

ICPSR 4354

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

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User Guide for SC: Screening Form

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DATA GUIDEBOOK

Screening Form

(SC)

Screening Form (SC)

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SCREENING (SC)

Introduction

PURPOSE: To screen prospective REACH II participants and determine their suitability for the study.

TIME OF DATA COLLECTION: The first study contact with the participant.

REQUIRED RESPONSE CARD(S):None required.

GENERAL INSTRUCTIONS:

The screening questionnaire incorporates two types of questions; questions that assist in answering eligibility determining questions; and the eligibility determining questions. All eligibility determining questions are yes/no questions and have responses in “boxes” to the immediate right of the questions. If a response is recorded in one of the shaded boxes on any of the eligibility determining questions, the respondent is determined ineligible, and the script for an ineligible caregiver is read at the conclusion of the form.

Generating the ID

This number is entered on every sheet at the top right hand corner. It is automatically generated by PoP during data entry. The data entry specialist, not the interviewer, is responsible for recording this number on the screening form since the number is not generated until after the screening interview. Therefore, during the screening interview this space is left blank.

Pre-screen

If the respondent answers “no” to any of the eligibility determining questions, he/she is ineligible for REACH II. The interviewer should read subscript A to the respondent and then terminate the call. Data collected for respondents who do not meet the pre-screen eligibility criteria should **NOT** be entered in PoP, but rather placed in an “ineligible prescreen” file at the site.

Screen

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

The screening portion of the questionnaire asks questions about the CG and CR. An additional section, Risk Assessment – Part I & II, collects information about how the CG and CR have been doing within the past month. The final section is the Eligibility Determination section. This sections reports whether the participant is “not eligible”, “eligible”, or “maybe” eligible.

Questions 21.1.1, 33 – 35, and 41 require special consideration regarding whether to determine the CG as eligible for the study or not. If the response to any of these questions is “Yes”, *and no other exclusion criteria are met*, the respondent should be classified as a “maybe” on the eligibility section of the form (question 50) and referred to the site Principal Investigator for resolution of the “maybe” status. *The remainder of the Screening form must be completed.* If the participant is excluded because of other criteria, the case is not referred to the site Principal Investigator. Note that if a “Yes” is recorded for any of these questions, the interview should probe and record details in the box at the bottom of this page to assist the Principal Investigator in resolving the “maybe” status. Once the interviewer consults with the site Principal Investigator and the eligibility status of the respondent is determined, the interviewer should go back to question 50 and enter “yes” or

“no” regarding eligibility determination. Question 52 should then be completed.

Specific Instructions:

Question 6.1 is bolded which instructs the screener to read all the racial categories. If the respondent answers before you read them, fill the answer in and continue onto the next question. If the respondent states he or she is biracial, ask the respondent “which group do you most identify with?” or would feel more comfortable being categorized as “no primary group”. Screeners need to be careful to probe the respondent in this situation without forcing a response. If the respondent asks why there is no biracial category, the screener can explain that the study is looking at certain groups, but the respondent has the option to choose to identify with a group, choose “no primary group” or choose “other” and specify his or her response. If the respondent has already identified him or herself as Hispanic or Latino/a in Question 6, this question must still be asked. Some people of Hispanic or Latino/a background will also identify a racial category, while others will choose other or no primary group.

Question 7.1 is where the screener places the respondent in one of the three groups identified for the study. In cases, where a respondent has identified him or herself as Hispanic or Latino/a and also chooses either White, Caucasian or Black, African-American as his or her primary racial group, the screener will mark Hispanic/Latino/a in this questions. For the purposes of this study, anyone who identifies as Hispanic/Latino/a will be placed in that category regardless of the other responses. Identification as Hispanic/Latino/a supercedes any other group identification.

Question 11 may be filled in without asking the caregiver if the caregiver’s relationship to the care recipient has been positively determined during the introduction to the screening form.

Question 12 of the pre-screen asks to record the number of years and months the CG has taken care of this particular CR. Do not include time taking care of other CRs. Include in the response any time spent caregiving prior to the CRs development of Alzheimer’s disease. If a CG has been taking care of the CR for 8 years, of which the CR has had Alzheimer’s disease of only the past 2 years, the correct response is 8 years, 0 months. If the number of years is less than ten, insert a leading zero in the first digit for both the year and the month (e.g. 3 years = “03”, 7 months = “07”). If a fraction of a year is given, the interviewer must convert the fraction to number of months (E.G. 1 and ½ years = “01 years” and “06 months”). If the amount of time is less than six months (a response of “00” years and “05 months” *or less*) the participant is not eligible for the study. Even though the CG is not eligible for the study, the remainder of the Screening form must be completed.

Question 17 may be filled in without asking the caregiver if the care recipient’s sex has been reported to the screener during the introduction to the screening form.

Question 20 records the caregiver’s relationship to the care recipient. If this information has already been determined earlier in the screening, simply confirm the answer to this question. Responses are bolded but if the respondent gives an answer after the question is read, it is not necessary to read all the responses.

