Section 5
Guidelines for Interactions with Participants

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Introduction

Interactions with Women's Health Initiative (WHI) Extension Study (ES) participants and their proxies occur during follow-up contacts to collect data from non-respondents, update contact information, and collect study outcomes. Participants are aging and developing vision problems, e.g., macular degeneration, and thus an increasing number of participants prefer to do a phone interview for the *Form 33- Medical History Update*. These contacts provide an opportunity to enhance study bonding and retention, as well as to become aware of potential problems with study participation. During these contacts, RC staff may become aware of issues troubling the participants (e.g., domestic violence), often beyond the scope of the study itself.

5.1 Interviewer Procedures

This section contains general procedures for research project interviewing of study participants. The guidelines describe the interview function and interviewing techniques, but they are not intended as specific instructions for completing forms. Those instructions are found in *Appendix A - Forms*.

These guidelines are described to assist ES interviewers as they perform their duties in the context of participant contact. They apply to all WHI staff members eliciting information from participants.

In the ES, interviewing to collect data is done by phone with participants who are on “No CCC mail follow-up” or who have not responded to the mailings.

5.1.1 Overview

As an interviewer, you are the participant’s link with the ES. While you do not act alone in establishing a relationship with the participant, an unpleasant interview experience could tip the balance for a participant who is beginning to lose interest or is contemplating withdrawal.

During interactions with participants, RC staff should keep the following general guidelines in mind:

- The ES is a research project, and personnel who staff the RCs are part of a research team.
- Research project interviewers are not caregivers, helpers, or advisors beyond the scope of the protocol.
- Individuals who take part in the study are *participants*, not patients; they join and remain voluntarily.
- Participants contribute to the content of scientific knowledge without gaining much for themselves.

5.1.2 Research Project Interviewing

For successful interviewing, you should have broad knowledge of the research project interview task as well as the forms and their completion. Your knowledge base should include the following:

- *Nature of research interviewing*: An interview is a social interaction designed to exchange information between a questioner and a respondent. The quality of the information exchanged depends upon the skill of the interviewer in handling that relationship.
- *Scope of research interviewing*: The research project interviewer collects data that will answer research questions.

The *research* interview contains elements that separate it from other kinds of interviewing. Strictly speaking, the research interview has the practical, utilitarian goal of data collection. In the WHIES, research project interviewers must combine the utilitarian objective with a more social objective of participant retention. The retention objective is an important one, and social interaction should be a part of every interview.

- *Significance of research interviewing*: The research project is dependent upon the reliability and validity of the data collected by its interviewers. Bias in interviewing can compromise data.

The interviewer reduces the chance of bias by presenting neutral reactions to all answers and by maintaining a brisk, regular pace of question delivery. Regardless of how carefully worded the questions and how neutrally presented, research interviews are subject to bias from two sources: interviewer delivery and participant responses. It is the interviewer's job to minimize bias from either source.

Interviewers can introduce bias into survey results by interpreting answers, favoring one answer over another, treating some questions as sensitive, reacting to liked or disliked participant characteristics, or using slanted probes or positive or negative filler words. To avoid these potential sources of bias, interviewers must perfect both neutral delivery and neutral response.

Participants can bias their responses by trying to answer questions when they simply don't know the answers. Even when the participant knows the answers, she doesn't always give them truthfully. What's more, she often doesn't realize that she's not being truthful. The participant may bias her response unconsciously by slanting answers to feel better, giving responses she thinks her friends would give, or providing answers she thinks the interviewer expects. The interviewer overcomes participants' emotional, unconscious bias tendencies by presenting questions at a regular pace and by maintaining neutrality.

5.1.3 Interviewer Roles

Although the ultimate goal of the research project interview is standardized and reliable data collection, the interviewer also plays an important role as the human conduit of information from participants to the database. The way the interviewer conducts the interviews both facilitates and standardizes the gathering of the data.

The following are some of the important roles of the interviewer:

Manage the Interview

- Control and focus the interview without dominating either the exchange or the participant. Your job is to get information, not to show what you know. The participant's answers to the questions are important. You convey that importance by your professional demeanor, by maintaining control of the situation, and by focusing on the content of the interview.
- Be politely firm and businesslike; timidity signals lack of confidence. If you communicate insecurity or hesitancy to participants, some of them will take advantage and assume a power position, others will feel sympathetic and assume a "mother" position. In either case, the participant's responses could be biased. The participant assuming the power position could distort strong opinions to keep the position; the mothering participant could try to make the interviewer's job easier by answering obligingly.

Collect Data

- Understand the purpose and meaning of the data items on the forms.
- Take no personal stake in the content of the interview. Make sure your opinions and behavior neither add to nor subtract from the research intention of any items in the forms.

Encourage Participation and Adherence

- The goal of any contact is to make the participant's RC encounters pleasant enough to be worth repeating.
- Be friendly but not chummy. Use a manner of speaking that is natural to you. If your usual manner is too casual, then with your supervisor's help, develop a firmness and modularity in this role that is genuine.
- Approach the interview with pleasure and assume the participant will do the same. Most people like being asked about themselves and their well-being; you are giving participants an opportunity to express themselves.
- Keep contact notes on personal conversation for use by the next interviewer. Record participant information that another interviewer might reasonably be expected to know, not gossipy kinds of information.
- Review contact notes before each new contact. Be careful when using comments recorded by another interviewer. There is a difference between "remembering" a participant and "talking about" a participant, which may be interpreted as a breach of confidentiality.

Leave the Door Open for Future Contact with No-Follow-up Participants

- Encourage respondents to remain in the study, but don't oversell or coerce. Many people will agree to participate to end a phone call and then never return materials.
- Leave the door open for participants who are reluctant to continue in the study so that you can make another try at a later time.
- Emphasize the contribution that a participant alone can make if you suspect that other persons in the household are influencing the respondent's decision about staying in the study.

Clarify the Nature of the Research Setting

- Give participants information about your role as an interviewer by making the following points:

  1) That you are a research project interviewer, not a source of primary care.
  2) That you are not in a position to diagnose or refer them to someone other than their primary care provider for further medical care.

Represent the Regional Center and the WHI ES

- Always be polite. Remember, you represent the RC and your co-workers.
- Call participants by name to make the experience with the RC more personal. Always use titles (Ms., Mrs.) and last names unless the participant requests otherwise.
- Impart to the participants respect for the confidentiality of the information they provide.
- Positive rapport with the participant influences the quality of the data obtained and the willingness of the participant to remain in the study for the duration. It is important that all interviewers maintain a professional and friendly manner at every contact with the participant.

5.1.4 Interview Guidelines

The research interview is a structured conversation designed to exchange information between a questioner and a respondent. The structure is provided by questions and scripts. The quality of the information exchanged depends upon the skill of the interviewer in handling that relationship. The following are some techniques to keep in mind as you conduct your interviews.

