Gallstone Ultrasound - Screening for gallstones. Not an X-ray.

- Allergy - Tests for allergy to selected substances such as dust and pollen.

- Audiometry/Tympanometry - Hearing tests for children.

- Physical Function Measures - Assessment of physical impairment in individuals age 60 and older.

- Health Interview - Interview to obtain information on reproductive history, emotional health, drugs, smoking and other health-related topics.

- Neurological Tests - Screens for Central Nervous System function. Consists of a self-administered computer test to assess memory and reaction time.

- Cognitive Test - Assessment of analytical skills in children. Not an IQ test.

Let's look in more detail at why each of these components have been included in the exam.

1. Physician Exam

The physician's examination includes blood pressure measurement, and examination of the heart, lungs and joints. It does not include a gynecological exam. For NHANES III, the components of the physician examination were chosen either to reflect major research areas in the survey where physical examination data could be used to complement questionnaire, laboratory data, other physiologic measurements, or to serve as a public service. For example:

- X-rays of the knee and extensive data on arthritic complaints will be obtained in the medical history. To complement this, the physical examination includes observation of swelling in the knee, and checking for knee pain and other knee problems.

- Another major study focus is diabetes, with a large proportion of participants receiving a glucose tolerance test. Complementing this, the physician will assess circulation in the legs and feet (circulation problems are often associated with the existence of diabetes).

- Similarly, for older Americans, physical function will be assessed by questionnaire materials and by a series of movement tests. To complement this, the physical examination includes observation of the range of motion at major joints and tests of neurologic function.

In addition, the physician is asked to make a general assessment of functional limitations based on the physician's examination findings and SP's medical history.

As a public service, the examination includes blood pressure measurement, which is an effective screener for cardiovascular problems. Examinees and their physicians will be notified in case any abnormalities or emergencies are detected.

2. <u>Blood Test</u>

It is important to draw blood from study participants for a number of reasons:.

- Knowledge can be gained about how healthy a person's body is by measuring for various substances in their blood. Information gathered from these tests can be compared to information gathered from interviews to get a more specific idea of the participant's overall well being.

- Blood tests can also provide early warnings of potential health problems, perhaps before physical signs appear. For example, a blood test for lead might indicate exposure to unsafe lead levels before an individual showed any physical signs of lead poisoning. This would be critical since the effects of lead poisoning cannot be reversed.

- Inconsistencies between interview data and blood test results could also be of importance with regard to health issues. For example, if low levels of iron were found in the blood of a person who described their diet as containing large amounts of iron rich food, this might indicate a problem in that person's ability to absorb iron properly.

- The blood test will also indicate the presence of the AIDS virus (This will <u>not</u>, however, be a personalized test. No one, including researchers, will be able to identify blood samples tested for AIDS with an individual. See Interviewer's Manual Section 8.4.). The AIDS test will <u>not</u> be done during the Dress Rehearsal.

- Blood tests help in <u>monitoring nutritional status</u>, one of the key goals of NHANES III. What researchers discover from this data can lead to health policy recommendations -- the need for more vitamin fortification, for example.

- The blood testing also provides information about the levels of cholesterol and other blood lipids, another important study goal.

For SP's age 40-74, a Glucose Tolerance Test (GTT) for diabetes is another important part of the blood test. Diabetes mellitus is a major public health problem in the United States that has been growing in its scope and impact for decades. Some of this impact is evidenced by the following facts:

- 5 million adults in the U.S. have been diagnosed as having diabetes.

- 4.5 million adults in the U.S. have undiagnosed diabetes.

- About a half a million Americans are newly diagnosed as diabetics every year.

- Diabetes affects virtually every organ system in the body. Persons with diabetes have significantly higher rates of conditions such as kidney disease, blindness, hypertension, heart disease, stroke, and disability.

- Diabetes is the leading cause of blindness among adults.

- Rates of hypertension, heart disease, and stroke appear to be twice as high in diabetics as in nondiabetics.

- Diabetes is the seventh leading underlying cause of death.

If a study participant has <u>questions about giving blood</u>, let them know that:

- blood tests can show how healthy their body is or detect potential problems early;

- blood tests combined with interview data give more complete information than either one alone;
- since the tests are done outside of the body, there is no risk to study participants;
- all materials used to draw blood are sterilized so there is no risk of getting AIDS or other diseases by having blood drawn;
- the amount of blood needed for the tests is small compared to all the blood in a person's body;
- the body is always making blood, so the few tubes taken out will be replaced by new blood in about a day;
- different tubes are used because blood for certain tests must be treated differently.

3. Body Measurements

This component of the exam will include height, weight, and other body measurements such as skinfold, girth and breadth. These measurements will be used to assess growth, obesity, overweight, and body fat distribution, and to provide information which can be used as a reference for later studies. Measurements of height and weight will allow for a revision of the child growth charts now in widespread use. Measuring body fat is important because the amount of body fat is associated with hypertension, adult diabetes, cardiovascular disease, gallstones, arthritis, and some forms of cancer, and it affects mental, physical, and social well-being.

4. Dietary Interview

Dietary intake and eating habits, as well as nutritional biochemistry levels collected in NHANES III, will be used to monitor the nutrition of the U.S. population. These data are also used to set food fortification and food safety policies for the country.

Diet is related to many health conditions prevalent in the U.S. today, including overweight, heart disease, diabetes, hypertension, elevated blood cholesterol, and some forms of cancer.

Depending upon the SP's age, different forms of the MEC Dietary Interview will be administered. All of these interviews will include a 24-hour recall (an in-depth interview detailing foods eaten during the past 24 hours), which is not given during the Food Frequency section of the Adult Household Questionnaire. SP's under 1 year old (proxy) and from 12-16 years old will be asked Food Frequency questions in the MEC (similar to those in the Adult Household Questionnaire).

5. Fundus Photograph

The fundus photograph is important in studying retinopathy (retinal anormalities) and macular degeneration, which are major public health problems for two groups of people in the United States, i.e. diabetics and the elderly, respectively. The NHANES III Eye Fundus Photography component provides the first opportunity to make national estimates for these two major causes of blindness.

Retinopathy is a condition where tiny blood vessel ruptures occur in the retina, damaging nerve cells and causing blindness if not treated, and is the first complication to develop in persons with diabetes. This is especially important considering the fact that diabetes is the leading cause of new blindness among adults in the United States.

In addition to investigation of retinopathy, fundus photographs will permit the study of other eye diseases in the U.S. population. Of particular importance is macular degeneration, which is a highly prevalent, disabling condition in the elderly which causes light to scatter within the eye so that there is a "built in" glare.

The five minutes required for each examined person to take a fundus photograph in NHANES III will yield enormously important new scientific data.