Question 21 requires special consideration regarding whether to determine the CG as eligible or not. If the response to question 21 is “no” AND the response to question 21.1 is “no” AND the response to 21.1.1 is “Yes,” AND *no other exclusion criteria are met*, this respondent should be classified as a “maybe” and referred to the site Principal Investigator for resolution of the “maybe” status. This question is asked to ensure that if the CG is randomized to the intervention, the CTIS system can be installed. If the CG does not have the equipment necessary to install the CTIS, it

may be available at a minimal cost. It is up to the discretion of the site Principal Investigator to offer this service.

Question 25 asks the number of hours the caregiver spends taking care of the CR. If the number of hours is less than ten, insert a leading zero digit on the data collection form (e.g. 5 hours = "05"). If a fraction of an hour is given, round to the nearest hour (e.g. 4 hours and 30 minutes = "05", 3 hours and 15 minutes = "03"). The CG is excluded if less than four hours per day is spent caring for the CR. If the CG is not eligible for the study, the remainder of the Screening form must be completed.

Question 30 is not an eligibility determining question in itself. If no exclusion criteria are met but the CR is reported to be bedbound, the interviewer should administer the MMSE to the CR at the beginning of the baseline interview to determine eligibility. If the MMSE score is 0 and the CR is bedbound, then he/she is ineligible for the study.

Question 32 asks about the number of times the care recipient has been hospitalized in the past year. If the respondent answers that the care recipient has been hospitalized more than three times in the past year, the screener needs to probe to determine if these hospitalizations were for illnesses other than psychiatric or Alzheimer's disease related illnesses.

Questions 33 and 34 require special consideration regarding whether to determine the CG as eligible or not. If the response is "Yes," *and no other exclusion criteria are met*, this respondent should be classified as a "maybe" and referred to the site Principal Investigator for resolution of the "maybe" status. CRs may have memory problems for reasons other than Alzheimer's disease or related disorders (ADRD). These individuals should not be included in the study. The Principal Investigator should attempt to verify a clinical diagnosis of dementia not due to memory problems because of a severe mental illness or past head injury respectively, by asking permission to contact the care recipient's primary care physician.

Question 35 requires special consideration regarding whether to determine the CG as eligible or not. If the response is "Yes," *and no other exclusion criteria are met*, this respondent should be classified as a "maybe" and referred to the site Principal Investigator for resolution of the "maybe" status. If a CR is blind or deaf and either disability prohibits him/her from completion of data collection or participation in the intervention, the CG/CR dyad should not be included in the study.

Question 37 -40: These questions assume that the caregiver has been told by a health professional that the care recipient has one or more of these diseases. If the caregiver asks 'have I been told by whom?' the screener can clarify.

Question 41 also requires special consideration regarding whether to determine the CG as eligible or not. If the response is "Yes," *and no other exclusion criteria are met*, this respondent should be classified as a "maybe" and referred to the site Principal Investigator for resolution of the "maybe" status. This question refers to the CR exclusion criteria of "history of Parkinson's Disease or a stroke with no reported decline in memory over the past year". Because REACH II is a study about Alzheimer's disease or related disorders (ADRD), it is essential that individuals with ADRD make up the study cohort. Some CRs may have multiple diseases. This is acceptable as long as the CR is also exhibiting deteriorating memory problems due to Alzheimer's disease.

Question 49: In cases where the interviewer suspects that the respondent may be cognitively impaired, the SPMSQ should be administered, at the discretion of the interviewer. The cut off point for the SPMSQ is a total score of 4. If the caregiver scores 4 or more, he or she is NOT eligible for inclusion in REACH II. A score of 3 and less would allow the caregiver to participate in

REACH II.

DATASET SUMMARY

THE CONTENTS PROCEDURE

Data Set Name:	WORK.SC	Observations:	995
Member Type:	DATA	Variables:	77
Engine:	V8	Indexes:	0
Created:	9:31 Wednesday, August 31, 2005	Observation Length:	808
Last Modified:	9:31 Wednesday, August 31, 2005	Deleted Observations:	0
Protection:		Compressed:	NO
Data Set Type:		Sorted:	NO
Label:			

