

A 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:
Center for Health Services Research
University of Colorado Health Sciences Center

for:

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

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Site ID

Participant ID

**FIRST PHASE RELIABILITY TEST
DRAFT SOCIAL WORK FORM**

1. **Participant Name:** _____
(Last) (First) (MI) (Suffix)

2. **Date Assessment Completed:** ____/____/____
month day year

3. **Reason for Assessment:**

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

4. **Staff Member Completing Assessment (Name):** _____
(Last) (First)

5a. Has the **Participant Moved** (i.e., changed living environment) since the last assessment?

- 0 - No [**If No, go to Item 6**]
- 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 6**]
- 2 - Yes, purpose of move was to decrease level of supervision or assistance [**Go to Item 6**]

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

6. **Highest Level of Education Completed:**

- 0 - No schooling
- 1 - 8th grade or lower (highest grade, if known): _____
- 2 - Some High School (highest grade, if known): _____
- 3 - High School completed
- 4 - Any Technical/Vocational School
- 5 - Any College/Graduate Work

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

8a. **Language:** Primary _____
Other _____

b. **Spoken English Fluency:** 0 - None 1 - Little 2 - Fair 3 - Fluent U - Unknown

c. **Reading Ability in Primary Language:** 0 - None 1 - Little 2 - Fair 3 - Fluent U - Unknown

9. **Marital Status:**

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

10. **Children (including stepchildren):**

Name	Age	City of Residence	Notes
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			
11.			
12.			

11. **Participant Lives With: (Mark all that apply.)**

- 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): _____

12. **Current Residence:** Indicate the participant's residence at the current time.

- 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): _____

13. **Transportation Needs:**

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 Day Health Center?

- 0 - No
- 1 - Yes

Notes (optional): _____

c. How does the participant get to activities outside of the Day Health 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): _____

INFORMAL SUPPORT

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

PROVIDER: Complete items 19-22 based on your discussion with the participant and his/her informal caregiver(s).

19. **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. This may include paid family members but no other paid care providers. 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 (if so, check Primary box for all who share primary responsibility).

NA - No informal caregiver [Go to Item 23]

	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

Notes (optional): _____

20. **Caregiver Relationship to Participant:**

	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 _____

21. **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.).

	Caregiver 1	Caregiver 2	Caregiver 3
Average number of hours/day	_____	_____	_____
Average number of days/month	_____	_____	_____

Notes (optional): _____

22. **Type of Care Provided**

	Caregiver 1		Caregiver 2		Caregiver 3	
a. 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
b. 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
c. 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
d. 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
e. 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
f. 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
g. 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
h. 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
i. Other (specify):	_____		_____		_____	

PROVIDER: Ask the participant to respond to Item 23 below.

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

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

EMOTIONAL/MENTAL HEALTH STATUS

24. **Mood** (Dominant Feeling State): Ask participant to describe his/her mood over the past week. **(Mark all that apply.)**

- 1 - Depressive
- 2 - Irritable
- 3 - Anxious
- 4 - Angry
- 5 - Happy
- 6 - Content
- 7 - Neutral
- 8 - Other: _____
- UA - This information could not be obtained due to participant's cognitive impairment

Notes (optional): _____

25. **Provider Perceived Affect:** Participant's affect appears to be: **(Mark all that apply.)**

- 1 - Flat
- 2 - Depressed
- 3 - Sad
- 4 - Angry
- 5 - Restricted/Withdrawn
- 6 - Fearful
- 7 - Anxious
- 8 - Nervous
- 9 - Calm
- 10 - Happy
- 11 - Other: _____

Notes (optional): _____

26. **Anxiety:** The following two items refer to anxiety, which can be manifested in tension, nervousness, and/or apprehension. Assess the participant's anxiety in the past week.

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

- 0 - Never [Go to Item 27]
- 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):**

- 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): _____

27. **Reported or Observed Depression or Depressive Symptoms:** Based on your observation and discussion with the participant, which of the following symptoms has the participant experienced in the past week? **(Mark all that apply.)**

- 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

Notes (optional): _____

28. **Participant Stress/Concerns about Own Life:** Ask the participant the following questions.

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 29**]
- 1 - Yes Describe: _____
- UA - This information could not be obtained due to participant's cognitive impairment [**Go to Item 29**]

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

- 0 - No [**Go to Item 29**]
- 1 - Yes Describe: _____

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

29. **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.]).

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 - Describe: _____

d. Any history of abuse of alcoholic beverages:

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

Notes (optional): _____

30a. **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.)