6. ECG (EKG)

The electrocardiogram (ECG) is a test of heart rhythm that helps detect cardiovascular disease. The public health care problems caused by cardiovascular disease are enormous. This disease is the leading cause of death and disability in the United States and a primary cause of time spent at the hospital as well as at the doctor's office. The assessment of cardiovascular disease-related risk factors has been a central component of the National health examination surveys. Data describing health problems related to cardiovascular disease has provided important information to researchers, health providers and policy makers from the public and private sectors of the health field.

7. Bioelectrical Impedance

This is another method of assessing total body fat, which is an important factor associated with a number of health problems (see "3. Body Measurements").

8. Spirometry

Chronic obstructive pulmonary (lung) diseases (COPDs) include asthma, chronic bronchitis, and emphysema. COPDs are important public health problems and are the fifth leading cause of death (mortality) in the United States. The mortality trends associated with COPDs are steadily rising. Through the spirometry test, lung impairment will be identified. In particular, the spirometry data through this survey will give us information on how widespread COPD's are in the U.S. population, and information that will be used in determining what "average" or "normal" pulmonary function is for this population.

Estimates of pulmonary function are also vital, for example, in studying occupational exposures and air quality. In addition, we are interested in documenting the effects of active and passive smoking by pulmonary function testing and will utilize national estimates of pulmonary function from NHANES III in other studies of these effects. And finally, the Office of the Assistant Secretary for Health has established smoking and health as one of 15 priority areas in their 1990 Objectives for the Nation. NHANES III spirometry data will be a vital source of information documenting the relationship of smoking to chronic obstructive pulmonary disease.

9. Dental Exam

Many strides have been made in reducing the consequences of dental and oral diseases in the United States. Some of these changes have been documented in the NCHS health surveys over the past decades. However, much work remains to be done, as can be seen from the following facts:

- In 1986, over half of the population reported having had a dental visit in the previous year.
- Americans over the age of two years made more than 450 million visits to dentist in 1986.
- There are many subgroups in the population who reported no dental visits in the previous year, such as persons over 55 years of age, black and Mexican American persons, and persons with a low family income.
- Almost a quarter of all Americans over age 45 had lost all of their natural teeth.
- Dental disease is the most prevalent condition in the United States; nearly everyone experiences some type of dental problem.
- About 29,000 developed oral cancer in 1987. Oral cancer is highly treatable in its early stages.
- Caries, or cavities, are found in 50% of children in the United States. Fortunately, this is lower than in previous years.
- Periodontal disease affected 77% of the adult population.
- Dental and oral problems are usually highly preventable if the proper steps are taken.

10. Bone Density

In order to study osteoporosis (deterioration of the bones), researchers need to develop reliable means of measurement. One of the potential means for detecting the disease is by measuring bone density, but in order for this measurement to be useful, reference data on what "normal" and "average" bone densities are must first be established. This reference data can then be used by clinicians and researchers when evaluating an individual's bone mass data, in a similar manner to the use of the NCHS Growth Charts for children.

However, reference data for bone density currently in use are based on small, non-representative samples. NHANES III will make a unique contribution to the understanding of osteoporosis by providing estimates of bone density at the hip in the general population. Bone density is a primary risk factor for osteoporosis fracture with risk of fracture increasing as bone density decreases.

The Food and Drug Administration (FDA) has also expressed interest in using the data to consider calcium fortification regulations.

11. X-Ray

Arthritis and other chronic musculoskeletal disorders are a major public health problem. These conditions are frequently disabling and painful.

Osteoarthritis is the most common joint disorder. By the ages of 70-79, almost everyone has some degree of osteoarthritis, and it affects more than 40 million adults in the United States. Rheumatoid arthritis is also common in older people. One in every 50 men and one in every 20 women over the age of 55 suffer from rheumatoid arthritis.

These conditions are major causes of disability and limitation of activity. Arthritis and rheumatism rank second only to heart disease as a cause of activity limitation in persons over 25. In 1984, it was estimated that over 12 million people had their activity limited by arthritis and musculoskeletal disorders.

The economic cost of these disorders was estimated to be over $65 billion in 1984. Lost earnings and services due to worker disability are a large part of these costs. Osteoarthritis is the second most common condition for which worker disability allowances were granted to persons over 50 in the U.S., while rheumatoid arthritis is an important cause of disability in younger workers. Another part of the cost of these conditions is the use of medical services. Arthritis and musculoskeletal disorders are important causes of hospitalization and visits to physicians, particularly among older Americans.

12. Gallstone Ultrasound

In its report to the Congress of the United States, the National Commission on Digestive Diseases identified gallstone disease as a major contributor to the total economic burden of illness in the United States. In 1985, an estimated 475,000 persons with gallstone disease had their gallbladders surgically removed with an average length of hospital stay of 7.5 days. The estimated costs associated with surgical care for

gallstone disease is approximately $4 billion per year. Despite the great expense and sickness associated with gallstone disease, there is only limited knowledge regarding how this disease is contracted in the United States.

The aims of this study are: 1) to discover how many people have gallstone disease and do not know it, and 2) to investigate factors associated with gallstone disease (e.g. diet, behavior, etc. These are called "risk factors"). Many commonly reported risk factors for gallstone disease are being measured in this study: age, educational level, family income, ethnicity, obesity, blood cholesterol, alcohol consumption, diabetes, female sex, number of births and oral contraceptive usage. To discover gallstones, a safe ultrasound examination of the gallbladder will be performed by highly trained and certified technicians.

13. Allergy

NHANES III will help NCHS and the Center for Biologics, Evaluation and Research of the FDA measure the prevalence of allergies in the United States and determine if the prevalence has changed since previous NHANES surveys, which indicated that approximately 20 percent of the U. S. population was affected by allergic diseases. The Health Resources and Services Administration will use the data to measure the degree to which allergies in the population impact on health care delivery systems. The FDA will use the data on standardized allergens (substances that cause allergic reactions, like pollen, animal hair, etc.) to assess how much they affect the general population. The National Heart, Lung, and Blood Institute will use the allergy data in conjunction with other exam and interview data to increase our understanding of chronic obstructive lung disease.

14. Audiometry/Tympanometry

Hearing loss severe enough to interfere with speech is experienced by approximately 8 percent of adults and 1 percent of children in the United States. Hearing loss at this level has consequences for quality of life, development in children, and other problems including the ability to function in school. New studies suggest that poor hearing among children is an increasing problem.

The NHANES III hearing component was developed by NCHS with the National Institute of Occupational Safety and Health (NIOSH) and the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS). NHANES III will involve two types of hearing tests. Tympanometry obtains information on the state of the middle ear; while air-conduction audiometry measures hearing thresholds. Hearing loss due to noise exposure can be determined through the air-conduction tests.

Information on distributions of hearing levels in the representative NHANES III sample of persons 6-19 years of age will provide a reference for studies on hearing loss among children. These data will also serve as a basis for follow-up studies on hearing and hearing loss.

