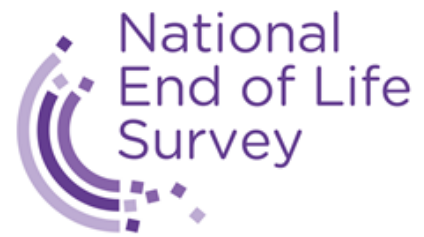


NATIONAL END OF LIFE SURVEY QUESTIONNAIRE



What is the survey about?

The National End of Life Survey is a nationwide survey asking bereaved relatives about the care provided to their loved one in the last months and days of their life. The purpose of the survey is to learn from people's experiences of end-of-life care in order to improve the services provided both to people who are dying, and to their loved ones.

Why did I get this questionnaire?

You got this questionnaire because you registered the death of a family member or friend between 1 September and 31 December 2022.

Can I do the questionnaire online?

Yes, please go to **survey.yourexperience.ie** to complete the survey online.

Can I ask someone to help me fill in the questionnaire?

Yes, you may wish to ask someone to help you answer some of the questions. Alternatively, you may pass the survey on to the person who knows most about the care provided to the person who has died.

Thank you for completing the survey. If you have any questions about the survey, please call our Freephone number on 1800 314 093 (Monday-Friday, 9am-5pm), visit www.yourexperience.ie or email us at info@yourexperience.ie.

To opt out of this survey, please call the Freephone number on **1800 314 093** or go to our website www.yourexperience.ie.

Your answers will remain anonymous and confidential, and will not affect your future care in any way.

Survey Code:

We're committed to excellence in healthcare



An Roinn Sláinte
Department of Health



Completing the questionnaire

- As you go through the questionnaire, please follow the instructions and answer the questions by ticking ☒ the most appropriate box (or boxes) using a black or blue pen.
- Don't worry if you make a mistake; just fill in the box ☐ and put a tick ☒ in the correct box or boxes.
- **There is space at the end of the questionnaire for your written comments.**
- **Please do not write your name or address anywhere on the questionnaire.**
- The questionnaire takes about 30 minutes to complete.
- The term 'healthcare staff' is used to refer to all staff working in this setting, which may include: care workers, healthcare assistants, doctors, nurses, social workers, physiotherapists, etc.
- Please fill in as much of the questionnaire as you can. If, however, you find that some of the questions bring back upsetting memories, please feel free to skip them.
- If the questionnaire raises issues that you would like to talk about, please contact the bereavement support services for further support, advice and information. An information leaflet on these services is included with this questionnaire.
- If you would like to make a comment or complaint and receive a response, please email the HSE at yoursay@hse.ie or phone 1890 424 555. You can also contact the Patient Advocacy Service, which supports people who wish to make a complaint, at 0818 293 003 or info@patientadvocacyservice.ie.

This survey is being carried out by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health. Your feedback is very important and will help us to identify what is working well and areas for improvement. The results from this survey may also be analysed by other researchers for this purpose.

Thank you again for completing the survey.

1.1 Background information

Q1. What was your relationship to the person who died?

- ☐ 1 Husband/wife/civil partner/partner
- ☐ 2 Son/daughter
- ☐ 3 Brother/sister
- ☐ 4 Parent
- ☐ 5 Other relative
- ☐ 6 Friend/neighbour
- ☐ 7 Staff in care home
- ☐ 8 Warden (sheltered accommodation)
- ☐ 9 Other:

Q2. This question is about the illnesses the person who died had in the last days and hours of their life.

(Please tick ALL the illnesses they had in the last days of life.)

- ☐ 1 Cancer (including leukaemia and lymphoma)
- ☐ 2 COVID-19
- ☐ 3 Dementia
- ☐ 4 Heart condition (e.g. heart failure)
- ☐ 5 Influenza or pneumonia
- ☐ 6 Lung condition (e.g. COPD)
- ☐ 7 Neurological condition (including stroke, motor neuron disease)
- ☐ 8 End stage renal (kidney) disease
- ☐ 9 I don't know
- ☐ 10 Something else:

Q3. How long had they been ill before they died?

