

Care Provider Name: _____
Est. Form Completion Time: _____

PROJECT TO DEVELOP AN OUTCOME-BASED CONTINUOUS
QUALITY IMPROVEMENT SYSTEM AND CORE OUTCOME AND
COMPREHENSIVE ASSESSMENT DATA SET FOR PACE

**DRAFT COCOA DATA SET
SOCIAL WORK FORM**

Conducted by:
The Center for Health Services Research

for:

Department of Health and Human Services
Centers for Medicare and Medicaid Services

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Information contained on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used only for purposes stated for this study, and will not be disclosed or released to others without the consent of the individual or establishment. Responses to the collection of the information are voluntary.

DRAFT COCOA DATA SET SOCIAL WORK FORM OVERVIEW/PROTOCOL

PURPOSE: The information is being collected as part of a two-site feasibility test for the purpose of testing the feasibility of data collection using the draft core outcome and comprehensive assessment (COCOA) data set for PACE. Proposed data collection protocols will also be tested. The two-site feasibility test will result in the refinement of data items and protocols as appropriate. Findings from this project are intended to guide the anticipated implementation of a national approach for outcome-based continuous quality improvement (OBCQI) and core comprehensive assessment of participants, in which PACE sites will collect data that will be used to determine and profile participant outcomes for their site.

HOW COLLECTED: This form will be completed by social workers providing direct care to the participant.

WHEN COLLECTED: This form will be completed for each participant at one time point during the two-site feasibility test.

Completion of the form should occur within 24 hours of the provider's assessment of the participant (ideally, the form will be completed as part of the participant's routine assessment).

INSTRUCTIONS: This form contains items to be completed by the social worker (this includes direct response to items and administering items to PACE participants). The social worker will complete the form and will record responses directly on the form. The social worker should mark the correct response as appropriate or print numbers/answers where requested. All items should be completed unless specifically directed to skip items based on a previous response. The Data Collection Coordinator (DCC) assigned at the site will receive the completed forms from the social worker. The DCC will submit completed forms to the Research Center.

Note: Some data items in this form are also included in other COCOA forms. The forms in which the item appears are noted in brackets next to each item. For example, item 23 in this form is included in this form and the Nursing and Recreational Therapy forms, as indicated by [RN, SW, RT] next to the question stem for item 23. The abbreviations for each of the COCOA forms are listed below for quick reference.

Intake = Intake Form; HEA = Home Environment Assessment Form; PCP = Primary Care Provider Form; RN = Nursing Form; REHAB = Rehabilitation Therapy Form; SW = Social Work Form; RT = Recreational Therapy Form; RD = Dietitian Form; PSQ = Participant Satisfaction Form; CSQ = Caregiver Satisfaction Form; EOL = End of Life Form; UTIL = Utilization Form.

Two-Site Feasibility Test

DRAFT SOCIAL WORK FORM

Site ID

Participant ID

1. **Participant Name:** [ALL]

(Last) _____ (First) _____ (MI) _____ (Suffix) _____

2. **Reason for Assessment:** [HEA, PCP, RN, REHAB, SW, RT, RD, PSQ, CSQ]

- ☐ 1 - Initial assessment
- ☐ 2 - Reassessment
- ☐ 3 - Annual reassessment

3. **Date Assessment Completed:** [ALL]

____/____/____
month day year

4a. **Medicare Number:** [INTAKE, SW]

_____(including suffix)

- ☐ NA - No Medicare

b. **Medicare Entitlement:**

- ☐ 1 - Part A and Part B
- ☐ 2 - Part A only
- ☐ 3 - Part B only
- ☐ 4 - Not Medicare entitled

c. **Medicaid Number:** _____

- ☐ NA - No Medicaid

d. **Medicaid Eligibility:**

- ☐ 1 - Medicaid and SSI
- ☐ 2 - Medicaid, no SSI
- ☐ 3 - Not Medicaid eligible

5. From which of the following **Inpatient Facilities** was the participant discharged during the past 14 days? **(Mark all that apply.)** [SW]

- ☐ 1 - Hospital
- ☐ 2 - Rehabilitation facility
- ☐ 3 - Skilled nursing home
- ☐ 4 - Other nursing home
- ☐ 5 - Other (specify: _____)
- ☐ NA - Participant was not discharged from an inpatient facility

6a. Has the **Participant Moved** (i.e., changed living environment) since the last assessment? [SW]

- ☐ 0 - No [If No, go to Item 9]
☐ 1 - Yes

b. Did participant move for the **Purpose of Changing the Level of Supervision or Assistance?**

- ☐ 0 - No, move was due to reason(s) other than changing the level of supervision or assistance [Go to Item c]
☐ 1 - Yes, purpose of move was to increase level of supervision or assistance [Go to Item 7]
☐ 2 - Yes, purpose of move was to decrease level of supervision or assistance [Go to Item 7]

c. **Reason for Move if Not to Change Level of Supervision or Assistance:**

7. **Participant New Address:** [INTAKE, SW]

Street Address (include house/apt. number)

City

State

ZIP Code

County: _____

8. **Participant New Phone Number:** [INTAKE, SW] (_____) _____ - _____ ext. _____

9. **Citizenship:** [INTAKE, SW] ☐ 1 - United States
☐ 2 - Other (specify: _____)

10. **Highest Level of Education Completed:** [SW]

- ☐ 0 - No schooling
☐ 1 - Some Elementary School (highest grade, if known): _____
☐ 2 - Elementary School completed
☐ 3 - Some High School (highest grade, if known): _____
☐ 4 - High School completed
☐ 5 - Any Technical/Vocational School
☐ 6 - Any College/Graduate Work

Notes (optional): _____

11. **Work History** (e.g., primary or most significant occupation, occupation at retirement, reason for retirement, possible environmental exposures, etc.): [SW]

12a. **Language:** [SW] Primary _____

Other _____

b. **English Fluency:**

Spoken: ☐ 0 - None ☐ 1 - Little ☐ 2 - Fair ☐ 3 - Fluent ☐ U - Unknown
Reading: ☐ 0 - None ☐ 1 - Little ☐ 2 - Fair ☐ 3 - Fluent ☐ U - Unknown

c. **Reading Ability in Primary Language (if other than English):**

☐ 0 - None ☐ 1 - Little ☐ 2 - Fair ☐ 3 - Fluent ☐ U - Unknown

13. **Marital Status: [SW]**

- ☐ 1 - Married
 ☐ 4 - Separated
☐ 2 - Widowed
 ☐ 5 - Never married
☐ 3 - Divorced
 ☐ 6 - Other (specify: _____)

14. **Children (including stepchildren): [SW]**

Number of children: _____

Number of children involved in care: _____ Describe in chart below.

