

Respondent's Name \_\_\_\_\_  
Last, First

### PARTICIPATION INFORMATION FORM

Today's Date \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

Interviewer's Name \_\_\_\_\_

*If applicable,*

Referring Name	_____
Referring Agency	_____
Date of Referral	____ / ____ / _____

Caregiver's Name \_\_\_\_\_

Care Recipient's Name \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Phone \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

Other Information:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Did the caregiver agree to be screened and is he/she eligible based on the prescreen questions?

No → Do not continue with screen, do not enter prescreen data into PoP

Yes ↓

Is caregiver eligible and willing to participate in REACH II and is he/she available, if assigned to an intervention, to begin visits within the next seven weeks?	
<input type="checkbox"/> No →	<span style="border: 1px solid black; padding: 2px;">File under pending; call back in future when CG has more availability</span>
<input type="checkbox"/> Yes →	<span style="border: 1px solid black; padding: 2px;">Proceed to next page</span>

Respondent's Name \_\_\_\_\_  
Last, First

Date of baseline interview \_\_\_\_ / \_\_\_\_ / \_\_\_\_ Time of baseline interview \_\_\_\_ : \_\_\_\_ AM / PM

CG's relationship to CR \_\_\_\_\_

Is care recipient bed bound? ( ) No ( ) Yes *(Defined as spending 22 hours a day in a bed or chair for at least 4 of the past 7 days)*

Is care recipient blind/deaf? ( ) No ( ) Yes

Is there other relevant information that REACH staff should know about CG or CR? ( ) No ( ) Yes

If Yes, specify:

\_\_\_\_\_  
\_\_\_\_\_

Directions to House \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Other information we should know before coming to home: (pets, safety, front door vs. back door, etc.)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



**NIA/NINR**

Resources for Enhancing Alzheimer's Caregiver Health

Screening Form (SC)

<b>Completion Log</b>		
	Person	Date
Data collected		/ /
Data entered		/ /
System ID		
Data verified		/ /
Data cleaned		/ /
Data prepared for transfer		/ /
Subject ID		



**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 ( )

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

- 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**

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

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

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

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

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

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

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

\_\_\_\_\_  
(Yrs) (Mos)

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

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

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)**

	No 0	Yes 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: Male 1 ( ) Female 2 ( )
17. What is the sex of \_\_\_\_\_(CR)? Male 1 ( ) Female 2 ( )
18. What is your date of birth? \_\_\_ / \_\_\_ / \_\_\_\_\_
19. What is \_\_\_\_\_(CR)'s date of birth? \_\_\_ / \_\_\_ / \_\_\_\_\_
20. (Tell me again), what is your relationship to the person you are caring for?
- |   |   |
|---|---|
| <p><b>Husband</b> 1 ( )</p> <p><b>Wife</b> 2 ( )</p> <p><b>Son</b> 3 ( )</p> <p><b>Daughter</b> 4 ( )</p> <p><b>Son-in-Law</b> 5 ( )</p> <p><b>Daughter-in-Law</b> 6 ( )</p> <p><b>Brother</b> 7 ( )</p> <p><b>Sister</b> 8 ( )</p> | <p><b>Nephew</b> 9 ( )</p> <p><b>Niece</b> 10 ( )</p> <p><b>Grandson</b> 11 ( )</p> <p><b>Granddaughter</b> 12 ( )</p> <p><b>Stepson</b> 13 ( )</p> <p><b>Stepdaughter</b> 14 ( )</p> <p><b>Other</b> 15 ( )</p> <p>20.1 Specify: _____</p> |
|---|---|

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

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

If no,

21.1 Do you have a phone in your home?

No 0 ( ) →

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

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)*

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

- 22. Is CG 21 years of age or older (see question 18)?
- 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)?
- 24. Are you planning to remain in the area where you live for the next six months?
- 25. On a typical day, how many hours do you spend directly caring for or supervising (CR)? \_\_\_ Hours
- 25.1 Does CG provide, on average, at least 4 hours of supervision or direct assistance per day for CR?

No 0	Yes 1
( )	( )
( )	( )
( )	( )
( )	( )
( )	( )
If "no" to any questions, CG is not eligible	

- 26. Are you planning to place (CR) into a nursing home (or other institution), or with another caregiver, within the next six months? (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.")
- 27. Are you receiving any treatment for cancer such as chemotherapy or radiation therapy excluding tamoxifen?
- 28. Are you currently in a study to help you take care of (CR) that assists you with your physical or mental health?
- 29. Did you or did (CR) participate in the previous REACH study?