- ☐ 1 They were not ill — they died suddenly → **GO TO Q103.**
- ☐ 2 Less than 24 hours
- ☐ 3 One day or more, but less than one week
- ☐ 4 One week or more, but less than one month
- ☐ 5 One month or more, but less than six months
- ☐ 6 Six months or more but less than 1 year
- ☐ 7 One year or more

Q4. Did they spend any time being cared for at home during the last three months of life?

- ☐ 1 Yes

Please write the name of the town/village and county where they were cared for at home:

Town/village:

County:

- ☐ 2 No, they were in a hospital, hospice, nursing home or a residential care facility for the whole three months → **GO TO Q22.**

2.1 Care at home

The following questions are about care received in the **last three months of life** at home. Please note that there are questions later in the questionnaire specifically related to care in the last two days of life.

If your relative or friend did not spend any time at home in the last three months of their life please go to Q22.

Q5. When your relative or friend was at home in the last three months of their life, did they get care and support at home from any of the services listed below?

These may be provided by different organisations, such as voluntary organisations, a private agency or the HSE. (Tick all that apply)

- ☐ 1 A public health nurse (sometimes called a PHN, district nurse or community nurse)
- ☐ 2 A paid carer (sometimes called home help or a care assistant)
- ☐ 3 A community palliative care nurse (sometimes called a homecare nurse, or hospice nurse)
- ☐ 4 A nurse at night
- ☐ 5 A GP (general practitioner/family doctor)
- ☐ 6 Social worker
- ☐ 7 Pharmacist
- ☐ 8 Occupational therapist (OT)
- ☐ 9 Physiotherapist
- ☐ 10 They did not receive care and support from these services **→GO TO Q22.**
- ☐ 11 Don't know **→GO TO Q22.**

Q6. In the last three months of their life, if your relative or friend required a home visit from the public health nursing team (sometimes referred to as the PHN, district nurse or community nurse) were they available to visit?

- ☐ 1 Yes, always
- ☐ 2 Yes, sometimes
- ☐ 3 No

☐ 4 They did not need a home visit from the public health nursing team **→GO TO Q8.**

☐ 5 Don't know **→GO TO Q8.**

Q7. Overall, did you feel they were treated with respect and dignity by the public health nurse?

- ☐ 1 Yes, always
- ☐ 2 Yes, sometimes
- ☐ 3 No
- ☐ 4 They did not see the public health nurse

Q8. In the last three months of their life, if your relative or friend required a home visit from a GP, were they available to visit?

- ☐ 1 Yes, always
- ☐ 2 Yes, sometimes
- ☐ 3 No

☐ 4 They did not need a home visit from the GP **→GO TO Q10.**

☐ 5 Don't know **→GO TO Q10.**

SECTION 2: CARE IN THE LAST THREE MONTHS OF LIFE

Q9. Overall, did you feel your relative or friend was treated with respect and dignity by their GP in the last three months of their life?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ No
- ☐ They did not see their GP
- ☐ Don't know

Q10. If your relative or friend wanted to talk to the GP about their condition, treatment or tests, did they have an opportunity to do so?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ They did not want to talk to the GP
- ☐ Don't know

Q11. In the last three months of their life, if your relative or friend required a home visit from the GP or GP out of hours service for help with urgent problems outside of normal working hours (after 5pm, at night and weekends), were they available to visit?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ No
- ☐ They did not need a home visit from their GP (family doctor) or the GP out of hours service
- ☐ Don't know

Q12. Did someone from a hospice, community palliative care team, or any other specialist palliative care service visit them at home in the last three months of their life?

- ☐ Yes
- ☐ No, this was not needed
- ☐ No, this was not offered
- ☐ Don't know

Q13. While at home, did healthcare staff help and support them with accessing additional equipment for their home, or making minor adaptations to their home?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ They did not need additional equipment or adaptations to the home
- ☐ Don't know

Q14. While at home, if they experienced pain, did healthcare staff do everything they could to relieve it?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ They did not have any pain

SECTION 2: CARE IN THE LAST THREE MONTHS OF LIFE

Q15. While at home, if they experienced symptoms other than pain (such as nausea, constipation, breathing difficulties or restlessness), did healthcare staff do everything they could to relieve them?

