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Medical Expenditure Panel Survey Cognitive Interview Guide (Summary of Cognitive Testing Process) 4/15/2011

Once the draft survey instrument has been finalized, it will be submitted to 2 rounds of cognitive testing with 24 English-speaking respondents in the first round and 20 English-speaking and 16 Spanish-speaking respondents in the second round. Cognitive testing consists of one-on-one interviews with respondents whose key characteristics match those of the survey population (in this case, adults age 18 and over who are currently in treatment for cancer or those who have been diagnosed and treated with cancer in the past). After describing the purpose of the study and informing the cognitive interview respondent of his/her rights as a research participant, the interviewer will administer the **Your Experiences with Cancer** survey along with a series of follow-up questions designed to understand respondent's thought processes related to the following:

- Comprehension do respondents understand the question as the survey designers intended?
- Recall can the requested information be recalled and what strategies for recall are respondents using?
- Judgment and estimation processes to what extent is the respondent motivated to take the time to accurately answer the question?
- Response processes do the pre-coded answers to closed end questions map accurately to the respondents' actual answers?
 Should the question be a closed ended or open ended item?
- Navigation are the instructions for navigating through the survey clear and easy to follow?

The information obtained from the follow-up questions about respondents' thought processes as they're answering the **Your Experiences of Cancer** survey will be used to identify and refine the following:

- Instructions that are insufficient, overlooked, misinterpreted, or difficult to understand
- Item wordings that are misunderstood or understood differently by different respondents
- Vague definitions or ambiguous instructions that may be interpreted differently

- Items that ask for information to which the respondent does not have access
- Confusing response option or response formats.

Specific terms and issues that will be tested for the **Your Experiences of Cancer** survey will also include:

- Respondent's interpretation of "lasting effects" of cancer.
- Cognitive issues respondents have experienced as a result of cancer and how best to ask about those issues.
- Respondent's ability to recall and answer questions about the impact of a cancer diagnosis and treatment that occurred many years or even decades previously.
- How respondents with multiple cancer occurrences respond to survey questions about the impact of cancer on specific areas of their lives.

The cognitive testing protocol will use a combination of general and specific probes to explore these issues. Some examples of such probes include:

- Comprehension
 - O What do you think this question is asking?
 - O What do you think "phrase" means?
 - O What do you think "phrase" includes or excludes?
 - O Tell me more about your answer.
- Recall
 - O How did you come up with your answer?
- Judgment/estimation
 - O How did you decide on your answer?
 - O How confident are you in your answer?
- Response process
 - O How did you decide on that response?
 - O How easy or hard is it to answer that question? Tell me about that.
 - O What, if anything should be added/dropped from this list of answer choices?
- Specific issues
 - O Tell me in your own words what "lasting effects of cancer" means to you? What does it include? What does it exclude? What time period does it cover?

- O What kinds of differences have you noticed in the way you perform mental task since your cancer diagnosis and treatment?
- O How easy or difficult was it for you to remember what happened with your cancer and its treatment that many years ago? Tell me what made it easy/difficult.

• FOR THOSE WITH MULTIPLE CANCER OCCURENCES

- 0 Which cancer occurrence are you thinking of as you answer this question?
- O How did you decide which one to think of as you answered this question?