Name of Involved Children	Age	Nature of Involvement (e.g., daily help with personal tasks, weekly grocery shopping, assists with medical decisions)
1.		
2.		
3.		
4.		
5.		
6.		

15. **Primary Contact Person: [SW]**

Name: _____
 (Last) (First) (MI) (Suffix)

Address: _____
 Street Address (include house/apt. number)

City State ZIP Code

Phone Number: Day: (_____) _____ - _____

Eve: (_____) _____ - _____

Pager: (_____) _____ - _____ (optional)

E-mail address: _____ (optional)

Relationship to Participant:

- ☐ 1 - Spouse
☐ 2 - Daughter or son (including step)
☐ 3 - Daughter-in-law or son-in-law
☐ 4 - Sibling
☐ 5 - Other relative (specify: _____)
☐ 6 - Friend
☐ 7 - Other (specify: _____)

Gender:

- ☐ 1 - Male
 ☐ 2 - Female

Primary Languages Spoken: _____

Interpreter Needed? ☐ 0 - No ☐ 1 - Yes

16. **Secondary Contact Person: [SW]**

Name: _____
(Last) (First) (MI) (Suffix)

Address: _____
Street Address (include house/apt. number)

City State ZIP Code

Phone Number: Day: () -
Eve: () -
Pager: () - (optional)

E-mail address: (optional)

Relationship to Participant:

- ☐ 1 - Spouse
☐ 2 - Daughter or son (including step)
☐ 3 - Daughter-in-law or son-in-law
☐ 4 - Sibling
☐ 5 - Other relative (specify: _____)
☐ 6 - Friend
☐ 7 - Other (specify: _____)

Gender:

- ☐ 1 - Male ☐ 2 - Female

Primary Languages Spoken: _____

Interpreter Needed? ☐ 0 - No ☐ 1 - Yes

Is either the Primary or Secondary Contact Person also next of kin?

- ☐ 1 - Primary Contact Person [Go to Item 18]
☐ 2 - Secondary Contact Person [Go to Item 18]
☐ 3 - Neither [Go to Item 17]

17. **Next of Kin** (If different from **Primary and Secondary Contact Person**): [SW]

Name: _____
(Last) (First) (MI) (Suffix)

Address: _____
Street Address (include house/apt. number)

City State ZIP Code

Phone Number: Day: () -
Eve: () -
Pager: () - (optional)

E-mail address: (optional)

Gender:

- ☐ 1 - Male ☐ 2 - Female

Relationship to Participant:

- ☐ 1 - Spouse
☐ 2 - Daughter or son (including step)
☐ 3 - Daughter-in-law or son-in-law
☐ 4 - Sibling
☐ 5 - Other relative (specify: _____)

Primary Languages Spoken: _____

Interpreter Needed? ☐ 0 - No ☐ 1 - Yes

18. **Participant Lives With: (Mark all that apply.) [SW]**

- ☐ 1 - Lives alone
- ☐ 2 - With spouse or significant other
- ☐ 3 - With other family member
- ☐ 4 - With a friend
- ☐ 5 - With paid family caregiver
- ☐ 6 - With paid help other than PACE staff or family caregiver (includes foster care)
- ☐ 7 - With other than above (specify: _____)

19. **Current Residence:** Indicate the participant's residence at the current time. [SW]

- ☐ 1 - Participant's owned or rented residence (house, apartment or mobile home owned or rented by participant/couple/significant other)
- ☐ 2 - Family member's residence
- ☐ 3 - Boarding home or rented room (not PACE housing)
- ☐ 4 - Board and care or assisted living facility (may provide congregate meals but no personal care or supervision; not PACE housing)
- ☐ 5 - PACE program-related housing
- ☐ 6 - Group home except foster care (provides around-the-clock personal care and supervision)
- ☐ 7 - Foster care in a group home
- ☐ 8 - Nursing home (temporary)
- ☐ 9 - Nursing home (permanent)
- ☐ 10 - Other (specify: _____)

20. **Financial Concerns: [SW]**

a. Do you have any concern regarding the participant's ability to afford rent/utility bills?

- ☐ 0 - No
- ☐ 1 - Yes

b. Do you have any concern about the participant's ability to afford necessary food/meals?

- ☐ 0 - No
- ☐ 1 - Yes

Notes regarding participant's financial situation, need for referral, etc. (optional):

21. **Primary PACE Physician:** [SW] _____

22. **Legal Status:** Does the participant have any of the following? **(Mark all that apply.)** Obtain copy of declaration to include in medical record. [SW]

☐ Legal guardian of person or estate

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

☐ Conservator of estate

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

☐ Conservator of person

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

☐ Health care proxy

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

☐ Durable power of attorney/health care

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

☐ Durable power of attorney/financial

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

Specify: _____ (____) _____ - _____ (____) _____ - _____
Name Phone (Day) Phone (Eve)

☐ None of the above

INFORMAL SUPPORT

23. **Description of Family Relationships/Informal Support Systems** (Note if close, distant, hostile, domestic violence, alcohol or drug abuse, medical problems, etc.): [RN, SW, RT]

24. **Informal Caregiver Information:** List the three main individuals (family members, neighbors, friends, or other volunteers) providing **unpaid** care to help maintain the participant at home. Indicate who is the primary caregiver by checking the box. (Primary caregiver is defined as the individual taking lead responsibility for providing or managing the participant's care, providing the most frequent assistance, etc. [other than PACE program staff]). More than one person may share this role. [SW]

☐ NA - No informal caregiver [Go to Item 29]

	Caregiver 1 (Primary <input type="checkbox"/>)	Caregiver 2 (Primary <input type="checkbox"/>)	Caregiver 3 (Primary <input type="checkbox"/>)
Name:	_____	_____	_____
Telephone Number:	_____	_____	_____
Age:	_____	_____	_____
Lives w/Participant:	<input type="checkbox"/> 0 - No <input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No <input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No <input type="checkbox"/> 1 - Yes

