

## ABSTRACT

Title of Document: WHAT DOES THIS QUESTION MEAN TO YOU? COGNITIVE INTERVIEWING TO PRETEST A QUESTIONNAIRE FOR OLDER ADULTS

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Seven cognitive interviews were conducted in adults aged 80 and older to pretest a questionnaire for the *Community Connections – Moving Seniors Toward Wellness* research project. Respondents participated in intensive one-on-one interviews. The questionnaire was administered, and respondents were probed for comprehension of question content. Older adults with physical limitations answered questions about depression based on physical rather than emotional status, made distinctions between capacity and performance regarding physical function, and failed to understand key medical terms. Wording of questions about personal hardiness was confusing to older adults. The findings were used to simplify wording throughout the questionnaire. Survey designers should be aware that questions about depression may be testing physical rather than emotional status. Questions about physical function should make a distinction between capacity and performance. Common language rather than

medical terminology should be used when surveying older adults. Rewritten  
hardiness questions may be useful in assessing older adults.

WHAT DOES THIS QUESTION MEAN TO YOU? COGNITIVE INTERVIEWING  
TO PRETEST A QUESTIONNAIRE FOR OLDER ADULTS

By

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## Dedication

This thesis, and the study and research that preceded it, I dedicate to my husband, Robert Glenn Newman, July 15, 1947 – March 8, 2001, for his unwavering support of my career change from music to nutrition. “Now you have to listen to me, hon: I have my Master’s degree.”

Love,

LK

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# Chapter 1: Background and Literature Review

## Introduction

Data from surveys of adults aged 65 and greater are of crucial importance for developing and instituting public policy and designing appropriate interventions for older adults (1). The quality of data gathered by surveys from older adults is important in the public health arena, since policies or programs using incomplete or erroneous survey-derived information may be ineffective, inappropriate, or not cost-effective (2). Therefore, misunderstanding or misinterpretation of survey questions by older adult respondents may directly or indirectly affect health care delivery, best-practice health care protocols, and quality and costs of health care.

For a survey to obtain accurate data, the questions must be asked in language appropriate and understandable to the target audience (3). Researchers typically pilot test their survey instruments, but numerous studies demonstrate that problems of wording and language are not detected by pilot testing (3).

One technique useful in the early stages of questionnaire development is cognitive testing of the instrument to discover problems of wording, language and context. Through an intensive, one-on-one interview called a cognitive interview (CI), the questionnaire is administered to representative members of the target population. Respondents are asked to paraphrase specific survey questions, verbalize their thoughts about the meaning of the questions, and make suggestions to improve wording. By focusing on language and wording comprehensible to respondents, interviewers gain

insight into the cognitive processes and needs of the target audience and have the opportunity to revise and improve the questionnaire in order to elicit more accurate data.

Survey methodologists at the cognitive research laboratory at the National Center for Health Statistics (NCHS) pioneered the use of CI to evaluate problems unique to older adults when they answer surveys (4). They found that CI was effective in identifying survey response problems in older adults, and were able to suggest wording that would result in more valid and reliable responses.

For the research reported here, seven cognitive interviews were conducted to pretest an Initial Needs Assessment Questionnaire designed by researchers at the University of Maryland for the *Community Connections – Moving Seniors Toward Wellness* research project.

*Community Connections – Moving Seniors Toward Wellness* is a federally-funded research and demonstration project being conducted by the Meals on Wheels Association of America (MOWAA) in cooperation with The U.S. Administration on Aging (AoA) and the University of Maryland, College Park Department of Nutrition and Food Science (5). The goals of the project are to improve the health and nutrition status of at-risk older adults by creating a continuum of community-based health and nutrition care including home delivered meals bundled with a broad array of prevention and wellness services.

The project targets older adults awaiting hospital discharge back to their pre-hospitalization residence, and the investigators are testing whether health outcomes of this vulnerable population will be improved if they can receive a continuum of health and nutrition services in a timely and efficient package (5).

The Initial Needs Assessment (INA) questionnaire was developed by the researchers. Some questions have been published and validated through numerous research studies for use in older adults, such as six questions from the Geriatric

Depression Scale (GDS), while other questions were developed by the researchers specifically for the Community Connections project.

As part of the pretesting of the INA, the principle investigator, Nadine Sahyoun, Ph.D., R.D., determined that cognitive testing would be helpful in guiding the design of the INA. Many of the questions on the INA had been validated but not cognitively tested. If comprehension problems were found that could be resolved through changes to the questions, not only would the Community Connections data be more accurate, but other researchers who use these questions might benefit. Because data from health and nutrition surveys are critical in establishing policy and interventions, the potential improvement in data quality could lead to more cost-effective, appropriate and effective government and privately-run health and nutrition programs.

The goals for the cognitive testing of the INA were:

- to test for lexical problems in the wording of questions. For example, a number of medical terms were used in the survey, such as “anemia” and “gastrointestinal problems.”
- to test for inclusion/exclusion problems. For example, who do respondents include when asked about “health care providers?”
- to test for temporal problems when respondents were asked to recall how many times they had visited particular health care providers within certain time periods.
- to determine whether problems with memory for recurring events within the recent past might compromise the accuracy of the data collected.
- to find out whether the syntax of questions was appropriate for the INA, which was to be administered orally.
- to understand whether older adult respondents would find any questions, particularly those about their outlook on life, upsetting or intrusive.

### *Rationale for Cognitive Testing of the INA*

One of the most important tools in epidemiological research is a survey, or questionnaire. In order to collect data, the survey needs to be able to delineate the characteristics of large and varied populations and to allow comparisons among sub-groups within the larger population (6). The questions in a survey must be able to measure the concepts or behaviors they're intended to measure so that the data collected represent true answers to the questions while avoiding as much random error as possible. Questions must be sensitive enough to measure actual differences or changes, but specific enough to avoid interpreting difference or change when there is none. Additionally, the data collected must be complete (7).

### *Assumptions of Data Collection by Surveys*

Data collection is predicated on the assumptions of standardization of questions and standardization of interviewer techniques (7). When designing a survey instrument, the goal is to ensure that observed differences among the data are not due to differences in data collection methodology.

Another assumption inherent in survey design is consistency of response to questions. It is assumed that a) all respondents understand the questions in the same way, b) that the respondents have and are able to retrieve the information required to respond, c) that the wording and content of the questions provide sufficient information so that the respondent can answer as required by the researcher, and d) that in interviewer - administered surveys, the interviewers always read the questions exactly the same way (7).

### Sources of Measurement Error

Several sources of measurement error are associated with data collected by surveys (7):

- error caused by the questions themselves, such as questions that are misunderstood, questions that can't be answered accurately, or questions that respondents refuse to answer.
- error connected with interviewers, which include not reading the questions as worded, asking leading questions, recording answers incorrectly, or biases engendered by the way interviewer and respondent relate based on such factors as differences in age, ethnicity or gender.
- error associated with the cognitive task of responding to survey questions.

The research reported here focuses on detecting and remedying error generated by survey questions and by the process through which respondents answer survey questions.

### The Four Steps of the Question-and-Answer Model

Cognitive psychology posits a question-and-answer model to represent the process by which respondents answer survey questions (7). Although seven major variants of the model are in use (7), the most frequently cited model (7) is Lessler and Tourangeau's Four-Stage Model (8). They conceptualizes the response process in four distinct stages, each of which can lead to errors in reaching the "true" answer as conceived by the questionnaire designer.

The first stage is *comprehension*, in which the respondent interprets the meaning of the question. The primary issue in this stage is to determine whether the respondent understands the question as the researcher intended (7). Potential errors can occur if the respondent interprets the question differently from the way the researcher intended, but

error can also occur when different respondents interpret the question differently from each other. Both types of error run the risk of invalidating comparison between respondents' answers.

The second stage of the response process is *retrieval*. In this stage, the respondent must search long-term memory for information applicable to the question. This is a complex step of the response process because a number of factors come into play that affect retrieval (7). First, the information needed to answer the question may never have entered long-term memory, so the respondent may find no relevant information.

When a long-term memory *is* laid down it must be encoded and stored . If the context in which the person is asked to retrieve the memory is unlike the context during which it was encoded, the respondent may incorrectly remember the event or fail to remember it at all (7).

Rare and distinctive events are more easily recalled than ongoing or routine events (7). Over time, respondents typically have experienced an increasing number of similar events, and rare events become fewer. Accurate recall of events becomes harder because fewer events are rare or unusual, and details of ongoing or repetitive events are blurred together.

Specific details of an event may become lost or distorted in the encoding process (7), while interpretations are added, perhaps even in the process of attempting to retrieve the memory in response to a survey question. These retrieval distortions can result in faulty memory of the time, place, and details of an event or even in forgetting that the event occurred altogether. These factors become even more salient when older persons are survey respondents, as is the case in the research that is the basis for this report, because over a longer life-span, the number of similar events increases, and the number of rare events diminishes.

When responding to questions, individuals use several processes for retrieval: they adopt a retrieval strategy for finding the relevant information; they may generate specific cues to help them retrieve the memory, such as linking the memory to a season of the year or a singular life event such as retirement; they may remember a specific incidence of the memory, such as the time they went to the dentist *with their grandchild*, that may help them retrieve the appropriate information to answer the question, and they may fill in a partial memory through inference or extrapolation from other similar memories. In this last case, the response to the survey question may be contaminated with inference or details from another event.

The third phase of response is estimation or *judgment*. Because of all the factors that influence the interpretation of questions and the retrieval of information from memory, judgment and estimation play a crucial role in the question-answer process. In this step, respondents can consider whether they understood the question, whether they have the information to answer it, how detailed their answer needs to be, and whether the question requires them to express a view on a topic they may not have thought about in some time, if at all. They also may weigh whether the answer that occurs to them needs to be modified in order to meet the perceived demands of the question. For example, if a respondent is asked how many times she visited the dentist in the last year, she may need to consider whether an orthodontist counts as a dentist, and was last December “this year” because it was only three months ago, or “last year” because it was in the previous calendar year. Or did she really visit the orthodontist in the most recent December, or was that already 2 years ago? Or should that be considered one year ago?

Because human memory is imperfect, respondents often use heuristics, or what Collins calls “cognitive short cuts” (7) during the judgment step. Especially when answering frequency questions, respondents need to make judgments about how to

compensate for missing or inaccurate recall. When recalling “rare” events, respondents may be able to count the number of occurrences, but if not, respondents resort to estimating strategies. The estimate may be reported, or the respondent may adjust the initial estimate based on the context of the survey, such as the available response categories (7).

The final step in the model is *response*, during which the respondent settles upon and reports an answer to the question. The response phase is divided into two sub-tasks: formatting and editing the response.

Formatting comes into play once the respondent has comprehended the question, retrieved relevant information about the question from memory, and judged salient information about how to answer the question. Formatting is required when the question demands a closed response, wherein pre-designated response categories are provided by the researcher. Response categories may influence the way the respondent interprets the question and may affect what recall and judgment strategies they use. For example, a question that offers the response categories of “three or more meals per day,” “two meals per day” and “one meal per day” may cause respondents to report only eating occasions they consider meals, and fail to report other eating occasions that they consider something else, such as a snack. Respondents may have trouble fitting complex answers into simple response categories. Much research has suggested that older adults have more trouble than younger respondents fitting their intended responses into predetermined response categories (4), so it is crucial to investigate response formatting strategies in order to choose appropriate response categories when designing surveys for older adults.

Respondents may also edit their answers before finalizing them in order to conform to perceived social desirability and self-presentation (7). The extent of editing



for social desirability may be increased in face-to-face interviews as opposed to phone or self-completion surveys. Additional factors that affect editing of responses for social desirability include how sensitive or invasive the respondent perceives the question to be, characteristics and manner of the interviewer, and whether others are present when the response is given (7). Editing for social desirability has been specifically noted in older respondents (2).

### *Interaction of the Four Steps of the Question-and-Answer Model*

Six of the seven Four-Step Question-and-Answer models explicate the model in terms of four consecutive steps; however, the Flexible Processing Model (9) proposes that the four steps are neither linear nor sequential. Rather, the four steps are employed as needed, and they feed back on each other in a complex, non-linear interplay.

Another model called the Survey Interaction Model suggests that not only cognitive processing, but also other psychological factors such as personality, motivation, and emotion, play a role in the process of answering survey questions (9).

### *Types of Response Difficulty*

One of the primary issues facing researchers using surveys is that respondents may have difficulty comprehending questions (step one of the response process). Comprehension problems may result from the vocabulary used in the survey. Health and nutrition terms that are so familiar to researchers as to be almost invisible are unfamiliar to some respondents. For example, researchers may use terms such as “myocardial infarction” or “cardiovascular disease” when respondents would better understand “heart attack” or “heart disease” and “stroke.” Using complex syntax for questions baffles respondents, especially when the questionnaire is presented verbally. Culturally different linguistic patterns, such as the passive voice used in scientific writing, are foreign and

confusing to respondents. Third, respondents unfamiliar with participating in surveys may be unsure of the task itself and the rules of how to respond (7).

Respondents may face uncertainty when trying to retrieve information from memory (step 2 of the response process).

Some respondents are unable or unwilling to fit the answer to a question into a given response category or may be unsure about the meaning of the response categories.

What is the difference between “true” and “very true?”

Respondents may be unsure of the appropriateness of their response. They may be uncertain that their answer is relevant to the question.

The respondent also may not be certain of the social desirability of the answer or may be concerned that their answer is not accurate.

Finally, pronunciation and communication difficulties may affect both respondents and interviewers. Some difficulties that may arise are speech difficulties arising from physical impairments such as stroke, auditory problems due to hearing loss, regional accents, and pronunciation and intonation patterns of individuals for whom English is not the primary language.

### *Factors in Interpretation of Questions*

Researchers have identified a number of problems that affect a respondent’s ability to understand and complete a questionnaire (10). Conrad and Blair have categorized the response difficulties into five types: lexical (terminology) problems, inclusion/exclusion problems, temporal problems, logical problems and computational problems (10,11).

Lexical problems revolve around the understanding of terms, the use of words, and the context in which they’re used in the survey. These problems occur when

questionnaires contain words, especially medical or health-related terms, that are familiar to the researcher but alien to respondents. The context of the word within the questionnaire may also cause confusion. Drennan cites the example of asking how many rooms are in the respondent's house. The respondent reported being unsure whether to include bathrooms or hallways as rooms (10).

Inclusion/exclusion issues arise when a respondent is unsure what to include within a category on a questionnaire. For example, who should be included in "health care providers?" Doctors, certainly. Nurses, maybe. Podiatrists? Ophthalmologists? Psychiatrists?

Temporal problems can occur when respondents are asked to report on time periods or time spent on activities. Some problems relate to interpreting wording, such as "within the last year." Is that within the last 12 months, or within the last calendar year? Others relate to estimating time usage, such as reporting how many times a person exercises per week. Uncertainty arises when the time varies from week to week, month to month, or is season-dependent.

Logical problems reflect respondent confusion over syntax and connectivity of sentences. When sentences that contain embedded questions, aggregated categories, or use connective words such as "other than" or "including," respondents may fail to answer parts of the question, or may fail to include or exclude the directed items. This can be a problem, for example, with food frequency questionnaires. Subar et al found that respondents only answered one of several embedded questions about use of fat free or low fat products even when instructed to answer them all (12). Respondents expressed frustration answering questions with foods aggregated in categories that weren't perceived as similar (apples, applesauce, and pears, for example).

Computational problems involve long-term memory and mental calculations. Many surveys query such events as number of doctor visits over time, and substantial evidence shows the unreliability of long-term recall for repetitive events (4,13). Much research on these issues has been done at NCHS, as cognitive researchers investigate how individuals access and use long term memory for singular or repetitive events, and attempt to discover and implement strategies that improve respondents' recall.

There are also a number of personal factors that impact a respondent's interpretation of survey questions. Respondents may have different conceptual or linguistic abilities that affect their comprehension of the questions.

A specific situation that often arises in surveys conducted in North America is the large number of individuals for whom English is a second language. Not only does this impinge upon respondent understanding of specific vocabulary, but it carries with it the possibility of different cultural perspectives that may flavor the meaning of the words and/or intent of the question. Researchers from Ryerson University in Toronto, Canada, conducted a qualitative study to assess the cultural relevance of a food frequency questionnaire among adults from Cantonese, Mandarin, Portuguese and Vietnamese speaking communities in Canada. They found differences in the cultural relevance of foods listed on the FFQ, difficulty with words that had multiple meanings, a difference in culturally appropriate portion sizes and that conducting surveys by telephone was a specifically Western concept (14).

Socio-economic status, level of education and literacy also play a role in how individuals interpret and respond to questions. In a study examining the wording of four instruments that were being adapted for oral use in low-literate Hispanic diabetics, the researchers found that respondents incorrectly interpreted certain words, found the

wording of some questions confusing, and were not familiar with medical terminology used in the survey (15).

Miller (6) found profound differences in the response behavior of persons who had never participated in a survey. Respondent lack of experience in survey participation led not only to difficulty interpreting questions and survey terminology, but respondents also failed to understand or follow questionnaire protocols such as realizing that they needed to fit their responses into given response categories (6).

Perhaps most germane to this research, adults aged 65 and greater have unique characteristics that impact on their response behavior (2). Although this is a highly varied population, problems with both storing and retrieving information seem to increase with age (2). Social desirability response set (SDRS) is the tendency for respondents to give answers that conform to perceived social norms (2). Older adults often score higher than other age groups on social desirability response, suggesting the SDRS may be a factor in how older adults edit their responses (Stage 4, *formatting*) to questionnaires (2). Some researchers have found that older adults are especially motivated to be good respondents, and to want the interviewer to view them in a positive light, characteristics that may bias their responses (2).

