

End-of-life questionnaire 01 01 2026

Further information about the questions can be accessed by clicking the  symbol in the digital end-of-life questionnaire after logging in.

1. Name of unit _____

Identification using:

- Personal identity number
- Temporary identity number

2a. Personal identity/temporary number _____

Enter the deceased person's personal identity number using 12 digits, i.e. including the century digits, e.g. 19121212-1212, or the deceased person's temporary number.

If the answer is temporary identity number, also answer 2b and 2c.

2b. Gender

- Male
- Female
- Other

2c. Age _____

3. First and last name of the deceased person _____

4. Date of death _____

Enter the date on which the person died, using eight digits in the format YYYY-MM-DD, for example 2026-01-01.

5a. Date of admission to the unit where death occurred _____

Enter the date on which the person was admitted to the unit or, in the case of municipal accommodation, moved in, using eight digits in the format YYYY-MM-DD, for example 2025-09-08.

In the case of home care, the date on which active home healthcare was initiated.

5b. Admitted from:

- Own home (also answer 5c)
- Nursing home/care home/group home/service apartments (LSS)
- Short-term nursing home
- Hospital: ward/clinic/ICU (not specialised palliative inpatient care)
- Specialist palliative inpatient care
- Other

Own home = Living in own home, summer residence, apartment, senior housing or assisted housing.

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Nursing home/care home/ group home/service apartments (LSS) = Accommodation providing full-time residence together with care and assistance. Needs are assessed individually and accommodation is provided on the basis of the Swedish Social Services Act or the Swedish Act on Support and Service for Certain Disabled Persons.

Short-term nursing home = A bed not at the person's own home, intended for the provision of temporary care and assistance around the clock. Select this for all forms of temporary, short-term places used to relieve the burden on care units, whether provided by municipalities or private organisations.

Hospital: ward/clinic/ICU (not specialist palliative inpatient care) = All types of inpatient care **except** specialist palliative inpatient care, which has a separate option.

Specialist palliative inpatient care = Units providing mainly specialist palliative inpatient care, whether located in a hospital or as a separate unit not connected to a hospital.

Other = Select this if none of the above options are suitable, for example in the case of unhoused people or people with unknown circumstances as regards housing.

5c. Was the person receiving care in their own home (multiple answers possible):

- Yes, specialist palliative care
- Yes, general home care
- No
- Not known

Specialist palliative care = Care provided by a specialist palliative care unit, consisting of a multi-professional team able to meet the needs of complex symptoms that are not alleviated by the primary healthcare measures taken. (The multi-professional team includes specialised staff with specific training in palliative care).

General home care = Care provided in the person's home or equivalent. Measures/interventions must have been preceded by healthcare and care planning.

No = The person was not being provided with care, except unpaid care from relatives or close friends.

Not known = It is not known what care the person was receiving, if any.

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

- Own home (also answer 6b + 6c)
- Nursing home/care home/group home/service apartments (LSS)
- Short-term nursing home
- Hospital: ward/clinic/ICU (not specialised palliative inpatient care)
- Specialist palliative inpatient care
- Other (also answer 6b)

Own home = Living in own home, summer residence, apartment, senior housing or assisted housing.

Nursing home/care home/group home/service apartments (LSS) = Accommodation providing full-time residence together with care and assistance. Needs are assessed individually, and accommodation is provided on the basis of the Swedish Social Services Act or the Swedish Act on Support and Service for Certain Disabled Persons.

Short-term nursing home = A bed not at the person's own home, intended for the provision of temporary care and assistance around the clock. Select this for all forms of temporary, short-term places used to relieve the burden on care units, whether provided by municipalities or private organisations.

Hospital: ward/clinic/ICU (not specialised palliative inpatient care) = All types of inpatient care **except** specialist palliative inpatient care, which has a separate option.

Specialist palliative inpatient care = Units providing mainly specialist palliative inpatient care, whether located in a hospital or as a separate unit not connected to a hospital.

Other = Select this if none of the above options are suitable, for example in the case of unhoused people or people with unknown circumstances as regards housing.

