

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

**DRAFT COCOA DATA SET
END OF LIFE (EOL) QUESTIONNAIRE
WRITTEN RESPONSE VERSION**

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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Two-Site Feasibility Test

DRAFT END OF LIFE (EOL) QUESTIONNAIRE

Written Response Version

Site ID

Participant ID

1. **Date Questionnaire Completed:** ____/____/____
month day year

2. **Name of Informal Caregiver Responding to Questionnaire:**

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

3. **Name of Associated Participant:**

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

4. **Date of Participant's Death:** ____/____/____
month day year

5. **Caregiver's Relationship to Participant:**

- ☐ 1 - Spouse
- ☐ 2 - Daughter or son
- ☐ 3 - Sister or brother
- ☐ 4 - Daughter-in-law or son-in-law
- ☐ 5 - Other relative
- ☐ 6 - Friend
- ☐ 7 - Guardian or other legal appointee (specify: _____)
- ☐ 8 - Other (specify: _____)

6. **Caregiver Gender:** ☐ 1 - Male ☐ 2 - Female

7. **Caregiver Race/Ethnicity: (Mark all that apply.)**

- ☐ 1 - American Indian or Alaska Native
- ☐ 2 - Asian
- ☐ 3 - Black or African-American
- ☐ 4 - Hispanic or Latino
- ☐ 5 - Native Hawaiian or Pacific Islander
- ☐ 6 - White
- ☐ UK - Unknown

8. **Where did the PACE participant spend his/her last week of life?**

- ☐ 1 - His/her home living environment
- ☐ 2 - Hospital
- ☐ 3 - Nursing home
- ☐ 4 - Hospice
- ☐ 5 - Other (specify: _____)

Advance Directives

9. Did the PACE participant have specific wishes or plans about the types of medical treatment he/she wanted while dying?
- ☐ 0 - No [**Go to Item 12a**]
- ☐ 1 - Yes
- ☐ UK - Unknown
10. Did a doctor or other care provider talk with you or the PACE participant about these wishes?
- ☐ 0 - No
- ☐ 1 - Yes
- ☐ UK - Unknown
11. Did a doctor or other care provider make a plan with you or the PACE participant that ensured that the participant's wishes for medical treatment were followed?
- ☐ 0 - No
- ☐ 1 - Yes
- ☐ UK - Unknown
- 12a. Did the PACE participant have a signed Durable Power of Attorney for Health Care naming someone to make decisions about medical treatment if he/she could not speak for him/herself?
- ☐ 0 - No
- ☐ 1 - Yes
- ☐ UK - Unknown
- 12b. Did the PACE participant have a signed Living Will giving directions for the kind of medical treatment he/she would want if he/she could not speak for him/herself?
- ☐ 0 - No
- ☐ 1 - Yes
- ☐ UK - Unknown
13. Had you or the PACE participant discussed his/her Living Will or Durable Power of Attorney for Health Care with his/her primary care physician?
- ☐ 0 - No
- ☐ 1 - Yes
- ☐ UK - Unknown

The next two questions are about the PACE participant's last week of life.

14. During the last week of the PACE participant's life, did he/she prefer a course of treatment that focused on extending life as much as possible, even if it meant more pain and discomfort, or on a course of treatment that focused on relieving pain and discomfort as much as possible, even if that meant not living as long?
- ☐ 1 - Extend life as much as possible
- ☐ 2 - Relieve pain or discomfort as much as possible
- ☐ UK - Unknown

15. To what extent were the PACE participant's wishes followed in the medical treatment he/she received during the last week of life? Were they followed...

- ☐ 1 - A great deal
- ☐ 2 - Very much
- ☐ 3 - Moderately
- ☐ 4 - Very little
- ☐ 5 - Not at all
- ☐ UK - Unknown

Pain and Symptom Management

Please answer the following questions considering the last week of the PACE participant's life.

16. Was there any time that members of the PACE site staff did not do everything they could to help control the PACE participant's pain?

- ☐ 0 - No, never
- ☐ 1 - Yes, a few times
- ☐ 2 - Yes, many times
- ☐ NA - The participant had no pain or refused pain medication **[Go to Item 19]**

17. Did the PACE participant ever have to wait too long to receive pain medication?

- ☐ 0 - No, never
- ☐ 1 - Yes, a few times
- ☐ 2 - Yes, many times

18. Do you feel that the PACE site staff should have done more to keep the PACE participant free from pain?

- ☐ 0 - No
- ☐ 1 - Yes, a little more
- ☐ 2 - Yes, a lot more

19. For symptoms other than pain, for example shortness of breath or nausea, do you feel that the PACE site staff should have done more to keep the PACE participant comfortable?

- ☐ 0 - No
- ☐ 1 - Yes, a little more
- ☐ 2 - Yes, a lot more
- ☐ NA - The participant had no symptoms other than pain

Overall Comfort or Distress

20. In the last week of life, did the PACE participant take pain medications?

- ☐ 0 - No, he/she refused pain medication
- ☐ 1 - No, due to reasons other than refusal
- ☐ 2 - Yes

21. Taking into account medications or other types of assistance provided to the PACE participant during the last week of life, how severe were pain and other symptoms he/she experienced?

- ☐ 0 - Not at all severe
- ☐ 1 - Not very severe
- ☐ 2 - Somewhat severe
- ☐ 3 - Very severe

22. How difficult were the emotional symptoms and problems he/she experienced in the last week of life?

- ☐ 0 - Not at all difficult
- ☐ 1 - Not very difficult
- ☐ 2 - Somewhat difficult
- ☐ 3 - Very difficult

Please provide below any additional comments you have regarding the care provided by the PACE staff at the end of the participant's life:

Thank you for your participation.

Please mail this completed questionnaire and the signed consent form to the Research Center using the postage-paid envelope.