Some researchers have reported that older adults have comprehension difficulties in relationship to reporting hospitalizations and doctor visits, but these findings are not consistent (2). Jobe and Mingay report that older adults prefer narrative answers to survey questions, and resisted confining their responses to response categories. They also reported difficulty with estimation and frequent editing of responses (4).

### Strategies for Improving Questionnaires

The traditional method of pre-testing a newly developed survey instrument is to field-test it by performing a pilot study in a small representative sample of respondents from the target group (4). During the field test, problems with specific questions are inferred when respondents either fail to give an answer or chose “I don’t know” responses (4). Studies in the late 1980’s, however, showed that field testing did not always reveal poorly designed questions (13). The same research suggested an innovative method capable of teasing out problems in questionnaire design and offering solutions. The methodology is derived from cognitive psychology, and is now known as *cognitive testing*. *Cognitive interviewing (CI)* refers to the process of interviewing members of the target population in order to cognitively test a survey.

### Background to Cognitive Methodology

In the 1980’s, researchers at the National Center for Health Statistics began to explore methods for improving the ability of survey instruments to elicit more effectively the data that researchers needed (8). Their research had shown that improvements in questionnaire design lagged behind other areas of survey methodology such as sampling and data processing. They hypothesized that methodology from the cognitive sciences might be used to effect an equivalent improvement in the design of questions for questionnaires.

Survey methodologists have traditionally been concerned with measuring and controlling the error associated with the process of answering questions. Their methods are typically to conduct pre-tests and quality check studies of survey instruments to evaluate the impact of survey characteristics such as wording, response categories, and question order on the rate of response error.

Cognitive scientists, on the other hand, study the mental systems by which people process information (8). They are interested in the processes of thinking, memory, understanding and judgment, and study these processes through controlled laboratory experiments with the goal of controlling for factors extraneous to the cognitive task they are investigating.

In the mid-1980's, NCHS initiated a comprehensive program for studying the cognitive aspects of survey methodology (CASM) in order to bring together experts from survey methodology and cognitive science. The goal of their initial project was to explore the use of laboratory methods and the methodology of the cognitive sciences in designing and testing health and nutrition questionnaires by comparing questions developed using cognitive methodology with questions developed by the exclusive use of traditional field testing (8).

#### *Putting Cognitive Methodology to Use*

Cognitive methodology provides tools for researchers to understand the processes by which respondents answer survey questions (7). It gives insight into the cognitive requirements for answering, and allows exploration of the factors that influence the answers respondents ultimately provide. By pre-testing questions using cognitive methods, it is possible to determine whether respondents understand the question's concept, consistently interpret the question in the same way, and interpret the question as the researcher intended.

#### *Tools of Cognitive Testing*

Many of the techniques used in cognitive testing were developed by psychologists in order to understand how individuals solve problems or remember (7). These methods have been adapted by survey methodologists to examine survey error resulting from the

response process and from the questions included in a survey. With the advent of the NCHS cognitive testing laboratory and similar research facilities at the Census Bureau, Research Triangle Institute in North Carolina, the techniques are constantly being revised to better serve the needs of research surveys in the fields of health and nutrition.

The fundamental methodology of the cognitive interview (CI) is a semi-structured interview conducted by a trained interviewer with an individual respondent who matches the characteristics of the intended survey sample (10). The interview may be carried out in a CI laboratory, such as that developed by NCHS (8), or in an environment similar to that in which the survey will be administered. The overall procedure consists of administering either the entire survey or questions that have been targeted in advance as potentially problematic. During the interview, the interviewer also uses CI methods to identify problems with questions or within the format of the questionnaire itself.

Problems discovered during CI can be resolved prior to field testing or using the survey, as will be described later.

Cognitive interviewing techniques fall under two general classifications: “think-aloud” interviewing and verbal probing (16). Think-aloud interviewing, also called “protocol analysis” (8), is based on methods from psychology and memory testing from the work of Ericsson and Simon in the 1970’s (16). The interviewer reads each question, and respondents are encouraged to “think aloud” about the process going on in their minds as they attempt to answer. The goals of the think-aloud process are to understand the cognitive process through which the respondent goes while formulating an answer, to reveal possible misunderstandings or misconceptions about the intent of the question, to understand how respondents recall information, and to reveal whether respondents recall information or simply guess (9). After asking the survey question, and asking the



respondent to think aloud, the interviewer says little other than to encourage the individual to verbalize thoughts.

Because most respondents are unfamiliar with verbalizing thought processes while answering, the interviewer typically must teach the respondent how to think aloud; therefore the interview often includes a think-aloud practice question. Most CI experts recommend a simple approach using a familiar setting (16). The usual example is to ask the respondent to visualize the place where she or he lives, and then to mentally count up the number of windows in the place. The respondent is asked to verbalize what she or he is seeing and thinking about during the counting (16).

The think-aloud technique has several advantages:

- the format is open-ended, so the respondent may reveal information that was not expected.
- because the interviewer simply reads the survey question and encourages the respondent to think aloud, interviewer bias is minimized.
- the interviewer requires little formal training or specialized expertise.

On the other hand, there are some disadvantages to the technique:

- interviewees must be taught to think aloud, which may be difficult for some interviewees, and may consume a great deal of time that could otherwise be devoted to the interview.
- respondents may stray from the subject of the survey question, using up a great deal of time in irrelevant details.
- thinking aloud may distort the respondent's perception of the question, leading to false conclusions about the question's ability to elicit the information desired by the researcher.

The second technique, verbal probing, has proved more useful to cognitive researchers (16). In this method, the interviewer asks the survey question, and then asks for information regarding the question. Probes may be crafted in advance of the interview, particularly if there is cause to suspect the question may be problematic (such as including an unfamiliar term). In a CI, the interviewer also has the opportunity to probe whenever the circumstances of the interview suggest it would be helpful, for example, when a respondent hesitates, looks puzzled, or cannot answer the question (9). There are six basic types of probes, shown in the table below.

Type of Probe	Example
comprehension	What does the term “anemia” mean to you?
confidence judgment	How sure are you that you that you have supplemental security income?
recall probe	How did you remember that you were discharged from the hospital eight weeks ago?
paraphrasing	Can you put that question in your own words?
specific probe	Why did you choose “excellent” instead of “good?”
general probes	Was that easy or hard to answer? How did you arrive at that answer?

*adapted from Willis: Cognitive Interviewing: A “How-to Guide” (16)*

The primary advantages of verbal probes are:

- focusing the interview on questions or subjects that are potential sources of error
- helping keep the interview on track so that time isn’t wasted on irrelevant details
- respondents find it easy to answer probes, and once they fall into the pattern, may offer spontaneous suggestions or comments in the manner of a think-aloud.

There are some disadvantages:

- some theorists suggest that probing creates an unrealistic and artificial process far removed from the actual conditions under which the survey will be administered.
- if probes are not carefully worded, they can be “leading;” that is, they may suggest an answer. Probes must use unbiased phrasing.

Both think-alouds and probes can be used concurrently or retrospectively during the CI (16). In concurrent probing, the interviewer asks a survey question, which the respondent answers. The interviewer follows that with an immediate probe question related to the question just answered. In retrospective probing, the interviewer administers either the entire survey or a block of related questions, and then asks the probe questions at the end. Concurrent probing has the advantage of occurring while the question is fresh in the respondent’s mind, but can also interrupt the flow of related questions and strip the survey process of contextual clues that assist the respondent in answering. Retrospective probing eliminates this issue, but by the time the survey or section is over, the respondent may have forgotten the thought process used for a particular question, and may fabricate an explanation (16)

Retrospective probing is especially useful when the CI is testing whether respondents are able to complete the survey, or when the goal of the CI is to assess the sequencing of questions or skip patterns in the survey (16).

Researchers at NCHS generally use a mixture of concurrent and retrospective probes in an interview.

### *Scripted and Spontaneous (Unscripted) Probes*

Scripted probes are developed before the interview by either the principle investigator or by a questionnaire development specialist, and are geared toward testing questions or terms that are anticipated to be problematic. If, for example, the survey

contains scientific, medical or other specialized terms, probes may be developed to assess respondent comprehension. Such probes are typically included in the questionnaire draft, are asked of all interviewees, and take the form, “What does (TERM) mean to you?”

Spontaneous probes are made up by the interviewer in response to specific occurrences in the interview. For example, if a respondent hesitates before answering, the interviewer may probe the reasons for the hesitation. Spontaneous probes may bring to light useful information about the phrasing, meaning or unexpected difficulties of questions. The respondent’s answer to a spontaneous probe may lead the interviewer to include the probe in subsequent interviews and follow up on issues that emerge. Experienced interviewers often become adept at spontaneous probing and teasing out unexpected and useful information (16).

Because each respondent and the dynamics of each interview are unique, the most successful interviews use a combination of scripted and unscripted probes.

Although not as formalized as think-alouds or verbal probes, interviewers may also use observations of the respondent’s behavior during the interview to help in the assessment of the questionnaire. Frowning, hesitation in answering, skipping questions, or placing answers in the wrong location on the form may all provide valuable clues. The interviewer can then probe the causes of the respondent’s difficulties (10).

### *Unique Characteristics of Cognitive Methodology*

As mentioned above, the purposes of cognitive interviewing are 1) to obtain information about the cognitive processes that respondents use to answer survey questions, and 2) to discover potential problems that may lead to response error and compromise the quality of survey data (4, 6, 13).

Cognitive interviews are not designed to collect survey data. Rather, they generate subjective, qualitative data about the survey instrument itself. They are useful in providing information about question design and content, survey instructions, and the layout and format of the instrument, including skip patterns.

Unlike survey interviewers, who must adhere strictly to the script when administering a survey, cognitive interviewers use the scripted questions as a starting point to elicit further details. Additional probes may be added concurrently or retrospectively to elucidate how respondents understand key concepts, how they perform cognitive tasks, and whether they can fit their answers into the response categories provided (13).

#### *Conducting a Cognitive Interview*

The CI is an intensive, semi-structured, one-on-one interview. Because of the time and intensity required for CI, only a small number of interviews is conducted. NCHS conducted 18 CI to identify problems with survey questions designed for older adults (4). Carbone et al conducted 23 CI in the process of developing nutrition surveys and messages for low-income populations (3).

The interview may be tape- or video-recorded (17) in order to capture all of the verbal responses and behavioral or vocal clues. Although CI is often conducted with only an interviewer and a respondent, in some cases an observer may be included to help record verbal or behavioral material (6). In the cognitive laboratory, observers are able to watch through a one-way mirror.

The interviews are verbal: the interviewer reads a survey question, and the respondent answers verbally, including any think-alouds or probes. To facilitate the verbal response process, the interviewer may use flash cards printed with the response

categories for the survey questions. The interviewer makes notes in addition to the audio or video recording. Interviews may last from 30 to 90 minutes (18).

### *Analysis of Interviews*

Cognitive interviews generate narrative reports that are primarily subjective and qualitative, and of necessity, are based on the researcher's own analysis and impressions (10). Some researchers have sought objectivity of analysis by devising taxonomies for classifying problems based on the four stages of the response process. Additionally, there are software programs that analyze and code large bodies of text for recurring themes (19). But in general, most researchers use a subjective approach to analyzing CI data (10).

### *Uses of Cognitive Interviewing Data*

Although CI data are qualitative, they are an invaluable resource in the process of survey design. As described above, they can be used to discover potential response errors, reveal terms that are misunderstood or not understood by respondents, highlight syntactical problems that obscure the meaning of questions, and illuminate problems in the order and skip patterns of questions (9).

Once the data are collected and the problems documented, researchers have the option to revise their questionnaires based on the findings in the CI. Lexical, inclusion/exclusion, logical and computational problems can be addressed and often solved or ameliorated. Some revisions that researchers make based on CI interviews include:

- simpler wording (“fluoride added to the water” instead of the standard “public water fluoridation”) (13)

- defining terms within the question (“cardiovascular disease, such as chest pain, heart attack or congestive heart failure”)
- deconstructing questions (that is, breaking a complex question into several single questions)
- simplifying sentence structure.
- including text that defines a time frame (“in the last year, since MONTH, YEAR, how many times have you had your teeth cleaned?”)

### *Cognitive Interviewing and Surveys for Older Adults*

In 2006, there are approximately 40 million individuals aged 65 and older; by 2030, it is expected that the number will almost double to 75 million (20). Collecting quality survey data from this growing cohort is critical for establishing public policy and designing appropriate interventions. Public policy analysts place increasing demands on researchers for type and quantity of data about older adults. As a result, surveys are often longer and include more complex questions that increase the cognitive burden on elderly respondents (4).

Policies and interventions based on erroneous or incomplete survey data may be costly and ineffective, and may negatively impact on patient care, practice protocols and health care delivery (2).

In order to improve the quality of data from older adults, investigators are beginning to examine the way older adults comprehend, interpret and answer survey questions. Although there is wide variation in the characteristics of adults aged 65 and older, certain special constraints to collecting accurate data have been noted among some older adults, especially the older old and frail elderly.

Low education and literacy can present challenges on health and nutrition related surveys because they often include language and terms that older adults may not commonly use. Older adults may not understand terms like “health plan,” “referral,” and “cardiovascular disease,” and may either become confused and fatigued, or pretend to understand and answer inaccurately (2).

Evidence from studies shows that most people have trouble recalling health-related events from the recent past, but recall among elderly, especially the frail and older-old tends to be even less accurate. Questions that ask about frequency of service use or health care visits may be viewed by respondents as tests on how well they can answer questions (2).

In the late 1980’s, researchers at the cognitive testing laboratory at NCHS set out to investigate whether cognitive interviewing would be effective in identifying problems with survey questions for older adults and to suggest improvements in question design for use with older respondents (4). They examined problems with interpretation of questions, recall of information and estimation and judgment strategies used to formulate a preliminary answer and eventually verbalize a final answer. They conducted CI in a sample of 18 older adults, eight of whom were between ages 65 and 74, and ten of whom were 80 or greater (oldest old). In the interviews, they used concurrent think-alouds and concurrent scripted and spontaneous probes (4).

The investigators found that respondents preferred giving narrative answers and resisted selecting from provided response categories, even when the question was read several times, as is typically recommended to survey interviewers when older adult respondents fail to select a response category (21).

The researchers discovered some interesting trends in respondents’ answers to questions regarding functional limitations, a category often included in surveys targeting



older adults. Many respondents reported having “no difficulty” with activities of daily living (ADL’s) such as standing for two hours; however, when probed during the CI, they revealed that they hadn’t actually tried standing for two hours for many years (4).

Problems were also discovered in a question about whether the respondents stayed in a chair all or most of the time. During the probes, the researchers found that some who responded “yes” actually stayed in their chairs less time than those who answered “no.”

Grouped instrumental activities of daily living (IADLs) also caused problematic responses; probing found that respondents could do some of the grouped activities but not others, and were forced to chose a response that was neither completely true nor completely false (4).

The CI probes also uncovered the fact that a number of respondents who reported no difficulty with specific ADLs actually had great difficulty but had come up with an accommodation to solve their problem, and therefore considered that they had no difficulty. An example was a respondent who reported no difficulty getting dressed. It turned out she had abandoned clothing she could no longer put on and had changed her style of clothing to suit her abilities.

Respondents tended to forget or ignore the qualifying phrase “by yourself and not using aids” when reporting that they had no difficulty performing activities. And many respondents underreported their level of difficulty in general, consistent with the findings of other research (4). Probing during the CI found that many respondents only reported having difficulty if they thought they had more difficulty than was warranted by their age.

As a result of the CI, the NCHS researchers were able to make general recommendations and suggest changes to specific surveys in order to refine and improve

data collection from older adults. This seminal research has been used and built upon by several other researchers who are interested in survey methodology for older adults.

Using CI techniques, Miller (6) conducted 21 interviews in rural southern Mississippi among low-income, less-educated individuals to determine response difficulties in this population. Fifteen of the participants were in their 50's or 60's, one was 74, and the other 5 were younger.

In addition to reporting similar findings, Miller found that the rural, low-income, less- educated participants in the Mississippi sample had difficulties reflective of their lack of knowledge of the norms expected in a research interview (6). Respondents again had problems fitting their responses into the provided response categories, but probing revealed that respondents didn't understand that they were ultimately supposed to select a response category, even if their true answer wasn't matched identically by any response category. Particularly difficult were scalar categories such as "mild," "moderate," "severe" and "extreme." One respondent reported that mild and moderate were the same (6).

Questions that required mathematical calculations were also problematic. Individuals often reported that events happened in a particular year and gave an age for themselves at the time of the event that didn't square with the year and their current age.

Medical terminology, even that which may be in use among some non-medical populations, was unfamiliar to respondents. Confusion and lack of knowledge were common regarding names for chronic health conditions, especially heart diseases. For example, one respondent reported that she had some kind of heart disease, but she could only be sure that she "had a bad heart." (6)

Based on the results of the CI, the investigator was able to make practical and specific revisions, such as avoiding abstract words and providing multiple types of

response categories to alleviate the need for mathematical calculations. From a theoretical viewpoint, the research contributed to understanding of cognitive strategies in lower income, lower education respondents, and suggested methods for collecting more accurate data from such individuals.

### Limitations of Cognitive Interviewing

Perhaps the most common criticism of cognitive interviewing is that it generates primarily qualitative data. A corollary criticism is that analyzing and interpreting the information gleaned from the interviews is subjective, and based in some measure on the interviewer's own impressions and biases (10). Because there is no set framework for analyzing and interpreting data, it is hard to ascertain the validity of conclusions reached based on cognitive data. In an attempt to increase objectivity and measurability of cognitive data, several researchers have developed algorithms to associate specific problems with particular responses (10). The algorithms are typically based on the four stages of the question-and-answer model: comprehension, retrieval, judgment and response.