15. Physical Functioning/Elderly (Ages 60+)

Being able to take care of ourselves as we get older is a concern most people share. In the MEC examination, respondents will be asked to do some very simple movements of their arms and legs including opening a lock, moving their arms at the shoulders, standing up from a chair and walking. These

tests will help us to understand how older people function in their everyday lives and what might be needed to help older people take care of themselves or other people more easily.

Most people find these tests to be fun and we are very careful to safeguard their safety.

16. <u>Health Interview</u>

There are three different versions of the health interview for different age groups: Adult - 17 years and older; Youth - 8 to 16 years; and Proxy - 2 months to 11 years. In general, the interview seeks to obtain information on reproductive history, emotional health, drugs, smoking, and other health-related topics.

The adult version (SP's 17+) includes questions on tobacco use, drug and alcohol use (including marijuana, cocaine and nonprescription medications), reproductive health (birth control practices, pregnancy and reproductive history, sexual activity) and mental and emotional health.

The youth version (SP's 8-16) includes most of the above topics as well as some diet related and activity questions. Some of the more sensitive questions are asked only of older youths.

The proxy version (SP's 2 months - 11 years) is much briefer and asks only about drug use, diet and a few other selected health items.

17. Neurological Tests

The NHANES III nervous system exam component involves several tests of central nervous system (CNS) function, including reaction time, memory, and psychomotor function, to test for neurological disease. Although the toxic effects (to the nervous system) of exposure to lead have been recognized for centuries, the nature and extent of the damage and the diversity of chemicals and metals which may produce these problems are only becoming evident in recent years; currently, there are no adequate standards of neuro-behavioral function against which to assess exposed populations. Data from NHANES III will be used to identify persons with slight-to-severe disturbances in CNS functioning and to characterize them according to demographic and other factors, especially age. NIOSH and NCHS will use the data to establish a reference population for use in special studies of groups at high risk of occupational exposure to toxic substances. The CNS tests in NHANES III will also be used to identify correlates (e.g., age, alcohol use) of impairment, and to examine the natural history of these problems (determined by re-examination and other forms of follow-up). Of special interest will be early, mild, and potentially preventable impairment.

18. Cognitive Testing/Children

Cognitive testing in the MEC will assess cognitive functioning in two different age groups. For children six years of age and over, this assessment involves several tests of analytical skills related to numbers, reading, and figures on a page. Older adults over the age of 60 also receive some cognitive testing, but this will be part of their Health Interview and not a separate MEC exam component. Overall, the major objective of these cognitive tests is to ascertain levels

of cognitive functioning and impairment in the population, and to assess the relationship between the test results and other measures of health. These are not IQ tests.

3.5 Data Uses

Participating in NHANES III means a contribution to valuable research:

- Data on the distribution of health problems and potential risk factors in the population gives researchers important clues on the causes of disease development.
- Information collected from this survey will be compared to information collected in previous and future NHANES surveys. This allows health planners to find out how much various health problems and risk factors have changed in the United States population over time.
- By identifying the health care needs of the population, both government and private agencies can establish policies and plan research, education, and health-promotion programs which will help improve the current health of the population and prevent future health problems. And, finding out about the kinds of health problems that are experienced by the population as a whole, and by specific age-race-sex groups, allows researchers to determine which subgroups of the population would benefit most from specific programs and policies.

3.5.1 Specific Benefits

Information collected in earlier NHANES surveys has been used to:

- Construct growth charts which enable pediatricians to follow a baby's growth and development. Millions of these growth charts have been distributed to doctors around the world. In NHANES III, we hope to improve on these growth charts by including younger babies in the survey.

- Determine the number of persons in the United States who have high levels of blood pressure and cholesterol. Heart disease is the leading cause of death in the United States and high levels of blood pressure and cholesterol are important risk factors for this disease. Educational programs have been developed based on this information and directed toward those groups of people with the greatest need. NHANES III will provide important information on what progress has been made as a result of increasing peoples' awareness of the importance of maintaining recommended levels of blood pressure and cholesterol.

- Determine the number of persons in the United States with iron deficiency anemia. This information is used to study which groups of persons are at high risk for anemia and to develop plans to reduce this risk. Information from NHANES III will be used to further study the iron deficiency status of children to determine whether anemia is still a serious health problem.

- Study the amount of lead in the blood of persons living in the United States. This information when compared to the amounts of lead used in gasoline, helped the U.S. Environmental Protection Agency decide to develop a plan to gradually eliminate the use of lead as an additive to gasoline. NHANES III will demonstrate how effective this plan has been and will provide additional information on the health effects of lead.

- Evaluate the diets of all people living in the United States. Researchers have used information collected from the earlier surveys to study the diets of special groups of people, including young children and the elderly. The information has been used to identify groups whose diets may lack necessary nutrients, such as calcium The earlier NHANES surveys showed that a substantial proportion of women do not receive enough calcium from their diets Partly because of this finding, NHANES III will collect additional information on

risk factors relating to osteoporosis to help researchers better understand why this condition has become such a serious health problem.

- Study the incidence of diabetes and other "hidden" health conditions. Over ten million adults have diabetes, a condition which is related to many other health problems, and half of them don't know it. If it weren't for past NHANES surveys, we wouldn't know how many people had "hidden" health problems like this.

3.5.2 What Newspapers and Magazines are Reporting About NHANES

During the past 25 years, the press has frequently reported on important findings from NHANES surveys. Below are summaries of some of the more recent reports, and which papers carried them. In addition, Exhibit 3-3, on the following pages, shows selected articles about NHANES data.

- There's a new way to compare your weight to what it ought to be that's much more realistic and effective than the old Metropolitan Life Insurance height and weight tables. It's call the Body Mass Index, and it is determined by a specified calculation of height vs. weight. "Established by the National Center for Health Statistics for the massive National Health and Nutrition Examination Survey, between 1976 and 1980 (NHANES II), the Body Mass Index is also being used ... to study problems of overweight around the country."
  ----Lexington, Kentucky
  Herald-Leader, 2/27/88

- Excessive exposure to the sun can cause patchy, leathery skin, warty growths, moles, liver spots, acne, varicose or spider veins, freckles, wrinkles, eczema, seborrhea, and malignant melanoma, say two research scientists. The scientists, Dr. Arnold Engel and Suzanne Hayes, came to these conclusions after studying the extensive data collected during NHANES I - "an unprecedented study" - during which almost 21,000 subjects across the U.S. received dermatological

lealth Experts Expose Ugly Side Of The Sun

MACON CHRONICLE-HERALD 1/25/88

CHICAGO (UPI) - Patchy, leathery skin? Warty growths? Moles? Liver spots? Acne? Varicose or spider veins? Freckles? Wrinkles? Eczema? Seborrhea? Malignant melanoma?

Blame it on the sun.

