



*English version of the questionnaire used for registering deaths in the  
Swedish Register of Palliative Care since February 8th 2021*

1. Unit identification code \_\_\_\_\_

Type of personal identity number:

- ☐ Correct personal identity number
- ☐ Temporary identity number

2. Personal/temporary identity number of the deceased person \_\_\_\_\_

**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 (year/month/day) \_\_\_\_\_ Time of death (hour/minute) (Optional data)  
\_\_\_\_\_

5 a. 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) \_\_\_\_\_

**5 b. 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 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
- ☐ State after fracture
- ☐ Multimorbidity
- ☐ Infection
- ☐ Other, namely: \_\_\_\_\_

**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

**7 c.** Have tests for Coronavirus (SARS-coronavirus-2) been taken?

- ☐ Not taken
- ☐ Negative test
- ☐ Positive test
- ☐ Taken, results not yet received
- ☐ Unknown

**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

**12 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
- ☐ No
- ☐ Don't know

**If the answer is Yes (stage 1-4), answer question 12 b.**

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

**12 b.** Were the pressure ulcers documented?

- ☐ Yes
- ☐ No
- ☐ Don't know

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

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

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

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

**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 14 b.**

**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  
☐ Yes, staff  
☐ No  
☐ Don't know

**16.** 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 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 next of kin(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 19 b.**

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 19 c.**

Death rattle was relieved: ☐ Completely ☐ Partially ☐ Not at all

- 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 19 d.**

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 19 e.**

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 19 f.**

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?**

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 \_\_\_\_\_