

Online supplementary material:

E4. The end of life questionnaire (ELQ) from 2011 01 01

The Swedish Palliative Register Form to be filled out in connection with the death of a person.

To be filled in by the responsible doctor or nurse. All reports are to be submitted through www.palliativ.se

1. Unit code _____ (received at registration of participation through the website www.palliativ.se)

2. Social insurance identification number _____

3. Name of the deceased _____ (used first name and surname)

4. Date of death _____

5. Date of admission to the unit where death occurred (for primary care/home care = “active home care”) _____

6. The place of death is best described as a:

- Nursing home
- Short-term care home
- Hospital ward – not palliative
- Hospice/palliative hospital ward
- Own home, with support from specialized palliative home care
- Own home, with support from basal home care
- Other _____

7. Main disease that caused death:

- Cancer
- Heart disease
- Lung disease
- Dementia
- Stroke
- Other neurological disease
- Diabetes
- Post-fracture condition
- Multimorbidity
- Other, namely _____

8. Will a forensic autopsy be performed?

- Yes, forensic autopsy
- Yes, clinical autopsy
- No

If the answer is Yes, forensic autopsy – answer only question 28-30.

If the answer is NO or Yes, clinical autopsy – continue to question 9.

9. According to the deceased’s medical history, death was

- Expected
- Not expected
- Don't know

If the answer is Yes or Don't Know, answer all the following questions.

If the answer to NO, answer only question 14, 16, 18, 28-30.

10. How long before death did the patient/person receiving care lose his/her ability of self-determination?

- Preserved ability until death.
- Hours
- Days
- Weeks
- Months or more
- Don't know

11. Has an informing "breakpoint" conversation from a doctor with the patient about impending death taken place, during the last period in life?

- Yes
- No
- Don't know

12. Did the place of death correspond with the person receiving care's/patient's latest spoken wish?

- Yes
- No
- Don't know

13 a. Did the person receiving care/patient have pressure ulcers before coming to the unit (mark the highest grade of pressure ulcer)?

- Yes, Grade 1
- Yes, Grade 2
- Yes, Grade 3
- Yes, Grade 4
- No
- Don't know

If the answer is Yes (Grade 1-4), answer question 13b.

If the answer is No or Don't Know, continue to question 14 a.

13b. Was the pressure ulcer documented?

- Yes
- No
- Don't know

14 a. Did the person receiving care/patient die with pressure ulcer (mark the highest grade of pressure ulcer)?

- Yes, Grade 1
- Yes, Grade 2
- Yes, Grade 3
- Yes, Grade 4
- No

- Don't know

If the answer is Yes (Grade 1-4), answer question 14b.

If the answer is No or Don't Know, continue to question 15 a.

14b. Was the pressure ulcer documented?

- Yes
- No
- Don't know

15 a. Did the person receiving care/patient have oral health inspection during the last week of life?

- Yes
- No
- Don't know

If the answer is Yes, answer question 15b.

If the answer is No or Don't Know, continue to question 16.

15 b. At the inspection of oral health, any abnormal findings that were noticed?

- Yes
- No
- Don't know

If the answer is Yes, answer question 15c.

If the answer is No or Don't Know, continue to question 16.

15c. Was the oral health inspection documented?

- Yes
- No
- Don't know

16. Was there anyone present at the moment of death?

- Yes, Next of kin
- Yes, Next of kin and Staff
- Yes, Staff
- No one
- Don't know

17. Has an informing "breakpoint" conversation from a doctor with the patient's next of kin about the about the impending death of the patient and that the care was focused on improving quality of life and symptom management, taken place during the last period in life?

- Yes
- No
- Don't know
- No Next of kin.

18. Have the next of kin had or will they be offered a follow-up appointment 1-2 months after death?

- Yes
- No
- Don't know
- No Next of kin.

19. Did the person receiving care/patient had parenteral fluids or nasogastric tube feeding of fluids or nutrition during the last day of life?

- Yes
- No
- Don't know

20. Were any of the following symptoms (20 a-f) prevalent at some time during the last week of life?

20a. Pain

- Yes
- No
- Don't know

If the answer is Yes, answer the following question.

If the answer is No or Don't Know, continue to question 20b.

Relief from pain:

- Relieved
- Partially relieved
- Unrelieved

20b. Death rattle

- Yes
- No
- Don't know

If the answer is Yes, answer the following question.

If the answer is No or Don't Know, continue to question 20c.

Relief from death rattle:

- Relieved
- Partially relieved
- Unrelieved

20c. Nausea

- Yes
- No
- Don't know

If the answer is Yes, answer the following question.

If the answer is No or Don't Know, continue to question 20d.

Relief from nausea:

- Relieved
- Partially relieved
- Unrelieved

20d. Anxiety

- Yes
- No
- Don't know

If the answer is Yes, answer the following question.

If the answer is No or Don't Know, continue to question 20e.

Relief from anxiety:

- Relieved
- Partially relieved
- Unrelieved

20e. Breathlessness

- Yes
- No
- Don't know

If the answer is Yes, answer the following question.

If the answer is No or Don't Know, continue to question 20f.

Relief from breathlessness:

- Relieved
- Partially relieved
- Unrelieved

20f. Confusion

- Yes
- No
- Don't know

If the answer is Yes, answer the following question.

If the answer is No or Don't Know, continue to question 21.

Relief from confusion:

- Relieved
- Partially relieved
- Unrelieved

21. Have a VAS, NRS scale or another validated scale for pain assessment been used for evaluation of pain during the last week of the patient's life?

- Yes
- No
- Don't know

22. Did the person receiving care/patient had severe pain during the last week of life (for example VAS>6 or severe pain according to another validated scale for pain assessment)?

- Yes
- No
- Don't know

23. Have a VAS, NRS scale or another validated scale for symptom assessment been used for evaluation of patients other symptoms during the last week of the patient's life?

- Yes
- No
- Don't know

24. Was medication prescribed for use as needed in the form of injections before death, for:

- Opioids for pain

- Yes
- No
- Don't know

- Death rattle

- Yes
- No
- Don't know

- Nausea

- Yes
- No
- Don't know

- Anxiety

- Yes
- No
- Don't know

25. How long time before death, did a doctor visit/examine the patient/person receiving care?

- Days
- Weeks
- Months or more
- Don't know

26. Has special competence outside the team/ward been consulted regarding the patient's not completely alleviated symptoms?

- Yes, pain unit
- Yes, palliative team
- Yes, other hospital unit
- Yes, paramedics
- Yes, spiritual representative
- No
- Don't know

27. Are you content with the end-of- life care provided for the person receiving care/patient?

- 1 (Not at all)
- 2
- 3
- 4
- 5 (Completely)

28. Date the questions were answered _____

29. The questionnaire is answered by

- Single staff
- In a group

30. Responsible informant (name) _____

- Doctor
- Nurse
- Other staff

E-mail address _____