An unprecedented study, involving extensive examinations of more than 20,000 Americans, ages one to 74, has found all these conditions are related to excessive exposure to the ultraviolet rays of the sun.

If the results sound distasteful, even frightening, that's the point.

"The general impression is the sun does a whole lot of bad things, but that's about it," says Dr. Arnold Engel, an epidemiologist with the *National Center for Health Statistics* in Hyattsville, Md. "But here we've listed a collection of specific skin conditions so people can have an ugly image they can keep in mind before they go out and bake themselves."

Medical authorities have been concerned for years about a rising incidence in malignant melanoma, or skin cancer, they believe may be related to the American obsession with a dark, even tan.

National Cancer Institute figures show that new cases of melanoma increased 29.7 percent between 1975 and 1984, up to 8.5 cases per 100,000 people annually. Deaths from the cancer are also up 16 percent.

"At a time when the new cases and deaths from most other cancers are dropping, skin cancer is on the increase," says Suzanne Haynes, with the Health Promotion Branch of NCI in Bethesda, Md.

"We've issued warnings and recommendations, but these particular messages may not have really gotten out to the public," Haynes says. "I wouldn't want to denigrate the risk of skin cancer, but it may be the public will pay more attention to the aesthetic."

Engel and Haynes reported recently in the Archives of Dermatology on data culled from the National Health and Nutrition Examination Survey conducted from 1971 to 1974. As part of the survey, 20,749 subjects received extensive examinations by dermatologists across the United States.

The subjects were categorized as having low, moderate and high sunlight exposure, based on their occupation and leisure time spent outdoors.

High exposure to the sun was associated with a host of damaging conditions: those mentioned above and a variety of eye, tongue and palate diseases. Overall, 36.7 percent of white men with high sun exposures had some skin damage, compared to 23.3 percent with little exposure. The figures for white women were 34.1 percent and 18.6 percent.

Sun-caused skin damage was far less frequent among blacks, primarily because their darker pigmentation is caused by increased levels of melanin, a chemical that protects the skin from ultraviolet rays.

However, Engel pointed out, more than a third of blacks in the high category did develop patchy complexions.

Engel said it is difficult to determine a "safe" level of sun exposure.

"It's a continuum, and it really depends on your personal susceptibility."

The NCI also recommends reducing exposure to the sun, examining the skin regularly for new, growing or irregularly shaped moles and seeing a doctor promptly if this sign of skin cancer is found.

"That last one is really important," Haynes says. "The survival rate of skin cancer is actually very high, about 80 percent, but it's even higher if the cancer is detected and treated early."

Many of the other conditions caused by the sun - age spots, varicose veins, and wrinkles - do not need to be treated, and in many cases cannot, Engel says. "But then again, they're not pretty either."

5 coffee studies differ on risk

DALLAS MORNING NEWS 11/17/83

Associated Press

BOSTON - Three new studies dispute a controversial report that linked coffee and heart disease, but two others suggest there still may be cause for concern.

The five studies, all being published Thursday, fail to resolve doubts about the safety of coffee. But one researcher said people who drink ordinary amounts should not be worried.

Norwegian researchers said in June that they had found that heavy coffee drinkers have 14 percent more cholesterol in their blood than do people who shun it. Cholesterol buildup leads to hardening of the arteries, and the scientists said coffee drinking could at least double the risk of heart disease.

To check the results, five teams around the world analyzed the results of large population studies. Three found no link between coffee and cholesterol. One found that coffee raises cholesterol only in young people, and the fifth suggested it does this only in women.

The five reviews were published in the *New England Journal of Medicine*, with a rebuttal from Dr. Dag S. Thelle and colleagues from the University of Tromso, Norway, who conducted the original study.

The Norwegians said differences in the way coffee is brewed in Norway could explain the conflicting findings, saying follow-up studies should be done in places with a "coffee culture" similar to that of Norway, where people drink lots of boiled black coffee and shun decaffeinated coffee.

Americans getting taller

BOSTON GLOBE 6/20/88

New data from the *National Center for Health Statistics* show an apparent increase in the average height of adults in the United States.

When researchers measured men in 1960-1962, they found the average height for those 18 to 74 years old was 5 feet 8 inches. But from 1971-1974 and from 1976-1980, the average was over 5 feet 9 inches.

The average woman in this age range was 5 feet 3 inches in the early '60s and a little more than a half inch taller in the '70s.

But as men and women got taller, they also got heavier: The average man weighed 166 pounds in the early '60s, but 172 pounds in the '70s. The average weight for women went from 140 pounds to 144 pounds.

Exhibit 3-3 (continued)

Childhood obesity U.S. epidemic

ROCKY MOUNTAIN NEWS 5/1/87

BOSTON (AP) - The proportion of American children who are overweight has increased more than 50% in two decades, and the nation is facing an epidemic of childhood obesity, say the authors of a new study.

Their research documents a striking increase in weight problems among grade-school children and teen-agers.

Obesity is common among white youngsters, although blacks are quickly catching up. The study estimates that about a third of preteen white boys are overweight.

The researchers found that from 1963 to 1980, there was a 54% increase in the prevalence of obesity among children ages 6 to 11, and a 39% rise among adolescents 12 to 17.

"Childhood obesity is epidemic in the United States," said Dr. William H. Dietz Jr. of New England Medical Center, a co-author of the study. "The implications are that there is going to be a major rise in the prevalence of adult obesity and its consequences."

The study, directed by Dr. Steven L. Gortmaker of the Harvard School of Public Health, is being published in the May issue of the *American Journal of Diseases of Children*.

The study did not examine what is causing the increase, but the researchers blame lack of physical activity.

The study found that the likelihood of obesity varies among social classes and regions of the country.

"The fattest kids in the United States are located in large urban areas in the Northeast," Gortmaker said. The skinniest ones live in the West.

Poor children are thinner than middle-class youngsters, although the poor are narrowing the weight gap. Children and teen-agers also tend to be fatter in the winter than in warmer months.

The study was based on an analysis of data on 21,680 children compiled by the National Center for Health Statistics. They estimated youngsters' obesity by measuring the amount of fat in their arms.

They started with the assumption that the 15% of the children who were the fattest in a 1960 survey were obese. Then they checked to see how many youngsters were as fat as that top 15% in later years.

They found that by 1980, 27% of those 6 to 11 and 22% of those 12 to 17 fit this definition of obesity.

Some categories were fatter than others. For instance, 28% of white teen-age girls were overweight, compared with 13% of black teenage boys.

Child obesity called epidemic

MILWAUKEE JOURNAL 5/1/88

Researchers cite more TV watching, fewer exercise programs

Boston, Mass. - The proportion of American children who are overweight has increased more than 50% over two decades, and the nation is facing an epidemic of childhood obesity, says a new study.

Its authors' research documents a striking increase in weight problems among both grade school children and teenagers.