5.1.4.1 Interview Techniques

Prepare for Each Interview

- Review the contact notes in the Member Details section of the Member Data Entry screen in WHIX or in the chart before beginning each contact.
- Make sure you have all the forms and materials necessary to complete the interview.
- Avoid interviewing someone you know. If you see the name of a friend or acquaintance among the participants, tell your supervisor.

Know the Forms Thoroughly

- Follow all instructions and suggested scripts contained on the form itself and in instructions in *Appendix A – Forms*. Following or not following the instructions, scripts, or recommended remarks makes the difference between consistent and inconsistent data.
- Study the questions and data items on the forms so that you understand what they mean. Use the form as a reference at all times.
- Practice parts of the interviews that seem awkward to you until you can ask the questions in a natural manner.
- Review the instructions for each form regularly. Do not rely solely on memory for detailed instructions on form use.
- Use the response categories that are given. Probe for specificity if necessary (see "Probe Carefully" below).
- Avoid as much as possible using the "other" or "don't know" category.
- Never assume you know what the participant means. Probe for clarity if necessary (see "Probe Carefully" below).
- Record open-ended answers verbatim.

- Record your comments in brackets on the form if you have strong impressions about a participant's answer. Indicate the question you are referring to, and make your comments as clear and concise as possible.

Maintain Professional Contact

- Treat every participant with graciousness and respect; treat none as a buddy.
- Do not give personal opinions on any study matters and do not give advice on personal matters even if you are asked.

Set the Appropriate Pace

- Use a brisk, businesslike pace, but don't rush the participant or show impatience.
- Vary from your established pace on cues from the participant. If the participant shows frustration or lack of understanding, then slow down. If the participant shows annoyance or jumps in with answers to anticipated questions, then speed up. But do not skip questions.

Maintain a Neutral Tone

- Speak distinctly, without unusual inflection that could draw undue attention to part of a question.
- Do not place emphasis on specific response alternatives.

Maintain a Neutral Response

- Record information faithfully regardless of whether you think it's good, bad, boring, or exciting.
- Keep your reactions to yourself, no matter what you may think of an individual or the feelings expressed. Practice *not feeling* a reaction; school yourself out of emotional attachment to the information you hear.
- Inspire confidence by your detachment so that participants feel comfortable giving you the unvarnished truth.
- Do not indicate surprise, pleasure, approval, or disapproval of any answer by word or action. Do not gasp, laugh, agree, or disagree. Even a slight intake of breath may indicate to a participant that you are reacting to an answer. Project smooth, gracious acceptance of information, no matter how outrageous the content.
- Repeat the question exactly as it is written if the participant misunderstands a word or a question and asks for clarification. Do not define words, interpret questions, or suggest answers. See "Lack of Understanding or Recall" for how to respond if a participant does not understand a question.

Deliver the Questions Thoughtfully

- Make your delivery smooth, natural, and enthusiastic. Avoid sounding like a robot.
- Sound fresh for everyone. You may ask the same questions a dozen times in a day, but participants hear them only once in their interview.
- Use the questions, scripts, or recommended remarks as they are written, without apology.
- Emphasize that there are no right or wrong answers; the only thing that matters is that she answers truthfully how she feels. This pertains to the subjective answers on some of the follow-up questionnaires.
- Do not try to justify questions or to defend a line of inquiry; you are asking questions that have been asked of many other participants.
- Keep the questions in the order they're written and maintain the flow of the conversation.
- Record open-ended answers in the exact words the participant uses.
- Tell your supervisor if you find a problem with the wording of a question.

Probe Carefully

Probing is a critical technique to master, as it is easy to fall prey to directing responses or altering the meaning of a question. Probes must be as uniform as possible within and across RCs.

- Use probes to elicit answers to either closed-ended or open-ended questions.
- If you feel a participant has provided an inappropriate response or doesn't understand the question, first try repeating the question and the response categories verbatim.
- Probe by asking sufficient supplemental questions to get the participant's answers in full but not so many that you don't get the accurate information.

- Avoid asking ‘leading’ questions when probing and do not suggest an answer.
- Do not insert your own ideas of what the participant might be saying. Do not agree or disagree with an answer.

Probing for answers to closed-ended questions:

In closed-ended questions, the need for probing arises when the participant gives an answer that is not included in the response categories. In this case repeat the response categories and ask the participant to choose the category that fits best.

Probing for answers to open-ended questions:

In open-ended questions two problems call for probing: the need to *clarify* a response and the need to *get additional information* in a response.

The following are examples of neutral probes to *clarify*:

What do you mean by that?
Why do you say that?
In what way was it a problem?
Could you rephrase that?

The following are some examples of neutral probes to get *additional information*:

Are there other (repeat the phrase from the question)?
How else would you describe (repeat the phrase from the question)?
What else (repeat the phrase from the question)?

Control Silence

Use silence at the right moment to show your patience while waiting for the participant to formulate an answer, but do not leave the silence too long or it will threaten the participant. In role playing with other interviewers, experiment with pauses to discover your own reactions to silences.

5.1.4.2 Special Situations with Participant Contacts

In conducting interviews with numerous participants, you will encounter special situations. They will be easier to deal with if you have thought about them ahead of time.

The following are some of the special situations you might encounter with ES participants or their contacts:

Emotion

- Be prepared for unusual circumstances. Talking about cancer or heart disease can arouse emotion in many people. Participants who have recently lost loved ones, especially to one of these illnesses, may become upset with some questions.
- Remain calm but not distant or cold; let the emotion run its course. Often participants who have experienced losses express strong motivation to continue with the project to contribute to the disease prevention effort.
- Stop the interview if a participant is clearly unable to finish. Be sure to arrange to call the participant within a few days — just to make sure everything is all right and to try to reschedule the interview.

Strong Objections to Questions

- Assume the burden of communication; take the blame for misunderstandings. If a participant fails to grasp the meaning of a question, admit that perhaps you didn’t deliver it clearly and repeat the question. Do not allow the participant to feel that the questions are too difficult for her to answer.
- If the participant is angry, reluctant or impatient about a single question or a series of related questions, cite “the office” or “the researcher.” Blame the project for objectionable material, not the participant for being objectionable.

- Respond in a non-defensive tone as though you have heard the objection before. Don't delay the interview any more than necessary; move on to the next question. If the participant pursues the objection, remind the participant that although the researcher had a purpose in including the question in the interview, the participant doesn't have to answer the question.
- If a participant hesitates or refuses to answer, repeat the question. Say, "Let me go over that again. If you don't want to answer, that's your choice; but my instructions are to ask each of the questions." Add that the participant's feelings or opinions about the question are important. If the participant still refuses, accept the refusal graciously and go on to the next question.