6b. Care provided by (multiple answers possible):

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- Specialist palliative care
- General home care
- No professional party
- Not known

Specialist palliative care = Care provided by a specialist palliative care unit, consisting of a multi-professional team able to meet the needs of complex symptoms that are not alleviated by the primary healthcare measures taken. The multi-professional team includes specialised staff with specific training in palliative care.

General home care = Care provided in the person's home or equivalent. Measures/interventions must have been preceded by healthcare and care planning.

No professional party = The person was not having any healthcare or other care provided by healthcare professionals. If the person was just being given home help, select this option.

Not known = It is not known what care the person was receiving, if any.

6c. Was a home care service being provided?

- Yes
- No
- Not known

Home care service = Help/assistance in the form of service and personal care in one's own home. Also includes personal assistance and housing support.

7. The person's underlying condition/disease that resulted in death (multiple answers possible):

- Cancer
- Cardiovascular disease
- Respiratory disease
- Cognitive disorder (dementia)
- Stroke
- Other neurological disease
- Multimorbidity
- Infection
- None of the above (person died of other causes)

The underlying condition(s) that resulted in death. Select multimorbidity if several diseases combined resulted in death rather than one specific underlying condition.

8. Was the death expected based on the person's medical history?

- Completely unexpected
- Known disease/condition, but death was not expected within one year
- Known disease/condition and death was expected within one year
- Completely expected, with steady deterioration; death was expected within one month

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- Not known

Completely unexpected = The death was unexpected, e.g. road accident, suicide, sudden cardiac arrest, stroke without previous signs of illness.

Known disease/condition, but death was not expected within one year = The disease/condition was known, but death from it was not expected within the next year. Serious disease e.g. cognitive disorder, heart failure, COPD, cancer with a good response to treatment but with a high level of functioning, the person was 'self-sufficient', and the disease was stable.

Known disease/condition and death was expected within one year = Disease/condition was known and death was expected within the next year, e.g. advanced cognitive disorder, severe heart failure, severe COPD.

Completely expected, with steady deterioration, death was expected within one month = Death was expected, e.g. advanced cancer, life support actions discontinued (ICU, dialysis), infections in people with severe cognitive disorders.

Not known = It is not known whether the death was expected or unexpected.

9. Was there a documented medical decision (entered as free text or a code) in the person's medical records stating that care provision was being transitioned to end-of-life palliative care?

- Yes
 No
 Not known

Documented conversation with a physician: The physician in charge has decided that the care provided should now focus on end-of-life palliative care. The decision should be documented in the person's medical records as a classification code, e.g. ICD-10 "Z51.5" or as free text with an appropriate searchable heading, e.g. "end-of-life care", "planning".

Select No if there is a decision but no documentation.

Select Not known if access to medical records is not possible.

10a. Was there a documented individual end-of-life care plan?

- Yes
 No
 Not known

Personalised care plan: The personalised end-of-life care plan should include planning for how the person's palliative care needs can be routinely identified, assessed and addressed.

A care plan describing the person's health and medical condition from a general perspective is **NOT** considered to be a personalised end-of-life care plan. General perspective in this case means, for example, monitoring for chronic diseases, diabetes checks, blood pressure.

Select Not known if access to medical records is not possible.

If the answer is YES, also answer 10b.

10b. Type of care plan (multiple answers possible):

- Swedish Palliative Care Guide (S-PCG)
 Standardised care plan
 Social care implementation plan

Swedish Palliative Care Guide (S-PCG) = The Swedish Palliative Care Guide is a person-centric aid for identifying, assessing and addressing the specific palliative care needs of individual patients. Select this option if specifically the Swedish Palliative Care Guide was used. For more information, see the Register's website.

Standardised care plan = (in the healthcare system:) A pre-determined healthcare and care plan, based on a

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systematically developed knowledge base, describing recommended healthcare measures for **end-of-life care**.

Select this option if a standardised care plan for end-of-life care was used but it was NOT the S-PCG.

Social care implementation plan = (in the social services system:) A care and support plan describing how the end-of-life care decided upon will be implemented for the individual person in practical terms.

11. Did the person have one or more **serious illness conversations** with healthcare professionals, i.e. an individually tailored conversation documented in the person's medical records, in which the content of further care was discussed based on the person's health condition, needs and wishes?