25. **Caregiver Relationship to Participant:** [SW]

	Caregiver 1	Caregiver 2	Caregiver 3
Spouse	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 1
Daughter or son (including step)	<input type="checkbox"/> 2	<input type="checkbox"/> 2	<input type="checkbox"/> 2
Daughter-in-law or son-in-law	<input type="checkbox"/> 3	<input type="checkbox"/> 3	<input type="checkbox"/> 3
Sibling	<input type="checkbox"/> 4	<input type="checkbox"/> 4	<input type="checkbox"/> 4
Other relative (specify)	<input type="checkbox"/> 5 _____	<input type="checkbox"/> 5 _____	<input type="checkbox"/> 5 _____
Friend	<input type="checkbox"/> 6	<input type="checkbox"/> 6	<input type="checkbox"/> 6
Other (specify)	<input type="checkbox"/> 7 _____	<input type="checkbox"/> 7 _____	<input type="checkbox"/> 7 _____

26. **Frequency of Care Provided by Informal Caregiver(s):** Please complete based on a typical month. This estimate should include any time provided caring for or in support of participant (e.g., spends time at participant's home to help with personal care, does household tasks, cooking, grocery shopping for participant, etc.). [SW]

	Caregiver 1	Caregiver 2	Caregiver 3
Number of hours/month	_____	_____	_____
Number of days/month	_____	_____	_____
Number of times/day	_____	_____	_____
Average time per visit	_____	_____	_____
Notes (optional):	_____		

27. **Type of Care Provided** [SW]

	Caregiver 1		Caregiver 2		Caregiver 3	
Personal care (ADLs)	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes
Meal preparation	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes
Housework, laundry, or other chores	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes
Shopping	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes
Managing money	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes
Taking medications	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes
Transportation	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes
Companionship, recreation	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes	<input type="checkbox"/> 0 - No	<input type="checkbox"/> 1 - Yes
Other (specify):	_____		_____		_____	
Notes (optional):	_____					

PROVIDER: Based on your judgment and discussion with each caregiver, complete Item 28 for each caregiver listed in Item 24 above. (Information obtained from the primary caregiver in Items 70 to 75 at the end of this form may inform your response to this item.)

28. Caregiver Willingness and Ability to Provide Care: [SW]

Caregiver 1

Motivated to keep participant at home: ☐ 0 - Not motivated ☐ 1 - Somewhat motivated ☐ 2 - Motivated

Capable of providing care -- Physically: ☐ 0 - No ☐ 1- Yes
Emotionally: ☐ 0 - No ☐ 1- Yes

Notes (optional): _____

Caregiver 2

Motivated to keep participant at home: ☐ 0 - Not motivated ☐ 1 - Somewhat motivated ☐ 2 - Motivated

Capable of providing care -- Physically: ☐ 0 - No ☐ 1- Yes
Emotionally: ☐ 0 - No ☐ 1- Yes

Notes (optional): _____

Caregiver 3

Motivated to keep participant at home: ☐ 0 - Not motivated ☐ 1 - Somewhat motivated ☐ 2 - Motivated

Capable of providing care -- Physically: ☐ 0 - No ☐ 1- Yes
Emotionally: ☐ 0 - No ☐ 1- Yes

Notes (optional): _____

PROVIDER: Ask the participant to respond to Items 29 and 30 below.

29. Participant Expectations of Program for next assessment period (include days of Center attendance, services expected, relevant care plan issues): **[SW]**

☐ UA - This information could not be obtained due to participant's cognitive impairment

30. Participant Goals: What would you like to change or accomplish over the next few months that we can help you with? **[PCP, RN, REHAB, SW, RT, RD]**

☐ UA - This information could not be obtained due to participant's cognitive impairment

QUALITY OF LIFE

PROVIDER: Ask the participant to respond to Items 31 to 40.

31. Cultural/Religious Affiliation: Do you have any cultural or religious beliefs, practices, rituals, or background of which (PACE program) staff should be aware? **[SW]**

☐ 0 - No

☐ 1 - Yes Describe: _____

☐ UA - This information could not be obtained due to participant's cognitive impairment

32. **Religious/Spiritual Affiliation:** [SW] _____

33. Do you participate in **Religious or Spiritual Activities/Services** as much as you would like? [SW, RT]

- ☐ 0 - Yes, I participate as much as I would like
- ☐ 1 - Somewhat - I participate in some activities but would like to be more involved
- ☐ 2 - No, I do not currently participate as much as I would like
- ☐ 3 - I am not interested in participating in religious or spiritual activities/services
- ☐ UA - This information could not be obtained due to participant's cognitive impairment

34. **Social Activities:** How often during the past week did you attend a social, religious, or recreational event or program at home or away from home? For example, you went to church or temple, to a party, out to dinner, watched a movie or play, or just got together with friends or family. [SW, RT]

- ☐ 1 - At least once every day
- ☐ 2 - Several times during the week, but not every day (2-6 times)
- ☐ 3 - One time
- ☐ 4 - Not at all
- ☐ UA - This information could not be obtained due to participant's cognitive impairment

35. **Socialization/Isolation:** The next two questions are about talking to family and friends (who do not live with you). [SW, RT]

a. During the past week, how many times did you talk to family or friends (besides people from [PACE site]) over the telephone?

- ☐ 1 - At least once every day
- ☐ 2 - Several times during the week, but not every day (2-6 times)
- ☐ 3 - One time
- ☐ 4 - Not at all
- ☐ UA - This information could not be obtained due to participant's cognitive impairment
- ☐ NA - Participant does not have telephone

b. During the past week, how many times did you talk to family or friends (besides people from [PACE site]) in person (that is, you saw them and talked with them)?

- ☐ 1 - At least once every day
- ☐ 2 - Several times during the week, but not every day (2-6 times)
- ☐ 3 - One time
- ☐ 4 - Not at all
- ☐ UA - This information could not be obtained due to participant's cognitive impairment

c. How often do you feel lonely or isolated?