Impatience with the Length of the Interview

- If a participant is anxious to finish the interview, say, "I need only a few more minutes of your time. Your answers are important to us, and we'd like to have all of them."

Curiosity about the Research

- Be ready with standard replies for people who want to know more about the research.
- Do not get involved in long explanations of the project, the forms, the research methods, or the outcomes of the study. Be sure to use standard responses.
- Invite participants to talk to your Principal Investigator (PI) or other appropriate staff person if they wish to carry a discussion further.

Second Guessing Purposes of Questions

- Do not invent your own explanations when participants want you to tell them why certain questions are included in the interview. For participants who persist, tell them that the researcher had a purpose for the question and that you must ask all the questions as they are written.
- Invite participants to talk to your PI or other appropriate staff person if they wish to carry a discussion further.

Advancing Age

- Gauge your pace according to the needs of the participant. Some older participants may require a slower delivery; others may be insulted by it.

Hard of Hearing

- Slow down for participants with hearing problems and speak in lower-pitched (more bass-pitched, not soft-spoken or high-pitched) tones. Female interviewers often increase their pitch when they speak louder which makes hearing more difficult for many participants who hear lower-pitched tones better.

Lack of Understanding or Recall

- Take responsibility for making questions understandable. Do not make participants feel that it's their fault if they don't understand a question.
- Take away the burden of not remembering: participants shouldn't feel ashamed by lack of recall. If a participant doesn't remember a date, lead a discussion back through some prominent seasons or events, repeating the phrase of the question as you go.
- Repeat the question at least once for the participant who does not understand the question. Repeat it twice if the participant has patience for it. After that, record whatever answer the participant offers and go on. Don't risk annoying the participant for the sake of an answer to a single question.
- If a participant asks what a word means, use only the definitions provided on the forms and in the instructions. If there are none, say "Whatever the word means to you." In some instances, you may also emphasize again that the researchers are interested in the participant's feelings and that you "can't really answer for" the participant or "put words in her mouth."

Wandering, Extra Talking

- Focus the participant's attention on the questions, while always being polite. Respond to attempts at idle conversation, no matter how interesting, with brief answers, then return to the form.

5.2 Guidelines for Participants with Cognitive Decline

These guidelines offer considerations and suggested strategies, not requirements, for working with WHI ES participants who have experienced some level of cognitive decline. These guidelines are meant to assist, not constrain, RC staff that must balance WHI ES procedural requirements with participants' capabilities and needs on a case-by-case basis. The ultimate purpose of these guidelines is to support the appropriate ongoing participation of WHI ES participants.

5.2.1 Identifying Potential Cognitive Decline in WHI Extension Study Participants

Steady, progressive cognitive decline resulting in significant impairment is not a normal aspect of aging. Health and social problems among older persons are dynamic and may vary over time. Thus, cognitive functioning can vary over time. WHI ES participants will experience transient changes in their memory, thinking, and behavior depending on current life events and daily stresses, acute illnesses, or specific medications. Most of the time, these changes are troublesome but not disabling. Rarely, WHI ES participants will have progressive or profound changes in their cognitive status.

Because cognitive deficiencies can vary from minor to severe, your response to them can vary from minimal to substantial. Your response to cognitive decline should be based on a consideration of its severity and significance with respect to functioning. A thoughtful approach to cognitive problems can help staff reduce barriers to WHI ES participation and identify care participants may need.

Procedures and tools for making an accurate evaluation of a participant's cognitive status and capabilities are complex and beyond the scope of these guidelines. Likewise, RC staff is not expected to formally assess a participant's cognitive status. Note that cognitive decline is not necessarily a reason for a participant to discontinue her participation in the WHI ES.

RC staff will become aware of a participant's potential cognitive decline in many ways:

- If the participant seems confused while completing annual data collection forms
- Based on information in medical records or health care provider reports provided to RC clinic staff
- Based on information provided by the participant, a family member, or friend about a participant's cognitive changes or their consequences in her day-to-day life

RC staff is encouraged to discuss her/his concerns about a participant's cognitive decline with other appropriate RC staff and investigators to determine if additional information or specific accommodations should be considered.

5.2.2 Addressing Cognitive Decline Concerns

When addressing cognitive decline concerns, it is important to be comfortable with and have some skill in carrying out interactions with such participants. Matters will not be made worse by assessing cognitive function with participants, and it may help. RC staff without comfort or skill in this area should refer these participants to other appropriate staff or investigators. It is preferable however, that RC staff proceed with a thoughtful assessment and discussion with the participant.

The primary consideration when ***potential*** cognitive decline is identified is the participant's ability to continue to provide appropriate data on WHI ES forms.

5.2.3 Assess Specific Concerns

- With the participant (e.g., *Have you noticed any changes in your memory or thinking lately?*)

  In almost all circumstances, it is appropriate for RC staff to be straightforward with participants and directly confront the issue when it is detected (e.g., *At times today, you seem a little confused or forgetful).* If the participant identifies issues or circumstances that readily explain the confusion, a notation in her chart may be the only action warranted at this point. If the participant describes (or you note): 1) progressive and significant confusion or memory problems; 2) contacts with health care providers to evaluate her cognitive decline; or 3) tangential or irrelevant responses to your questions, additional steps may be appropriate.

- With a family member, health care provider, or proxy

  Determine if they are aware of the participant's potential cognitive decline and what, if anything, has been done to address this issue.

  It is important to obtain the participant's permission to make such a contact (e.g., *I'm just a little concerned. Would it be okay if I talk with your* [family member, health care provider, or proxy] *to find out more about this?*). Document this discussion in the participant's chart. The person you contact may be knowledgeable about the participant's changes, aware of her participation in the WHI ES, and able to support or suggest accommodations for her ongoing participation.

5.2.4 Changing Level of Participation

If the cognitive decline does not seem to be permanent, or if she still seems able to complete her forms, you may decide to continue her participation as before. If the participant's cognitive decline in WHI ES continues (e.g., a "temporary" cognitive decline does not resolve, the participant continues to be confused when responding to questions), a change in participation status may be warranted. Appropriate changes may include changing to "no follow-up" or "proxy follow-up". Discuss the ongoing situation with appropriate investigators and staff (as above) before completing *Form 9 – Participation Status*. Refer to *Section 9 – Retention* for information on addressing retention challenges and making changes in WHI ES participation levels.