Obesity is particularly common among white youngsters, although blacks are quickly catching up. The study estimates that nearly a third of all white boys in their pre-teen years are overweight.

The researchers found that from 1963 to 1980, there was a 54% increase in the prevalence of obesity among children ages 6 to 11, and there was a 39% rise in obesity among adolescents 12 to 17.

"Childhood obesity is epidemic in the United States," said William H. Dietz Jr. of New England Medical Center, a co-author of the study. "The implications are that there is going to be a major rise in the prevalence of adult obesity and its consequences."

The study, directed by Steven L. Gortmaker of the Harvard School of Public Health, is in the May issue of the American Journal of Diseases of Children.

The study did not examine what's causing the increase in obesity, but the researchers believed lack of physical activity may be an important culprit.

The study found that the likelihood of obesity varies among social classes and regions of the country.

"The fattest kids in the United States are located in large urban areas in the Northeast," said Gortmaker. The skinniest ones live in the West.

Poor children are thinner than middle-class youngsters, although the poor are quickly narrowing the weight gap. Children and teenagers also tend to be fatter in the winter than in warmer months.

The study was based on an analysis of data on 21,680 children compiled by the National Center for Health Statistics. They estimated youngsters' obesity by measuring the amount of fat in their arms.

Dietz said few health problems were associated with young people's obesity.

"The problem is that the obese adolescent goes on to become the obese adult," he said. "As obese adults, they are even heavier than adults with onset of obesity in adulthood."

Among adults, obesity is a clear health risk. It is associated with high blood pressure, high blood cholesterol levels and diabetes.

In an earlier study, the researchers linked television watching with weight problems. They found that among adolescents, the incidence of obesity increases by 2% for each additional hour they average in front of the TV each day.

Despite the concern of many adults with physical fitness, Gortmaker noted that many schools had cut back on physical education programs, so youngsters were not getting as much exercise during school hours as they once did.

Increased food consumption, especially high-fat foods, also may play a role, they said.

Americans' cholesterol declines

DAILY PRESS & TIMES HERALD 2/20/87

CHICAGO (AP) - Americans' levels of blood cholesterol, a chemical linked to heart disease, declined significantly between 1960 and 1980, according to three nationwide surveys.

The studies conducted by the National Center for Health Statistics showed a "statistically significant" decline in age-adjusted cholesterol levels of 3 percent to 4 percent in the U.S. population aged 20 to 74, according to a report in today's Journal of the American Medical Association.

Cholesterol, a crystalline fatty alcohol found mainly in fatty foods, is needed by the body to make and maintain nerve cells and to synthesize natural hormones. In the bloodstream, however, it can lead to build-up of fatty tissue in the arteries and cause heart disease.

"For each 1 percent reduction in serum cholesterol level, an approximate 2 percent decline in coronary mortality can be explained," the researchers said.

The researchers said that notable and conflicting changes in Americans' nutrition and lifestyle occurred during the 20-year period, including:

- Reduced consumption of milk, cream, butter and lard, all high in saturated fat that can add to cholesterol levels. There was increased consumption of margarine, poultry and meat. Poultry is lower in saturated fat than red meat.
- Increased consumption of "fast food" and other restaurant food.
- New emphasis by medical groups on health promotion and disease-prevention.
- Introduction of new fat-lowering drugs.

The report suggested further research to explore the effects of diet and exercise on cholesterol.

Researchers said the percentage of people with cholesterol levels of high or moderate risk declined during the study period.

Cholesterol levels down

3/5/87 JEFFERSON CAPITAL NEWS

CHICAGO (AP) - Americans are winning the war against cholesterol, three new studies indicate.

The nationwide surveys conducted by the *National Center for Health Statistics* found a significant decline of 3 percent to 4 percent from 1960 to 1980 in cholesterol levels in people aged 20 to 74, according to a report in the latest issue of the Journal of the American Medical Association.

"For each 1 percent reduction in serum cholesterol level, an approximate 2 percent decline in coronary mortality can be explained," the researchers said.

Cholesterol, a crystalline fatty alcohol found mainly in fatty foods, is needed by the body to make and maintain nerve cells and to synthesize natural hormones. In the bloodstream, however, it can lead to a build-up of fatty tissue in the arteries and cause heart disease.

Notable and conflicting changes in nutrition and lifestyle occurred in the two decades leading to 1980, researchers said.

When mean cholesterol levels were compared on the basis of race and sex, the declines for white men and women were significant and those for black men and women were not.

Higher levels of education for men of both races corresponded with greater drops in cholesterol. Significant decreases were found among white women at all levels and a slight decrease noted for black women at higher education levels.

U.S. Cholesterol Levels Dropping

MACON JOURNAL 2/23/87

CHICAGO (UPI) - Cholesterol levels among Americans dropped significantly between 1960 and 1980, showing "our lifestyle is healthier than it was 20 years ago," researchers reported.

However, blacks as a group lagged far behind whites in lowering the amount of cholesterol in their blood, and both groups have a long way to go before achieving ideal levels, their study showed.

"This is your typical good news story - we've made a lot of progress but there is a lot of progress left to be made," said Dr. Richard Havlik.

Cholesterol, a waxy, fatty substance circulating in the blood, is considered a primary cause of atherosclerosis, or hardening of the arteries, making it a major risk factor in the development of heart disease. Recent studies suggest that 80 percent of American men have above-optimal levels of blood cholesterol and 15 percent are at high risk.

In assessing progress made in controlling cholesterol, Havlik and his colleagues at the *National Center for Health Statistics* outside Washington analyzed data from three national surveys conducted between 1960 and 1980.

exams as well as answered questions about their level of exposure the sun. After years of suspicion about the bad effects of excessive exposure, the NHANES I data finally provided linkages to specific problems.

---Providence (RI) Journal 1/29/88
---Macon, Missouri Chronicle-Herald, 1/25/88

- Americans are "winning the war" against cholesterol. Data from NHANES surveys showed that between 1960 and 1980 there was a decline of 3 to 4 percent in cholesterol levels in people age 20-74 -- a decline that has significant effects on coronary mortality.

  ---The Jefferson Capital News, 3/5/87
  ---Macon Journal, 2/23/87
  ---Virginia Daily Press and Times-Herald, 2/20/87

- The proportion of American children who are overweight has increased by a dramatic 50% in the last two decades, according to a study based on NHANES data. Researchers attribute the increase to watching television and less exercise.

  ---Milwaukee Journal, 5/1/87
  ---Rocky Mountain News, 5/1/87

- We just keep getting bigger all the time, according to data from NHANES II. In the early 1960's, men between 18 and 74 averaged 5'8" and 166 pounds, while women in the same age range averaged 5'3" and 140 pounds. By the late 1970's, according to the data, men in the same range averaged 5'9" and 172 pounds, with women measuring in at 5'3½" and 144 pounds.