- ☐ 0 - Never
- ☐ 1 - Sometimes
- ☐ 2 - Frequently, but not always
- ☐ 3 - Always
- ☐ UA - This information could not be obtained due to participant's cognitive impairment

Notes (optional): _____

36. **Satisfaction with Amount of Interaction/Contact:** How satisfied are you with the amount of time you spend with family, friends, and others? [SW, RT]

- | | | | | | |
|--------------------------|---------------------------|--|------------------------------|--------------------------|---|
| 0 – Very
satisfied | 1 – Somewhat
satisfied | 2 – Neither
satisfied nor
dissatisfied | 3 – Somewhat
dissatisfied | 4 – Very
dissatisfied | UA – This
information could not
be obtained due to
participant's
cognitive impairment |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

37. **Satisfaction with Living Situation:** How satisfied are you with where you live? [SW]

0 – Very satisfied	1 – Somewhat satisfied	2 – Neither satisfied nor dissatisfied	3 – Somewhat dissatisfied	4 – Very dissatisfied	UA – This information could not be obtained due to participant's cognitive impairment
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

38. **Worry About Support:** Do you worry about getting the support and care you need? [PCP, SW]

- ☐ 0 - No
- ☐ 1 - Yes, I worry a little
- ☐ 2 - Yes, I worry a lot
- ☐ UA - This information could not be obtained due to participant's cognitive impairment

Notes (optional): _____

39. **Resolution:** Do you feel peaceful and ready to accept the future? [SW]

- ☐ 0 - Yes, definitely
- ☐ 1 - For the most part
- ☐ 2 - Sometimes, but not very often
- ☐ 3 - No, not at all
- ☐ UA - This information could not be obtained due to participant's cognitive impairment

40. **Self-Rated Quality of Life: (Ask Participant.)** Think about all parts of your life – your health, your happiness and other feelings, your relationships and social activities, the religious or spiritual part of your life, and the money or financial part of your life. Considering all of these things, how would you rate your quality of life overall? [SW]

- ☐ 1 - Excellent, things couldn't be better
- ☐ 2 - Very good
- ☐ 3 - Good
- ☐ 4 - Fair
- ☐ 5 - Poor, things couldn't be much worse
- ☐ UA - This information could not be obtained due to participant's cognitive impairment

Notes (optional): _____

PROVIDER: Respond to Item 41 below.

41. **Provider Suspicion of Participant Abuse:** Based on your experience and interactions with the participant, is there reason to suspect any of the following? (Mark all that apply.) [PCP, RN, REHAB, SW, RT, RD]

- ☐ 1 - Physical Abuse: beating, over-medication, restraining, etc.
- ☐ 2 - Denial of Basic Needs: withholding of food, clothing, hygiene, lack of supervision, abandonment
- ☐ 3 - Psychological Abuse: verbal assaults, insults, threats, and isolation
- ☐ 4 - Material Abuse: thefts, misuse of funds, fraud, etc.
- ☐ 5 - Violation of Rights: coercion, locking in, etc.
- ☐ 6 - Self-Neglect: substandard housing, failure to obtain adequate medical care, food, or protection
- ☐ 7 - None

Notes (optional): _____

COGNITIVE FUNCTIONING

42. Recent Memory: [RN, SW]

- a. Does the participant remember events from one day to the next (for example, visits by family members or participation in recreational events)?

☐ 0 - No ☐ 1 - Yes

- b. Is the participant able to remind self about when to take medications?

☐ 0 - No ☐ 1 - Yes

43. Remote Memory: [SW]

- a. Ask participant the following personally relevant verifiable questions:

What is your birthplace? _____

What was your first job? _____

What is your date of birth? _____

- b. Based upon responses to **item a** above, rate remote memory level.

☐ 0 - Good
☐ 1 - Moderately impaired
☐ 2 - Severely impaired

44. Ability to Sustain Attention: Assess the participant's ability to sustain attention during structured and unstructured activity. [REHAB, SW, RT]

- a. Structured Activity (recreation, self-care, daily household activities)

☐ 0 - Independent – requires no cues or redirection to task
☐ 1 - Supervised – requires occasional verbal cues to redirect attention to task appropriately
☐ 2 - Assisted – requires consistent verbal and/or tactile cues to maintain attention to task
☐ 3 - Unable – unable to sustain attention sufficiently to be productive in most minimal sense

- b. Unstructured Activity (free conversation, free time)

☐ 0 - Independent – requires no cues or redirection to task
☐ 1 - Supervised – requires occasional verbal cues to redirect attention to task appropriately
☐ 2 - Assisted – requires consistent verbal and/or tactile cues to maintain attention to task
☐ 3 - Unable – unable to sustain attention sufficiently to be productive in most minimal sense

45. Reasoning: [SW]

- a. Abstract Reasoning (Ask participant to respond to the following question.)

What would you do if your home caught on fire while you were there? (Prompt participant for explanation of response, how he/she came to the conclusion.)

Describe response: _____

- b. Reasoning Skills (as observed in daily functioning at the Day Health Center)

☐ 0 - Excellent Reasoning - able to apply reasoning skills appropriately throughout the day.
☐ 1 - Slightly Impaired - occasionally exhibits lapses in reasoning, requiring redirection.
☐ 2 - Impaired - frequently exhibits lapses in reasoning, requiring redirection.

46. **Judgment** (Puts Self At Risk): Identify the participant's ability to use judgment and make decisions that affect his/her ability to function independently. [RN, REHAB, SW, RT]
- ☐ 1 - Judgment is good. Makes appropriate decisions.
 - ☐ 2 - Judgment is occasionally poor. May make inappropriate decisions in complex or unfamiliar situations; needs monitoring and guidance in decision making.
 - ☐ 3 - Judgment is frequently poor; needs oversight and supervision because makes unsafe or inappropriate decisions.
 - ☐ 4 - Judgment is always poor; cannot make any appropriate decisions for self. Makes judgments that constantly put self at risk.
47. **Awareness of Own Needs:** Identify the participant's level of understanding of his/her needs relating to health, safety, and welfare. [RN, SW]
- ☐ 1 - Understands those needs which must be met for self-maintenance.
 - ☐ 2 - Sometimes has difficulty understanding those needs which must be met, but will cooperate when given direction or explanation.
 - ☐ 3 - Does not understand those needs which must be met for maintenance AND will not consistently cooperate even though given direction or explanation.
48. **Ability to Understand Others** in participant's primary language (understanding information content -- however able; e.g., understanding spoken language, sign language, writing, or other means): [RN, SW, RT]
- ☐ 0 - No observable impairment. Understands complex or detailed instructions and participates normally in conversation.
 - ☐ 1 - With mild difficulty, understands one-step instructions and simple multi-step instructions. Able to participate in ordinary conversation.
 - ☐ 2 - Has moderate difficulty understanding simple, one-step instructions and participating in conversation; may need frequent prompting or assistance.
 - ☐ 3 - Has severe difficulty understanding simple instructions and conversation. May require multiple repetitions, restatements, demonstrations.
 - ☐ 4 - Unable to understand even simple language.
49. **Ability to Express Thoughts, Wants, Needs** in primary language (expressing information content -- however able; e.g., using spoken language, sign language, writing, or other means): [RN, SW, RT]
- ☐ 0 - Able to express complex ideas, feelings, and needs clearly, completely, and easily in most situations.
 - ☐ 1 - Has mild difficulty in expressing ideas and needs (choice of words, word order, or grammar may sometimes be unclear or confusing; may need minimal prompting or assistance).
 - ☐ 2 - Has moderate difficulty in expressing simple ideas or needs (choice of words, word order, or grammar commonly unclear or confusing; needs prompting or assistance).
 - ☐ 3 - Has severe difficulty expressing basic ideas or needs and requires considerable assistance.
 - ☐ 4 - Unable to express basic needs even with considerable prompting or assistance (e.g., communication is nonsensical or unintelligible).