- ¹ ☐ Yes, definitely
² ☐ Yes, to some extent
³ ☐ No
⁴ ☐ They did not need help with this

Q16. While at home, did healthcare staff help and support them with their emotional needs (e.g. feeling worried, feeling anxious, feeling low, etc.)?

- ¹ ☐ Yes, definitely
² ☐ Yes, to some extent
³ ☐ No
⁴ ☐ They did not need help with this
⁵ ☐ Don't know

Q17. While at home, if they needed help from healthcare staff, did they get it as soon as they needed it?

- ¹ ☐ Yes, always
² ☐ Yes, sometimes
³ ☐ No
⁴ ☐ They did not need any help from healthcare staff

Q18. Overall, while they were at home, did healthcare staff answer any questions you had in a way that you could understand?

- ¹ ☐ Yes, always
² ☐ Yes, sometimes
³ ☐ No
⁴ ☐ I didn't have any questions

Q19. Overall, while they were at home, did you have confidence and trust in the healthcare staff treating them?

- ¹ ☐ Yes, always
² ☐ Yes, sometimes
³ ☐ No

Q20. While at home, did the healthcare staff give you enough help and support to care for them?

- ¹ ☐ Yes, definitely
² ☐ Yes, to some extent
³ ☐ No
⁴ ☐ I did not need help with this
⁵ ☐ Don't know

Q21. Overall, how would you rate the care they got at home from healthcare staff in the last three months of their life?

(Please circle a number)

They received very poor care						They received very good care				
0	1	2	3	4	5	6	7	8	9	10

2.2 Care in a nursing home /residential care facility

The following questions are about care provided in a residential care facility, nursing home or long stay care setting during the **last three months of life**. If your relative or friend did not spend any time in one of these settings in the last three months of their life please go to Q35.

Please note that there are questions later in the questionnaire specifically related to care in the last two days of life.

Q22. Did your relative or friend stay in a nursing home/ residential care facility at any time during the last three months of their life?

- ☐ Yes, they stayed in a nursing home/residential care facility

Please write the name of the nursing home / residential care facility and the county it is located in in the space below:

Name of nursing home/ residential care facility:

County:

- ☐ No → GO TO Q35.
☐ Don't know → GO TO Q35.

Q23. How long had they stayed in a nursing home/residential care facility before they died?

- ☐ Less than one week
☐ One to four weeks
☐ Five to 12 weeks
☐ Longer than 12 weeks

Q24. During their stay in the nursing home/residential care facility, if they experienced pain, did healthcare staff do everything they could to relieve it?

- ☐ Yes, definitely
☐ Yes, to some extent
☐ No
☐ They did not have any pain
☐ Don't know

Q25. During their stay in the nursing home/residential care facility, if they experienced symptoms other than pain (such as nausea, constipation, breathing difficulties or restlessness), did healthcare staff do everything they could to relieve them?

- ☐ Yes, definitely
☐ Yes, to some extent
☐ No
☐ They did not have any symptoms
☐ Don't know

Q26. During their stay in the nursing home/residential care facility, did healthcare staff help and support them with their emotional needs (e.g. feeling worried, feeling anxious, feeling low etc.)?

- ☐ Yes, definitely
☐ Yes, to some extent
☐ No
☐ They did not need help with this
☐ Don't know

SECTION 2: CARE IN THE LAST THREE MONTHS OF LIFE

Q27. During their stay in the nursing home/residential care facility, did healthcare staff support them to do things they wanted to do (for example, participate in special family events, see a pet, etc.)?

- ¹ ☐ Yes, definitely
² ☐ Yes, to some extent
³ ☐ No
⁴ ☐ They did not need support
⁵ ☐ Don't know

Q28. During their stay in the nursing home/residential care facility, did healthcare staff help them with urgent problems outside of normal working hours (after 5pm, at night and weekends)?

- ¹ ☐ Yes, definitely
² ☐ Yes, to some extent
³ ☐ No
⁴ ☐ They did not need help with this
⁵ ☐ Don't know

Q29. During their stay in the nursing home/residential care facility, if they needed help from healthcare staff, did they get it as soon as they needed it?

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

Q30. During their stay in the nursing home/residential care facility, did healthcare staff answer your questions in a way that you could understand?