	<u>Never</u>	<u>Once/month or less</u>	<u>Several times a month</u>	<u>Several times a week</u>	<u>Every day</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 (as indicated above), 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

31. **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.*

- 0 - Never, with no special precautions. Has not wandered away from home, the Day Health Center, or other locations and no special precautions are in place or needed.
- 1 - Never, with special precautions. Has not wandered away from home, the Day Health Center, or other locations because special precautions have been instituted, such as continuous supervision and/or secured exits.
- 2 - Seldom (once/week or less). Has wandered away from home, the Day Health Center or other locations occasionally (once a week or less) since the last assessment.
- 3 - Often (more than once/week). Has wandered away from home, the Day Health Center or other locations more than once a week since the last assessment OR wanders once a week or more from some locations, but not others.

END OF LIFE CARE

PROVIDER: Complete items 32 and 33 below based on discussion with the participant or the informal caregiver if the participant is unable to respond.

32. Does the participant have requests or **Wishes for his/her Health Care** that (PACE site) staff should know about?

0 - No

1 - Yes Describe: _____

33. **Advance Directives:**

a. Does the participant have a signed Living Will (or Advance Directive) giving directions for the kind of medical treatment desired if ever the participant could not speak for him or herself?

- 0 - No
- 1 - Yes [Obtain copy to include in medical record.] [**Go to Item c**]

b. Does the participant wish to complete a Living Will (or Advance Directive)?

- 0 - No [**Go to Item 34**] Reason refused: _____
- 1 - Yes [**Go to Item 34**]
- UA - This information could not be obtained due to participant's cognitive impairment [**Go to Item 34**]

c. Has the participant or informal caregiver discussed the Living Will (or Advance Directive) with the health care team (for example, doctors, nurses, social workers) at (PACE site)?

- 0 - No
- 1 - Yes
- NA - Discussion not possible because participant is cognitively impaired and has no informal caregiver.

Notes (optional): _____

PROVIDER: Ask the participant to respond to items 34 and 35 below.

34. **Participant/Caregiver Conflict:**

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

- 0 - No [**Go to Item 35**]
- 1 - Yes
- UA - This information could not be obtained due to participant's cognitive impairment [**Go to Item 35**]

b. Did they agree with your decisions?

- 0 - No. Please explain: _____
- 1 - Yes [**Go to Item d**]

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): _____

35. **Funeral Arrangements/Plans:**

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

- 0 - No [**Go to Item c**]
- 1 - Yes
- UA - This information could not be obtained due to participant's cognitive impairment [**Go to Item 36**]
- R - Participant refuses to discuss [**Go to Item 36**]

Notes (optional): _____

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

- 0 - No
- 1 - Yes [**Go to Item 36**]

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): _____

QUALITY OF LIFE

PROVIDER: Ask the participant to respond to Items 36 to 46.

36. **Religious/Spiritual Affiliation:** _____

37. **Cultural/Religious Affiliation:** Do you have any cultural or religious beliefs or practices that you think (PACE site) staff should know about?

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

38. Do you participate in **Religious or Spiritual Activities/Services** as much as you would like?

- 0 - Yes, I participate as much as I would like
- 1 - Somewhat - I would like to be more involved
- 2 - No, I do not currently participate as much as I would like
- NA - 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

39. **Social Activities:** How often during the past week did you attend a social, religious, or recreational activity at home or away from home? (Examples might include going to church or temple, to a party, out to dinner, watching a movie or play, or just getting together with friends or family.)

- 1 - 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

40. **Socialization/Isolation:** The next two questions are about talking to family and friends (who do not live with you).

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): _____

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

- | | | | | | |
|--------------------------|--------------------------|--|---------------------------|--------------------------|---|
| 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"/> |

42. **Satisfaction with Quality of Interaction/Contact:** How satisfied are you with the quality of the time you spend with family, friends, and others?

- | | | | | | |
|--------------------------|--------------------------|--|---------------------------|--------------------------|---|
| 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"/> |

43. **Satisfaction with Living Situation:** How satisfied are you with where you live?

- | | | | | | |
|--------------------------|--------------------------|--|---------------------------|--------------------------|---|
| 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"/> |

Notes (optional): _____

44. **Worry About Support:** Do you worry about getting the support and care you need?

- 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): _____

45. **Resolution:** Do you feel peaceful and ready to accept the future?

- 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

Notes (optional): _____

46. **Self-Rated Quality of Life:** Think about all parts of your life – your health, happiness, relationships, social activities, the religious or spiritual part of your life, and the financial part of your life. Considering all of these things, how would you rate your quality of life overall?

- 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 47 below.

47. **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.)

- 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

48. **Ability to Sustain Attention:** Assess the participant's ability to sustain attention during structured and unstructured activity.

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

Notes (optional): _____

49. **Judgment (Puts Self At Risk):** Identify the participant's ability to use judgment and make decisions that affect his/her ability to function independently.

- 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.

50. **Awareness of Own Needs:** Identify the participant's level of understanding of his/her needs relating to health, safety, and welfare.

- 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.