PHYSIOLOGIC STATUS

50. **Alcohol Use/Abuse:** Ask participant about use of alcoholic beverages during the past year (at reassessment: since the last assessment). Explain what is meant by alcoholic beverages (i.e., beer, wine, liquor [vodka, whiskey, brandy, etc.]). [PCP, RN, SW]
- a. How often do you have a drink containing alcohol?
- ☐ 0 - Never [Go to Item c]
 - ☐ 1 - Monthly or less
 - ☐ 2 - Two to four times a month
 - ☐ 3 - Two to three times a week
 - ☐ 4 - Four or more times a week
 - ☐ UA - This information could not be obtained due to participant's cognitive impairment
- b. How many drinks containing alcohol do you have on a typical day when you are drinking?
- ☐ 0 - One or two
 - ☐ 1 - Three or four
 - ☐ 2 - Five or six
 - ☐ 3 - Seven to nine
 - ☐ 4 - Ten or more
 - ☐ UA - This information could not be obtained due to participant's cognitive impairment

c. PROVIDER: Do you suspect the participant may have a problem with alcohol dependency or abuse?

☐ 0 - No ☐ 1 - Yes

Notes regarding concerns, plans, etc. (optional): _____

d. Any history of abuse of alcoholic beverages: _____

51. Satisfaction with Care Provided for Pain and Symptom Management

a. Has there ever been any time that members of the (PACE site) staff did not do everything they could to help control your pain?

- ☐ 0 - No, never
☐ 1 - Yes, a few times
☐ 2 - Yes, many times
☐ UA - Participant was asked this question and was unable to answer due to cognitive impairment
☐ NA - No pain or refuses pain medication

b. Have you ever had to wait too long to get pain medication?

- ☐ 0 - No, never
☐ 1 - Yes, a few times
☐ 2 - Yes, many times
☐ UA - Participant was asked this question and was unable to answer due to cognitive impairment
☐ NA - No pain or refuses pain medication

c. Do you feel that the (PACE site) staff should be doing more to keep you free from pain?

- ☐ 0 - No
☐ 1 - Yes, a little more
☐ 2 - Yes, a lot more
☐ UA - Participant was asked this question and was unable to answer due to cognitive impairment
☐ NA - No pain or refuses pain medication

d. For symptoms other than pain, for example shortness of breath or nausea, do you feel that the (PACE site) staff should be doing more to keep you comfortable?

- ☐ 0 - No
☐ 1 - Yes, a little more
☐ 2 - Yes, a lot more
☐ UA - Participant was asked this question and was unable to answer due to cognitive impairment
☐ NA - No pain or refuses pain medication

52. Appearance: Describe participant's general appearance. **(Mark all that apply.) [PCP, RN, SW]**

- ☐ 1 - No concerns
☐ 2 - Inappropriately clothed for setting (e.g., for weather, trips outside the home)
☐ 3 - Physically unkempt
☐ 4 - Poor hygiene
☐ 5 - Other (specify: _____)

Comments (consider posture, clothes, grooming, hair, nails): _____

53a. **Personal Hygiene Affecting Socialization:** Does the participant's personal hygiene have a negative impact on his/her social interaction with others (e.g., others avoid talking to or spending time with participant because of skin hygiene, scalp problems, bad breath, etc.)? [RN, SW]

☐ 0 - No ☐ 1 - Yes

b. **Personal Hygiene Affecting Health:** Does the participant's personal hygiene have a negative impact on his/her health (e.g., not brushing teeth resulting in gum problems, inadequate bathing resulting in skin rashes)?

☐ 0 - No ☐ 1 - Yes

Notes (optional): _____

FUNCTIONAL STATUS

54. **Transportation Needs:** [SW]

a. Does the participant drive a car? ☐ 0 - No ☐ 1 - Yes

Notes (optional): _____

b. Does the participant need program transportation to bring him/her to the PACE Day Center?

☐ 0 - No
☐ 1 - Yes Days: _____
 Time: _____

Notes (optional): _____

c. How does the participant get to activities outside of the PACE Day Center (e.g., shopping, visiting friends)? **(Mark all that apply.)**

☐ 1 - Drives self
☐ 2 - Family or friends drive
☐ 3 - Uses public transportation (bus, taxi, subway, etc.)
☐ 4 - Public or private agency (specify: _____)
☐ 5 - Other (specify: _____)

Items 55 and 56 should be answered based on the past week. Mark one box for performance and one box for ability.

55. **Telephone Use:** Performance (what participant actually does) and ability (what participant is capable of doing) to answer the phone, dial numbers, and effectively use the telephone to communicate. [RN, REHAB, SW]

<u>Perfor-</u> <u>mance</u>	<u>Ability</u>	Definitions and illustrative circumstances:
<input type="checkbox"/>	<input type="checkbox"/> NA	- Participant does not have a telephone.
<input type="checkbox"/>	<input type="checkbox"/> 0	- Dials numbers and answers calls appropriately and as desired.
<input type="checkbox"/>	<input type="checkbox"/> 1	- Uses a specially adapted telephone (e.g., large numbers on the dial, teletype phone for the deaf) and calls essential numbers.
<input type="checkbox"/>	<input type="checkbox"/> 2	- Answers the telephone and carries on a normal conversation but has difficulty with placing calls.
<input type="checkbox"/>	<input type="checkbox"/> 3	- Answers the telephone only some of the time or carries on only a limited conversation.
<input type="checkbox"/>	<input type="checkbox"/> 4	- Does not answer the telephone at all but listens if assisted with equipment.
<input type="checkbox"/>	<input type="checkbox"/> 5	- Does not use the telephone at all.

