

English version of the questionnaire used for registering deaths in the Swedish Register of Palliative Care since January 1st 2018

1. Unit identification code _____
2. Personal identity number of the deceased person _____
3. First and last name of the deceased person _____
4. Date of death (year/month/day) _____ Time of death (hour/minute)
(Optional data) _____
- 5a. Date (year/month/day) when the person was admitted to the unit where the death occurred (for home care, please state the date when home care was initiated)

- 5b. Admitted from:
 - Nursing home – permanent stay
 - Nursing home – short-term stay
 - Hospital ward (not hospice/palliative in-patient care)
 - Hospice/palliative in-patient care
 - Own home with support from specialised palliative home-care team
 - Own home with support from general palliative home-care team
 - Own home with daily support from home care service
 - Own home without support
 - Other, specify _____
6. The place of death is best described as:
 - Nursing home – permanent stay
 - Nursing home – short-term stay
 - Hospital ward (not hospice/palliative in-patient care)
 - Hospice/palliative in-patient care
 - Own home with support from specialised palliative home-care team
 - Own home with support from general palliative home-care team
 - Own home with daily support from home care service
 - Own home without support
 - Other, specify _____
- 7 a. Disease/basic state that caused the death (more than one answer is possible):
 - Cancer
 - Cardiovascular disease
 - Respiratory disease
 - Dementia
 - Stroke
 - Other neurological disease
 - Diabetes

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- State after fracture
- Multimorbidity
- Infection
- Other, namely: _____

8. Based on the disease trajectory, was the death expected?

- Yes
- No
- Don't know

If the answer is Yes or Don't know, answer all the following questions. If the answer is No, answer only questions 13, 15, 17, 27-29.

9. How long before death did the person lose the ability to express his/her will and take part in decisions concerning the content of medical care?

- Retained ability until end of life
- Hour/hours
- Day/days
- Week/weeks
- Month or more
- Has never had the ability
- Don't know

10 a. Do the medical records include a documented decision by the physician responsible to shift treatment/care to end-of-life care?

- Yes, in free text
- Yes, as a classification code
- No
- Don't know

10 b. Did the person receive information about the transition to end-of-life care, i.e. an individually tailored and informed conversation with a physician that is documented in the medical records about being in the final stage of life and about care being focused on quality of life and symptom relief?

- Yes
- No
- No, lacks the ability to participate
- No, offered but declined
- No, guardian opposes
- Don't know

11. Was the person's last expressed wish about place of death known?

- Yes
- No
- Don't know

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12 a. Did the person have pressure ulcers upon arrival at your unit (specify highest category occurring)?

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

If the answer is Yes (category 1-4), answer question 12B.

If the answer is No or Don't know, skip to question 13A.

12 b. Were the pressure ulcers documented?

- Yes
- No
- Don't know

13 a. Did the person die with pressure ulcers (specify highest category occurring)?

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

If the answer is Yes (category 1-4), answer question 13B.

If the answer is No or Don't know, skip to question 14A.

13 b. Were the pressure ulcers documented?

- Yes
- No
- Don't know

14 a. Was the person's oral health assessed and documented at any time during the last week of life?

- Yes
- No
- Don't know

If the answer is Yes, answer question 14B.

If the answer is No or Don't know, skip to question 15.

14 b. Was any disorder noted during assessment?

- Yes
- No
- Don't know

15. Was anyone present at the time of death?

- Yes, close friend(s) or relative(s)
- Yes, close friend(s)/relative(s) and staff

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- Yes, staff
- No
- Don't know

16. Did the person's close friend(s)/relative(s) receive information about transition to end-of-life care, i.e. an individually tailored and informed conversation with a physician that is documented in the medical records about being in the final stage of life and about care being focused on quality of life and symptom relief?

- Yes
- Yes, offered but declined
- No
- Don't know
- Had no close friend(s)/relative(s)

If the answer is Yes, No or Don't know, go to question 17.

If the answer is Had no close friend(s)/relative(s), skip to question 18.

17. Was/were the person's close friend(s)/relative(s) offered a follow-up talk within 1-2 months of the death?

- Yes
- No
- Don't know

18. Did the person receive parenteral fluids/nutrition or enteral-tube feeding during the last 24 hours of life?

- Yes
- No
- Don't know

19. Did the person display breakthrough of any of the following symptoms (19A-F) at any time during the last week of life?

- 19 a.** Pain Yes No Don't know

If the answer is Yes, answer the following question.

If the answer is No or Don't know, skip to question 19B.

Pain was relieved: Completely Partially Not at all

- 19 b.** 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, skip to question 19C.

Death rattle was relieved: Completely Partially Not at all

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19 c. Nausea Yes No Don't know

**If the answer is Yes, answer the following question.
If the answer is No or Don't know, skip to question 19D.**

Nausea was relieved: Completely Partially Not at all

19 d. Anxiety Yes No Don't know

**If the answer is Yes, answer the following question.
If the answer is No or Don't know, skip to question 19E.**

Anxiety was relieved: Completely Partially Not at all

19 e. Dyspnoea Yes No Don't know

**If the answer is Yes, answer the following question.
If the answer is No or Don't know, skip to question 19F.**

Dyspnoea was relieved: Completely Partially Not at all

19 f. Confusion Yes No Don't know

**If the answer is Yes, answer the following question.
If the answer is No or Don't know, skip to question 20.**

Confusion was relieved: Completely Partially Not at all

20. Was the person's pain assessed at any documented time during the last week of life using VAS, NRS or another pain-assessment tool?

Yes No Don't know

21. Did the person experience severe pain at any time during the last week of life (e.g. VAS/NRS > 6 or severe pain according to another pain-assessment tool)?

Yes No Don't know

22. Were the person's other symptoms assessed at any time during the last week of life using VAS, NRS or another symptom-assessment tool?

Yes No Don't know

23. Was there an individual prescription of injectable PRN drugs on the drug list before death?

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- Opioids against pain Yes No Don't know
- Drugs against death rattle Yes No Don't know
- Drugs against nausea Yes No Don't know
- Drugs against anxiety Yes No Don't know

24. How long before death was the person last examined by a physician?

- Day/days
 Week/weeks
 Month or more
 Don't know

25. Were specialists outside the team/ward consulted concerning the person's symptom relief during the last week of life (more than one answer option is possible)?

- Yes, pain clinic
 Yes, palliative-care team
 Yes, other hospital unit
 Yes, social worker/physiotherapist/occupational therapist/dietician
 Yes, spiritual counsellor
 No
 Don't know

26. How satisfied is the team with the care delivered to the person during the last week of life?

- 1 = Not at all 2 3 4 5 = Completely

27. Date (year/month/day) of answering the questions _____

28. The questionnaire was answered by :

- A single employee Staff jointly

29. Name and occupation of registrant _____

- Physician Nurse Other staff

e-mail address _____