5.2.5 Strategies for Managing a Participant's Cognitive Decline

There are many strategies to consider for managing cognitive decline concerns, depending on the participant's particular situation. These may include:

- Nurture close relationships with the participants, their family members, and their proxies throughout the study, even when no problems exist.
- Provide accommodations (e.g., complete forms over the phone rather than by mail) that will help her continue to participate in the study.
- Provide the participant, her family member, or proxy with a referral to an outside provider, appropriate clinic, or other resource, if they want one. Most RCs already have local resource lists available.
- Actively involve a proxy or caregiver in helping the participant complete study forms. For more information about proxy procedures, refer to *Section 7.2 - Follow-up by Proxy*.
- Document ongoing assessment of the participant's cognitive status, as needed. Such informal assessments may be appropriate over the remainder of the study.

5.3 Guidelines for Suicidal Ideation

Since distress can vary in severity, so the response by the WHI ES staff must vary. Below you will find suggestions on how to handle three different levels of severity. As state laws governing how to respond to suicidal individuals may vary, each WHI ES PI should consult with a mental health professional to determine the best actions to take when severe distress or suicidality is detected.

It is recommended that each site determine those staff who have the level of comfort and sufficient experience to proceed with the assessment described in Level 1 below. Those staff who feel a participant may be seriously distressed but do not feel comfortable with addressing this with the participant, should ask the designated staff who can comfortably proceed to complete the interaction with the participant. The PI at the site should be made aware immediately of any participant with serious emotional distress symptoms, especially suicidal thoughts.

Level l: Significant symptoms of distress (e.g., depression)

RC staff who identify significant distress should:

1. Seek further information through paraphrasing to clarify the significance of her distress (I hear you saying . . . Did you say . . . etc.). If in doing so the participant does not express suicidal thoughts, proceed with the steps 2-5 below. If she does express suicidal thoughts proceed to Level 2.
2. Recommend to the participant that she contact her primary care physician who can evaluate and treat her or refer her for specialty care.
3. Request and document in writing (i.e., put in participant's file) permission from participant to follow-up with her within a few days.
4. Notify the responsible RC Staff Contact at the site.
5. Call participant within a couple of days for follow-up.

Level 2: Significant symptoms of distress (e.g., depression) with statement such as "life is not worth living, I wish I were dead."

Clinic staff should refer participant to the responsible WHI ES clinician (e.g., PI) for further evaluation. The responsible WHI ES clinician should assess suicidal intent through direct questioning.

1. If the participant's distress is so bad that she is planning to hurt herself then go to Level 3. If the participant denies that she is planning to hurt or kill herself, proceed through steps 2-6 below.
2. Encourage her to contact her personal physician immediately and offer assistance with that communication (e.g., transfer the call to her physician, if possible).
3. Request and document in writing her permission to contact a family member. Call family member and inform him/her of the situation. Repeat your recommendation to contact her personal physician as soon as possible.
4. Request and document in writing her permission to contact her personal physician. Call her physician and inform him/her of participant's status.
5. Request permission from participant to follow-up with her within a few days.
6. Call participant within a couple of days for follow-up and notify PI.

Level 3: Significant symptoms of depression with statements indicating suicidal intent

State laws vary regarding the responsibility a staff person has if a participant were suicidal. Therefore, each site should develop a set of guidelines that are consistent with state law. It is recommended that each PI consult with a mental health professional to develop them.

Generally, RC staff should:

Inform the participant of the importance of preventing her from hurting herself. Request and document in writing her permission to contact a family member, friend or family physician. If the participant refuses to tell her family/doctor, inform her that you are obligated to do so.

1. Call family member and/or physician and inform him/her fully.
2. Develop a policy consistent with state and local laws regarding the RC's responsibility to treat suicidal intent. Staff should consult with a mental health professional (i.e., psychiatrist, psychologist).

5.4 Guidelines for Domestic Violence (DV)

In the course of interacting with WHI ES participants, staff will encounter women who disclose or have evidence that they are in a situation involving domestic violence (DV). Since the level of risk may vary, the response by WHI ES staff can be flexible. State laws may have mandatory requirements governing how to respond to DV. Each RC therefore needs to ascertain any such jurisdictional reporting requirements and apply these within the suggested guidelines that follow. Each RC will also need to identify the staff member, best suited by experience and comfort level, who should interact with the participant regarding DV, and determine how the staff member receiving the original report should respond.

While many staff members may know information about DV, it is frequently difficult to know what words can be used. For this reason specific scripts for assessing the participant's status are included within the algorithm below. The purpose is to provide timely, emotionally sensitive support to women who reveal that they are currently or were recently in an unsafe, abusive relationship.

There are many factors that contribute to the difficulty staff have in discussing issues related to DV with study participants. Some of these factors may be:

a. The issue of DV is stigmatized in our society and therefore an uncomfortable subject;
b. Staff members may have personal experiences with DV by having witnessed violence in their family or personally being a survivor of DV;
c. The WHI study does not have DV as an outcome, and staff may not have been trained in appropriate assessment and brief intervention for women in situations involving DV.

Always discuss issues of DV in a private setting. Self-disclosure of domestic violence may involve a lot of risk-taking for the woman. This is especially true if the woman has never previously shared this information.

While some women may voluntarily self-disclose currently being in a relationship involving DV, many women will not self-disclose information due to various reasons, including fear of retaliation, low self-esteem, shame/embarrassment, isolation, a perception that the staff is not supportive of issues of DV, and lack of trust in the staff (fear that they will be reported).

Assure confidentiality of her answers

"Your answers to the questions on these forms are confidential. We will not share this information with anyone," (add "within limits of the law" where there are mandatory state or local laws regarding reporting of DV).

General Preparation for DV

Compile a list of DV resources for your RC.

- Perform in-service training for RC staff.
- Establish liaison with community resources.

Algorithm for Assessment and Resource/Referral Support

WHI participants may disclose that they are in relationships involving DV through their responses to questions on WHI forms or by mentioning this during a phone contact. If staff learn of a possible DV situation, conduct a brief assessment of:

a. The safety of the woman's current situation. "Was the abuse that you mentioned something that is happening in your relationship or your home right now?" "Do you feel safe being home tonight, or do you have a friend's house or would you like the name of a shelter that you might go to?"

   If there is current danger and the woman does not want to go to a friend's house or a shelter, ask "Are there guns, weapons, or knives in your house?" If yes, "Where could you take these so you would be safer?"

b. Her readiness to seek help, "You don't deserve to be in a situation where you are afraid of being hurt. Here is a list of community resources, supportive counselors, and of safe places for you to stay. Do you think that you might be interested in talking to one of these resource people now or in the future?" If the participant does not want the list, then mention, "If at any time you need the phone numbers, please contact me right away."

Resources:

K. Furniss. "Domestic Violence: What Nurses Need to Know."
Kaiser Permanente NW. "Domestic Violence Diagnosis & Assessment."
C.P. Mouton, S. Rovi, K. Furniss, N.L. Lasser. "The Associations between Health Status and Domestic Violence in Older Women: Results of a Pilot Study." J Womens Health Gend Based Med. 1999 Nov;8(9):1173-9.

