

ICPSR 4354

## **Resources for Enhancing Alzheimer's Caregiver Health (REACH II), 2001-2004**

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## **Questionnaire for SC: Screening Form**

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## **CODEBOOK**

### **Screening Form**

**(SC)**

### SCREENING FORM

1. Respondent's last name code \_\_\_\_\_
  2. Date of interview: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ **SCDAT**  
month day year
  3. Start time (military time): \_\_\_\_ : \_\_\_\_ **STTIM**  
hours minutes
  4. Interviewer's name: \_\_\_\_\_  
Last First
  - 4.1 REACH certification number: \_\_\_\_ **CERT** \_\_\_\_\_
  5. Has this respondent been screened before? No 0 ( ) Yes 1 ( ) **REDO**
- 

#### Introduction

Hello, my name is \_\_\_\_\_ from \_\_\_\_\_ and

(A) We received (a card/a phone call) from you indicating that you might be interested:

(B) We were given your name by \_\_\_\_\_ as someone who might be interested:

in a new project called REACH II sponsored by the National Institutes of Health. The purpose of this project is to evaluate the benefits of an in-home program designed to help families caring for individuals with memory problems. (*If referral source unknown ask: May I ask where you heard about our project?*)

How are you related to the person for whom you are providing care?

To see if you might be eligible to participate in this project, I would like to take about 10 minutes of your time to ask you some questions. Is this a convenient time?

***If yes:*** Before we begin, let me assure you than anything you say is strictly confidential. Also, there is no cost to participate in this project. Are you ready to begin?

***If no:*** When would be a better time for me to call you back?

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

Time: \_\_\_\_\_

**Pre-screen**

**INTRODUCTION:** *I would first like to ask some questions about you, as a caregiver. Then I would like to ask some questions about the \_\_\_\_\_(CR). Is this OK?*

6. Would you describe yourself as Hispanic or Latino/a? No 0 ( ) Yes 1 ( ) **GLAT**

6.1. How would you describe your primary racial group? **GRACE**

- 0 ( ) *No primary group*
- 1 ( ) *White, Caucasian*
- 2 ( ) *Black, African-American*
- 3 ( ) *Native American or Alaska Native*
- 4 ( ) *Asian*
- 5 ( ) *Native Hawaiian or other Pacific Islander*
- 6 ( ) *Other*

**GORAC**

6.1.1 Specify: \_\_\_\_\_

7. Is the respondent Hispanic/Latino/a; White/Caucasian or Black/African-American (see question 6 & 6.1)? **IDENE**  
If "yes,"

7.1 How did the respondent identify him/herself? **IDENW**

- 1 ( ) *Hispanic/Latino/a*
- 2 ( ) *White/Caucasian*
- 3 ( ) *Black/African Am.*
- 4 ( ) *Other than Hispanic, White or Black*

8. Does the respondent speak English or Spanish? **GTALK**

9. Does \_\_\_\_\_(CR) speak English or Spanish? **RTALK**

10. Does \_\_\_\_\_(CR) live with you? We consider living together as sharing cooking facilities. **LIVE**

11. Are you related to \_\_\_\_\_(CR)? **KIN**

12. How long have you taken care of \_\_\_\_\_(CR)? **YRTC YRTC**  
\_\_\_\_\_  
(Yrs) (Mos)

13. Has the CG taken care of CR for more than 6 months (see question 12)? **CARED**

14. Does \_\_\_\_\_(CR) have memory problems? **MEMOR**

15. As part of this study you may be assigned by chance to a group that receives regular home visits. If you are assigned to this group, would you be available to begin these visits within the next seven weeks? (If "no", file under pending and call back in the future) **AVAIL**

No	Yes
0	1
( )	( )
( )	( )
( )	( )
( )	( )
( )	( )
( )	( )
( )	( )
( )	( )
( )	( )
( )	( )
If "no" to any question, go to subscript A. Otherwise continue on next page	

**Subscript A**

*For those who are excluded based on the pre-screen: Thank you so much for answering my questions. Based on what you have told me about your situation, it does not seem that this is the best program for you. I would like to keep your name in our files, in case there is a program in the future which might better suit your needs. Is that okay with you? Do not continue the screening, do not enter prescreen data.*

**Screen**

*Note: If participant qualifies based on the pre-screen questions, all screening questions are required to be administered regardless of meeting inclusion or exclusion criteria.*

