

YEAR 15/16/17 QUARTERLY TELEPHONE INTERVIEWS

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1. Overview of measurements

All Health ABC participants, or their proxy informants, will be interviewed by phone every 3 months, beginning with their Year 15 interview. The telephone interview combines questions that have been used throughout the history of Health ABC (core questions) with new questions resulting from the specific aims of the End of Life in Very Old Age (EOL) ancillary study. The new telephone interview will vary from quarter to quarter, with some pages administered every quarter and others only one or two quarters. The Decedent Proxy Interview with the participant's next of kin will also continue, and is augmented with additional questions for the EOL study.

Overview of measures for the quarterly telephone contact:

- General health status
- Medical status
- Activities of daily living
- Symptoms
- Cognitive function
- Controlled Oral Word Association Test (COWAT) in Quarters 1 and 3, except for Year 17 (see Controlled Oral Word Association Test operations manual chapter)
- Telephone Interview for Cognitive Status (TICS) in Quarters 2 (except for Year 17) and 4 (See TICS operations manual chapter)
- Appetite and weight change
- Fatigue
- Informed care
- Decision making
- Well-being
- Depression screen

In addition, questions about the following will be asked twice a year, during the Quarter 1 and Quarter 3 interviews:

- Physical function (walking a quarter mile, climbing steps, lifting 10/20 lbs, heavy work, exercise)
- Volunteer and care-giving activities
- New medical conditions
- Hospitalizations
- Marital status, household occupancy and social network

Questions about decision-making preferences will be asked once a year, during the Quarter 2 interview.

See Interviewing Guidelines chapter for interview guidelines.

2. Specific aims of the ancillary study

The specific aims of the ancillary study are to better understand clinical trajectories and patient/family decision making among persons who have reached advanced old age (85 yr +). It is statistically projected that half of the remaining Health ABC participants will die during the 3-year observation window for this ancillary study. However, we are interested in the health and determinants of levels of care in all of the very old.

The study has been explained to participants as follows:

"Health ABC has received funding from National Institutes of Health to look at how people make decisions about their plans for medical care and who is involved in the decision making process. Health ABC investigators have developed some new questions that we would like to ask you, along with some of the same questions from past years."

Descriptive studies are always challenged to capture data about "what is" without changing it. Although we have been open with participants about our interest in studying decision making, we want to avoid the situation where participation in our study causes the participants to think differently about situations in which they previously saw no "choice" involved. In general, healthcare has become more interactive. Today, patients are usually expected to share decision-making responsibility with their health care providers. But we don't know to what degree that shift in attitude has occurred among the very old. Those who are now 85+ years old grew up in a time when medical advice was followed without question. If Health ABC participants continue to view healthcare in that way, we want to record it without changing things. In other words, if a participant sees a medical option as "doctors orders" even if the physician might believe it to be a suggestion, we don't want our interview questions to create a "decision-making event" where one did not previously exist from the participant's perspective. We will address this topic more specifically in association with particular questions being added to the interview.

The data collection for our ancillary study has been thoroughly integrated with the Health ABC core interview. Participants may not need to distinguish the source of the new questions and more frequent calls, but instead view the new format as the latest iteration of Health ABC. As long as there is no need on the part of participants to draw a distinction, do not introduce one. If a participant does question the new items, please refer to the ancillary study as the "decision-making study." But please restrict use of that designation to those situations where the participant asks for the clarity. This will help to reduce an unintended "intervention effect."

Within the research team, the ancillary study has been nicknamed the "EOL Study." Our grant title is "End of Life in the Very Old." Reviewers were enthusiastic about its potential contribution to understanding how persons navigate late old age when death is likely but not necessarily predicted. We were funded as part of the portfolio of research on end of life supported by the National Institute of Nursing Research. Yet, while we understand that many of the Health ABC participants are quite comfortable talking about end-of-life issues, we do not want to place undue focus on death. Let the participants take the lead on that topic. Before you begin interviewing, spend some time examining your own thoughts about dying so that if participants bring up the topic, you can be comfortable hearing what they want to say. On the other hand, if participants

choose to ignore the possibility of death, even when it is clearly right around the corner, let them have the space they need.