  ---Chicago Sun-Times, 6/19/88
  ---Philadelphia Inquirer, 6/22/88
  ---Boston Globe, 6/20/88

- "Poor Mexican-American children may be shorter on the average than other children in the United States because of malnutrition rather than genetic factors," according to two researchers in California who studied the data from NHANES I, which came from 355 Mexican-American children and 6,728 non-Hispanic children. This data was to be updated by the result of the Hispanic HANES study in the early and mid-1980's.

  ---Washington Post, 5/4/84

- Studies differ on the relationship between coffee and cholesterol. Out of five major studies on health data, NHANES II was one of three that did not find a link between the two.

  ---Dallas Morning News, 11/17/83
  ---USA Today, 11/17/83

- "Starvation has plagued mankind throughout history and still occurs periodically in different parts of the world. The most serious problem, however, is chronic undernutrition." Little reliable information on this problem in the United States was available until recent years, when several studies have sought to fill the gap. Among the most important of these is and has been the NHANES series.

  ---Discovery (University of Texas at Austin), March 1980

3.6 Answering Questions

Treating respondent questions in the same way as discussed in Section 2.4, here are more questions that you may encounter throughout the interviewing process, and suggested answers. Again these are not "canned" answers, but guidelines. General questions about the U.S. Public Health Service, what the study is about, confidentiality, and respondent selection were covered in Section 2.4.

1. WHAT ARE YOU GOING TO ASK? "The questions ask about health problems you have (had), experiences you have (had) when seeking help, and other health related matters. Most people find it rather interesting."

2. HOW LONG WILL IT TAKE? IF ASKED AFTER SCREENER: "The interview will probably take about 45 minutes (PER SAMPLE PERSON). It is sometimes shorter or longer, depending on what you have to say."

   IF ASKED AFTER THE SP INTERVIEW: The examination will probably take about three hours. For children 5 and under, it will only last about 1 hour.

3. I HAVE ALWAYS BEEN IN GOOD HEALTH (OR I HAVE HEALTH PROBLEMS), SO I WOULD NOT BE A GOOD PERSON TO TALK TO. "Your experiences and opinions are important too. We are interested in talking with all kinds of people with all kinds of experiences."

AND ABOUT THE EXAM ...

4. WHAT DOES THE MEC EXAM CONSIST OF? "The MEC exam consists of physical and dental examinations, biochemical measurements, dietary interviewing, cognitive testing for children and the elderly, and an interview which covers a range of health-related topics." IF NECESSARY, REFER TO THE MEC EXAM CARD.

5. WHAT ARE THE BENEFITS FOR ME?
   - Cash award for participating in the survey.
   - Results reported to your doctor.
   - Valuable health measurements.

6. DO I HAVE TO PARTICIPATE IN THE EXAMINATION? No, participation in all parts of the study is completely voluntary. There is no penalty for refusing to participate. Of course, we hope everyone will participate in all parts of the survey, because without your participation our information on the health of Americans may not be accurate. However, we can eliminate a particular procedure if you come for the rest of the examination.

7. HOW WILL I RECEIVE THE RESULTS OF MY EXAMINATION? With your permission these results will be sent to your doctor. A postcard will be sent to you at that time urging you to contact your doctor to discuss your results. Of course, if we should find something important to your health before that, you and your doctor will be notified.

8. CAN I TALK TO MY DOCTOR BEFORE AGREEING TO THE EXAM? Yes. We agree that this is a good idea. If you would like, we can have a survey representative contact your doctor to provide him/her with further information about the program.

9. WHAT IF I DON'T HAVE A DOCTOR? If you do not have a regular place to go for medical care, we can suggest places in your area where you can go for care.

10. I AM A WOMAN, AND I'M CONCERNED ABOUT PRIVACY.

    - A female is always present during the physicians exam.
    - There is no gynecological exam.
    - A gown and pants will be provided for you during the exam.
    - There may be a woman doctor on staff [ONLY AT SOME STANDS].

11. WHO WILL PAY ME FOR HOURS LOST AT WORK IF I COME IN FOR THE EXAM? We do have evening, Saturday and Sunday sessions. However, with your permission we will contact your employer. In most cases, employers agree to let employees take time off from work in order to take the exam and still receive full pay. We also have a compensation fee to help reimburse you for your time.

12. WILL I RECEIVE THE RESULTS OF MY AIDS TEST? No. The AIDS testing is being done in the NHANES III survey so we can determine how many people in the U.S. are infected with the AIDS virus. In order to make extra sure that the results are kept private, no identification that would allow us to identify you will be attached to the blood specimens tested for AIDS virus. Therefore, your test results will be anonymous. If you would like

to have an AIDS test and receive the results in a confidential manner, our staff can give you the name of a clinic in your area where you can go.

13. ARE THE TESTS THAT I MAY BE ASKED TO TAKE SAFE? We care about your safety. The tests and measurements we do have been selected because they are safe. We would like to point out that as in any similar examination, there may be some slight discomfort or soreness resulting from the collection of a blood specimen, the administration of the allergy skin test, or from the dental examination. If you are an adult and are chosen to receive X-rays of your hands and knees, this will add a small amount of radiation to your total lifetime exposure.

14. I AM A DISABLED PERSON, AND I'M CONCERNED ABOUT COMING TO THE MEC.

    - You can be scheduled during a session that will have few other people.

    - What would be the most convenient time for you?

    - Bring a friend or relative with you.

15. WHO CAN I CALL IF I HAVE QUESTIONS? Our staff will provide you with a phone number in your community that you can call for further information. You may also make a collect call to our spokesman, Chris Johnson, at the U.S. Public Health Service headquarters, phone (301) 436-8267.

16. HOW DO I KNOW MY RESULTS WILL BE KEPT CONFIDENTIAL? All the health information collected is kept in strictest confidence. Our staff is not allowed to discuss your participation in this study with anyone under penalty of Federal law: Section 308(d) of the Public Health Service Act (42 USC242m) and the Privacy Act of 1974 (5USC 552a). We cannot even release your results to your own doctor without your written consent. The results of your examination will be used to add to the results of all others participating in this important study and will contribute to a better understanding of the health of all persons living in the United States.

3.7 NHANES AT A GLANCE

An important aid in convincing respondents to cooperate with the study and in converting nonresponse is NHANES AT A GLANCE. NHANES AT A GLANCE is a notebook containing news articles, letters, endorsements, photographs and other materials to help you explain the goals and objectives of the study to the respondent and to show him or her that NHANES has community and national support. NHANES AT A GLANCE is updated regularly.

