

Attachment 1 – ACHCN Respondent Screening Script and questions to be cognitively tested

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Sample screening script for respondent contact by QDRL Recruiter/QDRL Staff for Adults with Chronic Health Care Needs questions recruited through newspaper advertisement/flyer

Dial respondent’s telephone number [hereafter referred to as R] as indicated on audiotape recording.

Note: Speak only to R. If the number is answered by an answering machine, call back at another time.

QDRL Recruiter/QDRL Staff: Good morning/afternoon, may I speak to (name)?

If R is not available or not at home, say, “Thank you” and try again at another time.

If the person who answered the phone (NOT R) asks, “Who is calling?” or “What’s this about?” say, “I am returning their call to me. I’ll try to reach them at another time.

If R has been successfully contacted, continue...

...Hello, my name is [QDRL Recruiter’s/QDRL Staff’s name]. I am calling from the National Center for Health Statistics. You may remember that you responded to an advertisement indicating that you were interested in answering some health-related and quality of life questions.

Wait for acknowledgment, such as, “Oh, yes, I remember.”

...In order to determine if you are eligible for our study, I’ll need a few minutes of your time to ask some background questions. Answering these questions is completely voluntary. We are required by law to use your information for statistical research only and to keep it confidential. The law prohibits us from giving anyone any information that may identify you without your consent. Is this a good time to ask the questions or should I call back later?

If not a good time to talk, schedule a time to call back.

If good time to talk, continue...

1. Where did you see our advertisement?

2. How old are you? [If under age 18 or over age 65, go to exit script 1]

3. Do you have any difficulty seeing even when wearing glasses?
Yes
If yes, please explain _____
No

4. Do you have any difficulty hearing?
Yes
If yes, please explain _____
No

5. Do you have any difficulty concentrating, remembering or making decisions?
Yes
If yes, please explain _____
No

6. Do you have any difficulty walking or climbing stairs?
Yes
If yes, please explain _____
No

7. Do you have any difficulty dressing or bathing?
Yes
If yes, please explain _____
No

8. Do you have any difficulty doing errands alone such as visiting a doctor's office or shopping?
Yes
If yes, please explain _____
No

9. Do you have any ongoing health or mental health conditions such as asthma, diabetes, anxiety or depression?
Yes
If yes, please list all ongoing health or mental health conditions

No

10. Do you regularly see any health care or mental health provider(s) for an ongoing physical or mental condition?
Yes
If yes, please describe the health care providers you regularly see

No

11. Over the past year, did you have any needs for medical or mental health care that were not met?
Yes
If yes, please explain _____
No

[If individual has not met any of the eligibility requirements go to exit script 2].

12. How many years of education do you have?
9 or less 10 11 12 13 14 15 16 17 18 19

13. Are you Spanish, Hispanic or Latino?
Yes
No

14. What race or races do you consider yourself to be? You may indicate more than one race.

White

Black or African American

Asian

American Indian or Alaska Native

Native Hawaiian or Other Pacific Islander

[If the recruitment needs for certain demographic groups have been achieved, go to exit script 3].

Entry Script:

...Based on your answers to the questions so far, we would like you to take part in our study. For this study we'd like you to come here to the National Center for Health Statistics in Hyattsville, MD/agreed mutual location. An interviewer will ask you questions about your physical, mental, and emotional health as well as quality of life. Then the interviewer will ask you to explain what you were thinking as you answered the questions. The interviewer will also ask you about your opinions of the questions. Your answers will help us find out if the survey questions will be easy for other people to answer. Everything you say will be kept private. With your permission, we would like to record your interview. The recording is a record of what we asked and what you said about the questions. Do you give permission to have your interview video recorded? *Yes/No*. **[If no, ask if for permission to audio record]**. Do you give permission to have your interview audio recorded? *Yes/No*. **[If no, go to exit script 4. At a minimum audio recording is essential for this project].**

Do you have any questions at this point? *Pause to answer questions*. If (not/you have no other questions), then let's get you on the schedule, ok? We will be interviewing (Day, Month/Date) through (Day, Month/Date) from 8 a.m. to 6 p.m. Looking at your schedule, when would you be available to participate? *Schedule*. **[If date/times not available go to exit script 5.]**

A reminder call will be made to you a few days in advance. Should you have any questions or need to change your appointment, please feel free to contact me [name] at [phone number]. Thank you for responding to our ad, and I look forward to seeing you here at (DATE/TIME) *Get respondent to cite date & time if possible*.

Exit script 1: I'm sorry, you have to be between the ages of 18 and 65 to take part in this study and therefore we won't be able to use you at this time. However, I would like to put your name and telephone number you gave me into our database so that I can contact you about other studies coming up in the future. Is that OK? *If yes, record name & telephone number. If no: OK, thank you for your time. Your name and telephone number will not be added to our database.*

Exit script2: I'm sorry, you have not met one of the eligibility requirements for this particular study. However, I would like to put your name and the information you gave me into our database so that I can contact you about other studies coming up in the future. Is that ok? *If yes, record name & number. If no: OK, thank you for your time.*

Exit script 3: Based upon your answers, it seems that we may already have a number of volunteers with very similar answers to yours. At this point we need to talk with people with some different characteristics. However, if we have cancellations or other slots open up, I may wish to call you back. Would it be okay if I kept your name, telephone number, and the information you provided in response to the eligibility questions until the end of this study? *If yes, make notation. If no,* Would it be okay if I added your name, telephone number, age, educational level, and race to our database so that I can contact you about other studies coming up in the future? *If yes, add to database. If no: OK, thank you for your time. Your name and any information you gave me will not be added to our database.*