3. Working with older participants

The Health ABC participants have shown their dedication to the study through their participation over the last fifteen years. They are very valued volunteers who deserve to interact with study staff who are always at their best. These are people who are willing, for very little in return, to contribute their time, energy, and honesty about their situations in the hope of making a difference. We need to do everything we can to continue to make their time with us an enjoyable experience. Time spent in making their interaction as pleasant as possible is time well spent, but must be carefully balanced with the awareness that lengthening the time of the telephone interview may cause participant fatigue and a loss of data.

Dealing successfully with older research participants also requires that we be sensitive to their potential needs and concerns. These needs may be related to hearing difficulties, challenges associated with attending to questions for the length of the phone interview, as well as competing personal difficulties (e.g., depression, an ill spouse, etc.).

We must also be aware that the information we collect as research data may identify a new medical problem that may need to be brought to the attention of a participant's primary care physician for follow-up. We, as a study staff, do not provide diagnosis or treatment. However, when participant consent has been obtained, we may need to notify appropriate parties (i.e., physicians, participants themselves, proxies, etc.) of a new abnormal finding. This should be accomplished by the clinic coordinator(s) after discussing the finding with the medical director/investigator.

4. Preparation for interview

4.1 Before interview

The interviewer should:

- Review the operations manual and training materials.
- Go through the interview carefully.
- Organize all the necessary materials, including pens, extra paper, a clipboard, etc.
- Be certain the interview room is neat and organized.
- Review the information available on the participant and information needed for the interview (e.g., time of appointment, name of participant, etc.)

4.2 At time of interview

At the time of the interview, the following should be available for each participant:

- A Data from Prior Visits Report should be generated with information that will be needed for the interview (see Appendix 1)
- The participant's contact information (address, phone number, proxy, next of kin, power of attorney, etc.)
- A Telephone Interview preprinted with the acrostic and Health ABC enrollment ID number. It is important to double-check the accuracy of the pre-printed acrostic at the top of the first page of the Telephone Interview as compared with the participant's name. After you print the participant's name on the first page of the Telephone Interview Workbook, look at the first letter of the first name and the first three letters of the last name to make sure that these match the pre-printed acrostic at the top of the page.
- The participant's chart. Field centers should also keep "progress notes" in the participant's chart. Progress notes may be used to record examiner comments and questions, and to document protocol problems and their resolution. Each entry should be dated and signed by the examiner recording the note.

5. Quarterly participant interview

Starred (★) items on data collection forms

As always, the goal is still to administer the complete Telephone Interview to all Health ABC participants. However, in the event that some participants may not be willing to complete the entire interview, we have identified those questions that are most important to administer. These priority questions are identified by a star (★) next to the question. If the participant is unwilling to complete the entire telephone interview, complete the starred questions first. Once the starred questions have been completed, continue to complete the other non-starred questions, if the participant is willing. Please mark "Refused" on all questions that the participant is NOT willing to complete.

5.1 Quarterly participant interview – specific question instructions

Pages 2 through 3

- These questions will be asked at each quarterly interview, so the time frame is "Since we last spoke to you about [3] months ago." Note that the first time these questions are asked, i.e., at the Year 16 Quarter 1 interview, the number of months since the last interview will be more than 3 months. See Data from Prior Visits Report to see how many months have passed since the last interview.
- Q 4: "Is there anything about your health that causes you concern?"

- If the participants says "No," don't probe based on the responses to the previous questions.
- If the participant names a concern, write it down exactly as they articulate it. Print succinctly and in small letters. Then choose a coding category from the list provided. Do NOT read the category list to the participants. However, if the participant names something that you think may be a diagnostic test, you could ask for clarification, e.g., "is this a test that your doctor has ordered?"

Pages 4 through 5

- These questions will be asked every 6 months, during the Quarter 1 and Quarter 3 interviews.
- Use the traditional Health ABC skip patterns and read responses as appropriate.

Pages 6 through 7

- These ADL questions will be asked every quarter.
- These are important data elements, so please take the time needed to collect complete data.