16. Sex of the caregiver: **CGSEX** Male 1 ( ) Female 2 ( )
17. What is the sex of \_\_\_\_\_(CR)? **CRSEX** Male 1 ( ) Female 2 ( )
18. What is your date of birth? **GDOB** \_\_\_ / \_\_\_ / \_\_\_\_\_
19. What is \_\_\_\_\_(CR)'s date of birth? **RDOB** \_\_\_ / \_\_\_ / \_\_\_\_\_
20. (Tell me again), what is your relationship to the person you are caring for? **REL**
- |                        |       |                            |        |             |
|------------------------|-------|----------------------------|--------|-------------|
| <b>Husband</b>         | 1 ( ) | <b>Nephew</b>              | 9 ( )  |             |
| <b>Wife</b>            | 2 ( ) | <b>Niece</b>               | 10 ( ) |             |
| <b>Son</b>             | 3 ( ) | <b>Grandson</b>            | 11 ( ) |             |
| <b>Daughter</b>        | 4 ( ) | <b>Granddaughter</b>       | 12 ( ) |             |
| <b>Son-in-Law</b>      | 5 ( ) | <b>Stepson</b>             | 13 ( ) |             |
| <b>Daughter-in-Law</b> | 6 ( ) | <b>Stepdaughter</b>        | 14 ( ) |             |
| <b>Brother</b>         | 7 ( ) | <b>Other</b>               | 15 ( ) | <b>RELS</b> |
| <b>Sister</b>          | 8 ( ) | <b>20.1 Specify:</b> _____ |        |             |

20.2 Is the caregiver the spouse of the care recipient? 1 ( ) Non-spouse  
2 ( ) Spouse **SPOUW**

21. Is this your home phone number? **PHON** No 0 ( ) Yes 1 ( )

*If no,*

21.1 Do you have a phone in your home? **PHOND**

No 0 ( ) →

21.1.1 Would you be willing to discuss putting a phone in your home? **PHONP**

No 0 ( ) → *Mark "no" for question 23. Respondent excluded.*

\*Yes 1 ( )

Yes 1 ( ) →

21.1.2 What is your home phone number?

\_\_\_\_ / \_\_\_\_\_ - \_\_\_\_\_

*\*If no other exclusion criteria are met, participant should be classified as "maybe" and PI should be notified. It is up to the discretion of the PI to offer this service to the caregiver.*

*Notes to assist in resolving respondents classified as "maybe" (not to be entered into PoP)*

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

	No 0	Yes 1
22. Is CG 21 years of age or older (see question 18)? <b>OFAGE</b>	( )	( )
23. Does CG have a phone line in his/her home that will enable the use of the CTIS system, or is he/she or the PI willing to have one installed (see question 21, 21.1, & 21.1.1)? <b>PHONH</b>	( )	( )
24. Are you planning to remain in the area where you live for the next six months? <b>MOVE</b>		
25. On a typical day, how many hours do you spend directly caring <b>CAREH</b> _____ Hours for or supervising (CR)?		
25.1 Does CG provide, on average, <u>at least 4 hours</u> of supervision or direct <b>CGTM</b> assistance per day for CR?	( )	( )
<i>If "no" to any questions, CG is not eligible</i>		

	No 0	Yes 1
26. Are you planning to place (CR) into a nursing home (or other institution), or with another caregiver, <u>within the next six months</u> ? (If on a waiting list as a form of insurance planning and not planning to imminently place within six months, check "no." If the plan is to place (CR) within six months or when there is a bed available, check "yes.") <b>ENH</b>	( )	( )
27. Are you receiving any treatment for cancer such as chemotherapy or radiation therapy excluding tamoxifen? <b>CGCA</b>	( )	( )
28. Are you currently in a study to help you take care of (CR) <u>that assists you with your physical or mental health</u> ? <b>STDY</b>	( )	( )
29. Did you or did (CR) participate in the previous REACH study? <b>AGAIN</b>	( )	( )
<i>If "yes" to any question, CG is not eligible.</i>		

**Screen – Care Recipient**

This next set of questions is about (CR).

