National End of Life Survey

Findings of the

National End of Life Survey 2023

National End of Life Survey

Thank you

Thank you to all of the bereaved family members and friends who participated in Ireland's first National End of Life Survey.

Without your participation and overwhelming generosity and willingness to share your experiences, the survey would not have been possible. We wish to acknowledge the loss of your loved ones and we appreciate how difficult it may have been to consider the answers to the questions in the survey. The survey ensures that your voice will be heard by those involved in changing and improving end-of-life care in Ireland.

Thank you also to the staff working across all healthcare settings and the community, as well as the General Register Office and Civil Registration Service offices for contributing to the success of the survey.

The survey was overseen by a national steering group and advisory group. We acknowledge the direction and guidance provided by these groups. Appendix 1 lists the members of these groups.

Finally, we thank the Irish Hospice Foundation for the significant and ongoing support it has provided in developing and publicising the survey.

About the National Care Experience Programme

The National Care Experience Programme seeks to improve the quality of health and social care services in Ireland by asking people about their experiences of care and acting on their feedback. The National Care Experience Programme is a joint initiative by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health. Patient and service user representatives and advocates are also involved at all levels of the programme's governance structures.

The National Care Experience Programme has a suite of surveys that capture the experiences of people using these services. The programme implements the National Inpatient Experience Survey, the National Maternity Experience Survey, the National Nursing Home Experience Survey, the National Maternity Bereavement Experience Survey and the National End of Life Survey.

The surveys aim to learn from people's feedback about the care received in health and social care services to find out what is working well, and what needs to be improved.

A National Care Experience Programme Survey Hub is available to provide support, guidance, information and resources to assist providers to develop, conduct and analyse their own surveys, and act upon the findings.

Find out more at www.yourexperience.ie.

About the National End of Life Survey

The National End of Life Survey was the first national survey to ask bereaved people about the care provided to a family member or friend in the last months and days of their life. The purpose of the survey was 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.

The findings of this national survey provide valuable information on the care provided to people using services and their families at end of life, acknowledge what is working well and identify areas where improvements are needed.

Executive Summary

4,570

bereaved relatives and friends of people who died between September and December 2022 took part

48%

response rate

89%

of those who took part rated the overall care that their relatives and friends received as 'good' or 'very good'

Responses received when participants were asked where their relative or friend died:

22.4%
At home

39.4%
Hospital

10.7%
Hospice

27.4%
Nursing Home

0.2%
Somewhere else

Areas of good care experience

- The respect and dignity shown by staff to the person who died
- Confidence and trust in healthcare staff
- Clear explanations provided to relatives and friends

Areas requiring improvement

- Continuity, availability and responsiveness of care
- Coordination between services and staff involved in care
- Help and support for the emotional needs of the person who died

What were the main findings of the National End of Life Survey?

In total, 4,570 bereaved family members and friends participated in the first National End of Life Survey. People who registered the death of a family member or friend that occurred between 1 September and 31 December 2022 were invited to participate. Participants[1] shared their experiences of the care their relative or friend received in the last months and days of their life, including the care they received at home, in a nursing home or residential care facility[2], in hospital and in a hospice. The majority of participants across these care settings said that the end-of-life care that their relative or friend received was either 'good' or 'very good' and that they had been treated with respect and dignity. However, communication and the continuity, availability and responsiveness of care were highlighted as areas which required improvement.

Care experiences in different settings

The survey explored the experiences of people who received care or died in various settings including hospitals, nursing homes, hospices and in their homes. It was clear that the people who died experienced a variety of pathways of care, involving multiple care settings and services in the last months and days of their lives.

Just under 40% of participants said that their relative or friend had died in a hospital, followed by 27% who died in a nursing home or residential care facility, 22% who died at home, and 11% who died in a hospice.[3] There were noteworthy differences in the profile of deaths that occurred in each setting. For example, those who died in hospital typically had a shorter duration of illness than those in other settings. This is an important consideration when comparing experiences in different settings.

Two survey questions asked about coordination in the last months and days of life. Question 64 asked participants if they felt there was good coordination between the different services and staff that cared for their relative or friend in the last three months of their life. In total, 1,699 participants (45%) answered that there 'definitely' was good coordination between the services and staff. Question 76 asked if there was good coordination between healthcare staff in the last two days, with 3,007 participants (74%) saying that there was 'definitely' good coordination.