- ¹ ☐ Yes, completely
² ☐ Yes, to some extent
³ ☐ No
⁴ ☐ I didn't have any questions

Q31. During their stay in the nursing home/residential care facility, did you feel welcome to visit at any time?

- ¹ ☐ Yes, always
² ☐ Yes, sometimes
³ ☐ No
⁴ ☐ I wasn't allowed due to visiting restrictions

Q32. During their stay in the nursing home/residential care facility, did you have confidence and trust in the healthcare staff treating them?

- ¹ ☐ Yes, always
² ☐ Yes, sometimes
³ ☐ No

Q33. Overall, during their stay in the nursing home/residential care facility, did you feel they were treated with respect and dignity by healthcare staff?

- ¹ ☐ Yes, always
² ☐ Yes, sometimes
³ ☐ No

Q34. Overall, how would you rate the care they received from healthcare staff in the nursing home/residential care facility?

(Please circle a number)

They received very poor care										They received very good care				
0	1	2	3	4	5	6	7	8	9	10				

2.3 Care in an acute hospital

The following questions are about care in an acute hospital (this is a hospital that has an emergency department or an urgent care centre). If your relative or friend did not spend any time in an acute hospital in the **last three months of their life** please go to Q48.

The questions that follow in this section are about care during your relative or friend's last hospital stay. Please note that there are questions later in the questionnaire specifically related to care in the last two days of life.

Q35. Did your relative or friend stay in an acute hospital at any time during the last three months of their life?

- ☐ Yes, they stayed in an acute hospital.

Please write the **name of the last acute hospital** in the space below:

Name of hospital:

Town:

- ☐ No → **GO TO Q48.**
- ☐ Don't know → **GO TO Q48.**

Q36. How long had they stayed in the hospital before they died?

- ☐ Less than 1 week
- ☐ 1 to 4 weeks
- ☐ 5 to 12 weeks
- ☐ Longer than 12 weeks

Q37. How many times had they been in hospital in the last three months including the last admission to hospital?

- ☐ Once
- ☐ Twice
- ☐ 3 or more times
- ☐ Not sure

Q38. During their last stay in hospital, if they experienced pain, did healthcare staff do everything they could to relieve it?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ They did not have any pain
- ☐ Don't know

Q39. During their last stay in hospital, if they experienced symptoms other than pain (such as nausea, constipation, breathing difficulties or restlessness), did healthcare staff do everything they could to relieve them?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ They did not have any symptoms
- ☐ Don't know

Q40. During their last stay in hospital, did healthcare staff help and support them with their emotional needs (e.g. feeling worried, feeling anxious, feeling low, etc.)?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ They did not need help with this
- ☐ Don't know

SECTION 2: CARE IN THE LAST THREE MONTHS OF LIFE

Q41. During their last stay in hospital, did healthcare staff provide enough help with urgent problems outside of normal working hours (after 5pm, at night and weekends)?

- ¹ ☐ Yes, definitely
² ☐ Yes, to some extent
³ ☐ No
⁴ ☐ They did not need help with this
⁵ ☐ Don't know

Q42. During their last stay in hospital, if they needed help from healthcare staff, did they get it as soon as they needed it?

- ¹ ☐ Yes, always
² ☐ Yes, sometimes
³ ☐ No
⁴ ☐ They did not need help
⁵ ☐ Don't know

Q43. During their last stay in hospital, did healthcare staff answer your questions in a way that you could understand?

- ¹ ☐ Yes, completely
² ☐ Yes, to some extent
³ ☐ No
⁴ ☐ I didn't have any questions

Q44. During their last stay in hospital, did you feel welcome to visit at any time?

- ¹ ☐ Yes, always
² ☐ Yes, sometimes
³ ☐ No
⁴ ☐ Not applicable
⁵ ☐ I wasn't allowed due to visiting restrictions

Q45. During their last stay in hospital, did you have confidence and trust in the healthcare staff treating them?

- ¹ ☐ Yes, always
² ☐ Yes, sometimes
³ ☐ No

Q46. Overall, during their last stay in hospital, did you feel they were treated with respect and dignity by healthcare staff?