- Yes, at the unit where the person died
- Yes, at another unit
- No
- No, unable to participate
- No, was offered but declined
- No, objection by guardian
- Not known

Yes, at the unit where the person died = It is documented in the person's medical records that the person had a serious illness conversation at the unit where the person died.

Yes, at another unit = It is documented in the person's medical records, in a record to which the end-of-life care team has access, that the person had a serious illness conversation at a unit other than the one at which the person died, either as part of the same care episode or previously.

No = There is no documentation stating that a serious illness conversation has taken place.

No, unable to participate = It is documented in the person's medical records that the person lacks sufficient capacity, for example in the case of a long-term severe cognitive disorder and is unable to participate in a serious illness conversation. Select this option also for young children.

No, was offered but declined = It is documented in the person's medical records that the person was offered a serious illness conversation but declined the offer.

No, objection by guardian = It is documented in the person's medical records that the person's guardian(s) e.g. parents object(s) to the person participating in a serious illness conversation.

Not known = Access to medical records is not possible.

12. Did the person have an **end-of-life conversation**, i.e. an individually tailored conversation documented in the person's medical records in which the physician provided information about transition to end-of-life palliative care?

- Yes
- No
- No, unable to participate
- No, was offered but declined
- No, objection by guardian
- No, but with another healthcare professional
- Not known

Yes = It is documented in the person's medical records that the person had an end-of-life conversation regarding the transition to end-of-life palliative care.

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No = It is not documented in the person's medical records that the person had an end-of-life conversation regarding the transition to end-of-life palliative care. If an end-of-life conversation was held but not documented, select this option.

Also to be selected in the case of unexpected deaths where life-saving efforts were made, for example.

No, unable to participate = It is documented in the person's medical records that the person lacks sufficient capacity, i.e. has insufficient consciousness or is cognitively impaired, and is therefore unable to participate in an end-of-life conversation regarding the transition to end-of-life palliative care. Select this option for infants as well.

No, was offered but declined = It is documented in the person's medical records that the person was offered an end-of-life conversation regarding the transition to end-of-life palliative care but declined the offer.

No, objection by guardian = It is documented in the person's medical records that the person's guardian(s) object(s) to the person having an end-of-life conversation regarding the transition to end-of-life palliative care.

No, but with another healthcare professional = It is documented in the person's medical records that a conversation was held with the person regarding the transition to end-of-life palliative care, but the conversation was with a member of staff who is NOT a doctor.

Not known = It is not known whether or not the person had an end-of-life conversation regarding the transition to end-of-life palliative care.

13. Did any of the person's relatives or close friends i.e. next of kin have one or more **serious illness conversations** with healthcare professionals, i.e. an individually tailored conversation documented in the person's medical records, in which the content of further care was discussed based on the person's health condition, needs and wishes?

- Yes, at the unit where the person died
- Yes, at another unit
- No
- No, was offered but declined
- Had no known relatives/close friends
- Not known

Yes, at the unit where the person died = It is documented in the person's medical records that the person's relatives/close friends had a serious illness conversation at the unit where the person died.

Yes, at another unit = It is documented in the person's medical records, in a record to which the end-of-life care team has access, that the person's relatives/close friends had a serious illness conversation at a unit other than the one at which the person died, either as part of the same care episode or previously.

No = There is no documentation stating that a serious illness conversation has taken place.

No, was offered but declined = It is documented in the person's medical records that the person's relatives/close friends were offered a serious illness conversation but declined the offer.

Had no known relatives/close friends = The person had no known relatives/close friends.

Not known = It is not known whether or not relatives/close friends received a serious illness conversation.

14. Did the person's relatives/close friends i.e. next of kin have an **end-of-life conversation**, i.e. an individually tailored conversation documented in the person's medical records in which the physician provided information about transition to end-of-life palliative care?

- Yes
- No
- No, was offered but declined

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- No, but with another healthcare professional
- Had no known relatives/close friends
- Not known

Yes = It is documented in the person's medical records that relatives/close friends had an end-of-life conversation regarding the transition to end-of-life palliative care.

No = It is not documented in the person's medical records that relatives/close friends had an end-of-life conversation regarding the transition to end-of-life palliative care. If an end-of-life conversation was held but not documented, select this option.