30. Is (CR) bedbound? (We consider bedbound as confined to a bed or chair for more than 22 hours per day, for at least 4 of the past 7 days). <b>BDBND</b>	No 0 ( )	Yes 1 ( )
31. Is (CR) receiving any treatment for cancer such as chemotherapy or radiation therapy excluding tamoxifen? <b>CRCA</b>	( )	( )
32. Has (CR) been in the hospital overnight more than three times in the past year? (Other than for psychiatric or Alzheimer's Disease related) <b>RHOSP</b>	( )	( )
<i>If "yes" to any questions*, CG is not eligible</i>		

- |  | No<br>0 | Yes<br>1 |
|--|---------|----------|
| *33. <b>Have you ever been told that (CR) had a severe mental illness before the age of 45?</b> <i>(Probe: for example, schizophrenia, obsessive compulsive disorder, hallucinations, paranoia, or nervous breakdowns.)</i> <b>SRMNT</b> | ( )     | ( )      |
| *34. <b>Have you ever been told that (CR) has memory problems because of a past head injury?</b> <b>CRMP</b>   | ( )     | ( )      |
| *35. <b>Is (CR) blind or deaf?</b> <b>RBLND</b>  | ( )     | ( )      |

- |   | No<br>0 | Yes<br>1 |
|---|---------|----------|
| 36. <i>Did the caregiver answer “yes” to more than one of these three questions?</i> <b>MMB</b> | ( )     | ( )      |
- If “Yes”  
caregiver is  
excluded

\* *If no other exclusion criteria are met, participant should be classified as “maybe” and PI should be notified to resolve eligibility criteria.*

*Notes to assist in resolving respondents classified as “maybe” – (not to be entered into PoP.)*

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- |   | No<br>0 | Yes<br>1 |
|---|---------|----------|
| 37. <b>Have you been told that (CR) has Alzheimer’s Disease?</b> <b>ALZHE</b> | ( )     | ( )      |
| 38. <b>Did CR have a decline in memory over the past year?</b> <b>DECME</b>   | ( )     | ( )      |
| 39. <b>Have you been told that (CR) has Parkinson’s Disease?</b> <b>PARKI</b> | ( )     | ( )      |
| 40. <b>Have you been told that (CR) has had a stroke</b> <b>STROK</b>         | ( )     | ( )      |

- |  | No<br>0 | Yes<br>1 |
|--|---------|----------|
| *41. <i>Did the caregiver answer “no” to question 37 &amp; 38, and “yes” to either question 39 or 40?</i> <b>PSYES</b> | ( )     | ( )      |

\* *If “yes” response is marked for question 41 and no other exclusion criteria are met, participant should be classified as “maybe” and PI should be notified to resolve eligibility criteria.*

*Notes to assist in resolving respondents classified as “maybe” – (not to be entered into PoP.)*

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**Risk Assessment - Part I**

Now I'd like to ask you about some of the problems you may have encountered while caring for (CR). Please indicate if any of these problems has occurred during the past month.

42. Within the past month, has (CR)...	No 0	Yes 1
42.1 <b>Been having any memory problems? Such as asking the same question over and over, forgetting what day it is, or losing or misplacing things? <span style="color: blue;">RAMEM</span></b>	( )	( )
42.2 <b>Been having any behavior problems? Such as arguing, being irritable, verbally aggressive or waking you or other family members up at night? <span style="color: blue;">RABEH</span></b>	( )	( )
42.3 <b>Needed help with daily activities, like bathing, changing clothes, brushing teeth, (or shaving)? <span style="color: blue;">RAACT</span></b>	( )	( )

43. *Did the caregiver answer "yes" to any of these three questions?* RA1Y

No 0	Yes 1
( )	( )
<i>If "no", CG is excluded.</i>	

**Risk Assessment - Part II**

Now I would like to ask you a few questions about you. Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions.

44. Within the past month, have you ...	No 0	Yes 1
44.1 <b>Felt overwhelmed? <span style="color: blue;">RAWHE</span></b>	( )	( )
44.2 <b>Had crying spells or felt like you often needed to cry? <span style="color: blue;">RACRY</span></b>	( )	( )
44.3 <b>Been angry or frustrated as a result of your caregiving? <span style="color: blue;">RAANG</span></b>	( )	( )
44.4 <b>Felt cut off from your family/friends? <span style="color: blue;">RACUT</span></b>	( )	( )
45. <b>On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. <span style="color: blue;">RASR</span></b>		
45.1. <i>Is the score 6 or higher?</i> <span style="color: blue;">RAGTS</span>	( )	( )
46. <b>Please rate your current health compared to what it was this time last year</b>	<b>Better 1 ( )</b>	<b>The Same 2 ( )</b>
		<b>Worse 3 ( )</b>
		<span style="color: blue;">RAHEA</span>
46.1 <i>Did the caregiver rate his or her health as worse?</i> <span style="color: blue;">RAWOR</span>	( )	( )

47. *Sub-score (add all "yes" responses)* RASUB \_\_\_\_\_

48. *Is the sub-score (question #47) at least 2?* RA2Y

No 0	Yes 1
( )	( )
<i>If "no", CG is excluded.</i>	

49. Did the respondent have frequent difficulty comprehending the questions in the interview (e.g., respondent had difficulty hearing, concentrating, or respondent required frequent repetition of questions)? **SCDIF** No 0 ( ) Yes 1 ( )