- ¹ ☐ Yes, always
² ☐ Yes, sometimes
³ ☐ No

Q47. Overall, how would you rate the care they received in the hospital?
(Please circle a number)

They received very poor care						They received very good care				
0	1	2	3	4	5	6	7	8	9	10

2.4 Care in a hospice

The following questions are about the care provided to people who stayed in a hospice in the **last three months of their life**. If your relative did not spend any time in a hospice in the last three months of their life please go to Q61.

The questions are about care during their last hospice stay. Please note that there are questions later in the questionnaire specifically related to care in the last two days of life.

Q48. Did your relative or friend stay in a hospice at any time during the last three months of their life?

☐ Yes

If 'Yes' please write the **name and location of the last hospice** they stayed in in the space below:

Name of hospice:

Town:

☐ No → GO TO Q61.

☐ Don't know → GO TO Q61.

Q49. How long had they stayed in the hospice before they died?

☐ Less than 1 week

☐ 1 to 4 weeks

☐ 5 to 12 weeks

☐ Longer than 12 weeks

Q50. During their stay in the hospice, if they experienced pain, did healthcare staff do everything they could to relieve it?

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ They did not have any pain

☐ Don't know

Q51. During their stay in the hospice, if they experienced symptoms other than pain (such as nausea, constipation, breathing difficulties or restlessness), did healthcare staff do everything they could to relieve them?

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ They did not have any symptoms

☐ Don't know

Q52. During their stay in the hospice, did healthcare staff help and support them with their emotional needs (e.g. feeling worried, feeling anxious, feeling low, etc.)?

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ They did not need help with this

☐ Don't know

SECTION 2: CARE IN THE LAST THREE MONTHS OF LIFE

Q53. During their stay in the hospice, did healthcare staff support them to do things they wanted to do (for example, participate in special family events, see a pet etc.)?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ They did not need support
- ⁵ ☐ Don't know

Q54. During their stay in the hospice, did healthcare staff provide help with urgent problems outside of normal working hours (after 5pm, at night and weekends)?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ They did not need help with this
- ⁵ ☐ Don't know

Q55. During their stay in the hospice, if they needed help from healthcare staff, did they get it as soon as they needed it?

- ¹ ☐ Yes, always
- ² ☐ Yes, sometimes
- ³ ☐ No
- ⁴ ☐ They did not need help
- ⁵ ☐ Don't know

Q56. During their stay in the hospice, did you feel welcome to visit at any time?

- ¹ ☐ Yes, always
- ² ☐ Yes, sometimes
- ³ ☐ No
- ⁴ ☐ I wasn't allowed due to visiting restrictions

Q57. During their stay in the hospice, did healthcare staff answer your questions in a way that you could understand?

- ¹ ☐ Yes, completely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ I didn't have any questions

Q58. During their stay in the hospice, did you have confidence and trust in the healthcare staff treating them?

- ¹ ☐ Yes, always
- ² ☐ Yes, sometimes
- ³ ☐ No

Q59. Overall, during their stay in the hospice, did you feel they were treated with respect and dignity by healthcare staff?

- ¹ ☐ Yes, always
- ² ☐ Yes, sometimes
- ³ ☐ No

Q60. Overall, how would you rate the care they received in the hospice?

(Please circle a number)

They received very poor care		They received very good care
--	--	--

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

2.5 Overall care in the last three months of life

The following questions are about the care provided during the **last three months of life**. Please note that there are questions later in the questionnaire specifically related to care in the last two days of life.

Q61. During the last three months of their life, did healthcare staff provide support to meet their religious or spiritual needs (things like talking, praying, quiet time or access to a religious or spiritual leader)?

- ¹ ☐ Yes, always
- ² ☐ Yes, sometimes
- ³ ☐ No
- ⁴ ☐ They did not need support with this

Q62. During the last three months of their life, were they involved as much as they wanted to be in decisions about their care?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ They did not want to be involved or were not able to be involved
- ⁵ ☐ Don't know

Q63. During the last three months of their life, did healthcare staff help and support them with family worries or concerns (e.g. caring for someone else in the family or help with difficult conversations)?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ They did not need help with this
- ⁵ ☐ Don't know

Q64. Did you feel that there was good coordination between different services (e.g. GP, hospital or hospice) and healthcare staff who cared for them in the last three months of their life?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ Not relevant to our situation
- ⁵ ☐ Don't know

3.1 Experience of care in the last two days of life

The following questions are about the experience of care in the last two days of life.