No, was offered but declined = It is documented in the person's medical records that relatives/close friends were offered an end-of-life conversation regarding the transition to end-of-life palliative care but declined this offer.

No, but with another healthcare professional = It is documented in the person's medical records that a conversation was held with relatives/close friends regarding the transition to end-of-life palliative care, but the conversation was with a member of staff who is NOT a physician.

Had no known relatives/close friends = The person had no known relatives/close friends.

Not known = It is not known whether or not relatives/close friends had an end-of-life conversation regarding the transition to end-of-life palliative care.

15. How long before death did the person lose the capacity to express their wishes and to participate in decisions about their care?

- Maintained this capacity until the end of life
- Hours
- Days
- Weeks
- A month or more/never had the capacity to make decisions/has not had the capacity to make decisions since admission
- Not known

The capacity to express one's wishes can take the form of saying yes/no to matters or asking for e.g. symptom alleviation or nursing interventions, or expressing specific wishes regarding e.g. visits, food/drink, sleep.

16. Where did the person wish to die?

- A preference was not asked for
- The person had no preference
- The person could not express their preference
- Own home
- Nursing home/care home/group home/service apartments (LSS)
- Short-term nursing home
- Hospital: ward/clinic/ICU (not specialised palliative inpatient care)
- Specialist palliative inpatient care
- Other location

Select the option that best matches the person's preference.

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A preference was not asked for = The information was not asked for, perhaps because the person died suddenly, or gave the impression of not wanting to discuss death.

The person had no preference = In response to a question asked by healthcare professionals, or spontaneously, the person stated that they had no preference.

The person could not express their preference = The person had lost the capacity to express their wishes and participate in decisions. Select this also for people who have never had the capacity to express their wishes, such as children.

Own home = Living in own home, summer residence, apartment, senior housing or assisted housing.

Nursing home/care home/group home/service apartments (LSS) = Accommodation providing full-time residence together with care and assistance. Needs are assessed individually and accommodation is provided on the basis of the Swedish Social Services Act or the Swedish Act on Support and Service for Certain Disabled Persons.

Short-term nursing home = A bed not at the person's own home, intended for the provision of temporary care and assistance around the clock. Select this for all forms of temporary, short-term places used to relieve the burden on care units, whether provided by municipalities or private organisations.

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Other location = Select this if none of the above options are suitable.

17a. Was the person's pain assessed at any documented time during the last week of life, using VAS, NRS or any other pain assessment tool?

- Yes
- No
- Not known

Even if pain was assessed indirectly using an indirect pain assessment tool, such as assessment by staff using IPOS, Yes should be selected. If the pain was assessed but not documented in the medical records, select No.

17b. Were the person's other symptoms assessed at any documented time during the last week of life, using VAS, NRS or any other symptom assessment tool?

- Yes
- No
- Not known

The use of another assessment tool also applies in cases in which the person cannot communicate their symptoms themselves, but the assessment of symptoms was instead made indirectly. Other symptoms can include nausea, unease/anxiety, breathlessness (dyspnoea) and confusion/delirium, and include all symptoms that cause discomfort or suffering and are systematically tracked using assessment, evaluation, actions and monitoring.

If a symptom was assessed, but not documented in the medical records, select No.

If the answer selected is YES, also answer 17c.

17c. Which symptom was assessed (multiple answers possible):

- Nausea
- Anxiety/distress
- Breathlessness (dyspnoea)
- Other (free text)

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Other (free text) = State here if any other symptoms, such as itching, diarrhoea, constipation, hallucinations or thirst, were assessed using a symptom assessment tool during the last week of life, and the results documented.

