



*English version of the questionnaire used for registering deaths in the Swedish Register of Palliative Care since January 1st, 2024*

**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
- ☐ Other

**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:

- ☐ Own home
- ☐ Nursing home – permanent stay/accommodation for people with disabilities (LSS)
- ☐ Nursing home – short-term stay
- ☐ Hospital: ward/patient facility/ICU (not hospice/palliative in-patient care)
- ☐ Hospice/palliative in-patient care
- ☐ Other

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

- ☐ Own home (answer questions 6b and 6c)
- ☐ Nursing home – permanent stay/accommodation for people with disabilities (LSS) (answer question 6b)
- ☐ Nursing home – short-term stay (answer question 6b)
- ☐ Hospital: ward/patient facility/ICU (not hospice/palliative in-patient care)
- ☐ Hospice/palliative in-patient care
- ☐ Other (answer question 6b)

**6b.** The care was provided by (more than one answer is possible):

- ☐ Specialised palliative care
- ☐ General home care
- ☐ Nothing known

**6c. Provision of in-home services?**

- ☐ Yes
- ☐ No
- ☐ Don't know

**7. 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
- ☐ Multimorbidity
- ☐ Infection
- ☐ Other

**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

**If the answer is Yes, answer question 9b.****9b. Type of care plan (more than one answer is possible):**

- ☐ The Swedish Palliative Care Guide
- ☐ Standardized care plan
- ☐ Social care plan

**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
- ☐ No, but from another staff member in the (health) care team
- ☐ 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

- ☐ No, but from another staff member in the (health) care team
- ☐ 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/accommodation for people with disabilities (LSS)
- ☐ Nursing home – short-term stay
- ☐ Hospital: ward/patient facility/ICU (not hospice/palliative in-patient care)
- ☐ Hospice/palliative in-patient care
- ☐ Other
- ☐ The person had no expressed desire
- ☐ The person could not express his wish
- ☐ 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       | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Don't know |
| Drugs against death rattle | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Don't know |
| Drugs against nausea       | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Don't know |
| Drugs against anxiety      | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> 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 \_\_\_\_\_