We understand that it may be difficult to reflect on this experience and we appreciate you taking the time to answer the questions.

If you had no contact with your relative or friend in the last two days of life please go to Q101.

Q65. During the last two days of their life, were they cared for:

- ☐ ¹ At home or in the home of a family member or friend.
- ☐ ² In a nursing home/residential care facility
- ☐ ³ In an acute hospital (a hospital that has an emergency department, or urgent care centre)
- ☐ ⁴ In a hospice
- ☐ ⁵ Somewhere else

Q66. In the last two days of their life, did the bed area and surrounding environment have adequate privacy for them?

- ☐ ¹ Yes, definitely
- ☐ ² Yes, to some extent
- ☐ ³ No
- ☐ ⁴ I was not with them in the last two days

Q67. In the last two days of their life, were you offered...

(tick all that apply)

- ☐ ¹ A family room with adequate peace and privacy for you to meet with healthcare staff
- ☐ ² A family room with tea and coffee making facilities
- ☐ ³ The option to visit at any time, including outside of regular visiting hours
- ☐ ⁴ The option to stay overnight
- ☐ ⁴ I was not offered any of these
- ☐ ⁵ Does not apply to our situation

Q68. During the last two days of their life, if they experienced pain, did healthcare staff do everything they could to relieve it?

- ☐ ¹ Yes, definitely
- ☐ ² Yes, to some extent
- ☐ ³ No
- ☐ ⁴ They did not have any pain
- ☐ ⁵ They did not see any healthcare staff during the last two days

Q69. During the last two days of their life, if they experienced symptoms other than pain (such as nausea, constipation, breathing difficulties or restlessness), did healthcare staff do everything they could to relieve them?

- ☐ ¹ Yes, definitely
- ☐ ² Yes, to some extent
- ☐ ³ No
- ☐ ⁴ They did not have any symptoms

SECTION 3: CARE IN THE FINAL TWO DAYS OF LIFE

Q70. During the last two days of their life, was there enough help available to meet their personal care needs (such as washing, dressing and toileting)?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ They did not need help with personal care needs

Q71. During the last two days of their life, was there enough help with nursing care, such as giving medicine and helping them find a comfortable position in bed?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ Don't know

Q72. During the last two days of their life, did healthcare staff help and support them with their emotional needs (e.g. feeling worried, feeling anxious, feeling low etc.)?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ They did not need help with this
- ⁵ ☐ Don't know

Q73. During the last two days of their life, did healthcare staff provide support to meet their religious or spiritual needs (things like talking, praying, quiet time or access to a religious or spiritual leader)?

- ¹ ☐ Yes, always
- ² ☐ Yes, sometimes
- ³ ☐ No
- ⁴ ☐ They did not need help with this
- ⁵ ☐ Don't know

Q74. During the last two days of their life, did they get enough help from healthcare staff to eat or drink?

- ¹ ☐ Yes, always
- ² ☐ Yes, sometimes
- ³ ☐ No
- ⁴ ☐ They did not want help
- ⁵ ☐ They were not able to eat or drink
- ⁶ ☐ Don't know

Q75. During the last two days of their life, did a member of the palliative care team, or any other specialist palliative care service, visit them?

- ¹ ☐ Yes
- ² ☐ No
- ³ ☐ Don't know

Q76. During the last two days of their life, did you feel that there was good coordination between the healthcare staff?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ Don't know

SECTION 3: CARE IN THE FINAL TWO DAYS OF LIFE

Q77. During the last two days of their life, was there adequate support to meet their needs outside of working hours (after 5pm, at night and at weekends)

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

Q78. During the last two days of their life, do you think your relative or friend was involved as much as they wanted to be in decisions about their care and treatment?

- ¹☐ Yes, definitely
- ²☐ Yes, to some extent
- ³☐ No
- ⁴☐ They were not able to be involved in decisions at this time
- ⁵☐ Don't know

Q79. During the last two days of their life, did healthcare staff discuss with you the level of treatment and care and its appropriateness (in terms of medical interventions and their illness) that your relative or friend would receive?