56. **Managing Finances:** Performance (what the participant actually does) and ability (what the participant is capable of doing) to take care of or direct others in handling financial business (e.g., writing checks, paying bills, handling medical insurance claims, etc.) in a responsible manner. **[SW]**

Perfor-
mance

Ability

Definitions and illustrative circumstances:

- | | | |
|--------------------------|--------------------------|--|
| <input type="checkbox"/> | <input type="checkbox"/> | 0 - (a) Handles financial business matters independently.
(b) Physically, cognitively and mentally able to handle financial matters but does not. |
| <input type="checkbox"/> | <input type="checkbox"/> | 1 - Needs help with some financial business matters and recognizes need for help. |
| <input type="checkbox"/> | <input type="checkbox"/> | 2 - Needs help with some financial business matters but <u>does not recognize need</u> for help. |
| <input type="checkbox"/> | <input type="checkbox"/> | 3 - Is unable to handle financial business matters. |

Notes (optional): _____

EMOTIONAL/MENTAL HEALTH STATUS

57. **Interval Mental Health History** (include mental health hospitalizations, treatments, relevant family history): **[PCP, SW]**

- 58a. **Chronic Mental/Emotional Condition:** Is there a history of any of the following (include currently inactive conditions)? **(Mark all that apply.) [PCP, SW]**

- ☐ 1 - Schizophrenia
☐ 2 - Major depression
☐ 3 - Mania/bipolar
☐ 4 - Personality disorder
☐ 5 - Other (specify: _____)
☐ 6 - None of the above
☐ UK - Unknown

- b. **Acute Mental/Emotional Condition:** Is there current behavioral or emotional evidence that the participant has any of the following? **(Mark all that apply.)**

- ☐ 1 - Schizophrenia or paraphrenia
☐ 2 - Psychotic depression
☐ 3 - Mania/bipolar
☐ 4 - Significant emotional instability or volatility
☐ 5 - None of the above

Notes (optional): _____

- 59a. **Mood (Dominant Feeling State):** Ask participant to describe his/her mood over the past week. **(Mark all that apply.) [PCP, RN, SW]**

- | | |
|---|--|
| <input type="checkbox"/> 1 - Depressive | <input type="checkbox"/> 5 - Happy |
| <input type="checkbox"/> 2 - Irritable | <input type="checkbox"/> 6 - Content |
| <input type="checkbox"/> 3 - Anxious | <input type="checkbox"/> 7 - Neutral |
| <input type="checkbox"/> 4 - Angry | <input type="checkbox"/> 8 - Other: _____ |
| | <input type="checkbox"/> UA - This information could not be obtained due to participant's cognitive impairment |

- b. **PROVIDER:**

Indicate if observed mood
congruent with statements:

- ☐ 0 - No **[Go to Item 60]**
☐ 1 - Yes **[Go to Item 61]**

60. **Provider Perceived Affect:** Participant's affect appears to be: **(Mark all that apply.)** [PCP, RN, SW]

- | | |
|---|--|
| <input type="checkbox"/> 1 - Flat | <input type="checkbox"/> 7 - Anxious |
| <input type="checkbox"/> 2 - Depressed | <input type="checkbox"/> 8 - Nervous |
| <input type="checkbox"/> 3 - Sad | <input type="checkbox"/> 9 - Calm |
| <input type="checkbox"/> 4 - Angry | <input type="checkbox"/> 10 - Happy |
| <input type="checkbox"/> 5 - Restricted/Withdrawn | <input type="checkbox"/> 11 - Other: _____ |
| <input type="checkbox"/> 6 - Fearful | |

Notes (optional): _____

61. **Anxiety:** The following two items refer to anxiety, which can be manifested in tension, nervousness, and/or apprehension. [PCP, RN, SW]

a. **Frequency of Anxiety (Reported or Observed):**

- ☐ 0 - None of the time
- ☐ 1 - Less often than daily
- ☐ 2 - Daily, but not constantly
- ☐ 3 - All of the time
- ☐ NA - Participant nonresponsive

b. **Severity of Anxiety** experienced by participant (record the most severe level experienced) **(Reported or Observed):**

- ☐ 0 - No anxiety
- ☐ 1 - Mild (experienced slight nervousness/apprehension)
- ☐ 2 - Moderate (experienced a significant amount of nervousness/ apprehension)
- ☐ 3 - Severe (experienced overwhelming nervousness/apprehension)
- ☐ NA - Participant nonresponsive

Notes (optional): _____

62. **Observed Depression or Depressive Symptoms:** Which of the following have you observed in the participant in the past week? **(Mark all that apply.)** [PCP, RN, SW, RT]

- ☐ 1 - Decreased level of energy and activity
- ☐ 2 - Slowing of thinking, language, and behavior
- ☐ 3 - Decrease in appetite
- ☐ 4 - Expressions of feelings of worthlessness or futility
- ☐ 5 - Crying spells
- ☐ 6 - Consistent sadness
- ☐ 7 - Sleep disturbances, insomnia, or excessive sleeping
- ☐ 8 - Other (specify: _____)
- ☐ 9 - None of the above

63. **Geriatric Depression Scale: (Ask participant.)** The next questions are about how you have felt over the past week. Please answer yes or no to each question. [PCP, SW]