Another complaint about cognitive testing is that it creates an artificial situation unlike that in which the survey will be answered in the field. By asking respondents to think aloud, and by probing their responses, researchers may affect the response process itself, calling the validity of interpretation into question. The very presence of a researcher may also influence the interviewee's behavior and comments. Some critics have cited the "Hawthorne effect," whereby respondents are more focused and attentive to the questions than they would be under typical survey conditions (10).

CI is also time-consuming, and may increase the fatigue, irritation and confusion of respondents, particularly older respondents. On the other hand, some respondents are

likely to perceive the CI as a more sociable process, enjoy the interaction, and consequently stray from the topic of the interview into extraneous subjects. Other critics contend that cognitive interviewing favors articulate, verbal individuals, although Miller's success with cognitively interviewing low-income, low-literacy rural individuals seems to belie the severity of this possible issue.

However, well-conducted CI, for example those conducted by NCHS survey methodologists both in the laboratory and in the field, have contributed valuable practical and methodological knowledge. The growing interest in and use of CI acknowledges their effectiveness in identifying and correcting problems in survey questions. Cognitive interviewing has proven most useful in improving the reliability of questions that measure complex psychological states such as well-being, perceived health, and happiness. It has proved useful in pretesting questions that could be perceived as sensitive or intrusive, for complex questions and for specific cohorts such as older adults, where surveys may present unique difficulties (10).

### *The Concept of Hardiness*

Hardiness, also called resilience (22), is defined as the ability to maintain or regain normal function after an adverse life event (23). In the 1970s, Kobasa (24) proposed the existence of a "hardy personality style" that helps certain individuals cope successfully with stressful events. Derived from concepts of existentialism, the construct of hardiness consists of three personality dimensions: *commitment*, a sense of existential purpose in an individual's perception of self, others and the events of life, *challenge*, a sense that the inevitable changes in life are sources of opportunity for growth and positive change, and *control*, an individual's sense of autonomy and ability to influence his or her destiny (23, 24).

Persons with high hardiness find life experiences, even negative ones, meaningful, perceive change as meaningful even when stressful, and place stressful events in the context of a rich and varied life. Persons low in hardiness find life boring, meaningless or threatening (24). They feel powerless when faced with change, are passive when interacting with their environment, and have little resiliency when stressful events occur. Evidence from research over the past 30 years indicates that stressful events may have a negative impact on health for low hardy persons (22-24).

### Hardiness Questionnaire

On December 12, 1985, an airplane carrying 248 U.S. Army soldiers home for Christmas from peacekeeping duties in the Sinai Desert crashed in Gander, Newfoundland, killing all aboard (25). In the aftermath of the tragedy, Army psychiatrists designed a survey instrument to assess physical and psychological factors that had an impact on the physical and mental health of first responders in the year following the disaster. Included in the questionnaire were 45 questions to measure “dispositional resilience” or “hardiness.” The questions on this Dispositional Resilience Scale (DRS) (Appendix A) were derived from an instrument developed by Kobasa (25).

In 2003, Sinclair et al (26) developed a short version of Bartone’s DRS. Sinclair’s DRS-II consists of 18 items, divided into three sets of six questions that test challenge, commitment and control. The DRS-II is based on a six-factor model in which each dimension is tested using a positive and a negative factor, as shown in Appendix B. High hardy personalities score high on the positive dimensions and low on the negative ones. Sinclair validated the instrument for use in a college student population and in members of an activated National Guard unit (26).

The DRS-II was included in our cognitive interviews to test whether the questions would be useful in assessing hardiness in older adults. The questions seemed promising; however, it was hypothesized that the syntax of some of the questions was excessively complex and that certain terms might not be readily understood by older adults.

## Chapter 2: Methods

### Purpose for Conducting Cognitive Interviews

In the process of developing an Initial Needs Assessment (INA) questionnaire for the *Community Connections – Moving Seniors Toward Wellness* demonstration project, the principal investigator determined that cognitively testing would be included in the pretesting of the instrument. The original version of the INA consisted of approximately 150 questions, some of which were drawn from previously used and validated questionnaires used in epidemiological surveillance such as the Geriatric Depression Scale (GDS). Additional questions had been written to gather data specific to the Community Connections project.

The INA was designed to be interviewer-administered using Computer Assisted Personal Interviewing (CAPI). CAPI software was created especially for the Community Connections Project, and was designed to eliminate post-interview data entry and prevent errors inherent in manual data entry (27). Interviewers would be trained how to download the INA and other Project questionnaires onto laptops, how to administer the survey, and how to upload completed questionnaires to the research website.

The intent of conducting CI interviews for the INA was to:

- ensure that the wording of questions was appropriate for verbal CAPI-assisted administration of the survey.
- achieve simple but precise wording that would be comprehensible to respondents representing a range of socio-economic status, education level, age, and degree of illness or impairment.

- streamline the INA to be the shortest, simplest questionnaire that would capture all needed data.
- identify problem questions, such as any that might include unclear syntax, unfamiliar terms or medical language that was too difficult for respondents.
- minimize respondent burden for the study cohort of recently hospital-discharged older adults.

During the course of the cognitive interviews, we hoped to ascertain whether respondents interpreted the questions as the researchers intended and whether the questions were able to elicit the data needed by the researchers.

Another objective was to identify any problems in the skip patterns of the questionnaire, where the answer to certain questions determines which question must be asked next. Because the CAPI does not allow the interviewer to look back at previously answered questions, it was important that any issues with the skip patterns be resolved prior to use of the questionnaire in the field. In addition, we wanted to eliminate any illogical question sequences that might confuse respondents.

In order to make the INA as efficient as possible, we wanted to eliminate any questions that gathered redundant information.

We wanted to test whether the introductory text for each set of questions communicated necessary instructions but was not too long.

There were several objectives specific to our target cohort of older adults. We wanted to find out whether any of the standard questions from other instruments needed to be tailored to fit the circumstances of hospital-discharged older adults. Questions that queried work-related topics, for example, might be eliminated or changed to reflect activities that the target cohort more commonly engage in.



Because the Community Connections Project would involve working with and through existing community organizations in six sites around the United States, the researchers needed to address concerns that had been brought up by participating organizations. One of their key concerns related to several questions included in the Geriatric Depression Scale. This set of six questions is a commonly used and previously validated screener for depression. However, some of the community liaisons felt that the questions might be construed as intrusive by INA respondents. Most problematic were the following two questions:

1. Do you often feel helpless?
2. Do you feel pretty worthless the way you are now?

Therefore, one specific objective of CI was to probe how respondents felt about being asked these questions and others that might appear intrusive or sensitive, and the results would be shared with the community liaisons.

During the CI, respondents would be encouraged to suggest improvements to any questions they found problematic, and the research team would have the opportunity to make any changes before the instrument was sent out into the field.

In addition to the pragmatic goals of improving the quality and accuracy of data gathered by the INA, cognitive testing in this particular cohort might help document cognitive strategies of older adults across a wide range of physical and cognitive abilities. We were specifically interested in the way recently hospital-discharged older adults estimated temporal questions, especially those that require short-term memory for repetitive events such as doctor visits. The goal was to assess respondents' familiarity with and recall of specific physician-diagnosed diseases and comfort with medical terminology.

During the planning phase for the cognitive testing, the research team expressed an interest in cognitively testing a set of questions that relate to psychological hardiness, so those eighteen questions were appended to the INA for the purposes of the cognitive interviews only. A description of the concept of hardiness and the rationale for including them in the CI follows this section. Therefore, an additional goal for the cognitive testing was to investigate respondent perception of questions regarding depression and hardiness. Because the hardiness questions had not been designed for older adults, it was felt that the cognitive interviews might indicate whether the questions were effective for older adults as written.

Based on previous research that used cognitive interviewing to pre-test questionnaires, we hypothesized that cognitive testing would illuminate questions that were interpreted differently by respondents and the researchers with the potential to affect the accuracy of the data collected. We hypothesized that when comprehension, lexical, temporal, and other cognitive problems existed, that many of the problems could be resolved by simplifying wording, deconstructing multi-part questions, and providing alternative response categories. We hypothesized that cognitive testing, as one facet of the pre-testing protocol, would result in a more efficient INA that would be better able to elicit the data needed for the Community Connections Project.

Cognitive testing is conceived of as an iterative process, in which the questions are written, cognitively tested, and rewritten to reflect changes suggested by the cognitive testing. Ideally, if time and budget permit, rewritten questions are cognitively tested in other members of the target population to ascertain whether the changes improve the ability of the questions to collect the data desired by the investigators. Because of the short period of time available to cognitively test the INA prior to its use in the field, the research team decided not to retest the rewritten INA questions; however, the rewritten

hardiness questions would be cognitively tested in seven more older adults. Therefore, the outcome measure of improvement to INA questions would be the ability of respondents in the field to answer questions without hesitation or other symptoms of poor comprehension. Although this is not a quantitative measure, it is considered a standard outcome measure of CI (4, 9). The outcome measure of improvement to the hardiness questions would be the ability of respondents to answer rewritten hardiness questions more easily, and verbal reports of any remaining problem during the second round of CI.

### Study Subjects

Cognitive interviewing consists of intense, one-on-one interviews with respondents who belong to the population targeted by the survey. Because of the intensive, time-consuming nature of the interviews, the lengthy transcribing process, and the amount of information generated, a relatively small number of interviews is typically conducted (4, 8). After consultation with Dr. Paul Beatty of NCHS, it was decided to conduct twelve cognitive interviews to test the INA with the appended hardiness questions.

Because the interviews needed to be completed within a very short time period (approximately six weeks), a convenience sample of twelve adults aged sixty and older would be recruited. An effort was made to recruit individuals of both genders, varying ethnic/racial background and socio-economic status, and as similar in health and nutrition status to the target population as possible. Individuals recently discharged from a hospital or rehabilitation center were especially encouraged to participate.

Participants were permitted to have a family member or other concerned person with them during the interview if they desired. A \$10.00 gift certificate from a local drug

store was provided to each participant at the conclusion of the interview. IRB approval for the protocol was granted by the University of Maryland, College Park.

Recruiting began in January, 2005. Members of the research team contacted community dietitians, two assisted living facilities, one in Prince George's County and the other in the city of Baltimore, Senior Centers in Montgomery and Prince George's Counties, Maryland and several Meals on Wheels Coordinators. Recruiting was done by in-person appointments with program directors, recruiting posters, email, and phone calls.

In all, ten sites were contacted. Several program directors did not feel comfortable asking their clients whether they wanted to participate, and more than half did not return phone calls or emails, probably because they are part time programs run by volunteers. Two sites, one a Meals on Wheels program in Montgomery County, the other an assisted living facility in Prince George's County, agreed to invite their clients to participate in cognitive interviews. The MOW program director provided a list of 11 clients who agreed to in-home interviews, and the registered dietitian at the assisted living facility personally introduced the interviewer to 9 residents, of whom 8 agreed to be interviewed. In all between the two sites, seven persons completed usable cognitive interviews.

The respondents were all 80 years old or greater; the oldest was 94. Six of the seven were female. Three identified themselves as African-American or black, three as Caucasian or white, and one as Native American. Five were widowed, one was divorced and one was separated. Two reported less than a high school diploma, two had received a high school diplomas, two had some college, and one had a Ph.D. Three lived in assisted living, while four were community living. Three of the four community-dwelling individuals received home delivered meals. Although all three of the assisted living respondents and three of the four community-dwellers had been hospitalized within the

last two years, none was hospital-discharged within the two week time frame that was proposed for the Community Connections participants.

### Design of the Interviews

The INA consisted of approximately 150 questions, divided into 10 sections, as follow:

1. Preliminary Basic Respondent Characteristics. This section gathered information specific to Community Connections Program participants, such as the client's assigned ID number, the hospital from which the individual was discharged, and Community Connections intervention group assignment.
2. Cognitive Assessment. These questions test the cognitive ability of respondents in order to ensure that they have sufficient cognitive function to reliably answer survey questions.
3. Physical Function Assessment, which surveys the respondent's degree of difficulty in completing activities of daily living (ADLs) and instrumental activities of daily living (IADLs).
4. Depression Status Assessment, which assesses the respondent's degree of depression.
5. Social Support, which inquires into the respondent's number and functionality of family, friends and others who provide help.
6. Nutrition Security, which asks about availability and sources of quality food, and ability to prepare foods.
7. Use of Food Assistance Programs.
8. Service Awareness and Needs Assessment, which inquires about the respondent's knowledge and use of available nutrition and health care services within their

- community. Included is one question about whether the respondent had received information about his or her health status and recovery time after hospitalization.
9. General Health Assessment, including physical health, disease status, impact of disease on food intake and state of dental health. The respondent is also asked to report current height and weight.
  10. Demographic Information, consisting of ethnicity, marital status, date of birth, education level, income, home ownership, and home location by urban, suburban or rural category.

Because the cognitive interviewing would take much longer than administering the survey alone, it was decided to cognitively test the INA in sections, consistent with protocols developed at NCHS for testing longer surveys (8). Each cognitive interviewee was randomly assigned to test one of the following groups of questions:

- General Health, Depression Status and Physical Function
- General Health, Social Support, and Service Awareness and Needs
- General Health, Nutrition Security, Use of Food Assistance Programs, and Cognitive Assessment

In addition, all seven respondents answered the demographic questions and the hardiness questions, all of which were cognitively tested.

Some of the questions throughout the INA were thought to have potential problems, especially those that included medical or nutrition terms, the depression assessment questions, and the hardiness questions, because the language in them was complex and at a higher reading level than the rest of the survey; therefore, scripted probes were written to be administered to all respondents in the CI. For example, in order to test for lexical problems, the following probes were included:

- What does the term “anemia” mean to you?

- What does the term “gastrointestinal disease” mean to you?

In order to gain insight into whether the Depression Status questions were perceived as intrusive, the following probes were planned:

- Do you feel offended if I say words like “worthless” or “helpless?”
- Would you prefer that I use different words?

To test the appropriateness of response categories, there were questions that inquired about why respondents chose specific response categories such as “excellent,” “very good,” or “good.” We hoped to gain insight into how respondents fit their answers into given categories.

It was expected that spontaneous probes would arise during the course of the interviews as well.

In order to avoid possible respondent fatigue or annoyance, we decided to keep the interviews to 45 to sixty minutes long. If a respondent appeared fatigued or otherwise uncomfortable, the interview could be terminated at any time.

An informed consent form that explained the purpose of cognitive interviewing was developed and approved by the IRB at University of Maryland, College Park.

### Interview Protocol

In order to schedule the interviews, the interviewer worked with the director of the Meals on Wheels program and with the registered dietitian at the assisted living facility. One interviewer conducted all the cognitive interviews.

For the Meals on Wheels clients who had agreed to participate, the interviewer scheduled appointments with each participant by phone, with a follow-up phone call the evening before the scheduled interview to confirm the time of the appointment and the continued availability of the participant.

For the residents at the assisted living facility, the interviewer and the dietitian scheduled several times when the residents would typically have free time, and residents were asked whether they were interested in being interviewed at that time. Those who consented were interviewed immediately on site. If the resident was alone in his or her room, the interview was conducted there; if not, the resident was assisted to a common area and the interview took place there.

The interviewer allowed 90 minutes for each interview to accommodate respondents who required additional time due to physical impairments. All interviews were audio-taped with permission from the interviewees.

Each participant gave informed consent. The consent form (appendix C) was three pages long, and without exception, all the interviewees requested that the interviewer read the informed consent form to them rather than reading it themselves. When probed about their request, several interviewees mentioned that their eyesight was not good enough to read the lengthy form. Almost all the respondents indicated that the form was too long or that “it’s less trouble” if the interviewer read the form aloud. Most of the respondents’ attention wandered during the course of listening to the consent form, necessitating rereading portions of the form. One respondent at the assisted living facility, who had suffered a stroke, was unable to sign her name, so the interviewer signed and the respondent placed an X. One of the respondents from the Meals on Wheels program was also unable to sign because of a stroke, but was able to use a signature stamp that she used for signing checks and other official documents.

Each participant received a coded identification number, which was used in lieu of a name on the interview form and the audio recording to preserve confidentiality. As an additional measure, the demographic information was not audio recorded.



For the seven respondents who completed the interview, the interviews lasted between 45 and 75 minutes. The interviewer began each interview by asking the demographic questions, and then asked the sets of questions that had been assigned to that respondent.

Both specific and spontaneous probes were used throughout to examine comprehension, retrieval, judgment and editing. (A text of the questions and specific probes is included in Appendix D.) Most of the probes were asked concurrently because it was immediately obvious that respondents remembered more details about their thought processes right after answering the question. The exception was that the probes for the depression assessment were retrospective. There are only 6 questions in the assessment, and the researchers felt that the probes would be most effective once the respondents had heard and answered the six related depression assessment questions.

Respondents were also asked to use concurrent think-alouds throughout all the sections of the survey instrument.

Initially, two practice questions designed to teach the think-aloud technique were included, but the attempt to practice the technique was confusing to respondents and wasted precious interview time, so after the second interview, the practice questions were dropped.

Although the INA was to be administered in the field using the CAPI software, the interviewer used a paper copy for the cognitive interviews. Both the survey questions and the specific probes were included in the print-out. The interviewer read each question exactly as it appeared in the INA and recorded the response on an answer sheet. If there was a probe, the interviewer asked it after the respondent had given an answer to the survey question. Respondents were frequently encouraged and reminded to think aloud about their process of answering the questions.

In addition to audio-taping the interviews, the interviewer made written notes as the respondents were answering probes and thinking aloud.