- ¹☐ Yes, definitely
- ²☐ Yes, to some extent
- ³☐ No
- ⁴☐ Does not apply to our situation

Q80. During the last two days of their life, did you have confidence and trust in the nurses who cared for them?

- ¹☐ Yes, always
- ²☐ Yes, sometimes
- ³☐ No
- ⁴☐ Does not apply to our situation

Q81. During the last two days of their life, did you have confidence and trust in the doctors who cared for them?

- ¹☐ Yes, always
- ²☐ Yes, sometimes
- ³☐ No
- ⁴☐ Does not apply to our situation

Q82. During the last two days of their life, did healthcare staff treat them with kindness and compassion?

- ¹☐ Yes, always
- ²☐ Yes, sometimes
- ³☐ No
- ⁴☐ Does not apply to our situation

Q83. Overall, during the last two days of their life, did you feel that they were treated with respect and dignity by healthcare staff?

- ¹☐ Yes, always
- ²☐ Yes, sometimes
- ³☐ No

3.2. Care experiences at the end of life

Q84. Were they told by a healthcare professional that they were likely to die?

- ¹ ☐ Yes
- ² ☐ No →GO TO Q86.
- ³ ☐ Don't know →GO TO Q86.

Q85. In your opinion, did the healthcare professional who told them that they were likely to die break the news to them in a sensitive and caring way?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ Don't know

Q86. Did healthcare staff talk to you about what to expect when your relative or friend was dying (for example symptoms that may arise)?

- ¹ ☐ Yes →GO TO Q88.
- ³ ☐ No →GO TO Q87.
- ⁴ ☐ Not applicable – they died unexpectedly →GO TO Q88.

Q87. Would a discussion about what to expect when they were dying have been helpful?

- ¹ ☐ Yes
- ² ☐ No

Q88. Where did they die?

- ¹ ☐ In their own home or in the home of a family member or friend

Name of town/village:

County:

- ² ☐ In a hospital – please write the name of the hospital below:

Name of hospital:

County:

- ³ ☐ In a hospice – please write the name of the hospice below:

Name of hospice:

County:

- ⁴ ☐ In a nursing home / residential care facility – please write the name of the facility below:

Name of nursing home:

County:

- ⁵ ☐ In an ambulance on the way to hospital / hospice

- ⁶ ☐ Somewhere else (please write below):

Q89. If they died in a healthcare setting (e.g. a hospital, hospice or nursing home), were they in single room?

- ☐ Yes
- ☐ No
- ☐ They did not die in a healthcare setting
- ☐ Don't know

Q90. On balance, do you think that they died in the right place?

- ☐ Yes
- ☐ No
- ☐ Not sure

Q91. Overall, how would you rate the care your relative received at the end of their life? (Please circle a number)

They received very **poor** care

They received very **good** care

0 1 2 3 4 5 6 7 8 9 10

3.3. Your experience of care and support

The following questions are about your experience of the care and support provided to you by healthcare staff in the last days of your relative or friend's life, and after they died.

Q92. Looking back over the last days of their life, were you given enough emotional help and support by healthcare staff?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ I did not need help with this
- ⁵ ☐ Not applicable, I didn't have any contact with healthcare staff

Q93. Looking back over the last days of their life, were you given enough help and support by healthcare staff to talk to children or young adults about your relative or friend's illness?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ I did not need help with this
- ⁵ ☐ Not applicable, I didn't have any contact with healthcare staff

Q94. Looking back over the last days of their life, were you involved as much as you wanted to be in decisions about their care and treatment?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ Not applicable, I didn't have any contact with healthcare staff

Q95. During the last days of their life, did healthcare staff explain their condition and care in a way that you could understand?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ Not applicable, I didn't have any contact with healthcare staff

Q96. During the last days of their life, did you feel you had enough time to discuss their care and treatment with healthcare staff?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ Not applicable, I didn't have any contact with healthcare staff

Q97. After your relative or friend died, did healthcare staff engage with you in a sensitive manner?