- | | | |
|---|----------------------------------|-----------------------------------|
| a. Are you basically satisfied with your life? | <input type="checkbox"/> 0 – No* | <input type="checkbox"/> 1 – Yes |
| b. Have you dropped many of your activities and interests? | <input type="checkbox"/> 0 – No | <input type="checkbox"/> 1 – Yes* |
| c. Do you feel that your life is empty? | <input type="checkbox"/> 0 – No | <input type="checkbox"/> 1 – Yes* |
| d. Do you often get bored? | <input type="checkbox"/> 0 – No | <input type="checkbox"/> 1 – Yes* |
| e. Are you in good spirits most of the time? | <input type="checkbox"/> 0 – No* | <input type="checkbox"/> 1 – Yes |
| f. Are you afraid that something bad is going to happen to you? | <input type="checkbox"/> 0 – No | <input type="checkbox"/> 1 – Yes* |
| g. Do you feel happy most of the time? | <input type="checkbox"/> 0 – No* | <input type="checkbox"/> 1 – Yes |
| h. Do you often feel helpless? | <input type="checkbox"/> 0 – No | <input type="checkbox"/> 1 – Yes* |
| i. Do you prefer to stay at home, rather than going out and doing new things? | <input type="checkbox"/> 0 – No | <input type="checkbox"/> 1 – Yes* |
| j. Do you feel you have more problems with memory than most? | <input type="checkbox"/> 0 – No | <input type="checkbox"/> 1 – Yes* |
| k. Do you think it is wonderful to be alive now? | <input type="checkbox"/> 0 – No* | <input type="checkbox"/> 1 – Yes |
| l. Do you feel pretty worthless the way you are now? | <input type="checkbox"/> 0 – No | <input type="checkbox"/> 1 – Yes* |
| m. Do you feel full of energy? | <input type="checkbox"/> 0 – No* | <input type="checkbox"/> 1 – Yes |
| n. Do you feel that your situation is hopeless? | <input type="checkbox"/> 0 – No | <input type="checkbox"/> 1 – Yes* |
| o. Do you think that most people are better off than you are? | <input type="checkbox"/> 0 – No | <input type="checkbox"/> 1 – Yes* |

Score: _____ (number of "depressed" [denoted by asterisk] answers)

- 1-4 No cause for concern
 5-9 Strong probability of depression
 10+ Indicative of depression

Five or more depressed responses warrants further evaluation.

☐ UA - This information could not be obtained due to participant's cognitive impairment

64. **Participant Stress/Concerns about Own Life:** Ask the participant the following questions. [PCP, SW]

a. Have there recently been any major changes or disruptions in your life that you would like to talk about?

☐ 0 - No [Go to Item 65]

☐ 1 - Yes Describe: _____

☐ UA - This information could not be obtained due to participant's cognitive impairment [Go to Item 65]

b. Are you experiencing stress, concern, or worry related to these changes?

☐ 0 - No [Go to Item 65]

☐ 1 - Yes Describe: _____

c. If yes, how upsetting are these concerns to you? _____

65. Describe **Participant's Social Behavior** in the past week based on your and others' observation and interaction with participant: **(Mark all that apply.) [SW, RT]**

- | | |
|--|---|
| <input type="checkbox"/> 1 - Friendly, cooperative | <input type="checkbox"/> 10 - Passive |
| <input type="checkbox"/> 2 - Interacts with other participants | <input type="checkbox"/> 11 - Confused |
| <input type="checkbox"/> 3 - Interacts with staff | <input type="checkbox"/> 12 - Unable to initiate interactions/participation |
| <input type="checkbox"/> 4 - Initiates recreational programs independently | <input type="checkbox"/> 13 - Unmotivated |
| <input type="checkbox"/> 5 - Motivated | <input type="checkbox"/> 14 - Uncooperative |
| <input type="checkbox"/> 6 - Helps other participants (as able) | <input type="checkbox"/> 15 - Antisocial, withdrawn, acts out, abusive |
| <input type="checkbox"/> 7 - Prefers keeping to self | <input type="checkbox"/> 16 - Focuses on illness/other problems |
| <input type="checkbox"/> 8 - Needs quiet space for activities | <input type="checkbox"/> 17 - Other (specify: _____) |
| <input type="checkbox"/> 9 - Willing to try | |

Notes (optional): _____

66a. **Frequency of Behavior Problems** (Reported or Observed): Has the participant exhibited any of the following behaviors since the last assessment? **(Respond for each item below.) [RN, SW, RT]**

	<u>Never</u>	<u>Once/month or less frequently</u>	<u>Several times each month</u>	<u>Several times a week</u>	<u>At least daily</u>
1) Verbal disruption: yelling, threatening, excessive profanity, sexual references, etc.	<input type="checkbox"/> - 0	<input type="checkbox"/> - 1	<input type="checkbox"/> - 2	<input type="checkbox"/> - 3	<input type="checkbox"/> - 4
2) Physical aggression: aggressive/combatative to self or others (e.g., hits self, throws objects, punches, dangerous maneuvers with wheelchair or other objects)	<input type="checkbox"/> - 0	<input type="checkbox"/> - 1	<input type="checkbox"/> - 2	<input type="checkbox"/> - 3	<input type="checkbox"/> - 4
3) Disruptive, infantile, regressive, or socially inappropriate behavior (other than above)	<input type="checkbox"/> - 0	<input type="checkbox"/> - 1	<input type="checkbox"/> - 2	<input type="checkbox"/> - 3	<input type="checkbox"/> - 4
4) Delirium, confusion, delusional, hallucinatory, or paranoid behavior	<input type="checkbox"/> - 0	<input type="checkbox"/> - 1	<input type="checkbox"/> - 2	<input type="checkbox"/> - 3	<input type="checkbox"/> - 4
5) Agitated (pacing, fidgeting, argumentative)	<input type="checkbox"/> - 0	<input type="checkbox"/> - 1	<input type="checkbox"/> - 2	<input type="checkbox"/> - 3	<input type="checkbox"/> - 4
6) Withdrawn/isolated	<input type="checkbox"/> - 0	<input type="checkbox"/> - 1	<input type="checkbox"/> - 2	<input type="checkbox"/> - 3	<input type="checkbox"/> - 4

b. **For any behavior present, describe circumstances** (e.g., time of day, location/setting).