Exit script 4: I'm sorry, willingness to be audio recorded is required in order to take part in this study and therefore we won't be able to use you at this time. Would it be okay if I added your name, telephone number, age, educational level, and race to our database so that I can contact you about other studies coming up in the future? *If yes, add to database. If no: OK, thank you for your time. Your name and any information you gave me will not be added to our database.*

Exit script 5: I see...ok, we were hoping to complete this particular study between (Month/Date) and (Month/Date), so it looks like we won't be able to schedule you at this time. Would it be okay if I added your name, telephone number, age, educational level, and race to our database so that I can contact you about other studies coming up in the future? *If yes, add to database. If no: OK, thank you for your time. Your name and any information you gave me will not be added to our database.*

ACHCN Questions to be cognitively tested

Introduction to cognitive interview

Lauren may have told you that we will be working on some questions that will eventually be added to national surveys. Before that happens, we like to test them out on a variety of different people. The questions we are testing today are about your physical, mental, and emotional health and quality of life. We are interested in your answers, but also in how you go about making them. I may also ask you questions about the questions—whether they make sense, what you think about when you hear certain words, and so on.

I will read each question to you, and I'd like you to answer as best you can. Please try to tell me what you are thinking as you figure out how to answer. Also, please tell me if:

*there are words you don't understand,
the question doesn't make sense to you,
you could interpret it more than one way,
it seems out of order,
or if the answer you are looking for is not provided.*

The more you can tell us, the more useful it will be to us as we try to develop better questions. Okay? Do you have any questions before we start? If yes, answer questions. If not, let's get started.

“The next questions are about any kind of health problems or conditions that may affect your well-being, daily activities or health on a regular basis. These conditions may affect the kind or amount of medical care, mental health or other health services you need or use.

Domain one: Medical care

Do you need or use medical care, mental health, or other health services on a regular basis? (Y/N)

A) Is this because of ANY medical, mental health or other health condition? (Y/N)

B) Is this a condition that has lasted or is expected to last for at least 12 months? (Y/N)

Alternatives to be tested:

1) Do you need or use medical care or other health services more than people your age? (Y/N)

2) Other than your annual check-up, do you need or use medical care or other health services on a regular basis? (Y/N)

Domain two: Mental health

Do you need or get treatment or counseling for any kind of mental health, substance abuse, or emotional problem? (Y/N)

A) Has this problem lasted or is it expected to last for at least 12 months? (Y/N)

Alternatives to be tested:

- 1) Do you need or use mental health treatment or support such as prescription medications or counseling services on a regular basis? (Y/N)
- 2) Do you need or use mental health treatment or support such as prescription medications, counseling, or substance abuse services on a regular basis? (Y/N)

Domain three: Prescription medications

Do you currently need or take prescription medicine (other than vitamins or birth control pills)? (Y/N)

A) Is this because of ANY medical, mental health or other health condition? (Y/N)

B) Is this a condition that has lasted or is expected to last for at least 12 months? (Y/N)

Alternatives to be tested:

- 1) Because of a physical, medical, or mental health condition that has a significant effect on your health, do you regularly need or use prescription medications? (Y/N) Follow-up question: 1A) How many prescription medications do you use for these conditions?" (Numeric response)
- 2) Because of a physical, medical, or mental health condition that has a significant effect on your health, do you regularly need or use prescription medications, supplements or over-the-counter medications? (Y/N) Follow-up question: 1A) How many medications do you use for these conditions?" (Numeric response)

Domain four: Therapies

Do you need or get special therapy? (For example: physical, occupational, speech or respiratory therapy) (Y/N)

A) Is this because of ANY medical, mental health or other health condition? (Y/N)

B) Is this a condition that has lasted or is expected to last for at least 12 months? (Y/N)

Alternatives to be tested:

- 1) Do you need or use rehabilitative, medical, or complementary/alternative therapies on a regular basis? (Y/N)

- 2) Do you need or use medical or other therapies such as dialysis, physical therapy, or acupuncture on a periodic or regular basis? (Y/N)

Domain five: Durable medical equipment / assistive technology

New questions to be tested:

- 1) Do you have an ongoing need for or use of medical equipment or assistive devices such as walking aids, communication devices, or breathing aids? (Y/N)
- 2) Do you have an ongoing need for or use of medical equipment or assistive devices such as prostheses, mobility aids, or medication pumps? (Y/N)

Domain six: Disability

Do you have difficulty doing or need assistance to do day-to-day activities? (For example: work, go to school, do housework, socialize, cook, do paperwork) (Y/N)

Alternative to be tested:

6 item disability screen as follows:

- 1) Are you deaf or do you have serious difficulty hearing? (Y/N)
- 2) Are you blind or do you have serious difficulty seeing even when wearing glasses? (Y/N)
- 3) Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (Y/N)
- 4) Do you have serious difficulty walking or climbing stairs? (Y/N)
- 5) Do you have difficulty dressing or bathing? (Y/N)
- 6) Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (Y/N)

Domain seven: Chronic condition status

These follow-up questions are asked repeatedly on the ASHCN instrument:

- A) Is this because of ANY medical, mental health or other health condition? (Y/N)
- B) Is this a condition that has lasted or is expected to last for at least 12 months?" (Y/N)

Alternatives to be tested: These alternative versions will only be asked once and will be posed as independent questions:

- 1) "Do you have ANY medical, mental health, or other health condition that has lasted or is expected to last for at least 12 months? (Y/N) Follow up: Do you have two or more of these on-going health conditions?" (Y/N)

- 2) "Do you have ANY serious medical, mental health, or other health condition that has lasted or is expected to last for at least 12 months? Follow up: Do you have two or more of these serious, ongoing health conditions?" (Y/N)