18. Did the person experience any of the following symptoms (18a – f) at any time during their last week of life?

18a. Pain

The pain was alleviated

- Yes
- No
- Not known

If YES



- Completely
- Partially, and the person was assessed as satisfied
- Partially, but the person was still assessed as in discomfort/distress
- Not at all
- Not known

18b. Death rattle

The death rattle was alleviated

- Yes
- No
- Not known

If YES



- Completely
- Partially, and the person was assessed as satisfied
- Partially, but the person was still assessed as in discomfort/distress
- Not at all
- Not known

18c. Nausea

The nausea was alleviated

- Yes
- No
- Not known

If YES



- Completely
- Partially, and the person was assessed as satisfied
- Partially, but the person was still

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assessed as in
discomfort/distress

- Not at all
- Not known

18d. Unease/Anxiety

- Yes
- No
- Not known

If YES



The unease/anxiety was alleviated

- Completely
- Partially, and the person was assessed as satisfied
- Partially, but the person was still assessed as in discomfort/distress
- Not at all
- Not known

18e. Breathlessness (dyspnoea)

- Yes
- No
- Not known

If YES



The breathlessness (dyspnoea) was alleviated

- Completely
- Partially, and the person was assessed as satisfied
- Partially, but the person was still assessed as in discomfort/distress
- Not at all
- Not known

18f. New-onset confusion/delirium

- Yes
- No
- Not known

If YES



The confusion/delirium was alleviated

- Completely

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- Partially, and the person was assessed as satisfied
- Partially, but the person was still assessed as in discomfort/distress
- Not at all
- Not known

State end-of-life confusion/delirium for new-onset conditions affecting awareness of reality, disorientation and ability to concentrate, with or without restlessness. Note that this does not refer to cognitive disorders, only to new-onset confusion/delirium.

If there was onset of a symptom, with the person being in discomfort/distress or judged to be in discomfort/distress at any time during the last week of life, select Yes.

As a result of the measure/intervention, the person experienced alleviation of the symptom.

Completely = The alleviation of the symptom had full effect, and the person no longer suffered from the symptom.

Partially, and the person was assessed as satisfied = The symptom alleviation was effective, although the symptom still remained to some extent. However, the person was judged to be satisfied, content, and the symptom was at an acceptable level for the person.

Partially, but the person was still assessed as in discomfort/distress = The symptom alleviation was partially effective, but the person was still assessed to be in discomfort/distress from the symptom; the symptom was NOT at an acceptable level for the person.

Not at all = The symptom alleviation had no effect.

Not known = It is not known whether or not the stated symptom was alleviated.

19. Was there an individual prescription of injectable PRN medications on the medication list before death?

Opioids for pain

- Yes
- No
- Not known

Medication for death rattle

- Yes
- No
- Not known

Medication for nausea

- Yes
- No
- Not known

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Anti-anxiety medication

- Yes
- No
- Not known

In cases where the person is a child and has another route of administration, e.g. via a feeding tube for rescue medication, this is equated with injection.

20a. Did the person have a pressure ulcer on arrival at your unit (state the highest category present)?

- Yes, category 1
- Yes, category 2
- Yes, category 3
- Yes, category 4
- Yes, unstageable
- Yes, suspected deep tissue injury
- No
- Not known

In the event of there being several pressure ulcers, the highest category should be stated.

Note that arrival at the unit may have taken place long before death occurred; this can be seen in the Swedish Register of Palliative Care's calculation of length of care.

Yes, category 1 = Skin redness that does not fade when subjected to pressure (non-blanchable erythema).

Yes, category 2 = Partial thickness skin loss.

Yes, category 3 = Full thickness skin loss.

Yes, category 4 = Full thickness tissue loss.

Yes, unstageable = Full thickness skin loss with unknown wound depth.

Yes, suspected deep tissue injury = Suspected deep tissue injury with unknown wound depth.

No = The person did not have any pressure ulcers.

Not known = It is not known whether or not the person had pressure ulcers.

20b. Did the person die with pressure ulcers (state the highest category present)?

- Yes, category 1
- Yes, category 2
- Yes, category 3
- Yes, category 4
- Yes, unstageable
- Yes, suspected deep tissue injury
- No
- Not known

In the event of there being several pressure ulcers, the highest category should be stated.

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Yes, category 1 = Skin redness that does not fade when subjected to pressure (non-blanchable erythema).

Yes, category 2 = Partial thickness skin loss.

Yes, category 3 = Full thickness skin loss.

Yes, category 4 = Full thickness tissue loss.

Yes, unstageable = Full thickness skin loss with unknown wound depth.

Yes, suspected deep tissue injury = Suspected deep tissue injury with unknown wound depth.