At the end of the interview, the respondents received a \$10.00 gift card to a local pharmacy as thanks for their participation.

When the interview was over, the interviewer reviewed the handwritten notes and added to or corrected them while the interview was still fresh. The tapes were reviewed as needed to accomplish this, and at the end of the data collection period, were transcribed in their entirety. After transcription, the tapes were destroyed as required by the IRB.

The signed informed consent forms were filed in a locked drawer separate from the response forms and text of the audio tape transcriptions.

#### Handling of Data

Because of the small number of cognitive interviews, transcription analysis software was not used. Instead, the transcription reports were reviewed by the interviewer and common themes and responses were summarized and reported to the researchers. Comments or suggestions that seemed especially insightful and useful were reported even if only one respondent made the comment.

In addition to the transcription reports, the following data were tabulated: self-reported race/ethnicity of interviewees, gender, marital status, date of birth or age, (whichever the respondent reported), education level, number of home-dwelling vs. institutionalized interviewees, and number of interviewees who received home delivered meals.

## Chapter 3: Results, Part 1

### Abstract

#### Objectives

To utilize cognitive interviewing as a formative evaluation of a novel questionnaire for older adults. To use the results to improve the ability of the questionnaire to collect data.

#### Design

Seven cognitive interviews were conducted in adults aged 80 and older to pretest a questionnaire for the *Community Connections – Moving Seniors Toward Wellness* research project.

#### Subjects/Setting

A convenience sample ( n = 7) of residents at an assisted living facility and recipients of home delivered meals was recruited.

#### Intervention

Participants participated in 45 – 60 minute one-on-one interviews. The novel questionnaire was administered, and respondents were probed for comprehension of question content.

#### Results

Older adults with significant physical limitations answered questions about depression based on physical rather than emotional status, made distinctions between capacity and

performance regarding physical function, and failed to understand key medical terms. Wording of questions about personal hardiness was confusing to older adults. The findings were used to simplify the hardiness questions and revise wording throughout the questionnaire. Hardiness questions were retested to assess improvement.

### Conclusions

Survey designers should be aware that questions about depression may be testing physical rather than emotional status. Questions about physical function should make a distinction between capacity and performance. Common language rather than medical terminology should be used when surveying older adults. Rewritten hardiness questions may be useful in assessing hardiness in older adults.

### Introduction

Data from surveys of adults aged 65 and greater are crucial for developing public policy and designing appropriate interventions for older adults. The quality of data gathered by surveys from older adults is important since policies or programs using incomplete or erroneous survey-derived information may be ineffective, inappropriate, or not cost-effective (2). Therefore, misunderstanding or misinterpretation of survey questions by older adult respondents may affect health care delivery, best-practice health care protocols, and quality and costs of health care.

For a survey to obtain accurate data, the questions must be asked in language appropriate and understandable to the target audience (3). Researchers typically pilot test their survey instruments, but numerous studies demonstrate that problems of wording and language are not detected by pilot testing (3).

One technique useful in the early stages of questionnaire development is cognitive testing of the instrument to discover problems of wording, language and context. In an

intensive, one-on-one interview called a cognitive interview (CI), the questionnaire is administered to representative members of the target population. Respondents are asked to paraphrase survey questions, verbalize their thoughts about the meaning of the questions, and make suggestions to improve wording. By focusing on language and wording comprehensible to respondents, interviewers gain insight into the cognitive processes and needs of the target audience and have the opportunity to revise the questionnaire in order to elicit more accurate data.

Survey methodologists at the cognitive research laboratory at the National Center for Health Statistics (NCHS) pioneered the use of CI to evaluate problems unique to older adults when they answer surveys (4). They found that CI was effective in identifying survey response problems in older adults, and used CI data to suggest wording that would result in more valid and reliable responses.

For the research reported here, seven cognitive interviews were conducted to pretest an Initial Needs Assessment Questionnaire (INA) designed by researchers at the University of Maryland for the *Community Connections – Moving Seniors Toward Wellness* research project. Eighteen questions validated by Sinclair et al (27) to assess psychological hardiness were cognitively tested within the questionnaire for their applicability to older adults.

*Community Connections – Moving Seniors Toward Wellness* is a federally-funded research and demonstration project being conducted by the Meals on Wheels Association of America (MOWAA) in cooperation with The U.S. Administration on Aging (AoA) and the University of Maryland, College Park Department of Nutrition and Food Science (5). The goals of the project are to improve the health and nutrition status of at-risk older adults by creating a continuum of community-based health and nutrition care including home delivered meals bundled with a broad array of prevention and wellness services.

The project targets older adults awaiting hospital discharge back to their pre-hospitalization residence, and the investigators are testing whether health outcomes of this vulnerable population will be improved if they can receive a continuum of health and nutrition services in a timely and efficient package (5).

The INA includes questions from other instruments such as Yesavage and Link's Geriatric Depression Scale along with questions developed specifically for the Community Connections project.

It was thought that cognitive testing would be helpful as a formative evaluation of the INA. Many of the questions on the INA had been validated for use in older adults but not cognitively tested. Cognitive testing has been used to refine surveys used in nutrition and health surveys, such as the USDA-funded FoodSmart Study (3) and the 1986 National Health Interview Survey (8). Data from cognitive interviewing has been used to reduce response error that occurs when respondents interpret health questions differently than the researchers intended (3).

The goals for the cognitive testing of the INA were:

- to test for lexical problems in the wording of questions. For example, a number of medical terms were used in the survey, such as “anemia” and “gastrointestinal problems.”
- to find out whether the syntax of questions was appropriate for the INA, which was to be interviewer-administered.
- to understand whether older adult respondents would find any questions, particularly those about their outlook on life, upsetting or intrusive.

## The Concept of Hardiness

Hardiness, also called resilience (22), is defined as the ability to maintain or regain normal function after an adverse life event (23). In the 1970s, Kobasa (24) proposed the existence of a “hardy personality style” that helps certain individuals cope successfully with stressful events. Derived from concepts of existentialism, the construct of hardiness consists of three personality dimensions: *commitment*, a sense of existential purpose in an individual’s perception of self, others and the events of life, *challenge*, a sense that the inevitable changes in life are sources of opportunity for growth and positive change, and *control*, an individual’s sense of autonomy and ability to influence his or her destiny (23, 24).

Persons with high hardiness find life experiences, even negative ones, meaningful, perceive change as meaningful even when stressful, and place stressful events in the context of a rich and varied life. Persons low in hardiness find life boring, meaningless or threatening (24). They feel powerless when faced with change, are passive when interacting with their environment, and have little resiliency when stressful events occur. Evidence from research over the past 30 years indicates that stressful events may have a negative impact on health for low hardy persons (23, 24).

## Hardiness Questionnaire

On December 12, 1985, an airplane carrying 248 U.S. Army soldiers home for Christmas from peacekeeping duties in the Sinai Desert crashed in Gander, Newfoundland, killing all aboard (25). In the aftermath of the tragedy, Army psychiatrists designed a survey instrument to assess factors that had an impact on the physical and mental health of first responders in the year following the disaster. Included in the questionnaire were 45 questions to measure “dispositional resilience” or “hardiness.”

The questions on this Dispositional Resilience Scale (DRS) were derived from an instrument developed by Kobasa (26).

In 2003, Sinclair et al (26) developed a short version of Bartone's DRS. Sinclair's DRS-II consists of 18 items, divided into three sets of six questions that test challenge, commitment and control. The DRS-II is based on a six-factor model in which each dimension is tested using a positive and a negative factor, as shown in Appendix B. High hardy personalities score high on the positive dimensions and low on the negative ones. Sinclair validated the instrument for use in a college student population and in members of an activated National Guard unit (26).

The DRS-II was included in our cognitive interviews to test whether the questions would be useful in assessing hardiness in older adults. The questions seemed promising; however, it was hypothesized that the syntax of some of the questions was excessively complex and that certain terms might not be readily understood by older adults.

### Methods

#### Study Subjects

Cognitive interviewing consists of intense, one-on-one interviews with respondents who belong to the population targeted by the survey. Because of the time-consuming nature of the interviews, the lengthy transcribing process, and the amount of information generated, a relatively small number of interviews is typically conducted (8, 13).

Because the interviews needed to be completed within six weeks, a convenience sample of seven adults aged sixty and older was recruited. An effort was made to recruit individuals of both genders, varying ethnic/racial background and socio-economic status,



and similar in health and nutrition status to the Community Connections target population.

Recruiting began in January, 2005. Members of the research team contacted community dietitians, two assisted living facilities, one in Prince George's County and the other in the city of Baltimore, Senior Centers in Montgomery and Prince George's Counties, Maryland and several Meals on Wheels Coordinators. Recruiting was done through in-person appointments with program directors, posters, email, and phone calls. (Example recruiting flyer is found in Appendix F).

In all, ten sites were contacted. Several program directors did not wish to participate, and more than half did not return phone calls or emails. Two sites, a Meals on Wheels program in Montgomery County and an assisted living facility in Prince George's County, agreed to invite their clients to participate. The MOW program director provided a list of 11 clients who agreed to in-home interviews, and the registered dietitian at the assisted living facility introduced the interviewer to nine residents, of whom eight agreed to be interviewed. In all, seven persons completed usable cognitive interviews. A \$10.00 gift certificate from a local drug store was provided to each participant at the conclusion of the interview. IRB approval for the protocol was granted by the University of Maryland, College Park.

The respondents were all 80 years old or greater; the oldest was 94. Six of the seven were female. Three identified themselves as African-American or black, three as Caucasian or white, and one as Native American. Five were widowed, one was divorced and one was separated. Two reported less than a high school diploma, two had received a high school diplomas, two had some college, and one had a Ph.D. Three lived in assisted living, while four were community living. Three of the four community-dwelling individuals received home delivered meals.

## Design of the Interviews

The INA consisted of approximately 150 questions, divided into 10 sections.

Three sections were of particular interest:

11. Physical Function Assessment, which surveys the respondent's degree of difficulty in completing activities of daily living (ADLs) and instrumental activities of daily living (IADLs).
12. Depression Status Assessment, which assesses the respondent's degree of depression.
13. General Health Assessment, including physical health, disease status, impact of disease on food intake and state of dental health.

Because cognitive interviewing takes much longer than simply administering the survey, it was decided to cognitively test the INA in sections, consistent with protocols developed at NCHS for testing longer surveys (8). The demographic and hardiness questions were cognitively tested in all seven respondents.

## Interview Protocol

The interviewer scheduled appointments with community dwelling participants by phone, with a follow-up call the evening before the interview to confirm the time of the appointment and the continued availability of the participant. Residents at the assisted living facility who consented were interviewed immediately on site. If the resident was alone in his or her room, the interview was conducted there; if not, the resident was interviewed in a common area. All interviews were conducted by one interviewer, and were audio-taped with permission from the interviewees. The interviewer also took handwritten notes.

Each participant gave informed consent and received a coded identification number, which was used on the interview form and the audio recording to preserve confidentiality. Demographic information was not audio recorded. The interviews lasted between 45 and 75 minutes. After each interview, the interviewer reviewed the handwritten notes and tapes. At the end of the data collection period, the tapes were transcribed in their entirety.

Cognitive interviewing techniques fall under two general classifications: “think-aloud” interviewing and verbal probing (16). During think-aloud interviewing, the interviewer reads each question, and respondents are encouraged to “think aloud” about the process going on in their minds as they attempt to answer. The goals of the think-aloud process are to understand how a respondent goes about formulating an answer, to reveal possible misunderstandings or misconceptions about the intent of the question, to understand how respondents recall information, and to reveal whether respondents truly recall information or simply guess (9). After asking the survey question and reminding the respondent to think aloud, the interviewer says little other than to encourage the individual to verbalize thoughts.

In the second technique, verbal probing, the interviewer asks the survey question, and then asks for information regarding the question. *Scripted* probes are crafted in advance of the interview, particularly if there is cause to suspect the question may be problematic (such as including an unfamiliar term). During the CI, the interviewer may also ask *spontaneous* probes when a respondent hesitates, looks puzzled, or cannot answer the question (9). Scripted and spontaneous probes may be used after each question (concurrent) or at the end of a set of questions or the entire survey (retrospective).

Concurrent and retrospective scripted and spontaneous probes and think-alouds were all used in the seven interviews. Probes were planned to detect respondent problems with comprehension of medical or nutrition terms, syntax of questions, and estimating time and frequency of recurring health events, such as visits to doctors. Probes were also designed to gain insight into the cognitive processes by which older adults answer survey questions related to health and nutrition.

### Results

Although the reports from the cognitive interviews are qualitative, and only seven useable CI were completed, several themes emerged from the interviews.

#### Depression Assessment

We were particularly interested in cognitively testing questions intended to assess depression (Appendix G). There was concern that the terms “helpless” and “worthless” in questions three and five might be considered demeaning or excessively invasive by respondents.

Because the Depression Status Assessment is short, it was decided to ask the six questions sequentially and probe the entire section retrospectively. The probes are shown in Appendix H.

Respondents stated that they were not at all offended by the words “worthless” or “helpless.” Two respondents stated that the words, “didn’t bother [them] at all.” When asked if a different word would be preferred, one respondent laughed and replied, “They’re all the same to me.”

An additional and unexpected finding came to light during the probes. Respondents who answered affirmatively to questions that indicate risk for depression cited physical limitations rather than depression as reasons for their answers. When asked

what “helpless” meant, one respondent answered, “Like you can’t do anything for yourself. But I can, though.” This person had answered yes to “Do you often feel helpless?” When probed, the respondent indicated that the yes answer meant “physically helpless.”

When probed about being “basically satisfied,” “bored” and “staying home,” all the respondents indicated that physical limitations were the cause of any lack of satisfaction or boredom they reported. One wheelchair-bound respondent reported that she was not basically satisfied and was bored because “. . . I sit here all day long. And there’s no place to sit outside even if I could get someone to take me out.” Another respondent who answered yes to “Do you often get bored?” explained the boredom with, “Sometimes I’d like not to be here [at the nursing home]. I’d like to be back at my home.”

When probed, respondents who answered that they preferred to stay at home and not try new things reported that they chose this response because of difficulty getting out because of their physical limitations. One respondent who answered yes said that it wasn’t because she didn’t like to go out, but “because I have to use the walker, and the wheelchair sometimes.” When asked to explain farther, the respondent stated that going outside would be easier if there were someone to help, and added, “I’m glad to go out. I used to go to my son’s house, but I can’t get up his steps now.”

#### Interpretation of Physical Function Questions

The questions querying physical function were in the following form:

**PHYFUN1A. Because of a health or physical impairment how much difficulty do you have bathing (READ OUT RESPONSES TO PARTICIPANT AND SHOW CARD)?**

No difficulty.....1 (NEXT QUESTION IS PHYFUN2A)  
Some difficulty.....2 (NEXT QUESTION IS PHYFUN1B)  
A lot of difficulty.....3 (NEXT QUESTION IS PHYFUN1B)  
Unable to do.....4 (NEXT QUESTION IS PHYFUN1B)  
Don't know.....77 (NEXT QUESTION IS PHYFUN2A)  
Refused.....88 (NEXT QUESTION IS PHYFUN2A)

**PHYFUN1B. Is someone available to help?**

No.....1 (NEXT QUESTION IS PHYFUN1C)  
Yes.....2 (NEXT QUESTION IS PHYFUN1C)  
Don't know....77 (NEXT QUESTION IS PHYFUN1C)  
Refused .....88 (NEXT QUESTION IS PHYFUN1C)

**PHYFUN1C. Do you need any [more] help?**

No.....1 (NEXT QUESTION IS PHYFUN2A)  
Yes.....2 (NEXT QUESTION IS PHYFUN2A)  
Don't know....77 (NEXT QUESTION IS PHYFUN2A)  
Refused .....88 (NEXT QUESTION IS PHYFUN2A)

Other activities included dressing/undressing, care of personal appearance, walking across the room, and instrumental activities of daily living (IADLs) such as doing housework or taking care of finances.

Perhaps because of their level of physical impairment, respondents interpreted questions about functional ability in reference to their *capacity*, or what they were able to do, rather than their *performance*, that is, what they actually do. Interviewees were quite careful to distinguish the difference: several respondents answered at least one physical function question with, “I don’t do that anymore.” In response to a question querying difficulty traveling via car or public transportation, another respondent answered, “I haven’t tried it.”

Although this information did not suggest that the ADL questions needed to be rewritten, it suggested that older adults may answer questions regarding physical function based on capacity rather than performance. Jobe and Mingay also report that older adults in their sample tended to interpret physical function questions as capacity questions (4).

However, their respondents reported “no difficulty” in doing the actions, although probing revealed that many had not tried in years. Our respondents bluntly stated they hadn’t tried.

#### Failure to Comprehend Medical Terms

In the General Health Assessment section, the researchers were interested in respondent comprehension of medical and disease-specific terms. Most of the disease terms appeared in the following question, so it was extensively probed.

**GENHLTH5. Which of the following health conditions, if any, were reasons for your recent institutionalization?**

- Heart disease, including coronary heart disease, angina, heart attack, congestive heart failure or myocardial infarction
  - Respiratory diseases such as emphysema, pneumonia, chronic obstructive disease (COPD) or asthma
  - Kidney diseases, i.e., renal failure
  - Gastrointestinal problems
  - Hypertension, sometimes called high blood pressure
  - Diabetes
  - Mental health conditions such as dementia or depression
  - Diarrhea or other bowel problems
  - Stroke or cerebrovascular accident
  - Bone related disease
  - Anemia
  - Cancer
- (NEXT QUESTION IS GENHLTH6A)

The problem terms were:

- anemia: All the respondents answered yes or no; however when probed about what anemia was, answers included, “When you don’t have enough blood,” “I can’t explain, but I know what it means,” and “I don’t know.” Two respondents knew and correctly defined the term.