Mouton CP, Rodabough RJ, Rovi SL, Hunt JL, Talamantes MA, Brzyski RG, Burge SK. Prevalence and 3-year incidence of abuse among postmenopausal women. Am J Public Health. 2004 Apr;94(4):605-12.

Baker MW, Lacroix AZ, Wu C, Cochrane BB, Wallace R, Woods NF. Mortality risk associated with physical and verbal abuse in women aged 50 to 79. J Am Geriatr Soc. 2009 Oct;57(10):1799-809.

5.5 Guidelines for Contacts with Participants' Survivors

These guidelines offer considerations, scripts, and activities for contacts with WHI ES participants' survivors (e.g., next-of-kin, spouses, or proxies) after a participant has died. These contacts may occur when you:

- Try to contact the participant about routine activities (e.g., to collect annual data) and learn that she is deceased.
- Contact a participant's survivor to provide final medical history information (i.e., *Form 33 – Medical History Update*)—this usually occurs because RC staff have previously learned about the participant's death, either from survivors, notification by another participant, reading an obituary, or other sources (e.g., online databases).
- Are contacted by a survivor to inform staff of the participant's death.
- Are contacted by a survivor in response to a routine communication (e.g., *WHI Matters* mailing).
- Are contacted by a survivor in response to a written or voice mail expression of sympathy and/or request for final medical history information.

5.5.1 WHI Extension Study Expectations for Staff Contacts with a Participant's Survivor

Except within the scope of one's professional licensure, you are not expected to (nor should you) screen for the severity of a survivor's emotional response (e.g., depression, suicidal ideation) nor are you expected to treat that response. However, all staff should maintain a professional demeanor, convey understanding, and offer to end or postpone the interaction for an appropriate period of time. Refer to *Section 5.3 – Guidelines for Suicidal Ideation* for guidelines should you have concerns about a survivor's distress.

5.5.2 General Considerations for All RC Staff

Initial contacts with a participant's survivor. As outlined above, the initial contact with a participant's survivor may occur unexpectedly. If a RC learns of a participant's death via a written source (e.g., obituary, written notification), RC staff should exercise appropriate clinical judgment and consider waiting at least one month after the participant's death before initiating a contact for medical history information.

Generally, all RC staff who routinely make or respond to outside phone calls (e.g., receptionists) should be prepared for possible contacts with participants' survivors. The initial contact, whether initiated by a survivor or a RC staff person, at minimum, should begin with an expression of sympathy and gratitude for the participant's contribution to the WHI ES. It may then be appropriate to refer the caller to a staff person who can begin the process of obtaining final medical history information. Below is a sample script to use for these initial contacts:

Thank you so much for letting me know. I'm sorry to hear about _______ and offer my deepest sympathy. When did this happen? [Pause and document the date, as needed, for completing *Form 120 – Initial Notification of Death*.] *She was an important part of the Women's Health Initiative study over the years and we will miss her. You can be proud of the valuable contribution she has made to women's health care through her participation in this study.*

We would like to get some information to help complete her health records for the study. Is this a good time to talk with you or someone else about her health history or should I have someone call you at another time?

Refer the caller to an appropriate staff person to begin an interview for *Form 33 – Medical History Update* or take down contact information and best time to call. Note that the caller may identify another person to give medical history information, ask the RC to wait for a period of time, express concern about providing such information, or refuse to provide this information. You should be prepared to respond to any of these scenarios.

Form 120 – Initial Notification of Death. Regardless of how the initial information about a participant's death is received, RC staff should initiate a *Form 120* and key-enter the available information in WHIX so that future participant mailings will be stopped. Depending on the circumstances of the initial notification, it may be appropriate to just enter an approximate date of death and the person providing the information.

Sympathy note. Upon hearing of a participant's death, mail out a sympathy note or card to the next-of-kin or proxy. This note can contain hand-written text similar to the script above (e.g., expression of sympathy, recognition of participant's contribution to the study, setting the stage for future contact about participant's medical history).

Local resource list. The RC should be sure there is a short local resource list available that staff can offer to a survivor. Rather than trying to determine if a particular resource is needed or appropriate, RC staff should consider just generally offering it to each survivor (e.g., at the end of the contact—"*We have a list of resources that I can mail you."*). The resource list may include:

- a basic counseling resource that is relatively low cost or sliding scale
- health information resources (e.g., American Heart Association, American Cancer Society)
- crisis line (contact this resource first to make sure it is appropriate)
- additional resources, such as local/regional treatment sites (e.g., emergency rooms), bereavement/counseling services provided by religious organizations or a hospice group (which often offer services even if the participant did not use the hospice organization), web sites (e.g., http://www.aarp.org/relationships/grief-loss/, see "Understanding the grieving process" below)

Review and update this resource list at least every 6 months to confirm that it is still current.

Understanding the grieving process. There are many excellent resources (books, articles, web sites, professionals at your institution and in the community) available for learning more about bereavement and grieving. The most important point to remember is that there is no one "normal" response to loss and a person's response may have very little to do with the current interaction. Manifestations of grieving can take many different forms based on one's previous experience with loss, relationship with the participant, personality, and current life circumstances. A normal affect, anger, crying, withdrawal, denial, and a desire to talk things through are all possible responses. You are not expected to manage these responses beyond maintaining a professional demeanor, conveying understanding, and offering to end or postpone the interaction for an appropriate period of time. Some excellent resources related to grief and bereavement may be found on the World Wide Web, including:

- http://www.aarp.org/relationships/grief-loss/, The "Life After Loss" website for the American Association of Retired Persons. Includes information about common reactions to loss and many other practical resources.

5.5.3 Considerations for Staff Who Collect Medical History Information from Next of Kin (NOK)

RC staff who contact survivors for medical history information should have good interaction skills and a very basic understanding of the grieving process. Sometimes these contacts can extend longer than expected or just be emotionally draining. If you are the most appropriate person to make the contact, be sure that the call is made when you are not rushed, in a space where you will not be interrupted, and you are prepared operationally and emotionally.