If Yes,

49.1. Was the SPMSQ administered? <b>SPMSQ</b>
No 0 ( ) → Why not? <b>WHYNO</b>
Yes 1 ( ) → Score: <b>SCORE</b>
→ 49.1.1 Is the score 4 or greater? <b>SPGT4</b>

No	Yes
0	1
( )	( )
If "yes", CG is not eligible	

**Eligibility Determination**

50. Is the caregiver eligible to participate in the study? **GELIG**

No 0 ( ) *Not eligible, at least one exclusionary criterion (gray box) met: I really appreciate you taking the time to answer my questions. At this time, it does not appear that this program would be the best for you. With your permission, however, we would like to retain your name in our files should there be a program in the future that might be better suited to your needs.*

Yes 1 ( ) *Eligible, all questions answered and no exclusionary criteria (gray box) met: (Go to script on last page)*

**GPART**

No 0 ( ) →	50.1 Could you please tell me why not?
Yes 1 ( )	<b>WPART</b>

Maybe 2 ( ) *Needs PI consult to determine eligibility, DO NOT ENTER IN POP UNTIL MAYBE STATUS IS RESOLVED: I really appreciate you taking time to answer my questions. At this time, I would like to evaluate the information you have given me, and call you back to let you know if you qualify for the program. Is this okay? When would be a convenient time for me to call?*

No 0 ( ) →	50.2 Could you please tell me why not?
Yes 1 ( )	

51. End time (military time): **ENTIM**  
 \_\_\_\_\_ hours \_\_\_\_\_ minutes

52. Was there a need to resolve a maybe status? **MAYBE** No 0 ( ) Yes 1 ( )  
 If yes,

52.1	How was the maybe status resolved? _____	<b>RESO1</b>	_____
	_____	<b>RESO2</b>	_____
	_____	<b>RESO3</b>	_____

**Script for eligible participants**

I really appreciate you taking the time to answer my questions. At this time, it appears that this program might be right for you. If you choose to participate in the study, you are taking part in a research study of caregivers who care for people with memory problems.

If you join the study, you will be asked questions about your and your family member’s health and well-being. These questions will take about two hours and will be conducted in your home. The same questions will be asked again at six months.

You will be assigned, by chance, to one of two groups. If you are assigned to the first group, you will receive home and phone visits by a member of the research team. During these visits you will be provided with basic information about caregiving and memory loss and ways of managing behavior problems or other areas related to caregiving. In addition to these visits, a touch-tone screen-phone will be installed in your home. The screen-phone works like a normal telephone but has additional features that will allow you to interact with a computer system to access information about caring for someone with a memory problem. You will be instructed on how to use the phone and later asked to evaluate its usefulness. The system will be provided free of charge and it will be removed from your home at the end of the project.

If you are assigned to the second group, you will receive helpful information about memory-related problems and caregiving at the initial home interview and then again in 6 months. You will also receive two phone calls to check on how you are doing. At the end of six months you will be invited to a workshop about caregiving and resources that are available to you to provide care.

There are no physical risks to you or to your family member. If you choose to participate in this study it might help you better understand the problems you may be having as a caregiver for someone with memory loss. The information also will be used to help other caregivers like you.

Each person who joins the study will be paid \_\_\_when information is collected at the beginning and when information is collected at six months.

Your participation in this study is voluntary. You may refuse to take part in the study or end you participation at any time without risk of penalty or loss of any benefits that you or your loved one are otherwise entitled to receive.

**Do you have any questions? Are you willing to participate in the study?**

**If yes:** With your permission, I would like to arrange a convenient time for \_\_\_\_\_ to come to your home while your CR is there. During this visit \_\_\_\_\_ will provide you with more specific information about the project, ask you to sign a written consent form giving us your permission to include you in our project, and then ask you some questions about you and your family member’s health and well-being.

**Some of the questions that we ask will be regarding the prescription and nonprescription medications that**

**you and your family member currently take. To help prepare for this portion of the visit, please have all of your medications and all of your family member's medication on hand for the visit. We will also be asking your permission to record social security numbers and Medicare numbers for both you and \_\_\_\_\_(CR), so if you could have that information handy as well, we'd appreciate it.**

**Now, when are the best times to come to your home? \_\_\_\_\_.**

**Do you have any questions I can answer? Thank you very much for speaking with me.**