*Recommendation: change the wording to “anemia, which is when you don’t have enough iron in your blood.”*

- gastrointestinal problems: Several respondents answered no, but then answered yes to “diarrhea or other bowel problems.” When probed, they did not recognize the term “gastrointestinal.” One respondent said, “Say it at a lower level, honey.”

*Recommendation: remove “gastrointestinal problems” and itemize specific conditions of interest.*

- Only one respondent knew the meaning of “cerebrovascular.”

*Recommendation: just say “stroke.”*

- bone-related disease: One respondent wanted to know whether a hip replacement counted. When probed, one mentioned arthritis, but no one mentioned osteoporosis specifically.

*Recommendation: mention conditions that should be included.*

#### Hardiness

Three primary problems emerged with the hardiness questions: confusing syntax of some questions, questions that were interpreted based on physical rather than psychological limitations, and poorly understood terminology.

Questions testing negatively scored factors confused respondents. For example:

#### **Question 14: Trying hard doesn’t pay since most things still don’t turn out right.**

- This double negative and complex syntax did not work: no respondent could comprehend the question as written. Every respondent asked to have the question repeated, and still found the question confusing. One respondent gamely asked, “What was the beginning of that?” The only way to elicit a response was to ask the question in the positive: “Does trying hard pay off for you?”

This question tests the factor *powerlessness*; a negative response correlates to positive on the dimension of *control*. The simplest solution would be to turn the question



into its positive, but that changes the dimension being tested. Another option was to chose a different question from the original 45-question DRS that measures powerlessness.

*Recommendation: Use an alternate question from the DRS such as **The tried and true ways are always best**, or convert the question to positive voice: **Does trying hard pay off for you?***

As in the depression assessment, respondents tended to answer based on physical function. For example:

**Question 18: I carefully plan just about everything I do.**

- All respondents understood the intention of the question, but some insisted they could no longer plan because they relied on someone else to help them do things. Is the question is testing the intended dimension of *rigidity* in disabled older adults or is it testing pragmatism?

The following question not only elicited responses based on physical rather than psychological frailty, but also contained terms that were not well understood by respondents:

**Question 11: I see really stressful events as opportunities to grow personally.**

- Respondents were generally puzzled by the term “to grow personally,” so the question was then asked using “to become a stronger person.” This question was typically answered in terms of stressful physical events that had recently befallen respondents, such as diseases, strokes, and other disabling medical events.
- One respondent mentioned that she “just quit” when she had a stroke, but was ready to “get back up” once she felt physically better.
- Another answered, “I don’t worry about much. [My illness] made me look at the world differently.” This wording change to “become a stronger person” was not

perfect: one person replied, “I don’t think I’m going to get any stronger,” and when probed, said he meant “physically stronger.”

*Recommendation: change question to read **When bad things happen, I see it as a chance to become emotionally stronger.*** This may alleviate the tendency to answer from the perspective of physical events and physical strength. The simpler wording was more comfortable for the interviewer, and may be easier for respondents with low literacy or cognitive and aural impairments to comprehend.

#### Retesting of the Hardiness Questions

The rewritten hardiness questionnaire was cognitively tested in seven more individuals in order to assess whether the rewritten questions were easier to comprehend. Changes recommended from the first set of interviews were incorporated to simplify wording and syntax, and one question was replaced by a more simply worded question from the DRS-II that tested the same factor.

Seven adults aged 60 and greater were recruited to test the rewritten questionnaire. All seven respondents were asked the demographic questions and the 18 rewritten hardiness questions. Scripted probes tested understanding of specific terms and overall comprehension of the questions.

All seven respondents reported that the questions were clear. The final probe asked, “Do you have any comments or suggestions for me about ways to make this questionnaire easier for people like you to understand or answer?” All seven respondents reported that the questions were, “all fine,” “questions are pretty well thought out,” and “most of the time you should get the answers you need.” All seven respondents were able to give a synonym or description that captured the implications of terms that were probed, and none felt that new wording was needed for these expressions.

## Conclusions

The seven initial cognitive interviews illuminated some important strategies that this sample of older adults used when answering survey questions, such as interpreting the questions in the Depression Status Assessment in light of physical rather than psychological limitations. While these responses don't negate the ability of the questions to screen for depression, they suggest that older adults may respond in a realistic manner to physical limitations and environmental barriers rather than responding based solely on a state of psychological depression. It would be interesting to follow up on the provocative question of the interaction of physical and psychological function and their relation to perceived and actual environmental barriers for older adults with physical limitations.

When asked about physical function, respondents made a clear distinction between capacity and performance. Jobe and Mingay found that their older adult cognitive interviewees made the same distinction, but their respondents reported "no difficulty" in doing the actions, although probing revealed that many had not tried in years (4). Our respondents clearly stated they hadn't tried.

The interviews highlighted several syntax and terminology problems within the questionnaire, and replicated the findings of other studies that indicate the importance of using lay terms when asking survey questions rather than more technical terms.

The second set of CI suggest that simplifying the wording and syntax of the DRS-II improves the ability of the DRS-II to collect data on psychological hardiness in adults aged 60 and greater. In the seven CI, the respondents stated that the questions were understandable, and, when probed, were able to provide responses that indicated they understood key terms and were able to follow the syntax of even the negatively-worded questions.

### Limitations

A primary limitation was the small number of interviews. The cognitive testing had to be completed within a very short time period in order to collect data, review it, and make recommendations before the INA had to be distributed for use in the field. Because of these time constraints, only seven interviews were completed instead of the intended twelve.

Secondly, six of the seven respondents were quite physically limited, which affected the way they interpreted questions regarding physical function and depression. Probing showed that these participants interpreted the physical function questions in terms of capacity rather than performance, and filtered their answers to the depression assessment through the lens of realistic physical limitation. These findings were provocative and novel, but must be approached with caution, as they may be representative only of older adults with serious physical limitations.

Last, as is always the case with cognitive interview data, there is the potential for bias. Although a strong effort was made to include all the scripted probes in every interview, this did not always occur. Interviewees were easily distracted, and often wandered off topic when given the opportunity to think aloud, so some scripted probes failed to elicit usable responses from some respondents.

### Future Directions

The most provocative findings of this research were that older adults with significant physical limitations answered questions regarding physical function based on capacity rather than performance, and depression status based on physical limitations. Because physical function and depression impact nutritional status and risk among older adults (30), these findings may significantly assist in correctly assessing the role of

physical limitation in functional and emotional status, and the impact of these three related factors on nutrition status and risk. It is essential, therefore, to further investigate these findings in a larger and more varied sample of older adults. If a person who answers yes to “Do you feel often feel helpless?” means, “Yes, because I can’t walk up the steps to my son’s apartment,” we can help her up those stairs, not treat her for depression.

## Chapter 4: Results, Part 2

The goals of the cognitive interviews were:

- to discover potential problems within the Initial Needs Assessment (INA) survey instrument that might be detrimental to collecting accurate data during the Community Connections intervention.
- to use information gathered during the CI to improve the INA so that it would elicit more accurate data.
- to gain insight into the cognitive processes by which members of the target population of hospital-discharged adults aged 60 and greater answer health and nutrition related survey questions.

Although the reports from the cognitive interviews are qualitative, and only 7 useable CI were completed, several themes did emerge from the interviews. Probes were planned to illuminate lexical, temporal, and logical problems within the survey questions. In addition, spontaneous probes arose within each interview. Some of the spontaneous probes proved so helpful that they were converted to planned probes and used in all the succeeding interviews. Several examples will be mentioned below.

### Consent Form

Cognitive testing had not been planned for the informed consent form; however, several valuable insights occurred regarding the format of the form itself in this sample of older adults. The informed consent document (Appendix C) as approved by the IRB at University of Maryland was three pages long. It included two example questions intended to demonstrate the type of questions the interviewer would be asking, along with

required sections such as the title and purpose of the research, confidentiality and risk of participation statements and contact information for the investigators.

It was intended that respondents would read and sign the consent form, but none of the seven participants wanted to read the form; therefore the interviewer read the consent form aloud to each participant. When probed about their request, several interviewees mentioned that their eyesight was not good enough to read the lengthy form. Almost all the respondents indicated that the form was too long or that “it’s less trouble” if the interviewer read the form aloud. Most of the respondents’ attention wandered during the course of listening to the consent form, necessitating rereading portions of the form. One respondent at the assisted living facility, who had suffered a stroke, was unable to sign her name, so the interviewer signed and the respondent placed an X. One of the respondents from the Meals on Wheels program was also unable to sign because of a stroke, but was able to use a signature stamp that she used for signing checks and other official documents. In addition, the interviewer suspected that at least one of the respondents was a non-reader, but this was not probed.

In addition, the inclusion of sample questions was confusing to participants. One respondent objected that the questions didn’t apply to her, so she should not be included in the study. Other respondents thought the interview had started, and were confused when the interviewer went on to read the rest of the consent form and ask for a signature.

In light of these indications of potential issues for seeking informed consent in older adults, particularly those with physical or cognitive limitations or low literacy, several compensations may be considered:

- design consent form to be read to participants
- shorten consent form as much as possible while still including required elements
- do not include example questions

For the second set of CI to test revisions to the hardiness questions, a shortened consent form designed to be read aloud was submitted to and approved by the IRB.

### Demographic Questions

Although no probes had been planned for the demographic questions, respondents revealed two helpful pieces of information. When asked, “What is your date of birth?” one respondent was unable to remember the year of birth. The INA follows that question with an alternative version, “What age range does your age fall into?” which the respondent was able to answer. Given that respondents in the Community Connections intervention would be recently discharged from the hospital, and might be older-old, not in optimal health, and perhaps affected by medication, it makes sense to keep the alternate version of the question for those who might face the same difficulty as this respondent; however, unless the respondent was unable to recall the specific date of birth, the alternate would be skipped.

Another respondent, when asked the highest level of education achieved, reported “professional training,” which was not a response option. A possible option would be to add a response category of “trade school or professional training.”

### Practicing the “Think-aloud” Technique

Following the protocol of researchers at the QDRL at NCHS (17), the Community Connections researchers included a short training session at the beginning of the CI to teach each respondent how to “think aloud.” The practice questions are shown below.



Most people aren't used to thinking out loud while answering a question, so we'll do 2 practice questions before we get to the questionnaire. These two questions are just to give you practice answering questions the way we've been talking about.

Do you have any questions before we begin?

OK, here's the first practice question. It's about eating meals. Remember to think out loud while you answer the question.

**How many meals did you eat yesterday?**

**Probe:** What time period were you thinking about when you answered the question?

**Probe:** What did you count as a meal?

Here's the second practice question. Remember to keep thinking out loud.

**How many windows are there in the place where you live?**

**Probe:** Did you count windows that are in doors, like French doors?

So that's how we're going to do the interview. Just answer the questions the way you normally would, and I'll remind you to think out loud, and ask you some additional questions.

*Figure 1: Practice think-aloud questions*

Unfortunately, the practice questions took up an inordinate amount of time and prevented the interviewer from completing cognitive testing of all the intended INA questions, so after the first two interviews, the practice questions were dropped, and the interviewer simply described the process to the other five interviewees.

*General Health Questions*

The thirty-eight questions in the General Health Assessment section queried physical health, sources of payment for health care, medical conditions, dental health, and the impact of physical and dental health on appetite and food intake. Both planned and spontaneous probes were used concurrently throughout. (See Appendix D for questionnaire with planned probes included.) The General Health Assessment was administered to all seven interviewees.

Prior to the cognitive interviews, all the questions for which scaled responses were desired were standardized to use a five point Likert scale with the responses “excellent,” “very good,” “good,” “fair,” or “poor” in order to minimize confusion for the respondents. A hand card (Appendix I) was provided with the responses printed in large type. During the interviews, the interviewer offered the hand card to the respondents, and preference for the hand card was probed retrospectively after the General Health Assessment portion of the interview was complete.

In the General Health Assessment section, the researchers were interested in:

- comprehension of medical and disease-specific terms
- how respondents understood terms such as “health facility” and “institutionalization”
- whether respondents understood the agencies that might be sources of their healthcare payments
- whether any questions were repetitive or superfluous

Most of the disease terms appeared in the following question, so it was extensively probed.

**GENHLTH5. Which of the following health conditions, if any, were reasons for your recent institutionalization?**

- Heart disease, including coronary heart disease, angina, heart attack, congestive heart failure or myocardial infarction
  - Respiratory diseases such as emphysema, pneumonia, chronic obstructive disease (COPD) or asthma
  - Kidney diseases, i.e., renal failure
  - Gastrointestinal problems
  - Hypertension, sometimes called high blood pressure
  - Diabetes
  - Mental health conditions such as dementia or depression
  - Diarrhea or other bowel problems
  - Stroke or cerebrovascular accident
  - Bone related disease
  - Anemia
  - Cancer
- (NEXT QUESTION IS GENHLTH6A)

The problem terms were:

- anemia: All the respondents answered yes or no; however when probed about what anemia was, answers included, “When you don’t have enough blood,” “I can’t explain, but I know what it means,” and “I don’t know.” Two respondents knew and correctly defined the term.

Recommendation: change the wording to “anemia, which is when you don’t have enough iron in your blood.”

- gastrointestinal problems: Several respondents answered no, but then answered yes to “diarrhea or other bowel problems.” When probed, they did not recognize the term “gastrointestinal.” One respondent said, “Say it at a lower level, honey.”

Recommendation: remove “gastrointestinal problems” and itemize specific conditions of interest.

- Only one respondent knew the meaning of “cerebrovascular.”

Recommendation: just say “stroke.”

- bone-related disease: One respondent wanted to know whether a hip replacement counted. When probed, one mentioned arthritis, but no one mentioned osteoporosis specifically.

Recommendation: mention conditions that should be included.

**GENHLTH9. Has a health professional (such as a doctor or a nurse) ever told you that you have any of the following conditions:**

- Arthritis
- Gastrointestinal problems
- Anemia
- Respiratory diseases such as emphysema, pneumonia, chronic obstructive disease (COPD) or asthma
- Mental health conditions such as dementia and depression?
- Diarrhea or other bowel problems?
- High blood cholesterol
- Hypertension, sometimes called high blood pressure
- Heart disease, including coronary heart disease, angina,, heart attack, congestive heart failure or myocardial infarction
- A stroke or cerebrovascular accident
- Cancer

This question followed soon after the previous one, with the intention of distinguishing which diseases had been diagnosed by a health professional from the reason for the individual's institutionalization. However, the respondents in these interviews did not make that distinction. When asked for their reason for institutionalization, they answered yes to any condition they had, and consequently interpreted GENHLTH9 as being the same question as GENHLTH5. One respondent said, "I already told you that!"

However, the researchers decided to keep the questions intact in the INA, and preliminary reports from the Community Connections intervention suggest that respondents did make a distinction between the meaning of the two questions (28). This difference may reflect the artificiality of the cognitive interview situation, differences among individual respondents, and perhaps a greater degree of illness, disability and cognitive impairment in the CI participants.

Respondents demonstrated some variability in their definition of "health care facilities." One person defined them as what we would call long-term care facilities, while most mentioned hospitals. Similarly, the word "institutionalized" was hard for

respondents to define, but they seemed to understand the questions well enough. Further, because the Community Connections participants would be recently hospital-discharged, it was felt that the context would lead them to interpret the question as the researchers intended; therefore no changes were made.

Some respondents were unsure of how their care was being paid for. Two respondents answered that they did not have private insurance but later in the question mentioned specific private insurance plans they had. A possible solution would be to rephrase the response category text to, “private insurance such as Kaiser-Permanente or Blue Cross/Blue Shield.”

All of the respondents said they received social security, but most were unsure whether social security paid any of their health care costs.

The one payment most people didn’t know was Supplemental Security Income (SSI), but as far as the interviewer could tell, that was because no one received SSI.

On balance, the research team decided that these issues could be resolved during administration of the survey; therefore, the researchers decided to leave the question as it was.

### *Physical Function*

The questions querying ADLs were in the following form:

**PHYFUN1A. Because of a health or physical impairment how much difficulty do you have bathing (READ OUT RESPONSES TO PARTICIPANT AND SHOW CARD)?**

No difficulty.....1 (NEXT QUESTION IS PHYFUN2A)  
Some difficulty.....2 (NEXT QUESTION IS PHYFUN1B)  
A lot of difficulty.....3 (NEXT QUESTION IS PHYFUN1B)  
Unable to do.....4 (NEXT QUESTION IS PHYFUN1B)  
Don't know.....77 (NEXT QUESTION IS PHYFUN2A)  
Refused.....88 (NEXT QUESTION IS PHYFUN2A)

**PHYFUN1B. Is someone available to help?**

No.....1 (NEXT QUESTION IS PHYFUN1C)  
Yes.....2 (NEXT QUESTION IS PHYFUN1C)  
Don't know....77 (NEXT QUESTION IS PHYFUN1C)  
Refused .....88 (NEXT QUESTION IS PHYFUN1C)

**PHYFUN1C. Do you need any [more] help?**

No.....1 (NEXT QUESTION IS PHYFUN2A)  
Yes.....2 (NEXT QUESTION IS PHYFUN2A)  
Don't know....77 (NEXT QUESTION IS PHYFUN2A)  
Refused .....88 (NEXT QUESTION IS PHYFUN2A)

Other activities included dressing/undressing, care of personal appearance, getting in and out of bed, walking across the room, and instrumental activities of daily living (IADLs) such as doing housework like scrubbing floors or washing windows or taking care of finances.