Considerations for making the contact. When you are contacting a participant's survivor to obtain a participant's final medical history information, consider the following:

- Delay contact for at least one month after the participant's death (use clinical judgment), but avoid contacting survivors around the participant's birthday or on the same day of the death in subsequent months.
- Consider sending a letter letting the survivor know you will be calling about the participant (so they can gather information) and then follow-up with the actual medical history update call a week or so later.
- Convey professionalism and understanding, particularly if the survivor wishes to delay or postpone the interview or becomes emotional (in which case, you should offer to postpone the interview; see *Section 5.1.4.2 – Special Situations with Participant Contacts*).
- Ensure that the person you are talking with is the appropriate person from whom to obtain this information (*"Are you able to provide this information or is there someone else we should talk to?"*).
- Follow the basic interview script for *Form 33*; see *Form 33* forms instructions in *Appendix A – Forms).*
- Make use of good interviewing skills (see *Section 5.1 – Interviewer Procedures*).
- If the survivor is angry, very reluctant to talk, or emotional, do not "blame" the person for his or her feelings or engage in debates about possible objections. You might say, *"It sounds like this is not the best time to talk. Thanks for your time today and I am sorry about your loss."* You will need to judge whether or not it is truly appropriate to offer to call back or whether such an offer might be met with an immediate refusal. In the latter case, instead of making the offer to call back, you might want to just end the call and postpone further contact for an appropriate amount of time. When you follow-up again, you may find some reluctant next-of-kin are now willing to talk.
- If encounters turn difficult, always keep in mind that you are doing the best you can and have all good intentions, even if sometimes you feel like you're not saying the "perfect" thing.
- Offer options for obtaining this information if there is ongoing resistance to doing the interview (e.g., mail or fax medical records or death certificate).
- If the participant is angry, reluctant or impatient about a single question or a series of related questions, cite "the office" or "the researcher." Blame the project for objectionable material, not the participant for being objectionable.

Some survivors may be willing to complete *Form 33* by mail, but not over the phone. In this case, mail the *Form 33* to the NOK. Follow-up for non-response to this mailing should be sensitive to the NOK's possible emotional needs to delay. If a participant's next-of-kin refuses to provide this information or will not sign a medical release, note this information in the participant's progress notes. Your local Institutional Review Board (IRB) may have additional guidelines to consider. Refer to *Section 8.2.7 - Reports of Death* and *8.5 – Fatal Events* for additional information on procedures related to documenting and investigating a participant's death. *Section 7.2 – Follow-Up by Proxy* also provides some guidelines on identifying and contacting proxies.

5.5.4 Family or Proxy Requests for Information*

Family members, friends, or designated proxies may ask for specific information about the participant who has died. Here is a possible script for responding to such requests:

We are committed to protecting our participants' confidentiality, so I hope you understand that we must follow careful guidelines and procedures before releasing information to people.

After offering this introductory explanation, provide the survivor with the specific guideline below based on the information requested.

- **WHI records**: A participant's WHI records, including consent forms (not medical records obtained outside those generated by WHI) may be made available to the legal NOK upon written request.
- **Results of blood analyses**: Only those analyses that were done at local laboratories during the original WHI (e.g., complete blood count at baseline and Observational Study [OS] Year 3) may be made available to legal next-of-kin upon written request. Analyses done at central labs are not contained in the local databases and are logged centrally by an ID number only, so they are not available to study participants or their next-of-kin.

- **Study information and findings:** Findings from the WHI are being published on an ongoing basis. The National Institutes of Health (NIH) maintains a web page of study information and updates a list of selected publications at http://www.nhlbi.nih.gov/whi/index.html. Information can also be found on the WHI Participant Website at http://www.whi.org.

***** Participant rights (even after death) dictate that information or records about her death may only be released to the legal next-of-kin. Although state laws may vary slightly, in general, legal next-of-kin is defined as:

- husband, if the participant was married
- children, if the participant was single and has children (unless the children are all minors)
- mother and father, if the participant was single (if mother and father are deceased, then her sisters and brothers are considered legal next of kin)
- other (if none of the above apply)

5.6 Special Populations Considerations

An important goal of the ES is to recruit and retain a representative sample of postmenopausal women of various ethnic, racial, and socioeconomic backgrounds. This includes women with low literacy levels, visual problems, or other conditions that may challenge their ability to participate. Regardless of whether a RC has been designated as a minority site, it is expected that the sample from each RC will include women from a variety of backgrounds. This section on special population considerations is written as a guide to facilitate RC staff to optimally address the needs of women with a variety of experiences and backgrounds. It recognizes that women will be included in the study who have differences that must be considered as they are recruited and participate in the study.

This section begins with a general discussion of special considerations in cross-cultural counseling and interactions. Information is provided regarding cultural values, beliefs, and behaviors that need to be considered when counseling and interviewing participants as well as suggested approaches for maximizing successful cross-cultural interactions. The special needs of older women are presented, followed by those of women of ethnic minorities. General issues that need to be considered with all minority group women are presented as well as special considerations for women from specific minority groups. The reader is cautioned that these general characterizations may not apply to all minority women. These guidelines are simply meant to offer perspectives that will aid in dealing with these subgroups of women more sensitively, thereby encouraging participation. It should also be noted that some of these issues may be relevant as well for women who are not minorities. This section also considers approaches that should be used with women with special needs.

The final part of this section includes the guidelines for Spanish Translation. Several RCs have been identified to recruit Hispanic participants and require the Spanish version of WHI ES documents. This information is included as a matter of record of how ES documents were translated into Spanish and for reference by RCs in the translation of RC-specific documents.

5.6.1 Special Considerations in Cross-Cultural Counseling and Interaction

One key to cross-cultural counseling is an understanding of value systems in other cultures and their influence on health and nutrition. Every culture has a value system that directs behavior by setting norms.

Cultural Values

A value is a standard that people use to assess themselves and others. It is a widely held belief about what is important and desirable for well-being. Working with participants from diverse backgrounds requires understanding your own values as well as the values of other groups. Too often we interpret the behavior of others as negative because we don’t understand the underlying value system of their culture.

There is a natural tendency for people to be "culture bound," to assume that their values or customs are more sensible and right. Cross-cultural counseling and interaction presents special challenges because they require you to work with participants without making judgments as to the superiority of one set of values over another.

To enhance your understanding of cultural differences in values the following list provides a general comparison of Traditional American values with values commonly found in some other countries.

Traditional American Values	**Other Cultures' Values**
Personal control over environment	Fate
Change and variety	Tradition
Competition	Cooperation
Individualism	Group welfare
Future orientation	Past orientation
Directness	Indirectness/"Face"
Informality	Formality
Time Importance	Human interaction importance
Duration of life	Quality of life

Examples of Potential Differences in Values

- Participants and health-care staff may differ on the value of time. Most of us are ruled by time schedules. If "being on time" and "not wasting time" are not familiar concepts to the participant, a 9 o'clock appointment may not be kept until 10 or 11 o'clock. This may be considered entirely appropriate behavior.
- Decisions regarding medical screening or food intake might not be decided by the individual, but by group or family agreement. Thus, a woman may not follow the practices suggested because of extended family values and traditions.
- A woman may not believe that her health habits are related to well-being, but rather attributes her well-being to "fate." Thus prevention will be viewed as a "waste of one's time."

Health Beliefs

Cultures vary in their beliefs of the cause, prevention, and treatment of illness. These beliefs dictate the practices used to maintain health. The value of "good health" is also variable. The traditional American culture emphasizes duration of life, whereas some other cultures place greater emphasis on the quality of life.