Always carry your copy of NHANES AT A GLANCE with you in the field. It is designed for you to show to the SP in any situation where you think it might help in gaining cooperation. These might include the following:

- In large urban areas where individuals are distrustful of strangers at the door;
- Among specific target groups (the elderly, Hispanics, etc.) where we have letters of endorsement from community and national leaders with whom they might identify;
- With SPs who are distrustful of or misunderstand the purpose of the study;
- Any situation where gaining the SP's cooperation depends on establishing the legitimacy and value of the study to the individual and to the community.

4. SPECIAL TARGET GROUP CONSIDERATIONS

For certain groups that will be included in the study, it may be helpful to focus attention on their special needs or characteristics in order to obtain maximum cooperation. At this time we will talk primarily about the elderly, but in the future we will be adding information about other target groups -- minority groups, for example.

4.1 The Elderly

Older persons are an important part of the national population, and will be one particular focus of NHANES III. According to a recent Wall Street Journal article:

> "Right now, one in eight Americans is 65 or over; by 2030, almost one in five will be. People 85 and over are one of the fastest growing age groups: 2.7 million today, about five million by the year 2000, and at least 16 million - more than five percent of the population - by 2050, when even the youngest baby boomers will be there".

Yet there is not much data on this population group, and the Federal government is now realizing how little is known about the health, economic status, and habits of older Americans. We do not, for example, know how many people in this age group have high blood pressure, low blood counts, or arthritis. NHANES III is part of this effort, which will be critically important in attempting to meet current and future health care needs. One of the special features of NHANES III is that persons age 75 and older will be participating for the first time in this study.

However, older respondents are going to have some unique concerns about participating in the study -- primarily concerns relating to their physical health and how they are able to cope with it. Some items to watch for:

a) Confidence: This group is likely to feel less confident about their ability to perform in general, whether it be to read something properly, remember something, hear what you say, or sit through a three-hour exam, much less get to the exam.

YOUR RESPONSE: Be extra-patient. Offer lots of encouraging comments, and downplay any instances of fumbling around, slowness of response, loss of concentration, or inability to recall. Avoid putting any kind of pressure on elderly respondents, either verbally or with body language. Allow extra time for everything. Your aims should be to make their tasks easy.

b) Physical Need: Elderly respondents are more likely to have problems hearing, seeing, talking, walking, getting up and sitting down, and so on.

YOUR RESPONSE: Be attentive. If you think your respondent is having trouble hearing, ask "Should I repeat the question?" If you think s/he is getting tired, take a break. If s/he is having trouble getting up to get something, offer to do it yourself (e.g., get up to get vitamins).

c) Transportation to the MEC: If the older respondent is very apprehensive about getting to the MEC either by taxi, public or personal transportation, go ahead and offer to bring them there yourself (or other staff person bring them). Let them know that they can bring along a companion if that will make them feel more comfortable.

4.2 Interviewing Respondents With Health Impairments

In this study you will be interviewing a number of respondents who have impairments either because of age, illness or accidental injury. In this section, we are going to discuss in more detail some of the difficulties you may encounter when interviewing respondents who have impairments. While we will discuss these impairments in relation to older people, you may also encounter younger people with some of these conditions.

When you interview an older respondent, you need to address your own attitude towards the aging and the elderly. Your fears and assumptions could create a barrier between you and the respondent. Fear or discomfort with the elderly might make you sound stiff or insincere. In general, try and be sensitive, matter-of-fact, flexible, and patient. Let the SP know that s/he is not threatened by any aspect of the study (an older respondent might, for example, fear that participating in the study will result in him/her being placed in a nursing home).

First, let's begin by talking about some of the sensory impairments you may encounter, then about some physical impairments and disorientation or confusion. Finally, we'll discuss some other types of problems that may confront you and how to handle them.

4.2.1 Auditory-Limitations in Hearing

A gradual hearing loss begins about age 20. As age increases, sharpness and accuracy of hearing often diminish. This type of hearing loss may make a person misunderstand words, which is often interpreted as confusion. Inability to hear well, i.e., noise from other sources (people talking, dishwasher or TV operating, etc.) may make it difficult for a hearing impaired

person. Apparently, in the English language, consonants are more important in the identification of words than vowels, i.e., they are slightly softer in sound. Unfortunately, some consonants, e.g., s, z, t, f and g, are some of the higher frequency sounds which are lost when hearing impairment occurs.

Hearing limitations may be detected by the presence of a hearing aid or by behavioral cues, such as the appearance of inattentiveness or a strained facial expression, particularly when listening. People with hearing limitations may lean toward the interviewer with their "good" sides, tilt their heads, or cup their hands behind their ears. Others with hearing problems may show none of these behavioral signs but may answer questions inappropriately or frequently ask the interviewer to repeat questions.

People with hearing limitations may tire easily or show annoyance because of pain or auditory blurring when the interviewer speaks too loudly. It requires a great deal of effort for them to listen and to sort and file sounds into meaningful thoughts, especially when the conversation and the interviewer are both strange to them. Hard of hearing people may tire and give up, so be patient.

In short, some of the behavioral manifestations of hearing loss are:

- A tendency to confuse words which sound alike or occur out of context;
- An increase in the volume of speech on the part of the hearing impaired speaker (they compensate);
- Positioning of the head to increase hearing in the good ear;
- Asking for statements to be repeated: becoming confused over oral statements or questions;

- Blank looks: inappropriate answers;
- Isolation and withdrawal from normal social participation; and
- Shorter attention span (especially when two people are talking at once), due to confusion.

Hearing impairment affects daily life in such a way that, as a result, a hearing impaired person:

- Might be incorrectly judge forgetful;
- Might be incorrectly regarded as confused;
- Might withdraw to protect his/her dignity;
- Might not hear alarms (think of all the high-pitched alarm sounds there are); and
- Might be depressed at the loss of sounds important to them, i.e., bird song, children's voices, music, etc.

Here are some tips on communicating with hearing impaired persons:

- Speak slightly louder than normal and, if you can, lower the pitch of your voice. Remember that shouting will not make your message any clearer, however, and may sometimes distort it.
- Speak a little slower than your normal rate without making it stilted or unnatural.
- Avoid chewing, eating or covering your mouth with your hands when speaking to a hearing impaired older person.
- The best distance when speaking to elderly hearing impaired persons is from 3 to 6 feet (0.9 to 1.8m).
- Facial expression, gestures, lip and body movements all give cues to the hearing impaired person. Therefore, good lighting on the face of the speaker is important.

- Wait until you are visible to the older person before speaking, and face the respondent when you speak. If possible, arrange the environment so that the speaker's face and body can be seen easily.

- Communication with hearing-impaired older persons is much more difficult when there are other noises.

- Never speak directly into the person's ear. This may distort your message and further hide all visual cues.

- If the hearing impaired older person does not appear to understand what is being said, rephrase the statement in short, simple sentences. Of course, you may not rephrase interview questions -- simply repeat an interview question.

- Whenever possible, give the hearing impaired older person a clue to the topic of conversation, such as "Now we're going to talk about things people do most days, like bathing."