51. **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):

- 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.

52. **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):

- 0 - No observable impairment. 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).

53. **Recent Memory:**

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 remember when to take medications?

- 0 - No
- 1 - Yes

54. **Remote Memory:**

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**, rate remote memory level.

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

55. **Reasoning:**

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.

INFORMAL CAREGIVER ITEMS

PROVIDER: Ask the participant's primary informal caregiver (as recorded in Item 19) to respond to Items 56 to 64 below. The first two items ask about the caregiver's observations of the participant. The next items ask about the caregiver's own needs and experiences.

- NA - No informal caregiver [Skip remaining data items and complete information box at end of form.]

56. **Pain Interfering with Daily Activities:** In the past week, how often has pain gotten in the way of (participant's) normal routine? (NOTE: If [PARTICIPANT'S] level of pain has changed in the past week, answer should be based on the most recent level of pain.)

- 0 - Participant had no pain during the past week
- 1 - Pain does not get in the way of normal routine
- 2 - At times, but not every day
- 3 - Every day, but not constantly
- 4 - All of the time

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

- 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

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

59. **Caregiver Knowledge of What to Do In An Emergency:**

Instructions to Interviewer: Ask the participant's primary informal (unpaid) caregiver to respond to the following questions. **DO NOT READ THE RESPONSE OPTIONS TO THE CAREGIVER.** Simply ask the question and mark the responses given by the caregiver (without prompting). If the caregiver's response(s) are not listed, mark "Other responses" and write in the response(s) on the line provided. **If the caregiver responds "I don't know," mark "Unknown."**

a. If (PARTICIPANT) needed help in a life-threatening emergency, what would you do? **(Mark all that apply.)**

- 1 - Call 911
- 2 - Call PACE doctor
- 3 - Follow emergency instructions as provided by PACE
- 4 - Stay with (PARTICIPANT) and make sure he/she is safe until help arrives
- 5 - Adhere to advance directive
- 6 - Other responses (specify): _____
- UK - Unknown

b. If (PARTICIPANT) needed urgent care (in a non-life-threatening situation), what would you do? **(Mark all that apply.)**

- 1 - Call PACE doctor
- 2 - Follow emergency instructions as provided by PACE
- 3 - Stay with (PARTICIPANT) and make sure he/she is safe until help arrives
- 4 - Other responses (specify): _____
- UK - Unknown

c. PROVIDER: Based on the caregiver's responses to questions a and b above, do you feel the caregiver needs further education on how to respond in a life-threatening or non-life-threatening situation?

- 0 - No, knowledge appears adequate
- 1 - Yes, needs further education

60. **Managing Care:**

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

61. **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)**.

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

Notes (optional): _____

62. **Caregiver Coping:**

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

c. Would you like us to arrange respite care that would allow you time away from your caregiving responsibilities?

- 0 - No
- 1 - Yes

Notes (optional): _____

63. **Caregiver Support:** Caregiving can be difficult and challenging. Do you feel that you have adequate social and emotional support to meet your current needs?

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

Notes (optional): _____

64. **Additional Caregiver Comments/Concerns:** Are there any other issues or concerns you would like to discuss?

PROVIDER: Complete Item 65 for each caregiver listed in Item 19 in this form. If participant lives in a nursing home, skip remaining data items and complete information box at end of form.

65. Caregiver Willingness and Ability to Provide Care:

- | | | | |
|--|--|--|--|
| a. Motivated to keep participant at home/in the community | Caregiver 1 | Caregiver 2 | Caregiver 3 |
| | <input type="checkbox"/> 0 - Not Motivated | <input type="checkbox"/> 0 - Not Motivated | <input type="checkbox"/> 0 - Not Motivated |
| | <input type="checkbox"/> 1 - Somewhat Motivated | <input type="checkbox"/> 1 - Somewhat Motivated | <input type="checkbox"/> 1 - Somewhat Motivated |
| | <input type="checkbox"/> 2 - Motivated | <input type="checkbox"/> 2 - Motivated | <input type="checkbox"/> 2 - Motivated |
| | Caregiver 1 | Caregiver 2 | Caregiver 3 |
| b. Physically Capable of providing care | <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 |
| c. Emotionally Capable of providing care | <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 |

Notes (optional): _____

The following information should be completed by the PACE care provider or staff member after completing the COCOA form.

1. Estimated form completion time (in minutes): _____
2. Approximate time of day assessment completed:
 - 1 - Morning
 - 2 - Afternoon
 - 3 - Evening
3. Location where assessment was completed:
 - 1 - Day health center [**Go to Item 4**]
 - 2 - Participant residence [**Stop Here**]
4. Is this a day the participant typically attends the day health center?
 - 0 - No
 - 1 - Yes

**Please return the completed form to your site's Data Collection Coordinator.
Thank you for your participation.**