Asking these questions to this group of respondents highlighted an issue known to affect survey responses in older adults: whether respondents interpret questions about functional limitation in reference to their capacity to perform the activity or their actual performance of the activity (4). In survey methodology, *capacity* refers to what a person is able to do, and *performance* is defined as what a person actually does (4). As shown in some of the responses below, several respondents in the cognitive testing protocol interpreted these questions as performance questions, and were careful to distinguish that from their capacity.

Perhaps because of the level of physical impairment of these respondents, respondents frequently answered, “I don’t do that anymore.” In response to a question querying difficulty traveling via car or public transportation, a respondent answered, “I haven’t tried it.” Although this information did not suggest that the ADL questions needed to be rewritten, it was helpful to the research team in understanding how older adults may strategize in answering questions regarding physical function.

Because the CI protocol encourages respondents to ask questions or offer suggestions about the wording of questions, one respondent wondered aloud how best to answer the following question:

**PHYFUN17A By yourself and not using any aids, do you have any difficulty raising your arms above your head?**  
No difficulty.....1 (NEXT QUESTION IS PHYFUN18A)  
Some difficulty .....2 (NEXT QUESTION IS PHYFUN17B)  
A lot of difficulty .....3 (NEXT QUESTION IS PHYFUN17B)  
Unable to do.....4 (NEXT QUESTION IS PHYFUN17B)  
Don’t know.....77 (NEXT QUESTION IS PHYFUN18A)  
Refused.....88 (NEXT QUESTION IS PHYFUN18A)

The respondent expressed uncertainty about how to answer because one arm could be raised without difficulty and the other was completely motionless because of a stroke. Because such scenarios seemed likely to occur in the target population for the survey, it was recommended that the researchers decide what category this type of response should fall into, and that help text could be created for Community Connections interviewers to inform them of the correct response category.

Jobe and Mingay found that older adults were likely to ignore the phrase “without using any aids” and answer that they had no difficulty performing activities for which they actually used an aid such as a cane or walker (4). The Community Connections research team decided to probe what respondents considered “aids” to include; therefore the following planned probe was included:

**Probe: When I say “not using any aids,” what do you think I’m talking about?**

**What items do you think are included in the term “aids?”**

All the respondents who were asked this probe mentioned wheelchairs, and one listed wheelchairs, canes and walkers. One very disabled respondent mentioned a person who helped with dressing and other personal grooming tasks. As noted above, this group of respondents did not appear to underreport difficulty with ADLs, and were quite clear about activities they no longer attempted. Their interpretation of functional aids appears to agree with the interpretation required by the questions about ADLs. Perhaps because most of these respondents had obvious functional limitations, they reported levels of difficulty that seemed congruent with what the interviewer observed. For example, a wheelchair user answered the following question:

**PHYFUN6A. Because of a health or physical impairment how much difficulty do you have walking across the room?**

by stating, “I can’t walk. I have to use a wheelchair.” Because of these findings, it was not considered necessary to reword questions on the INA about functional ability.

### Depression Assessment

Representatives of some of the community organizations selected to participate in the Community Connections intervention expressed reservations about the wording of some of the Depression Assessment questions. (All six questions are shown in Appendix G.)

Of specific concern were questions 3 and 5, because it was felt that the terms “helpless” and “worthless” might be considered pejorative or demeaning by potential participants in the Community Connections intervention. Another concern was that the questions were invasive. Therefore, the researchers were particularly interested in



cognitively testing this section. Although these 6 questions are well validated for use in older adults, it was hoped that cognitive testing would reveal whether CI participants found these questions insensitive, invasive or insulting. The results of the CI would be presented to organizations participating in the Community Connections intervention in order to address these concerns before the intervention started.

Because the Depression Status Assessment is short, it was decided to ask the six questions sequentially and probe the entire section retrospectively. The planned probes are also shown in Appendix H.

Respondents stated that they were not at all offended or put off by the words “worthless” or “helpless.” Two respondents stated that the words, “didn’t bother [them] at all.” When asked if a different word would be preferred, one respondent laughed and replied, “They’re all the same to me.”

When asked what “helpless” meant, one respondent answered, “Like you can’t do anything for yourself. But I can, though.” This person had answered yes to DEPASSMT3, “Do you often feel helpless?” When probed, the respondent indicated that the yes answer meant “physically helpless.”

When probed about being basically satisfied, bored and staying home, all the respondents indicated that physical limitations were the cause of any lack of satisfaction or boredom they reported. One wheelchair-bound respondent defined “basically satisfied” as being happy, and reported that she was not basically satisfied and was bored because “. . . I sit here all day long. And there’s no place to sit outside even if I could get someone to take me out.” Another respondent who answered yes to DEPASSMT2, “Do you often get bored?” explained, “Sometimes I’d like not to be here [at the nursing home]. I’d like to be back at my home.”

Similarly, when probed, respondents who answered that they preferred to stay at home and not try new things reported that they actually chose this response because of the difficulty in getting around in the world because of their physical limitations. One respondent who answered yes to DEPASSMT4 said that it wasn't that she didn't like to go out, but "because I have to use the walker, and the wheelchair sometimes." When asked to explain farther, the respondent stated that going outside would be easier if there were someone to help, it would be easier, and added, "I'm glad to go out. I used to go to my son's house, but I can't get up his steps now."

While these responses certainly don't negate the ability of the questions to screen for depression, they suggest that older adults may be responding in a realistic manner to physical limitations and environmental barriers rather than responding based solely on a state of psychological depression. It would be extremely interesting to follow up on the provocative question of the interaction of physical and psychological function and their relation to perceived and actual environmental barriers for older adults with physical limitations.

### Temporal Estimation

Most people have difficulty accurately recalling health-related events such as timing and number of doctor visits, and a number of studies suggest that older adults have greater difficulty than younger respondents (2). Recalling or estimating when health-related events took place is problematic for survey respondents (10). Because a number of questions in the INA require respondents to recall such information, the research team included a number of probes throughout the sections of the INA to gauge how respondents might strategize when answering questions that included estimation of time frames and occurrence of health-related events, and to gain insight in how respondents in

the Community Connections intervention could be helped to recall such events more accurately. A representative example follows.

<b>GENHLTH34 . Have you visited the dentist:</b>
Within the past 12 months.....1 (NEXT QUESTION IS GENHLTH35A)
In the last 2 years.....2 (NEXT QUESTION IS GENHLTH35A)
Never been to a dentist.....3 (NEXT QUESTION IS GENHLTH36)
Don't know .....77 (NEXT QUESTION IS GENHLTH36)
Refused .....88 (NEXT QUESTION IS GENHLTH36)

Not surprisingly, respondents hesitated when asked this question. One respondent answered, “I go once a year,” but then added, “But I haven’t been this year.” When asked, “Do you remember the last time you went?” the respondent mentioned that “it must have been last spring.” When asked how she arrived at that answer, the respondent replied, “I don’t go in the wintertime, so it must have been in the spring. It’s hard for me to go.” When probed, “How are you sure it was last spring?” the respondent avoided answering by changing the subject.

Answering the same question, another respondent answered no to all the response options. When probed, this respondent indicated, “Not since I moved here.” The respondent had reported that it was over two years since admittance to the assisted living facility, suggesting that memory for the events was congruent.

A third respondent reported never going to the dentist, but when probed explained that the dentist came to assisted living facility for appointments.

The variety of responses, not only to the survey question, but also to the probes, suggests that there is no single strategy to help respondents recall health care visits accurately. A small wording change could avoid the problem encountered by the respondent whose dentist paid on-site visits:

Recommendation: Change question to read, “Have you been seen by a dentist . . .”

### Questions About Nutrition

Questions on the INA were either derived from existing instruments previously validated for use with older adults, or were written or adapted for the Community Connections research project from research in the field of older adult nutrition, social support and use of community resources, including food assistance. Although many of the questions do not query specific nutritional facets of health, they query factors that are known to impact on nutritional status and risk in older adults (29). There are, however, several questions that ask specifically about food intake, appetite, and food security. Although some planned probes had been written, in the interviews it was quite clear that respondents understood the nutritional questions, perhaps because they did not contain unusual or scientific terms. The following question, however, was problematic:

**GENHLTH29. How often do you limit the kind or amount of food you eat because of problems with your teeth or dentures?**

Not one of the respondents answered in terms of problems with teeth or dentures. The respondent in the first interview hesitated, so the interviewer asked the interviewee to think aloud while attempting to answer the question. Although the respondent never directly said so, it became clear that the respondent did not answer the question. When probed about the expression “limit the kind or amount of food,” the respondent lost track of what the question was. Upon more probing, the respondent suggested asking, “How often do you have to *be careful* about the food you eat . . .”

Another respondent stated that “limit the kind or amount of food” referred to being full, and did not answer in relationship to problems of teeth or dentures, even when reminded to. When asked directly whether it was because of problems with teeth or dentures, the respondent replied, “No, it’s just when I’m full.”

When probed, a third respondent who had answered yes to the question explained, “Sometimes they give me food I don’t like.” “When probed whether the limiting of food was due to dentures, the respondent retorted, “No. Dentures have nothing to do with it.”

A fourth respondent reported basing the answer on whether she felt “up to par” on a given day.

Recommendation: Change the question to read: “Because of problems with your teeth or dentures, how often do you limit the kind and amount of food you eat?” Placing the reference to teeth and dentures first cues respondents to think in terms of dental problems. It might also be helpful to teach interviewers for the Community Connections survey to reread the question after the respondent answers to make sure that the individual has answered based on dentition rather than other possible reasons. Although it is important not to lead respondents, other researchers experienced in interviewing older adults have suggested that rereading questions to be certain they’ve been heard in their entirety is a valid neutral probe (21).

### Questions About Hardiness

Three primary problems emerged with the hardiness questions: confusing syntax of some questions, questions that were interpreted based on physical rather than psychological limitations, and poorly understood terminology.

Questions testing the negatively scored factors confused respondents. For example:

#### **Question 14: Trying hard doesn’t pay since most things still don’t turn out right.**

- This double negative and complex syntax did not work: no respondent could comprehend the question as written. Every respondent asked to have the question repeated, and still found the question confusing. One respondent gamely asked,

“What was the beginning of that?” The only way to elicit a response was to ask the question in the positive: “Does trying hard pay off for you?”

This question tests the factor *powerlessness*; a negative response correlates to positive on the dimension of *control*. The simplest solution would be to turn the question into its positive, but that changes the dimension being tested. Another option was to chose a different question from the original 45-question DRS that measures powerlessness.

*Recommendation: Use an alternate question from the DRS such as **The tried and true ways are always best**, or convert the question to positive voice: **Does trying hard pay off for you?***

As in the depression assessment, respondents tended to answer based on physical function. For example:

**Question 18: I carefully plan just about everything I do.**

- All respondents understood the intention of the question, but some insisted they could no longer plan because they relied on someone else to help them do things. Is the question testing the intended dimension of *rigidity* in disabled older adults or is it testing pragmatism?

The following question not only elicited responses based on physical rather than psychological frailty, but also contained terms that were not well understood by respondents:

**Question 11: I see really stressful events as opportunities to grow personally.**

- Respondents were generally puzzled by the term “to grow personally,” so the question was then asked using “to become a stronger person.” This question was typically answered in terms of stressful physical events that had recently befallen respondents, such as diseases, strokes, and other disabling medical events.

- One respondent mentioned that she “just quit” when she had a stroke, but was ready to “get back up” once she felt physically better.
- Another answered, “I don’t worry about much. [My illness] made me look at the world differently.” This wording change to “become a stronger person” was not perfect: one person replied, “I don’t think I’m going to get any stronger,” and when probed, said he meant “physically stronger.”

*Recommendation: change question to read **When bad things happen, I see it as a chance to become emotionally stronger.*** This may alleviate the tendency to answer from the perspective of physical events and physical strength. The simpler wording was more comfortable for the interviewer, and may be easier for respondents with low literacy or cognitive and aural impairments to comprehend.

### Conclusions

The cognitive interviews met the goal of discovering problems with in the questions on the INA, as described above. Even with only seven interviews, it was possible to discern which questions posed comprehension, lexical or temporal problems for respondents. The interviews also demonstrated that some of the questions that were thought to be difficult were actually interpreted by respondents as the researchers had intended, and did not need to be reworded. It appeared that several questions simply required a help screen to coach the Community Connections interviewers how to categorize common answers or explain terms in simpler language if needed by particular respondents.

Because the INA was not retested through CI, the outcome measure for improvement was of necessity the ability of the questionnaire to elicit the desired data in the field. Preliminary reports from the Community Connections intervention indicate that

both questions that were revised, and those that were deemed not to need revision, are being interpreted correctly by participants in the intervention (28).

On March 22 – 23, 2005, a training session was provided by the research team for community organizations who had been selected to participate in the Community Connections intervention. The results of the cognitive interviews were presented at the training session, with the following objectives:

- to assuage concerns that questions in the Depression Assessment were excessively personal and might be perceived as insulting by respondents
- to assure potential Community Connections interviewers that the INA had been pretested in a sample similar to the target population for the intervention, and found to flow comfortably for both interviewers and respondents
- to train interviewers how to help respondents choose appropriate response categories using neutral guidance
- to demonstrate that, based on the cognitive interviews, help screens had been devised where needed to guide interviewers in presenting standardized explanations for terms that might not be understood by respondents
- to assist interviewers in strategies to deal with respondent behaviors such as failure to select a specific response category, wandering off-topic, or desire for social conversation.

Each of the above objectives was met through a powerpoint presentation of the results of the cognitive interviews, a role-playing demonstration by members of the research team to demonstrate techniques for successfully survey recently hospital-released older adults, and the opportunity for interviewer-trainees to ask questions of the research team. In addition, a section on the cognitive interviewing process and results



was included in the training manual presented to interviewer-trainees to use as an on-going reference.

Based on verbal feedback from representatives of the community organizations present at the training, the five objectives were successfully met during the two-day training session.

#### Retesting of the Hardiness Questions

In July and August, 2005, the rewritten hardiness questionnaire was cognitively tested in seven more individuals in order to assess whether the rewritten questions were easier to comprehend, whether simplified response categories improved the ability of respondents to choose a response category.

Based on recommendations derived from the first seven CI, the syntax and wording were simplified in questions 5, 9, 10, 11, 13 and 17. In addition, Question 14, ***“Trying hard doesn’t pay since most things still don’t turn out right,”*** which was found to be incomprehensible to all seven respondents in the initial testing, was replaced by a different item from the original Bartone DRS scale. The replacement item, which also tests the factor *powerlessness*, reads, ***“The tried and true ways are always best.”*** The revised DRS II is included as appendix J.

A convenience sample of seven community-dwelling adults was recruited from a community in Prince George’s County, Maryland. Of the respondents, one was aged 60 – 69, two were aged 70 – 79, and four were aged 80 and greater. Three were male and four were female. One identified as African-American or black, one identified as Hispanic or Latino, and five identified as Caucasian or white. Four were married and three were widowed. One reported receiving a high school diploma, three reported completing a

bachelor's degree, one reported some post graduate work, and two reported completing Ph.D.s. None of the respondents had been hospital-discharged within the last year.

All seven respondents were asked the demographic questions and the 18 rewritten hardiness questions. As in the first set of interviews, scripted probes were devised, and unscripted probes were used as the need arose. The scripted probes are included as appendix K. Participants gave informed consent, and the interviews were audio recorded. The interviewer took written notes during the interviews. Each audio tape was transcribed, and themes were noted. A theme was considered significant if 4 or more of the 7 respondents mentioned the same idea.

#### Results of the Second Set of Cognitive Interviews

All seven respondents reported that the questions were clear. The final probe asked, "Do you have any comments or suggestions for me about ways to make this questionnaire easier for people like you to understand or answer?" All seven respondents reported that the questions were, "all fine," "questions are pretty well thought out," and "most of the time you should get the answers you need." One respondent stated that the answer categories were easy to use. The same respondent noted that the content of the questions might make some people miserable, but was not personally problematic, remarking, "You'd have to be very unhappy to hate this." Another respondent commented that some questions included two concepts in the same question, citing the first question, which asks whether ". . . *the successes I've had in life are due to my effort and ability.*" This respondent asked how to respond if the successes were due to one but not the other.

Specific terms were also probed for comprehension, including "face up to [problems]," "alienated, or emotionally disconnected," and "all alone in the world." All

seven respondents were able to give a synonym or description that captured the implications of these terms, and none felt that new wording was needed for these expressions.

The reverse-worded question, *“Things don’t turn out no matter how hard I try”* was tested with the probe, “What is this question asking?” All seven respondents were able to give an explanation that indicated comprehension of the inverted syntax.

#### Conclusions from the Second Set of Cognitive Interviews

The seven CI of the revised hardiness questionnaire suggest that simplifying the wording and syntax of the DRS-II and replacing a particularly convoluted question with a simpler one that measures the same factor did improve the ability of the DRS-II to collect data on psychological hardiness in adults aged 60 and greater. In the seven CI, the respondents stated that the questions were understandable, and, when probed, were able to provide responses that indicated they understood key terms and were able to follow the syntax of even the negatively-worded questions.

This sample, however, included six college-educated respondents, which does not represent the typical proportion of adults aged 60 and greater who have completed college; therefore, it would be helpful to cognitively test the questionnaire in a more varied sample of older adults to ensure that the questions are understood equally well by persons with lower education levels. Latino and African-American persons were under-represented, and no persons of Asian heritage were interviewed, so it would be beneficial to cognitively test the questions in individuals of these ethnicities in order to discover whether cultural differences play a role in how the questions are interpreted and answered.