- Some consonants are louder or more visible than others. For example, 'p' is easier to see on the lips than 'k'. Therefore, some words or parts of conversations may be more easily heard or understood than others.

- Do not exaggerate sounds when speaking. This distorts the message and makes the use of visual cues from your face difficult to understand.

- Hearing impaired individuals take longer to respond; give them time.

- Do not make sudden movements that could startle the respondent who gets no prewarning from sound.

4.2.2 Limitations on Vision

Between the ages of 40-45, certain changes begin in the eyes. The lens and the muscle begin to stiffen. Many people who never wore glasses before need them to read. With advancing age, other changes take place in the eyes which can often

a. Make the environment seem faded; and

b. Cause light refraction and a loss of some visual detail.

Some results of this can be that more light is required to see; yet glaring lights cause discomfort and, in the case of night driving, are hazardous.

Difficulties in vision may be identified by the presence of thick or dark glasses, a cloudy film over the eyes, or other discoloration of the eyes. However, some visual problems have no obvious signs. In these cases, the interviewer may be able to infer visual limitations by the manner of the respondent's mobility and balance.

People with visual loss depend upon immediate sounds and tactile sensations to maintain their sense of security. They may be fearful, distrusting, and awkward in movement.

Some of the behavioral manifestations of visual loss are:

- A handshake may be missed because the offered hand is not seen.

- A respondent may be unable to read letters of introduction and explanation, identification and hand cards, etc.

- The respondent may be unwilling to sign his/her name to consent forms because s/he may not be able to read some or all of the forms and may not wish to say so.

- Vision impaired individuals may be unable to recognize other people. They may also be unable to distinguish an object from its background (objects may be knocked over and/or dropped).

- Vision impaired individuals may be unwilling or unable to move about freely because of inability to see objects in their paths.

Vision impairment can affect daily life in such a way that a vision impaired person:

- Might mismatch clothing -- select bizarre combinations;
- Might apply makeup inappropriately;
- Might wear clothing that is stained because 1) the stains weren't removed because they were not seen when they first occurred, and 2) because at the time of selection the stains may not be observed;
- Or might appear to be an inadequate housekeeper because crumbs, spills and dirt are not observed and therefore not cleaned up.

Here are some tips on communicating with vision impaired people:

- Before speaking, position yourself where the respondent may be able to see at least your outline or a shadowy form.
- Use a calm, reassuring voice and speak clearly and softly at first. Say who you are.
- Do not touch or shake hands until you have spoken first.
- Don't make sudden movements.
- Give letters of introduction, information, consent form, etc., to the respondent and say "here's a letter; why don't you look at it while I read it out loud, just so we both are clear about what it states." Try to do this where there is a maximum amount of light.
- Encourage the respondent to seek the help of significant others in reading such documents.

- Don't judge the respondent's cleanliness or appropriateness of choice of clothing.

4.2.3 Physical Impairments

Physical impairments have many causes, including:

- Accidents which may also be the result of sensory impairment(s).
- Osteoporosis (deterioration of the bones).
- Arthritis and rheumatism which can cause severe pain and crippling.
- Stroke which can leave the patient weak or paralyzed.

Note that stroke patients may have hearing and visual impairments, and difficulty in speaking (slurred speech), understanding what is said to them, reading, writing, understanding writing, and confusing words. Stroke victims may also cry or laugh more easily than they did previously. It is important that as an interviewer you realize that a stroke patient who is crying may not really be upset -- the crying may be an involuntary act which has little to do with an emotional upset. If you remember this, you will not be unduly upset yourself.

A. Limitations in Language Function

Limitations in language function have many causes. People with limitations in language function probably know what they want to say, but are unable to form words. (Do not assume such people lack intelligence.) People with limitations in language are especially sensitive to the attitude and moods of

others and may become irritated over minor incidents. They are often frustrated about their inability to communicate. There may be marked loss of self-confidence and self-worth.

Some tips on handling limitations in language function are:

- Give the respondent time to answer without pressure and be attentive.
- Try to give non-spoken cues and gestures, so that the individual will feel comfortable responding in this fashion.
- Let individuals write if they wish to and are able.

B. Limitations On Mobility

If a person is limited in mobility or has experienced paralysis, you should be careful about the physical arrangements of the interview -- seating, lighting, the availability of a table -- so as to minimize the need for the older person to move or to perform on his/her affected side.

When interviewing people with physical impairments, please remember that:

- They may not be able to sit for long and may have to move around.
- They may tire more easily and you may have to allow them to rest or reschedule to complete the interview.

In such circumstances, please be considerate of the respondent's needs.

4.3 Minority Populations

Based on 1980 Census data, Blacks and Mexican-Americans are the two largest minority groups in the United States. Although strides have been made in improving the health and longevity of the U.S. population, statistical trends show a persistent, distressing disparity in key health indicators among these two important subgroups of the population. For example:

- In 1983, life expectancy was 75.2 years for Whites and 69.6 years for Blacks, a gap of 5.6 years. Nevertheless, Blacks today have a life expectancy already reached by Whites in the early 1950's, or a lag of about 30 years.
- Infant mortality rates have fallen steadily for several decades for both Blacks and Whites. In 1960, Blacks suffered 44.3 infant deaths for every 1,000 live births, roughly twice the rate for Whites, 22.9. Moreover, in 1981, Blacks suffered 20 infant deaths per 1,000 live births, still twice the White level of 10.5, but similar to the White rate of 1960.

Until the completion of Hispanic HANES in 1985, researchers could make very few statements about Mexican-American health or Hispanic health in general -- little national data existed. Today this data is just being published, and we now know that, for example, Mexican-Americans between the ages of 20 and 44 are 2.4 times as likely to have diabetes as non-Hispanics, and twice as likely between the ages of 45 and 74.

Vital to the health status of these two large minorities is the existence of health statistics. Reliable data are central to measuring progress in public health, and are the key to assessing the current health status of the Nation and measuring health status trends. Data are vital in recognizing the sources of and solutions to problems; identifying health

disparities between segments of the population; and targeting efforts directly to specific needs.

The data available have pointed to disparities in death rates, health status, and health care utilization between minorities and non-minorities, but more detailed data are needed to enhance the understanding of the processes underlying the disparities and to provide a better basis for rational program planning, implementing, and monitoring. The effort to obtain reliable data is especially challenging because minority populations are growing rapidly, changing rapidly, highly mobile, and, therefore, difficult to track, yet they have greater health problems than non-minorities.

NHANES III will oversample Blacks and Mexican-Americans. This oversampling will improve the precision of the health data for these two groups and allow comparison with other groups. It is important that you convince minority population SP's of the importance of their participation, i.e., their participation is especially valuable since they can have the satisfaction of knowing that they have "personally contributed" to the increased knowledge of minority health.