Circumstances

1) Verbal disruption

2) Physical aggression

3) Disruptive, infantile, regressive, or socially inappropriate behavior (other than above)

4) Delirium, confusion, delusional, hallucinatory, or paranoid behavior

5) Agitated

6) Withdrawn/isolated

67. **Wandering:** Has the participant wandered since the last assessment? (Wandering is defined as straying or becoming lost in the community due to impaired judgment. Example: A confused participant leaves home unattended and is not able to find his or her way back.) *Assess the participant using the ratings below.* [RN, SW, RT]

- ☐ 0 - *Never* This rating is used for any of the following circumstances (if mark 0, check the appropriate response [a, b, or c]):
- ☐ a. Never wanders away from home, the day health center, or other locations.
 - ☐ b. Has not wandered since the last assessment.
 - ☐ c. Has not wandered because special precautions have been instituted, such as continuous supervision and/or secured exits.
- ☐ 1 - *Seldom (once/week or less)* Has wandered away from home, day health center or other locations occasionally (less than once a week) since the last assessment.
- ☐ 2 - *Often (more than once/week)* This rating is used for any of the following circumstances:
- Has wandered away from home, day health center or other locations once a week or more since the last assessment.
 - Wanders once a week or more, from some locations, but not others.

END OF LIFE CARE

PROVIDER: *Ask the participant to respond to Items 68 to 71 below.*

68. Do you have requests or **Wishes for your Health Care** that you would like the staff here to know about? [PCP, SW]

- ☐ 0 - No
- ☐ 1 - Yes Describe: _____
- _____
- _____
- ☐ UA - This information could not be obtained due to participant's cognitive impairment

69. **Advance Directives:** [SW]

- a. Do you now have a signed Living Will (or Advance Directive) giving directions for the kind of medical treatment you would want if ever you could not speak for yourself?

- ☐ 0 - No [**Go to Item b**]
- ☐ 1 - Yes [Obtain copy to include in medical record.] [**Go to Item c**]
- ☐ UA - This information could not be obtained due to participant's cognitive impairment. [**Go to Item 70**]

- b. Would you like to complete one?

- ☐ 0 - No [**Go to Item 71**] Reason refused: _____
- ☐ 1 - Yes [**Go to Item 70**]

- c. Have you discussed your Living Will (or Advance Directive) with your health care team (for example, doctors, nurses, social workers) at the Center?

- ☐ 0 - No
- ☐ 1 - Yes
- ☐ UA - This information could not be obtained due to participant's cognitive impairment

Notes (optional): _____

70. **Participant/Caregiver Conflict:** [SW]

a. Have you discussed your Living Will, DNR Status, and/or other health care wishes with your family?

☐ 0 - No [**Go to Item 71**]

☐ 1 - Yes

☐ UA - This information could not be obtained due to participant's cognitive impairment [**Go to Item 71**]

b. Did they agree with your decisions? If yes, go to Item d. If not, please explain: _____

c. Which family members disagree with your decisions?

1) Name: _____ Relationship: _____

2) Name: _____ Relationship: _____

3) Name: _____ Relationship: _____

d. Do you have objections to our discussing your wishes with your family?

☐ 0 - No

☐ 1 - Yes

Notes (optional): _____

71. **Funeral Arrangements/Plans:** [SW]

a. Do you have plans/wishes for funeral or burial/cremation arrangements?

☐ 0 - No [**Go to Item c**]

☐ 1 - Yes [**Go to Item b**]

☐ UA - This information could not be obtained due to participant's cognitive impairment [**Go to Item 72**]

☐ R - Participant refuses to discuss [**Go to Item 72**]

Notes (optional): _____

b. Have you expressed your plans/wishes to your family or friends?

☐ 0 - No [**Go to Item c**]

☐ 1 - Yes [**Go to Item 72**]

Notes (optional): _____

c. Would you like help with considering your plans/wishes and/or communicating them to your family or friends?

☐ 0 - No

☐ 1 - Yes

Notes (optional): _____

CAREGIVER ITEMS

PROVIDER: Ask the participant's primary informal caregiver to respond to Items 72 to 77 below.

☐ NA - No informal caregiver [This form is complete.]

72. **Observed Depression or Depressive Symptoms:** Which of the following have you observed in **(participant)** in the past week? **(Mark all that apply.)** [SW]

- ☐ 1 - Decreased level of energy and activity
- ☐ 2 - Slowing of thinking, language, and behavior
- ☐ 3 - Decrease in appetite
- ☐ 4 - Expressions of feelings of worthlessness or futility
- ☐ 5 - Crying spells
- ☐ 6 - Consistent sadness
- ☐ 7 - Sleep disturbances, insomnia, or excessive sleeping
- ☐ 8 - Other (specify: _____)
- ☐ 9 - None of the above

73. **Caregiver Expectations of Program** for next assessment period (include days of Center attendance, services expected, relevant care plan issues): [SW]

74. **Managing Care:** [SW]

a. Is there anything we need to know that makes it difficult for you to manage the care of **(participant)**?

- ☐ 0 - No
- ☐ 1 - Yes - Describe: _____

b. Would you like education or training to help you manage care of **(participant)**?

- ☐ 0 - No
- ☐ 1 - Yes - Describe: _____

c. How likely is it that you will continue to provide care to **(participant)**?

- ☐ 0 - Very likely
- ☐ 1 - Somewhat likely
- ☐ 2 - Unlikely

75. **Caregiver Stress:** Almost everyone feels some degree of stress from time to time. At times you may feel no problem with anything; at other times, things seem to pile up and you feel tense, angry, or afraid. Let's call that feeling stress. Please indicate the amount of stress you are presently feeling as you take care of and try to help **(participant)**. [RN, SW]

- ☐ 0 - No stress
- ☐ 1 - A little stress
- ☐ 2 - Some stress
- ☐ 3 - A good bit of stress
- ☐ 4 - A great amount of stress

Notes (optional): _____

76. **Caregiver Coping:** [RN, SW]

a. How often do you find it difficult to cope with caring for **(participant)**?

- ☐ 0 - Never
- ☐ 1 - Rarely
- ☐ 2 - Sometimes
- ☐ 3 - Frequently
- ☐ 4 - Always

b. Do you ever feel that you need a break and don't feel you can take one?

- ☐ 0 - Never
- ☐ 1 - Rarely
- ☐ 2 - Sometimes
- ☐ 3 - Frequently
- ☐ 4 - Always

Notes (optional): _____

77. **Caregiver Support:** Caregiving can be difficult and challenging. Do you feel that you have adequate social and emotional support to meet your current needs? [RN, SW]

- ☐ 1 - Yes, always
- ☐ 2 - Yes, most of the time
- ☐ 3 - No, frequently inadequate
- ☐ 4 - No, I often feel overwhelmed

Notes (optional): _____

Please respond to the evaluation questions and return completed materials to the Data Collection Coordinator at your site.

Thank you for your participation.