A woman may follow a specific process in seeking health care. Family is much more important in some cultures. The family supports and is frequently involved in the treatment, unlike Western medicine where the person is dealt with as a separate individual (not a part of a larger family).

5.6.2 Non-Verbal Communication

Your personality and communicating style affect the counseling process. The woman may easily detect attitudes you think you are concealing. Genuine interest and concern for the woman are essential qualities for RC staff members during cross-cultural counseling and interaction.

- Silence. You may view silence as awkward, however, other cultures are quite comfortable with periods of silence.
- Verbal Communication. How you speak is as important as what you say in cross-cultural interactions. Your tone of voice should be positive, avoiding condescending, disinterested, or unpleasant tone. The volume should be audible, but not so loud as to make the woman feel uncomfortable. Often we mistakenly assume that a louder voice is clearer and therefore more easily understood by the participant. Articulate each word and adjust your rate of speech, if necessary. Speech that is too rapid might not be understood, while speech that is too slow might actually bore the woman.

  Don't try to imitate an ethnic communication style which is not naturally your own. For example, using Black American language and communication style, when you are not Black American, may be interpreted as ridicule.

- Formality. Anglo-Americans tend to be informal in their verbal communication, but some other cultures prefer to keep a relationship more formal. Don't assume a first-name basis is appropriate for client relationships. Many Black Americans may view being addressed by their first name as too familiar and may infer disrespect. With any participant, terms of endearment such as "honey," etc. should be avoided. Asking the woman how she prefers to be addressed is the easiest solution, or assume formality when in doubt.
- Rapport. It is important to establish rapport with the participant when beginning the conversation. Use "small talk" to reflect genuine concern for the woman. However, too much chatting, too many questions, or being "too nice" may cause uneasiness or raise suspicion.

5.6.3 Getting Accurate Information

All staff are concerned with getting accurate information from participants, and this is multiplied when the interaction is cross-cultural. Finding approaches that get better information is easier once you are aware of some additional barriers to communication.

Possible Barriers

There are several reasons why a participant of a different culture may not provide a staff member or counselor with good information.

- Lack of trust.
- Participant feels the information you want is inappropriate.
- Participant is uncomfortable with age, sex, education level, or race of the counselor or staff member.
- Participant will make an effort to "please" the counselor or staff member.

Suggested Approaches

- Establish rapport and show genuine concern.
- Ask questions in several different ways to double-check information.
- Adjust style of interaction to complement differences in age between you and participant.
- Use open-ended questions.

5.6.4 Preparing for Cross-Cultural Counseling or Interaction

- Understand your own cultural values and biases.
- Acquire basic knowledge of cultural values, health beliefs, and nutrition practices for participant groups you routinely serve.
- Be respectful of, interested in, and understanding of other cultures without being judgmental.

Enhancing Communication

- Ask how the participant prefers to be addressed.
- Avoid language that may be offensive or misunderstood.
- Choose a speech rate and style that promotes understanding and demonstrates respect for the participant.
- Avoid slang, technical jargon, and complex sentences.
- Use open-ended questions or questions phrased in several ways to obtain information.

Promoting Positive Change

- Build on cultural practices, reinforcing those which are positive, and promoting change only in those which are harmful.
- Check for participant understanding and acceptance of recommendations.
- Remember that not all seeds of knowledge fall into a fertile environment to produce change. Of those that do, some will take years to germinate. Be patient and provide counseling in a culturally appropriate environment to promote positive health behavior.

Information adapted from: "Cross Cultural Counseling: A Guide for Nutrition and Health Counselors." USDA, US Department of HHS, FHN 250, September 1986.

5.6.5 Working with Ethnic Minorities

5.6.5.1 Ethnic/Racial Sensitivity

Considerations:

- May have a preference for interacting with individuals who are representative of own minority group.
- May not have a personal physician or system of regular medical care.
- May perceive members of own minority group to be more aware of and sensitive to life circumstances, perspectives and concerns.
- May perceive lack of employment of individuals from minority groups on clinic staff as an indication of prejudice.
- May become offended if it appears that they or others from ethnic/racial minority groups are treated differently or are not respected.
- Published statistics and information on minority community may not be accurate.
- There may be varying perspectives and experiences in ethnic subgroups within African-American, Hispanic, Native American, and Asian minority groups.

Solutions:

- Make sure staff, particularly receptionist, is pleasant, respectful, and positive.
- Stress that participation in WHI ES does not replace the need for regular medical care.
- Select a staff that is representative of the community and that reflects a balance of ethnic/racial groups.
- Have a staff member of the same ethnic/racial background of the women available to explain study protocols, consent forms, and questionnaires.
- Appoint a local advisory committee; include reputable minority community representatives. Ensure that members are clear about their role and level of involvement.
- Become thoroughly familiar with minority community characteristics, information channels, and power structure.
- Recognize the diversity of ethnic viewpoints within minority subgroups that can influence responses to the study protocols.

5.6.5.2 Personality Motivational Factors

Considerations:

- May perceive research as a form of exploitation in which non-minority individuals reap the benefits.
- May be concerned about being used as a "guinea pig" in research.
- May believe that only minority scientists should study minority populations.
- May have past history of being exploited by sales people under the guise of a survey or research study.
- May be less prone to self-disclosure in research, particularly to someone from another ethnic or racial group.

Solutions:

- Explain that the study will provide important information for all women of all ethnic and racial backgrounds.
- Note that women from all ethnic and racial groups are included in the study.
- Inform the woman that researchers from all ethnic and racial groups from across the country are involved in conducting the study.
- Have a staff person of the same ethnic and racial background of the woman available to explain information and to assist in completing questionnaires as needed.
- Present study through public forums, such as churches, community associations, fraternal groups, and in ethnically-focus newspapers.
- Obtain sponsorship of various individuals or organizations that have a reputation of showing concern for the welfare of the minority community.
- Use the media to inform and motivate the community about the study.
- Send letter about project on official agency stationery before initial contact. If initial contact is in person, have identification available from official agency.

5.6.5.3 African-American (Black)

Considerations:

- May be quite religious. May not readily accept interventions or actions that are perceived to be against God's will or God's plan in nature.
- More likely to believe in destiny.
- May put a high degree of trust in personal physician regarding all health matters.
- May not participate in health research without the perceived support of physician or regular health care provider.

Solutions:

- Explain carefully and simply the procedures to be used and the reasons for using them.
- Inform local health care providers about the study and that some of their patients may be involved.

5.6.5.4 Hispanic

Considerations:

- May not feel comfortable speaking English.
- May seek informal approval from husband or older son for decision making.
- May be concerned that personal information (for example, income or immigration information) will place family at risk.
- May be suspicious of government involvement in a research project if family members have lived in oppressive societies with government informers.