### Limitations of the Research

The seven initial cognitive interviews illuminated several lexical, temporal and comprehension problems within the INA questionnaire. The interviews also highlighted some important strategies that this sample of older adults used when answering survey questions, such as interpreting the questions in the Depression Assessment in light of genuine physical limitations, and making a clear distinction between capacity and performance when asked about ADLs. This set of interviews also replicated the findings of other studies that indicate the importance of using lay terms rather than more technical terms familiar to researchers, health care providers, and nutrition professionals.

There were, however limitations. The cognitive testing of the INA had to be completed within a very short time period in order to collect data, review it, and make recommendations before the INA had to be distributed for use in the field. Because of the time constraints, only seven interviews were completed instead of the intended twelve. This meant that four sections of the INA, which assessed Social Support, Nutrition Security, Use of Food Assistance Programs and Service Awareness and Needs, were each cognitively tested in only one interview, which severely limited the usefulness of the responses to probes in those sections.

A second major limitation was that three of the seven interviewees resided in an assisted living facility, which did not match the Community Connections target audience of recently hospital discharged older adults. Also, three of the four free living participants were frail and homebound, as evidenced by their receiving home delivered meals. These six persons were quite physically limited, which affected the way they interpreted questions regarding physical function and depression. Probing showed that these participants interpreted the physical function questions in terms of capacity rather than performance, and filtered their answers to the depression assessment through the lens of

realistic physical limitation. These findings were provocative and novel, but must be approached with caution, as they may be representative only of older adults with serious physical limitations.

Last, as is always the case with cognitive interview data, there is the potential for interviewer bias. Although a strong effort was made to include all the preplanned probes in every interview in order to collect data from those probes from several respondents, this did not always occur. Interviewees were easily distracted, and often wandered far off topic when given the opportunity to think aloud, so some preplanned probes failed to elicit usable responses from some respondents.

Although the interviewer made a strong effort to avoid encouraging respondents to consider the interview a social visit, this was not totally successful. The freeform format of the interviews was conducive to respondent reminiscing and chatting. For example, when reminded that the interview could be terminated at any time if the respondent was tired, one interviewee replied, “Oh, no, I like the questions. I like knowing what’s going on in the world.”

Recommended strategies for keeping in-person surveys on track were only moderately successful. As a result, most of the interviews covered far fewer questions from the INA than originally intended, another reason for failure to cognitively test some sections more than once.

### *Future Directions*

Because of its demonstrated success in revealing question design problems that aren’t uncovered in pilot or field testing (3, 10), cognitive testing has become a much-used tool in questionnaire design. The effectiveness of the cognitive testing laboratory at NCHS has encouraged cognitive testing of health and nutrition related surveys (4, 13).

NCHS has demonstrated the usefulness of cognitive interviewing to understand the unique response strategies of older adults and the benefits of CI in tailoring questions to gather data from older adults (4).

But cognitive interviewing is most effective when it is used in tandem with other pretests, such as pilot testing and field testing, as each methodology is likely to reveal different useful information (4). It is also ideal to perform cognitive testing, revise survey questions based on the results of the CI, and then cognitively test the revised instrument to ensure that the changes have effectively improved the ability of the instrument to collect the required data (4).

Although it was not possible to retest the revised INA because of the imminent start of the Community Connections intervention, the success of the cognitive interviewing process and the favorable reception of its outcome by community organizations using the INA, the research team is interested in using cognitive testing for future survey instruments that will be used with older adults.

Cognitively testing the 18 hardiness questions from Sinclair's DRS-II showed that the wording required simplification in order to be well-understood by older adults. Retesting the revised instrument suggested that simplification did improve the ability of older adults to comprehend and answer the questions. Further, the questions appear to be useful in assessing the hardiness of older adults. Other studies have examined the relationship of hardiness to self-care practices and perceived health status in adults aged 55 – 92 (30), and its mediational effect on social support and health outcomes in older adults (23). It would be interesting to examine whether hardiness plays a role in nutrition status and outcome in older adults, particularly those at risk for malnutrition because of factors such as depression, and loss of physical function or appetite.

The most provocative findings of the present CI were that in this sample, older adults with significant physical limitations 1) answered questions regarding physical function by clearly delineating whether they were answering based on capacity or performance, and 2) answered questions assessing depression status based on realistic physical limitations. Because physical function and depression assessment are key areas in assessing nutrition status and potential nutritional risk in older adults these findings may play a significant role in correctly assessing an individual's perception of the roles of physical limitation in functional and emotional status, and the impact of these three related factors on nutrition status and risk for malnutrition. It is essential, therefore, to further investigate these findings in a larger and more varied sample of older adults. If it turns out that a person who answers yes to "Do you often feel helpless?" means, "Yes, because I can't walk up the steps to my son's apartment," we can help her up those stairs, not treat her for depression.

## Appendix A: Bartone Dispositional Resilience Scale

From Bartone, P.T., Ursano, R.J., Wright, K.M., and Ingraham, L.H. (1989). The impact of a military air disaster on the health of assistance workers. A prospective study. *Journal of Nervous and Mental Disease*. 1989;177(6):317-28.

### Instructions

Below are statements about life that people often feel differently about. Circle a number to show how you feel about each one. Read the items carefully and indicate how much you think each one is true in general. There are no right or wrong answers; just give your own honest opinions.

Not at all true = 0  
 A little true = 1  
 Quite true = 2  
 Completely true = 3

- |   |   |   |   |   |
|---|---|---|---|---|
| 1. Most of my life gets spent doing things that are worthwhile (*CM+)     | 0 | 1 | 2 | 3 |
| 2. Planning ahead can help avoid most future problems (*CO+)              | 0 | 1 | 2 | 3 |
| 3. Trying hard doesn't pay, since things still don't turn out right (CO)  | 0 | 1 | 2 | 3 |
| 4. No matter how hard I try, my efforts usually accomplish nothing (*CO)  | 0 | 1 | 2 | 3 |
| 5. I don't like to make changes in my everyday schedule (*CH)             | 0 | 1 | 2 | 3 |
| 6. The "tried and true" ways are always best (*CH)                        | 0 | 1 | 2 | 3 |
| 7. Working hard doesn't matter, since only the bosses profit by it (*CM)  | 0 | 1 | 2 | 3 |
| 8. By working hard you can always achieve your goals (*CM+)               | 0 | 1 | 2 | 3 |
| 9. Most working people are simply manipulated by their bosses (CM)        | 0 | 1 | 2 | 3 |
| 10. Most of what happens in life is just meant to be (*CO)                | 0 | 1 | 2 | 3 |
| 11. It's usually impossible for me to change things at work (CO)          | 0 | 1 | 2 | 3 |
| 12. New laws should never hurt a person's pay-check (CH)                  | 0 | 1 | 2 | 3 |
| 13. When I make plans, I'm certain I can make them work (*CO+)            | 0 | 1 | 2 | 3 |
| 14. It's very hard for me to change a friend's mind about something (CO)  | 0 | 1 | 2 | 3 |
| 15. It's exciting to learn something about myself (*CH+)                  | 0 | 1 | 2 | 3 |
| 16. People who never change their minds usually have good judgment (CH)   | 0 | 1 | 2 | 3 |
| 17. I really look forward to my work (*CM+)                               | 0 | 1 | 2 | 3 |
| 18. Politicians run our lives (CM)  | 0 | 1 | 2 | 3 |
| 19. If I'm working on a difficult task, I know when to seek help (*CO+)   | 0 | 1 | 2 | 3 |
| 20. I won't answer a question until I'm really sure I understand it (*CH) | 0 | 1 | 2 | 3 |
| 21. I like a lot of variety in my work (*CH+)                             | 0 | 1 | 2 | 3 |
| 22. Most of the time, people listen carefully to what I say (*CO+)        | 0 | 1 | 2 | 3 |
| 23. Daydreams are more exciting than reality for me (CM)                  | 0 | 1 | 2 | 3 |
| 24. Thinking of yourself as a free person just leads to frustration (*CM) | 0 | 1 | 2 | 3 |
| 25. Trying your best at work really pays off in the end (*CM+)            | 0 | 1 | 2 | 3 |
| 26. My mistakes are usually very difficult to correct (*CO)               | 0 | 1 | 2 | 3 |
| 27. It bothers me when my daily routine gets interrupted (*CH)            | 0 | 1 | 2 | 3 |
| 28. It's best to handle most problems by just not thinking of them (CO)   | 0 | 1 | 2 | 3 |
| 29. Most good athletes and leaders are born, not made (*CO)               | 0 | 1 | 2 | 3 |
| 30. I often wake up eager to take up my life wherever it left off (*CH+)  | 0 | 1 | 2 | 3 |
| 31. Lots of times, I don't really know my own mind (*CM)                  | 0 | 1 | 2 | 3 |
| 32. I respect rules because they guide me (*CH)                           | 0 | 1 | 2 | 3 |
| 33. I like it when things are uncertain or unpredictable (*CH+)           | 0 | 1 | 2 | 3 |
| 34. I can't do much to prevent it if someone wants to harm me (*CO)       | 0 | 1 | 2 | 3 |
| 35. People who do their best should get full support from society (CH)    | 0 | 1 | 2 | 3 |
| 36. Changes in routine are interesting to me (*CH+)                       | 0 | 1 | 2 | 3 |



- |   |  |
|---|--|
| <p>37. People who believe in individuality are only kidding themselves (CM) ... 0 1 2 3</p> <p>38. I have no use for theories that are not closely tied to facts (CH) ..... 0 1 2 3</p> <p>39. Most days, life is really interesting and exciting for me (*CM+)..... 0 1 2 3</p> <p>40. I want to be sure someone will take care of me when I'm old (CH) ..... 0 1 2 3</p> <p>41. It's hard to imagine anyone getting excited about working (*CM) ..... 0 1 2 3</p> <p>42. What happens to me tomorrow depends on what I do today (*CO+)... 0 1 2 3</p> | <p>43. If someone gets angry at me, it's usually no fault of mine (CO) ..... 0 1 2 3</p> <p>44. It's hard to believe people who say their work helps society (CM) ..... 0 1 2 3</p> <p>45. Ordinary work is just too boring to be worth doing (*CM) ..... 0 1 2 3</p> <p>* Items belong to short (30-item) form (Cronbach's alpha = .82, N = 178).</p> <p>+ Items are positively scored; all others are negatively scored.</p> <p>CM = commitment (Cronbach's alpha = .82, N = 172).</p> <p>CO = control (Cronbach's alpha = .66, N = 172).</p> <p>CH = challenge (Cronbach's alpha = .62, N = 172).</p> |
|---|--|

## Appendix B: Sinclair DRS-II

from Sinclair RR, Oliver CM. Development and validation of a short measure of hardiness. Defense Technical Information Center Report. 2003.

**Instructions:** Each of these statements reflects ways people sometimes feel. I'm going to read each statement and ask you to use the scale below to indicate the extent to which you feel each statement is true.

1 = Definitely False	2 = Mostly False	3 = Don't know	4 = Mostly True	5 = Definitely True
1.	_____	My successes are because of my effort and ability.		
2.	_____	No matter how hard I try, my efforts usually accomplish nothing.		
3.	_____	I enjoy most things in life.		
4.	_____	Sometimes, life seems meaningless to me.		
5.	_____	I take a head-on approach to facing problems in my life.		
6.	_____	It bothers me when my daily routine gets interrupted.		
7.	_____	I feel confident I can handle just about any challenge.		
8.	_____	I often feel helpless.		
9.	_____	Most of my life gets spent doing things that are worthwhile.		
10.	_____	I often feel alienated from the people around me.		
11.	_____	I see really stressful events as opportunities to grow personally.		
12.	_____	I don't like to make changes in my everyday schedule.		
13.	_____	My successes are related to the choices I make.		
14.	_____	Trying hard doesn't pay since most things still don't turn out right.		
15.	_____	Most days, life is really interesting.		
16.	_____	I usually feel all alone in the world.		
17.	_____	I often wake up eager to take up my life wherever it left off.		
18.	_____	I carefully plan just about everything I do.		

# Appendix C: Informed Consent Form For Cognitive Interviews

## INFORMED CONSENT FORM

**Identification of Project/Title** Community Connections: Moving Seniors toward Wellness:  
Cognitive Interviewing to Test the Survey Questionnaire

**Statement of Age by Participant** I state that I am over 18 years of age and wish to participate in a research project conducted by the Meals on Wheels Association of America and the University of Maryland.

**Purpose** The goal of this project is to pretest the questionnaire developed for the Community Connections: Moving Seniors Toward Wellness project. Cognitive interviewing is a technique used to make sure that respondents understand the questionnaire, and that it is able to gather the information it was intended to collect.

**Procedures** I will be asked to participate in an hour-long interview where an interviewer will be asking me questions about my health, my ability to perform everyday tasks, and about nutrition or health services that I might need. I may be asked to follow instructions to perform simple tasks such as counting backwards and naming common objects. During the interview, I may be asked to repeat questions in my own words or explain how I answered certain questions. The interviewer may ask me to suggest how the questions could be rewritten to make them easier for me to understand. The interviewer may also ask me how the questions relate to my own life experiences. This interview will only be tape-recorded with my permission. Here are some sample interview questions:

**During the 6-month period before you were hospitalized or institutionalized, were you ever worried about getting enough foods for your health?**

No  
Yes  
Don't know  
Refused

**Think-aloud:** How easy or hard was it to answer that question?  
What does the word "institutionalized" mean to you?

**Do you have mouth problems that make it hard for you to eat such as loose teeth or mouth sores?**

No  
Yes  
Don't know  
Refused

**Comprehension:** What does the term "mouth sores" mean to you? What  
mouth problems did you think of when I asked the question?

In addition, I will be asked to allow the interviewer to assess the type, amount and nature of foods available in my kitchen and pantry, and assess the condition of the appliances in

my home, if applicable.

**Confidentiality** All the information we collect will be confidential and may be used for publication and presentations. My name or contact information will not link me to the answers I provide. Only researchers at the University of Maryland will have access to all the information I give, including the audiotapes. After the researchers review the audiotapes, they will be destroyed no later than September 1, 2005.

**Risks** I am aware that the only known risks of participating in this study are possible fatigue or tiredness that may happen from answering questions.

**Benefits, Freedom to Withdraw & Ability to Ask Questions** I understand the information I provide will be used in the future to improve the health and nutrition services offered to hospital-discharged older adults. I understand that I am free to ask questions and to withdraw from the study at any time without penalty.

**Contact Information of Investigator(s)** If I have any questions about the study, I am aware that I can contact the Principal Investigators:

Nadine Sahyoun, PhD, RD  
Department of Nutrition and Food Science  
0112 Skinner Hall  
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College Park, MD 20740  
Email: [nsahyoun@umd.edu](mailto:nsahyoun@umd.edu)  
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University of Maryland  
College Park, MD 20740  
Email: [lenagonio@verizon.net](mailto:lenagonio@verizon.net)  
Telephone: (301) 405-0775

**INFORMED CONSENT FORM**

**Contact  
Information of  
Institutional  
Review Board  
(IRB)**

For any questions about my rights as a research subject or reports of research-related injury, I am able to contact the:

Institutional Review Board Office  
University of Maryland  
College Park, MD 20740  
Email: [irb@deans.umd.edu](mailto:irb@deans.umd.edu)  
Telephone: (301) 405-4212

I have read and understand this consent form, and I volunteer to participate in this research study. I understand that I will receive a copy of this form.

Name of Participant (please print): \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix D: Questions and Scripted Probes for Cognitive Interviews

### PART A: GENERAL HEALTH NEEDS ASSESSMENT

**GENHLTH1. How would you describe your state of health before you were hospitalized? Would you say it is:**

- Excellent .....1 (NEXT QUESTION IS GENHLTH2)
- Very good.....2 (NEXT QUESTION IS GENHLTH2)
- Good .....3 (NEXT QUESTION IS GENHLTH2)
- Fair .....4 (NEXT QUESTION IS GENHLTH2)
- Poor .....5 (NEXT QUESTION IS GENHLTH2)
- Don't know .....77 (NEXT QUESTION IS GENHLTH2)
- Refused .....88 (NEXT QUESTION IS GENHLTH2)

**Probe:** What time period did you think of when you answered that question?

**GENHLTH2. How would you describe your overall health?**

**Would you say it is:**

- Excellent .....1 (NEXT QUESTION IS GENHLTH3)
- Very good.....2 (NEXT QUESTION IS GENHLTH3)
- Good .....3 (NEXT QUESTION IS GENHLTH3)
- Fair .....4 (NEXT QUESTION IS GENHLTH3)
  
- Poor .....5 (NEXT QUESTION IS GENHLTH3)
- Don't know .....77 (NEXT QUESTION IS GENHLTH3)
- Refused .....88 (NEXT QUESTION IS GENHLTH3)

**Probe:** What time period did you think of when you answered that question?

**Probe:** Why did you choose [CATEGORY] instead of [Category] or [CATEGORY]?

**GENHLTH3. Please tell me what kind of institution you have just been discharged from. Is it a:**

- Hospital? .....1 (NEXT QUESTION IS GENHLTH4)
- Rehabilitation center? .....2 (NEXT QUESTION IS GENHLTH4)
- Nursing home? .....3 (NEXT QUESTION IS GENHLTH4)
- Don't know .....77 (NEXT QUESTION IS GENHLTH4)
- Refused .....88 (NEXT QUESTION IS GENHLTH4)

**Probe:** What does the word "institution" mean to you?

**Probe:** Would you choose a different word than “institution?”

**GENHLTH4A. What date were you discharged?**

Date of discharge: |\_\_| |\_\_| / |\_\_| |\_\_| / |\_\_| |\_\_|

Gave a date.....1 (NEXT QUESTION IS GENHLTH5)

Don't know.....77 (NEXT QUESTION IS GENHLTH5)

Refused.....88 (NEXT QUESTION IS GENHLTH5)

IF RESPONDENT CANNOT STATE THE DATE, ASK:

**GENHLTH4B. How many days has it been since you were discharged?**

(DISCHDAYS)

Number of days:|\_\_| |\_\_|

Gave a date.....1 (NEXT QUESTION IS GENHLTH5)

Don't know.....77 (NEXT QUESTION IS GENHLTH5)

Refused.....88 (NEXT QUESTION IS GENHLTH5)

What was/were the reason/s for your recent institutionalization? Were you admitted because of (SELECT ALL THAT APPLY):

**GENHLTH5A. A bone related disease?**

No.....1 (NEXT QUESTION IS GENHLTH5B)

Yes.....2 (NEXT QUESTION IS GENHLTH5B)

Don't know.....77(NEXT QUESTION IS GENHLTH5B)

Refused.....88 (NEXT QUESTION IS GENHLTH5B)

**GENHLTH5B. Gastrointestinal problems?**

No.....1 (NEXT QUESTION IS GENHLTH5C)

Yes.....2 (NEXT QUESTION IS GENHLTH5C)

Don't know.....77 (NEXT QUESTION IS GENHLTH5C)

Refused.....88 (NEXT QUESTION IS GENHLTH5C)

**GENHLTH5C. Anemia?**

No.....1 (NEXT QUESTION IS GENHLTH5D)

Yes.....2 (NEXT QUESTION IS GENHLTH5D)

Don't know.....77 (NEXT QUESTION IS GENHLTH5D)

Refused.....88 (NEXT QUESTION IS GENHLTH5D)

**GENHLTH5D. Diabetes?**

No.....1 (NEXT QUESTION IS GENHLTH5E)

Yes.....2 (NEXT QUESTION IS GENHLTH5E)

Don't know.....77 (NEXT QUESTION IS GENHLTH5E)

Refused.....88 (NEXT QUESTION IS GENHLTH5E)

**GENHLTH5E. Respiratory diseases such as emphysema, pneumonia, chronic obstructive disease (COPD) or asthma?**

No.....1 (NEXT QUESTION IS GENHLTH5F)  
Yes.....2 (NEXT QUESTION IS GENHLTH5F)

Don't know.....77 (NEXT QUESTION IS GENHLTH5F)  
Refused.....88 (NEXT QUESTION IS GENHLTH5F)

GENHLTH5F. A fall?