- ¹ ☐ Yes, definitely
- ² ☐ Yes, to some extent
- ³ ☐ No
- ⁴ ☐ Not applicable, I didn't have any contact with healthcare staff

Q98. Did healthcare staff give you practical information on what to do after your relative or friend died, including information on registering their death?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ I did not need this information
- ☐ Not applicable, I didn't have any contact with healthcare staff

Q99. If you sought support after your relative or friend died, who provided that support?

(Tick all that apply)

- ☐ GP/doctor
- ☐ Nurse
- ☐ Social worker
- ☐ Pastoral care or healthcare chaplain
- ☐ Bereavement counsellor
- ☐ Bereavement helpline
- ☐ I did not access any supports
- ☐ Not sure
- ☐ Other

Q100. Overall, and taking all services into account, how would you rate the care and support you received? (Please circle a number)

I received very
poor care and
support

I received very
good care and
support

0 1 2 3 4 5 6 7 8 9 10

4. Other Comments

Thank you very much for taking part in this survey. We would like to give you the opportunity to tell us in your own words about the care you and the person who died received. To do this, you may like to answer the questions below. You can use the back page of the questionnaire if you need more space. Comments will be entered into a secure database after removing any information that could identify you.

This anonymised feedback will be looked at by HIQA, the HSE and the Department of Health to try to understand and improve experiences of health and social care at end of life. In the future, other researchers may also analyse anonymised data from this survey after all personal information that could identify you has been removed. We will give examples of feedback in the final survey reports to provide a fuller understanding of bereaved relatives' experiences.

Q101. Overall, what was good about the care your relative or friend received?

Q102. Was there anything that could have been improved?

Q103. Do you have any other comments or suggestions about the care your relative or friend received?

5. Information about you and your relative/friend

In this section, we would like to know a little more about you both. This will help us to make better use of the information you have given us.

Q104. What is your gender?

- ☐ Male
☐ Female
☐ Other
☐ Prefer not to say

Q105. How old are you?

- ☐ 18-29 years
☐ 30-39 years
☐ 40-49 years
☐ 50-59 years
☐ 60-69 years
☐ 70-79 years
☐ 80-89 years
☐ 90 + years

Q106. What is your ethnic or cultural background?

(Tick **ONE** box only)

White:

- ☐ Irish
☐ Irish Traveller
☐ Roma
☐ Any other White background

Black or Black Irish:

- ☐ African
☐ Any other Black background

Asian or Asian Irish:

- ☐ Chinese
☐ Indian/Pakistani/Bangladeshi
☐ Any other Asian background

Other, including mixed group/ background:

- ☐ Arabic
☐ Mixed, please specify:

- ☐ Other, please write your ethnic group here:

Q107. Your relative/friend was:

- ☐ Male
☐ Female
☐ Other
☐ Prefer not to say

SECTION 5: PERSONAL INFORMATION

Q108. Please indicate the ethnic background of the person who died:

(Tick **ONE** box only)

White:

- ¹ ☐ Irish
- ² ☐ Irish Traveller
- ³ ☐ Roma
- ⁴ ☐ Any other White background

Black or Black Irish:

- ⁵ ☐ African
- ⁶ ☐ Any other Black background

Asian or Asian Irish:

- ⁷ ☐ Chinese
- ⁸ ☐ Indian/ Pakistani/ Bangladeshi
- ⁹ ☐ Any other Asian background

Other, including mixed group/
background:

- ¹⁰ ☐ Arabic
- ¹¹ ☐ Mixed, please specify:

- ¹² ☐ Other, please write your ethnic group here:

Q109. What age was your relative/friend when they died?

(Please enter their age in numbers)

 years old

Q110. Did the person that died have:

- ¹ ☐ A medical card?
- ² ☐ Private health insurance?
- ³ ☐ **Both** a medical card and private health insurance?
- ⁴ ☐ **Neither** a medical card nor private health insurance?

If you would like to talk about your bereavement experience or discuss upsetting memories brought on by completing this questionnaire, please feel free to contact the HSE/Irish Hospice Foundation bereavement support freephone service on 1800 80 70 77 to talk to a bereavement support volunteer.

THANK YOU VERY MUCH FOR COMPLETING THE SURVEY

Please check that you have answered all of the questions that apply to you.

Please return this questionnaire in the Freepost envelope provided. No stamp is needed.

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DRAFT