Page 8

- This physical activity and exercise question will be asked every six months, during the Quarter 1 and Quarter 3 interviews.
- Note that this question is not starred. If the participant is having difficulty with the phone interview, consider skipping this question, particularly if the previous questions about physical function and ADLs suggest a low level of function.

Pages 9 through 11

- These physical activity and exercise questions will be asked once a year, during the Quarter 1 interview.
- Note that these questions are not starred. If the participant is having difficulty with the phone interview, consider skipping these questions, particularly if the previous questions about physical function and ADLs suggest a low level of function.

Page 12

- These symptom questions come from the condensed version of the Memorial Symptom Assessment Scale. They are designed to illicit the frequency of common symptoms and the extent to which they are troublesome to the participant.
- These questions will be asked every quarter.
- To assure consistency, please reread the response options for frequency and distress without attempting to define the anchor points for the participant.

Pages 13 through 15

- This "Telephone Interview for Cognitive Status" or TICS will be used twice each year, in Quarters 2 (except for Year 17) and 4.
- Specific instructions for administering the TICS are in the Telephone Interview for Cognitive Status operations manual.

Page 16

- The "Controlled Oral Word Association Test" is an alternative measure of cognitive status, and is being used in the alternate quarters (Quarters 1 and 3, except for Year 17).
- Specific instructions regarding administrating the Controlled Oral Word Association Test are in the Controlled Oral Word Association Test operations manual.

Page 17: Work and care-giving questions will be asked during Quarter 1 and Quarter 3 interviews.

Page 18

- Appetite and weight change questions will be asked every quarter.
- These are key questions for both Health ABC core and the EOL ancillary studies.

Pages 19 through 24

- The core Health ABC questions about medical conditions have been supplemented by two new questions: one about kidney failure and one about whether any condition has been described as one that may "limit life."
- These questions will be asked during the Quarter 1 and Quarter 3 interviews. Thus the time frame provided to the participants is "In the past 6 months." Note that the first time these questions are asked, i.e., at the Year 16 Quarter 1 interview, the number of months since the last interview will be more than 6 months. See Data from Prior Visits Report to see how many months have passed since the last interview.

Page 25: Questions about fatigue will be asked every quarter.

Pages 26 through 27: Informed Care questions will be asked every quarter.

- The intent of this new section, titled "Informed Care," is to ascertain the degree to which participants perceive that they are receiving the desired amount of information about their condition and care, and to learn if they have had an opportunity to ask questions and express opinions.
- The most recent encounter with a provider (physician or nurse practitioner) is used as the prototype, no matter when that encounter occurred. This would not include an appointment for lab tests, x-rays, etc.
- If someone accompanied the participant, and the participant says that their companion asked questions or expressed opinions, please re-ask the question "Did **you** feel as though you could have asked questions/expressed concerns if you wanted to?" If participant reports more than one visit with different companions or one visit with multiple companions, simply record information about one companion.

Page 28

- The aim of Question #72 in the new section "Decision Making" is to illicit whether the participant perceives that they made a decision or choice about a health matter since the last contact (approximately 3 months). If the participant says "No," don't probe, regardless of how much evidence you have that they have had hospitalizations, tests, procedures, etc. The issue is the perception of choice. Do not prompt for decisions.

- If the participant indicates a positive response, record what they say exactly as it is said. Then code the type of decision using the categorical choices. DON'T read the list of categories. But you may seek clarification by asking a question such as "Was X a type of diagnostic test?"
- Questions on this page will be asked every quarter.

Pages 29 through 30

- This new section on "Preferences" regarding health care will be asked only once a year, during the Quarter 2 interview.
- Question #73 is a variation on the Degner Decision Scale. It seeks to learn the degree to which participants simply follow medical advice without questioning it, or whether participants perceive themselves as active participants or directors of their own health care.
- With respect to Questions #74 through #81, if the participant does not give a "Yes" or "No" answer, but instead provides limitations on the occasions where they would elect the treatment in question, record the response as "Not sure."
- With respect to Questions #84 through #85, you may expand upon the definitions provided if the participant questions what is meant by a given term. The following guidelines apply:
 - To record a "Yes" response to the questions about a power of attorney for health care or a living will, a signed legal document must exist.
 - If a participant indicates some doubt, use "Don't know" as the response.
 - If a participant explains that he or she has a durable power of attorney that includes a living will, or language that expressly states what types of treatment he or she would wish to have, you may enter a positive response for question #85. Question #84 is intended to capture whether they have an appointed surrogate decision maker and question #85 captures whether they have written instructions about the types of care they would or would not want.