No.....1 (NEXT QUESTION IS GENHLTH5H)

Yes.....2 (NEXT QUESTION IS GENHLTH5G)  
Don't know.....77 (NEXT QUESTION IS GENHLTH5H)  
Refused.....88 (NEXT QUESTION IS GENHLTH5H)

GENHLTH5G. If yes, did your fall result in a broken bone?

No.....1 (NEXT QUESTION IS GENHLTH5H)

Yes.....2 (NEXT QUESTION IS GENHLTH5H)  
Don't know.....77 (NEXT QUESTION IS GENHLTH5H)  
Refused.....88 (NEXT QUESTION IS GENHLTH5H)

GENHLTH5H. Mental health problems? (GH5G)

No.....1 (NEXT QUESTION IS GENHLTH5I)

Yes.....2 (NEXT QUESTION IS GENHLTH5I)  
Don't know.....77 (NEXT QUESTION IS GENHLTH5I)  
Refused.....88 (NEXT QUESTION IS GENHLTH5I)

GENHLTH5I. Diarrhea or other bowel problems?

No.....1 (NEXT QUESTION IS GENHLTH5J)

Yes.....2 (NEXT QUESTION IS GENHLTH5J)  
Don't know.....77 (NEXT QUESTION IS GENHLTH5J)  
Refused.....88 (NEXT QUESTION IS GENHLTH5J)

**GENHLTH5J. High blood cholesterol?**

No.....1 (NEXT QUESTION IS GENHLTH5K)  
Yes.....2 (NEXT QUESTION IS GENHLTH5K)  
Don't know.....77 (NEXT QUESTION IS GENHLTH5K)

Refused.....88 (NEXT QUESTION IS GENHLTH5K)

GENHLTH5K. Hypertension, sometimes called high blood pressure?

No.....1 (NEXT QUESTION IS GENHLTH5J)  
Yes.....2 (NEXT QUESTION IS GENHLTH5J)



Don't know.....77 (NEXT QUESTION IS GENHLTH5J)

Refused.....88 (NEXT QUESTION IS GENHLTH5J)

GENHLTH5L. Heart disease, including coronary heart disease, angina,, heart attack, congestive heart failure or myocardial infarction?

No.....1 (NEXT QUESTION IS GENHLTH5M)

Yes.....2(NEXT QUESTION IS GENHLTH5M)

Don't know.....77 (NEXT QUESTION IS GENHLTH5M)

Refused.....88 (NEXT QUESTION IS GENHLTH5M)

GENHLTH5M. A stroke or cerebrovascular accident?

No.....1 (NEXT QUESTION IS GENHLTH5N)

Yes.....2 (NEXT QUESTION IS GENHLTH5N)

Don't know.....77 (NEXT QUESTION IS GENHLTH5N)

Refused.....88 (NEXT QUESTION IS GENHLTH5N)

GENHLTH5N. Cancer?

No.....1 (NEXT QUESTION IS GENHLTH5O)

Yes.....2 (NEXT QUESTION IS GENHLTH5O)

Don't know.....77 (NEXT QUESTION IS GENHLTH5O)

Refused.....88 (NEXT QUESTION IS GENHLTH5O)

GENHLTH5O. Or something else?

No.....1 (NEXT QUESTION IS GENHLTH6)

Yes.....2 (NEXT QUESTION IS GENHLTH6)

Don't know.....77 (NEXT QUESTION IS GENHLTH6)

Refused.....88 (NEXT QUESTION IS GENHLTH6)

Please specify:\_\_\_\_\_

**Probe: Now I'm going to ask you about some of the terms I used in that list of illnesses and injuries. I want you to tell me in your own words what these terms mean.**

**What is "bone related disease?"**

**What is "anemia?"**

**What would you consider "mental health problems?"**

**Are there any other words I used in that list that were hard to understand?**

**Thank you. Your answers are very helpful to me. Now I'm going to return to the questionnaire.**

## Appendix E

### Summary of Components of the Initial Needs Assessment Questionnaire

#### Personal Communication from Uche Akobundu

Use of Food Assistance Programs - we created these questions in-house and adapted reasons for non-participation from the Martin et al., 2003 article (see attached - *also, do hang on to this article FYI, I am going to provide it for additional reading as we move into the Hunger/Food Insecurity part of the NFSC470 course. It might be useful to you as you continue work on the Poverty Budget assignment*).

Service Awareness and Needs Assessment - we included specific services from those typically offered at Elderly Nutrition Programs (see attached Annual Report) in this section. Other services were included based on the recommendation of the project assessors and other collaborators.

General Health - Questions in this section were mostly adapted from the DETERMINE Checklist, input from our collaborators and knowledge of health impairments typical among the older adult population.

In addition, questions in the social support section relating to anticipated help from neighbors were adapted from the following:  
Martin, K., Rogers, B., Cook, J., & Joseph, H., 2004. Social capital is associated with decreased risk of hunger. *Social Science & Medicine*, 58(12):2645-55 (see attached).

## Appendix F: Sample Recruiting Poster for Cognitive Interviews



**MEALSONWHEELS**®  
association of america  
"So No Senior Goes Hungry"

# Volunteers Needed for a Research Study

- WHO:** Men and women 60 years old and older
- WHAT:** Help us test a questionnaire about health and nutrition in seniors
- WHEN:** February 1 – February 15
- WHERE:** Right in your own home
- WHY:** We are testing whether seniors who receive health and social support services in addition to Meals on Wheels get better faster and function better. We need to know if our questionnaire collects the correct information.

**To volunteer: Call Uche Akobundu or Liz Enagonio at 301-405-0775 or email [lenagonio@verizon.net](mailto:lenagonio@verizon.net)**

**Token of appreciation offered!**

Research conducted by Meals on Wheels Association of America and the University of Maryland.

## Appendix G: Depression Status Assessment Questions

### SECTION PREFACE

These next questions are to find out about your outlook on life in general. I am going to ask you these questions because I am interested in how things are going for you. I'll ask all the questions before I ask your opinion about them, but feel free to make comments at any time. Please answer these questions with "Yes" or "No". Remember, all your answers will remain confidential. Are you ready to begin?

### DEPASSMT1. Are you basically satisfied with your life?

No.....1 (NEXT QUESTION IS DEPASSMT2)  
Yes.....2 (NEXT QUESTION IS DEPASSMT2)  
Don't know....77 (NEXT QUESTION IS DEPASSMT2)  
Refused .....88 (NEXT QUESTION IS DEPASSMT2)

### DEPASSMT2. Do you often get bored?

No.....1 (NEXT QUESTION IS DEPASSMT3)  
Yes.....2 (NEXT QUESTION IS DEPASSMT3)  
Don't know....77 (NEXT QUESTION IS DEPASSMT3)  
Refused .....88 (NEXT QUESTION IS DEPASSMT3)

### DEPASSMT3. Do you often feel helpless?

No.....1 (NEXT QUESTION IS DEPASSMT4)  
Yes.....2 (NEXT QUESTION IS DEPASSMT4)  
Don't know....77 (NEXT QUESTION IS DEPASSMT4)  
Refused .....88 (NEXT QUESTION IS DEPASSMT4)

### DEPASSMT4. Do you prefer to stay at home rather than going out and doing new things?

No.....1 (NEXT QUESTION IS DEPASSMT5)  
Yes.....2 (NEXT QUESTION IS DEPASSMT5)  
Don't know....77 (NEXT QUESTION IS DEPASSMT5)  
Refused .....88 (NEXT QUESTION IS DEPASSMT5)

### DEPASSMT5. Do you feel pretty worthless the way you are now?

No.....1 (NEXT QUESTION IS DEPASSMT6)  
Yes.....2 (NEXT QUESTION IS DEPASSMT6)  
Don't know....77 (NEXT QUESTION IS DEPASSMT6)  
Refused.....88 (NEXT QUESTION IS DEPASSMT6)

### DEPASSMT6. In general, how would you describe your emotional well-being (INTERVIEWER: READ OUT RESPONSE OPTIONS TO RESPONDENT)?

Excellent.....1 (SECTION- PHYSICAL FUNCTION)  
Good .....2 (SECTION- PHYSICAL FUNCTION)  
Fair.....3 (SECTION- PHYSICAL FUNCTION)  
Poor.....4 (SECTION- PHYSICAL FUNCTION)  
Don't know....77 (SECTION- PHYSICAL FUNCTION)  
Refused .....88 (SECTION- PHYSICAL FUNCTION)

## Appendix H: Scripted Probes for Depression Status Assessment

### **Probes (retrospective):**

Do you feel offended by terms like “worthless” and “helpless?”

Would you prefer that I use different words?

When I asked if you were basically satisfied with your life, you answered [CATEGORY].

1) Can you tell me more about why you chose category?

2) What did you think I meant by “basically satisfied?”

3) (If [YES] to bored): Why do you say you’re bored?

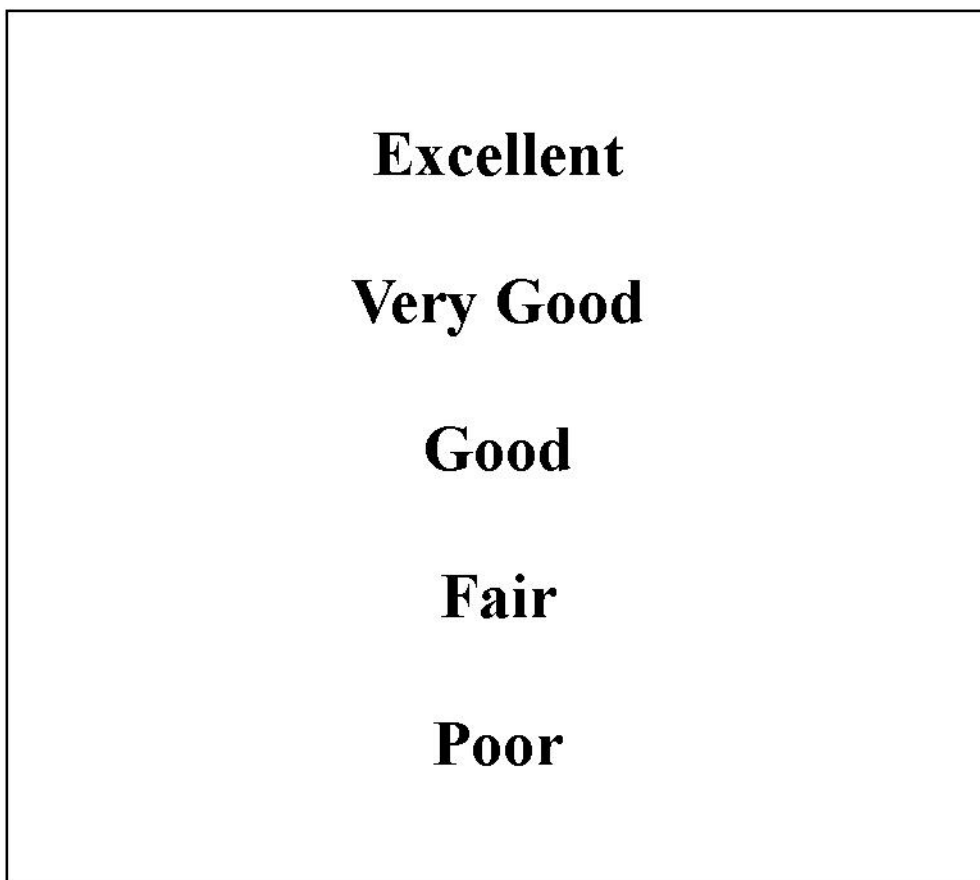
4) What did you think I meant when I asked if you felt “helpless?”

5) What did you think I meant when I asked if you felt “worthless?”

6) (If [YES] to prefer to stay home): Tell me why you prefer to stay home. What did you think I meant by “doing new things?” Do you like to go out if you can do familiar things? Think aloud about this question for me.

7) What did you think I meant by “emotional well-being?” Why did you choose [CATEGORY] instead of any other category?

## Appendix I: Example Hand Card



Hand card for General Health Questions

## Appendix J: Revised Hardiness Instrument

1 = definitely false	2 = false most of the time	3 = true about half the time, false about half the time	4 = true most of the time	5 = definitely true
1. (CO +)	_____	The successes I've had in life are due to my effort and ability.		
2. (CO -)	_____	Things don't turn out right no matter how hard I try.		
3. (CM +)	_____	I enjoy most things in life.		
4. (CM -)	_____	Most days, life seems meaningless to me.		
5. (CH +)	_____	When I have a problem in my life, I face up to it.		
6. (CH -)	_____	It bothers me when my daily routine gets interrupted.		
7. (CO+)	_____	I feel confident I can handle just about any problem.		
8. (CO-)	_____	I often feel helpless.		
9. (CM+)	_____	I spend most of my time doing things that are worthwhile.		
10. (CM-)	_____	I often feel alienated, or emotionally disconnected, from the people around me.		
11. (CH+)	_____	When bad things happen, I see them as a chance to become a stronger person.		
12. (CH-)	_____	I don't like to make changes in my everyday routine.		
13. (CO+)	_____	When I succeed, it's because I made good choices.		
14. (CO-)	_____	The tried and true ways are always best.		
15. (CM+)	_____	Most days, my life is really interesting.		
16. (CM-)	_____	I usually feel all alone in the world.		
17. (CH+)	_____	I often wake up eager to get on with my life.		
18. (CH-)	_____	I carefully plan just about everything I do.		

## Appendix K

### CI Probes for Revised Hardiness Questionnaire June, 2005

1. The successes I've had in life are due to my effort and ability.  
Probe: What do you mean by "successes?"

Probe: What efforts or abilities did you think of when you answered the question?

NOTES:

2. Things don't turn out right no matter how hard I try.  
Probe: What is this question asking?

Probe: Would it be easier if I asked, "No matter how hard I try, things don't turn out right."?

NOTES:

3. I enjoy most things in life.



4. Most days, life seems meaningless to me.

5. When I have a problem in my life, I face up to it.

Probe: What does “face up to it” mean to you?

NOTES:

6. It bothers me when my daily routine gets interrupted.

Probe: What kind of interruptions were you thinking of?

Probe: When you hear the word “bother” in that question, what does that mean to you?

NOTES:

7. I feel confident I can handle just about any problem.

Probe: What kind of problems do you think this question is asking about?

NOTES:

8. I often feel helpless.

How do you feel when I ask you that question?

NOTES:

9. I spend most of my time doing things that are worthwhile.

10. I often feel alienated, or emotionally disconnected, from the people around me.

Probe: What does alienated mean to you?

Probe: Is it the same thing as emotionally disconnected?

Probe: Is there a better word you would like me to use?

NOTES:

11. When bad things happen, I see them as a chance to become a stronger person.

Probe: What does “become a stronger person” mean to you?

Probe: How *do* you react when bad things happen?

NOTES:

12. I don't like to make changes in my everyday routine.

13. When I succeed, it's because I made good choices.

Probe: What successes were you thinking of when you answered this question?

NOTES:

14. The tried and true ways are always best.

15. Most days, my life is really interesting.

16. I usually feel all alone in the world.

Probe: What does "all alone in the world" mean to you?

NOTES:

17. I often wake up eager to get on with my life.

18. I carefully plan just about everything I do.

**Do you have any comments or suggestions for me about ways to make this questionnaire easier for people like you to understand or answer?**

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