No 0	Yes 1
( )	( )
( )	( )
( )	( )
( )	( )
If "yes" to any question, CG is not eligible.	

**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). No 0 ( )    Yes 1 ( )
- 31. Is (CR) receiving any treatment for cancer such as chemotherapy or radiation therapy excluding tamoxifen?
- 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)

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

- |   | 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> | ( )     | ( )      |
| *34. <b>Have you ever been told that (CR) has memory problems because of a past head injury?</b>  | ( )     | ( )      |
| *35. <b>Is (CR) blind or deaf?</b>  | ( )     | ( )      |

36. *Did the caregiver answer “yes” to more than one of these three questions?*

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

\*41. *Did the caregiver answer “no” to question 37 & 38, and “yes” to either question 39 or 40?*

	No 0	Yes 1
( )	( )	( )

*\* 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?</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?</b>	( )	( )
42.3 <b>Needed help with daily activities, like bathing, changing clothes, brushing teeth, (or shaving)?</b>	( )	( )

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

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

**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?</b>	( )	( )
44.2 <b>Had crying spells or felt like you often needed to cry?</b>	( )	( )
44.3 <b>Been angry or frustrated as a result of your caregiving?</b>	( )	( )
44.4 <b>Felt cut off from your family/friends?</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. _____</b>		
45.1. <i>Is the score 6 or higher?</i>	( )	( )
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>
46.1 <i>Did the caregiver rate his or her health as worse?</i>	( )	( )

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

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

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)?* No 0 ( ) Yes 1 ( )

If Yes,

49.1. Was the SPMSQ administered?	
No 0 ( )	→ Why not? _____
Yes 1 ( )	→ Score: ____
↓ 49.1.1 Is the score 4 or greater?	
No 0 ( )	Yes 1 ( )
If "yes", CG is not eligible	

**Eligibility Determination**

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

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)*

No 0 ( )	→	50.1 Could you please tell me why not? _____ _____
Yes 1 ( )		

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):* \_\_\_\_ : \_\_\_\_  
hours minutes

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

52.1 How was the maybe status resolved? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**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 by mail, helpful information about memory-related problems and caregiving. 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.**



**NIA/NINR**

Resources for Enhancing Alzheimer's Caregiver Health

SPMSQ Form (SP)

Completion Log		
	Person	Date
Data collected		____/____/____
Data entered		____/____/____
System ID		
Data verified		____/____/____
Data cleaned		____/____/____
Data transferred		____/____/____
Subject ID		

**SPMSQ**

**Finally, I would like to ask you some general questions.**

1. Date administered:     /    /      
month day year
2. Interviewer's name: \_\_\_\_\_  
Last, First
- 3 REACH certification number:

Ask questions 4-14 in this list and record all answers. Record total number of **wrong answers** based on 10 questions, adjusting if indicated in Question 14. For each question, check Wrong or Correct. Mark the total score in Question 15.

	Wrong	Correct
4. <b>What is the date today?</b> <u>    </u> / <u>    </u> / <u>    </u> <span style="margin-left: 100px;">month</span> <span style="margin-left: 20px;">day</span> <span style="margin-left: 20px;">year</span>	0 ( )	1 ( )
5. <b>What day of the week is it?</b> _____	0 ( )	1 ( )
6. <b>What is the name of this city?</b> _____	0 ( )	1 ( )
7. <b>What is your telephone number?</b> _____	0 ( )	1 ( )
8. <b>How old are you?</b> _____	0 ( )	1 ( )
9. <b>When were you born?</b> _____	0 ( )	1 ( )
10. <b>Who is the current President of the United States?</b> _____	0 ( )	1 ( )
11. <b>Who was the President just before him?</b> _____	0 ( )	1 ( )
12. <b>What was your mother's maiden name?</b> _____	0 ( )	1 ( )
13. <b>Subtract 3 from 20 and keep subtracting 3 from each new number, all the way down. 20, 17, 14, 11, 8, 5, 2</b> _____	0 ( )	1 ( )

14. Subtotal number of wrong answers/errors (questions 4-13)          

15. **What was your highest level of formal education?** \_\_\_\_\_  
*Allow one more error if subject had no grade school education. (SUBTRACT 1)*  
*Allow one fewer error if subject had education beyond high school. (ADD 1)*

16. Total number of wrong answers/errors          

**\* Caregiver who has 4 or more errors is excluded from participating in REACH II**