Page 31

- These questions will be asked once a year, at the first quarter.
- Questions #87 and #88 are about health insurance. Research shows that resources such as insurance and access to medical care can affect health in ways that are sometimes important and surprising.

Page 32

- These questions will be asked every quarter.
- Question #89 is a global quality of life question. If the participant does not understand the question as read, you may paraphrase it "Would you say that, in general, your life (not your health) is good, very good, excellent, fair or poor?"

Page 33

- These questions are from the Brief Resilience Scale-14 (Wagnild & Heather 1997) and seek to learn if participants have retained a sense of mastery over life. The degree of agreement with the five statements is asked in a two-step process. First, a Yes/No response seeks the direction of the response. If the participant immediately provides a

- response that contains a degree of agreement or disagreement, record "Yes" or "No" as appropriate and validate the response by asking the second question as it is written.
- These questions will be asked every 6 months, during the Quarter 2 and Quarter 4 interviews.

Page 34

- These questions are an adaptation of the Depression Screen (PHQ-2).
- They will be asked every quarter.

Page 35

- Marital status and household occupancy questions will be asked during Quarter 1.

Pages 36 through 40

- The remaining questions (social network, and current contact information) are from previous versions of Health ABC telephone interviews.
- They will be asked twice a year, during the Quarter 1 and Quarter 3 interviews.

Page 41

- The purpose of the questions on this page is to discover whether or not the participant has a hearing problem that would have interfered with the cognitive tests and whether or not the participant's responses to the questions in the entire questionnaire were reliable.

5.2 Concluding the interview

When you've gone through the entire interview, you need to bring the phone call to closure. Some important things to remember are:

- Thank the participant. Don't forget to do this.
- Tell them that you will be contacting them again in 3 months (give the month).

Suggested script: "Thank you very much for answering these questions. I enjoyed talking with you. Please remember to call us if you are admitted to a hospital or nursing home for any reason so that we can better understand changes in your health. We would also like to hear from you if you move or if your mailing address changes. We will be calling you in a few months from now to find out how you've been doing."

- Review the interview form and any other comments or observations for completeness. You may need to clarify an answer while the participant is still on the telephone.
- Don't be in a hurry to hang up. Allow for a few minutes of winding down conversation. But have a way to politely cut off the conversation if the participant wants to keep on talking long after the interview is over.
- Immediately after the phone call, write down any notes about how the interview went.

**Appendix 1 Data from Prior Visits
Report**

**Health ABC
Year 16Q1 Data from Prior Visits Report**

Participant Name: Health ABC Enrollment ID#: Acrostic:
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I. YEAR 15Q4 INTERVIEW

- 1) Status of Year 15Q4 participant or proxy interview:
 - Participant completed
 - Proxy completed
 - Missed interview
- 1a) If missed Year 15Q4 interview, reason for missed interview:
- 2) Reliability of Year 15Q4 participant or proxy interview:
 - Participant reliability
 - Proxy reliability

II. LAST REGULARLY SCHEDULED CONTACT

- 3) Last regularly scheduled contact:
- 4) Date of last interview (either participant or proxy):
- 5) Number of months since last interview (either participant or proxy):

III. QUESTIONS ABOUT MEDICAL CONDITIONS

- 6) Date questions regarding medical conditions were asked:
- 7) The "visit" questions regarding medical conditions were last asked:

IV. PROXY INTERVIEW

- 8) Has the participant ever had a proxy interview?
- 8a) For which contact(s)?

V. EVENTS REPORTED

The following Event Forms have been entered to date for this participant:

Event Form Reference #	Type of Event	Date Reported	Date of Event
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VI. DATE OF DEATH