Solutions:

- If the person answers the telephone in Spanish, the staff person calling should continue the conversation in Spanish.
- Use the formal and respectful form of the pronoun "you" in Spanish, that is, "usted," when talking to Spanish women.
- The husband or child, if a husband is not available, should be informed about the study to encourage their informal permission.
- Carefully explain the confidentiality of information obtained in the study.
- Assure the woman that personal information will not be provided to other government agencies.
- Explain that personal data will not be reported at the individual level; only group data will be reported.

5.6.5.5 Native American

Considerations:

- May not be comfortable speaking English.
- May associate certain health problem as “normal” part of aging which do not require medical intervention.
- May de-emphasize personal health problems or complaints.

Solutions:

- Provide a trained interpreter or interviewer who speaks the language.
- Work with local Indian Health Service or Native American health care providers to develop referrals and follow-ups.
- Explain that not all symptoms are caused by aging.
- Explain why it is important to maintain health for the benefit of self and especially for the family unit.

5.6.5.6 Asian

Considerations:

- May be highly concerned about personal social status issues.

- May not readily provide information that could be perceived to shame or reflect poorly on self, or family members.
- May hesitate to respond to questions about income, educational level, living arrangements, and household composition.

Solutions:

- Assure the woman that all information is confidential and that personal information will only be reported as group data.
- Explain why information on income, education, and family background are important to the study.

5.6.6 Working with Women with Special Needs

Considerations:

- May not be able to read or write English or Spanish well.
- May not be able to see well enough to read or complete study forms alone.
- Mobility may be compromised.
- May not be able to complete study forms without assistance.
- May require additional time for completion of study forms.
- May become frustrated and discontinue participation.
- May have child care responsibilities for grandchildren or other young children that may interfere with participation.

Solutions:

- Let women know that assistance can be provided in completing forms if they require it.
- Provide assistance if possible in completing study forms for women who have a low literacy level, visual problems, or physical mobility problems. Ensure that answers recorded are those of the woman, not of the person providing assistance.
- Exclude volunteers who can not speak in local RC languages or dialect. Only use translators who are part of the bilingual RC staff or volunteer translators for which levels of fluency in both languages are known to be satisfactory.
- Identify women who require assistance in completing study forms. Incomplete forms or inappropriate responses indicate that a woman is likely to need assistance.
- Designate a family member or person in the household to aid women who require assistance in completing study forms at home if one is available. Clearly identify designated person, note on RC forms, and train in approach to providing assistance. Training should emphasize having the designee focus on obtaining and recording the woman's response and <u>not</u> their own. Items on questionnaires that are sensitive or may be embarrassing to provide answers to family member should be completed with the assistance of RC staff rather than with assistance of family member.

5.6.7 Working with Older Women

Recognize the diversity and heterogeneity of older women: They will vary widely on dimensions of health and functional status, educational background, standard of living, and cultural background. The potential for certain health problems increase with advancing age.

5.6.7.1 Health and Functional Impairments

Considerations:

- Vision and hearing may be impaired.
- Cognitive impairments such as memory, performance and certain dimensions of intelligence may decline with age. The speed at which information is processed may also be slower. The woman may have difficulty retrieving relevant information.
- May easily fatigue, sometimes become confused.
- May become emotionally distressed (cry) because questions asked evoke sad memories.

Solutions:

- Appeal to the woman's altruism. Tell her that participation is important for future generations.
- Speak slowly, clearly, provide redundant cues (position yourself so that they can both see and hear you speak). Use the low frequency range of your voice; do not yell.
- Be alert for signs of fatigue. If possible, give the woman a brief rest period. Reschedule, if necessary.
- Strike a balance between compassion and objectivity.
- Repeat questions and response categories.
- Do not overload the woman with information.

5.6.7.2 Personality and Motivational Factors

Considerations:

- May be less interested in general in topics of the study and may object to the relevance of certain types of data for the study.
- May be more readily influenced by interviewers and more susceptible to interview bias.
- Ethnic/cultural group differences may be more extreme.

Solutions:

- Clearly identify yourself.
- Emphasize the importance of the study and the need for questions and procedures.
- Be sensitive to bias and try not to express opinions.
- Recognize differences in communication styles (language) among different ethnic groups.

5.6.7.3 Cohort Differences (Life Experience Effects)

Considerations:

- On average, today's older women have fewer years of formal education than younger women and have encountered fewer tests and standardized interviews.
- May disregard standardized scale formats.
- May sidestep questions and converse "on the side." Information that older women have to report is inherently more complex because they have a lifetime to summarize.
- May misunderstand questions or response options.
- May have different standards about the appropriateness of being asked for certain types of information (e.g., income data; functional status data).
- May be more easily insulted at being asked particular questions (e.g., ability to stand from a chair when answer seems obvious).

Solutions:

- Explain carefully the procedures to be used and the reasons for using them.
- Give the woman a road map of what will happen, how long it will take.
- Anticipate and address participant fears and anxieties about questions being asked, procedures being used.
- Clarify questions and response options using language more familiar to the woman as needed.
- Explain that sensitive information will not be reported at the individual level; only group data will be reported.
- Emphasize the importance and value of the data to be collected and how it will help current and future generations, etc.
- Emphasize that while some questions may not be appropriate to them, they have to be asked of everyone.
- Promise to provide (and follow through) general information about the study as a whole as it becomes available.

5.7 Spanish Translation

These guidelines for Spanish language translation address:

- Translation of documents for which there is no previous Spanish translation;
- Materials used in health promotion projects, with particular focus on multi-center trials; and
- Checking the acceptability of previously translated documents.

1. Documents are translated by a certified Language Services Specialist, who is skilled in grammatical rules and localized regionalisms. The translation will be entered on a computer with Spanish-language capabilities, including spell-check and thesaurus. All target audiences and their particular regional Spanish will be taken into account, including U.S. Border, Mexican, Central and South American, Caribbean (Cuban, Puerto Rican, Dominican) and Peninsular (Spain). A low literacy audience must be taken into account.
2. Documents are proofread word by word, line by line by the translator, to ensure accuracy. During this review, the translator scans for errors, general syntax, and readability.
3. Translated documents are then edited by a fully bilingual English/Spanish editor/proofreader who was not involved with the original translation of the document. Translators and editors have complete command of Spanish and are skilled in grammatical rules and localized regionalisms. All target audiences, and their particular regional Spanish, is taken into account, including U.S. Border, Mexican, Central and South American, Caribbean (Cuban, Puerto Rican, Dominican) and Peninsular (Spain).
4. Changes by the editor are incorporated and a second draft is prepared and scrutinized for any remaining grammatical/typographical errors.