No = The person did not have any pressure ulcers.

Not known = It is not known whether or not the person had pressure ulcers.

21. Was an assessment of the person's oral health documented at any point during their last week of life?

- Yes
- No
- Not known

Yes = During their last week of life, an oral health assessment was carried out and documented in the person's medical records.

No = No documented assessment of oral health occurred in the last week of life. If an oral health assessment was performed but not documented, select this option.

Not known = It is not known from the documentation if an oral health assessment took place; select this option if medical records are not available for all/part of the last week.

22. Did the person receive parenteral fluids or nutrition during the last 24 hours of life?

- Yes
- No
- Not known

Parenteral fluids or nutrition: Non-oral and non-tube administration, e.g. intravenous or subcutaneous. The question refers to liquids used for volume substitution, e.g. for dehydration, and not to dilution liquids for medicines. Select Yes if administration was initiated during the last 24 hours of life, or if it was initiated earlier but was not terminated until at some point during the last 24 hours of life.

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

- Last 24 hours
- Days
- Weeks
- Month or more
- Not known

Medical examination means that a physician physically sees the person and assesses their condition. Telephone calls or reports from a physician's round do not count as a medical examination.

24a. Was external expertise consulted to meet the person's end-of-life needs?

- Yes
- No
- Not known

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External expertise = Specialist expertise that is not available at your workplace/in your team.

If the answer is YES, also answer 24b.

24b. Which expertise was consulted (multiple answers possible)?

- Pain service
- Palliative care team/palliative care consultant
- Other hospital unit
- Paramedical practitioner
- Spiritual representative
- Other

Pain service = The pain service was consulted.

Palliative care team/palliative care consultant = Palliative care team or palliative care consultant. Select this if information about a specific palliative intervention, such as the prescription of symptomatic drugs, was requested. If the person had been enrolled with the palliative care team for support for a long period of time, this is stated under question 6b instead.

Other hospital unit = A different hospital unit, for example the radiotherapy unit.

Paramedical practitioner = Paramedical practitioner, such as an occupational therapist, physiotherapist, dietician or speech therapist.

Spiritual representative = Spiritual representative, such as a deacon, priest, imam, rabbi or spiritual counsellor.

Other = Expertise not listed in the other options, e.g. play therapy, clown medicine.

25. Was anybody present in the same room at the time of death?

- Yes, a relative or close friend (next of kin)
- Yes, a relative or close friend (next of kin) and staff
- Yes, staff only
- No
- Not sure/don't know

Yes, a relative or close friend (next of kin) = Relative or close friend (next of kin) were present in the same room as the person at the time of death. Select this even if relative or close friend were present but asleep in the room, for example.

Yes, a relative or close friend (next of kin) and staff = Both relative or close friend (next of kin) and staff were present in the same room as the person at the time of death.

Yes, staff only = Staff were present in the same room as the person at the time of death, e.g. extra duty staff, regular staff. Do not select this if the person was only 'checked on' at regular intervals, but nobody was actually in the room at the exact time of death.

No = No person was present at the time of death. Select this if the relatives or close friends (i.e. next of kin) were in the same property (the shared home) as the person who died, but were NOT in the same room, if the person explicitly or implicitly wished to be alone and the relatives or close friends/staff were adhering to this wish, or if the relatives or close friends/staff temporarily left the room and the person died at that moment.

Not sure/don't know = It is not known whether or not anybody was present at the time of death.

26. Was a planned bereavement follow-up session offered to the person's relatives or close friends (i.e. next of kin)?

- Yes

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- No
- Not known
- Had no known relatives/close friends

A bereavement follow-up session is a planned session held some time (around 6–8 weeks) after the death. Bereavement follow-up session is distinct from the support often provided around the time of death, but healthcare professionals can at this time offer a bereavement follow-up session.

27. Have you had an opportunity for joint reflection on the death at your workplace?

- Yes
- No
- Not known

An opportunity for joint reflection can involve using the four cornerstones to reflect on how the team carried out the care and sharing any feedback provided by the person/relatives/close friends, for example. This can be combined with completing the end-of-life questionnaire together.

28. Date (yyyy-mm-dd) on which the questions were answered