-----Variables Ordered by Position-----

#	Variable	Type	Len	Format	Label
1	ID	Char	7		SUBJECT ID
2	SCDAT	Num	8	MMDDYY10.	DATE OF INTERVIEW
3	STTIM	Num	8	TIME5.	TIME OF SCREEN START
4	REDO	Num	8		RESPONDENT SCREENED PRIOR
5	GLAT	Num	8		SC DESCRIBE HISPANIC
6	GRACE	Num	8		SC PRIMARY RACIAL GROUP
7	GORAC	Char	20		SC PRIMARY RACIAL SPECIFY
8	IDENE	Num	8		ELIG WHITE BLACK HISP
9	IDENW	Num	8		WHICH WHITE BLACK HISP
10	GTALK	Num	8		ELIG CG ENGLISH SPANISH
11	RTALK	Num	8		ELIG CR ENGLISH SPANISH
12	LIVE	Num	8		ELIG CG LIVE CR
13	KIN	Num	8		ELIG CG RELATED CR
14	YRTCY	Num	8		YEARS TAKEN CARE OF CR
15	YRTCM	Num	8		MONTHS TAKEN CARE OF CR
16	CARED	Num	8		ELIG CG CARED CR GT 6 MOS
17	MEMOR	Num	8		ELIG CR HAVE MEMORY PROBLEMS
18	AVAIL	Num	8		ELIG AVAIL IN 7 WEEKS
19	CGSEX	Num	8		CG SEX
20	CRSEX	Num	8		CR SEX
21	GDOB	Num	8	MMDDYY10.	CG BIRTH DATE
22	RDOB	Num	8	MMDDYY10.	CR BIRTH DATE
23	REL	Num	8		CG RELATIONSHIP TO CR
24	RELS	Char	20		CG RELATIONSHIP TO CR SPECIFY
25	SPOUW	Num	8		IS CG SPOUSE OF CR
26	PHON	Num	8		CG PHONE NUMBER
27	PHOND	Num	8		CG PHONE HOME
28	PHONP	Num	8		CG PHONE DISCUSS
29	OFAGE	Num	8		ELIG IS CG 21 OR MORE
30	PHONH	Num	8		ELIG CG PHONE HOME
31	MOVE	Num	8		ELIG PLANNING TO MOVE
32	CAREH	Num	8		HOURS CARING FOR CR
33	CGTM	Num	8		ELIG AT LEAST 4 HOURS
34	ENH	Num	8		ELIG IMMINENT PLACE IN NH
35	CGCA	Num	8		ELIG CG RECEIVEING CHEMOTHERAPY
36	STDY	Num	8		ELIG OTHER STUDY FOR MH
37	AGAIN	Num	8		ELIG CG CR PARTIC REACH1
38	BDBND	Num	8		IS PARTICIPANT BEDBOUND
39	CRCA	Num	8		ELIG CR RECEIVING CHEMOTHERAPY
40	RHOSP	Num	8		CR HOSP OVERNIGHT
41	SRMNT	Num	8		CR MENTAL ILLNESS
42	CRMP	Num	8		CR MEMORY PROBLEM
43	RBLND	Num	8		CR BLIND OR DEAF

DATASET SUMMARY (continued)

-----Variables Ordered by Position-----

#	Variable	Type	Len	Format	Label
44	MMB	Num	8		ELIG MENTAL MEMORY BLIND
45	ALZHE	Num	8		TOLD CR HAS ALZHEIMERS
46	DECME	Num	8		CR DECLINE IN MEMORY
47	PARKI	Num	8		TOLD CR HAD PARKINSONS
48	STROK	Num	8		TOLD CR HAD STROKE
49	PSYES	Num	8		ELIG PARKINSON STROKE
50	RAMEM	Num	8		RA MEMORY PROBLEMS
51	RABEH	Num	8		RA BEHAVIOR PROBLEMS
52	RAACT	Num	8		RA DAILY ACTIVITIES
53	RA1Y	Num	8		ELIG RA FIRST YES SCORE
54	RAWHE	Num	8		RA FELT OVERWHELMED
55	RACRY	Num	8		RA HAD CRYING
56	RAANG	Num	8		RA BEEN ANGRY
57	RACUT	Num	8		RA FELT CUT OFF
58	RASR	Num	8		RA STRESSFUL SCALE RATE
59	RAGTS	Num	8		RA STRESSFUL SCALE GT 6
60	RAHEA	Num	8		RA RATE CURRENT HEALTH
61	RAWOR	Num	8		RA RATE CURRENT HEALTH WORSE
62	RASUB	Num	8		RA SUB SCORE
63	RA2Y	Num	8		ELIG RA SECOND YES SCORE
64	SCDIF	Num	8		CG DIFFICULTY COMPRENHEND
65	SPMSQ	Num	8		WAS SPMSQ ADMINISTERED
66	WHYNO	Char	35		WHY NO SPMSQ
67	SCORE	Num	8		SCORE OF SPMSQ
68	SPGT4	Num	8		ELIG SPMSQ GT FOUR
69	GELIG	Num	8		CG ELIGIBLE
70	GPART	Num	8		CG WILLING TO PARTICIPATE
71	WPART	Char	35		WHY CG NOT WILLING
72	ENTIM	Num	8	TIME5.	TIME OF SCREEN END
73	MAYBE	Num	8		ANY NEED TO RESOLVE MAYBE
74	RESO1	Char	45		HOW WAS MAYBE RESOLVED1
75	RESO2	Char	45		HOW WAS MAYBE RESOLVED2
76	RESO3	Char	45		HOW WAS MAYBE RESOLVED3
77	CERT	Num	8		SC REACH CERTIFICATION NUMBER