



English version of the questionnaire used for registering deaths in the Swedish Register of Palliative Care since January 1st, 2022

1. Unit identification code _____

Identification:

- Correct personal identity number
- Temporary identity number

2. Temporary identity number _____

If the answer is TEMPORARY IDENTITY NUMBER answer questions 2 b and 2 c.

2 b. Sex:

- Male
- Female
- Unknown

2 c. Age _____

3. First and last name of the deceased person _____

4. Date of death _____

5 a. Date when the person was admitted to the unit where the death occurred _____

5 b. Admitted from:

- Nursing home – permanent stay/accommodation for disabled (LSS)
- Nursing home – short-term stay
- Hospital: ward/patient facility/ICU (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 home-care team
- Own home with support from home care service
- Own home without support
- Other

6. The place of death is best described as:

- Nursing home – permanent stay/ accommodation for disabled (LSS)
- Nursing home – short-term stay
- Hospital: ward/patient facility/ICU (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 support from home care service

- Own home without support
- Other

7 a. Disease/basic state that caused the death (more than one answer is possible):

- Cancer
- Cardiovascular disease
- Respiratory disease
- Cognitive disorder (dementia)
- Stroke
- Other neurological disease
- Diabetes
- State after fracture
- Multimorbidity
- Infection
- Other

7 b. Did the person have an ongoing or previous Covid-19 infection?

- No
- Yes, ongoing infection
- Suspected ongoing infection
- Previous infection (fallen ill/positive test) within 30 or fewer days before death
- Previous infection (fallen ill/positive test) more than 30 days before death
- Unknown

8. Do the medical records include a documented decision by the physician responsible (in free text or as a classification code) to shift treatment/care to end-of-life care?

- Yes
- No
- Don't know

9. Was there a documented individual care plan for end-of-life care?

- Yes
- No
- Don't know

10. 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

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

11. Did the person's next of kin(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

- Yes
- No
- No, offered but declined
- Had no known close friend(s)/relative(s)

- Don't know

12. 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

13. Where did the person wish to die?

- Own home
- Nursing home – permanent stay/short-term stay/ accommodation for disabled (LSS)
- Hospital (not hospice/palliative in-patient care)
- Hospice/palliative in-patient care
- The person had no expressed desire
- The person could not express his wish
- Other
- Wishes were not asked for

14 a. 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

14 b. 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

15. Did the person display breakthrough of any of the following symptoms (15A-F) at any time during the last week of life?

15 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 15 b.

Pain was relieved:

- Completely
- Partially
- Not at all
- Don't know

15 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 15 c.

Death rattle was relieved:

- Completely
- Partially
- Not at all
- Don't know

15 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 15 d.

Nausea was relieved:

- Completely
- Partially
- Not at all
- Don't know

15 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 15 e.

Anxiety was relieved:

- Completely
- Partially
- Not at all
- Don't know

15 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 15 f.

Dyspnoea was relieved:

- Completely

- Partially
- Not at all
- Don't know

15 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 16.

Confusion was relieved:

- Completely
- Partially
- Not at all
- Don't know

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

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

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

- Yes, stage 1
- Yes, stage 2
- Yes, stage 3
- Yes, stage 4
- Yes, not classifiable
- Yes, suspected deep skin damage
- No
- Don't know

17 b. Did the person die with pressure ulcers (specify highest stage occurring)?

- Yes, stage 1
- Yes, stage 2
- Yes, stage 3
- Yes, stage 4
- Yes, not classifiable
- Yes, suspected deep skin damage
- No
- Don't know

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

- Yes
- No
- Don't know

19. Did the person receive parenteral fluids/nutrition during the last 24 hours of life?

- Yes
- No
- Don't know

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

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

21. Were specialists outside the team/ward consulted concerning the person's symptom relief during the end 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
- Other
- No
- Don't know

22. Was anyone present at the time of death?

- Yes, close friend(s) or relative(s)
- Yes, close friend(s)/relative(s) and staff
- Yes, staff
- No
- Don't know

23. Was/were the person's next of kin(s) offered a follow-up talk?

- Yes
- No
- Don't know
- Had no known close friend(s)/relative(s)

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

- Yes
- No
- Don't know

25. 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

26. The questionnaire was answered by:

- A single employee
- Staff jointly

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