1 'Participants' is used to refer to the person who completed the questionnaire. The terms 'relative or friend', or 'the person who died' are used to refer to the person who received care.

2 Hereafter, nursing homes or residential care facilities are referred to as 'nursing homes' for the sake of brevity.

3 In total, eight participants said that their relative or friend died in an ambulance or 'somewhere else'.

Participants' comments also highlighted this topic, with many expressing a desire for better continuity, availability and responsiveness between the various services, settings and professionals involved in end-of-life care.

Participants whose relative or friend died in a hospice were more likely to rate their end-of-life care as 'good' or 'very good' (98%), when compared with a nursing home or residential care facility (92%), hospital (84%) or those who died at home (89%). There were a number of other notable differences in responses to questions based on where the person died. For example, 99% of participants whose relative or friend died at home said that they had died 'in the right place', compared with 94% for hospices, 89% for nursing homes and 75% for hospitals.[4] In addition, participants were most likely to say they always felt welcome to visit their relative or friend in a hospice at any time (95%) in the last three months, compared with a nursing home (81%) or a hospital (58%).[5] When asked about visiting hospitals and other healthcare settings in the last two days of their relative or friend's life, most participants said they were given the option to visit at any time, including outside of regular visiting hours.

Areas of good care experience and areas requiring improvement

The survey included three free-text questions, which asked participants to describe what was good about the care their relative or friend received, what could be improved and for any further comments or suggestions. In their responses to these questions, participants highlighted the respect and dignity with which their relative or friend was treated. In addition, a large number of comments praised staff for the care they provided, as well as the physical, spiritual and emotional support that was made available.

"I have little to compare to, but I felt my wife was given care that was second to none. The compassion and commitment from the doctors, nurses and staff was excellent. I cannot express my gratitude enough."

When asked to describe in their own words what could be improved, participants highlighted issues relating to the continuity, availability and responsiveness of care; and a desire for clearer and more consistent communication.

"Coordination of various medical teams and communications with family - this seemed to be entirely lacking and most contact with doctors was because you bump into them as opposed to a formal way of getting information."

4 Question 90 asked participants 'On balance, do you think that they died in the right place?'

5 The denominator for these figures includes those who said the question was not applicable to them or those who were not allowed to visit due to restrictions.

Using the methodology described in Appendix 3, questions where participants reported good care experiences and questions where there was the most room for improvement were identified. These questions were also highlighted due to their strong relationship with participants' overall ratings of the care both they and their relative or friend received at home, in nursing homes or residential care facilities, in hospitals and hospices.[6]

Participants highlighted some areas of good care received during their relative or friend's last months and days of life. For example, most participants had confidence and trust in the healthcare staff caring for their relative or friend. Participants also said that their relatives or friends were treated with respect and dignity and with kindness and compassion in the last two days of their life. In addition, participants felt that staff did everything they could to help manage their relative or friend's symptoms (such as nausea, constipation, breathing difficulties or restlessness), and explained their relative or friend's condition and care in a way they themselves could understand.

A number of areas for improvement in end-of-life care were also identified using the methodology in Appendix 3. For example, some participants felt that their relative or friend did not get help from healthcare staff as soon as they needed it, as well as help and support with their emotional needs (such as feeling worried, feeling anxious, feeling low). Some participants felt that there was a lack of coordination between healthcare staff during the last two days of their relative or friend's life. In addition, participants said that they were not given enough help and support by healthcare staff to talk to children or young adults about their relative or friend's illness.

Participants' responses relating to different care settings also provided a number of important insights. Across each of the four main settings included in the survey, participants highlighted their confidence and trust in staff, the kindness and compassion of staff, as well as symptom management and the respect and dignity with which the person who died was treated.

For those who received care at home, access to out of hours general practitioner (GP) care and support for religious and spiritual needs were two of the lower-scoring questions. While for those who received care in a nursing home, support to be involved in family events, and being involved in decision-making were two of the lower-rated areas.

Participants whose relative or friend received care in a hospital identified emotional support for the person who died, and getting help when it was needed as two lower-scoring areas. For those who died in a hospice, support for involvement in family events and sensitive communication at end of life were lower-rated areas.

6 Relationships were calculated based on correlations of relevant questions with overall experience ratings for each setting and or questionnaire section: Q21, Q34, Q47, Q60, Q91, Q100. Appendix 3 also shows areas of good experience and areas needing improvement for each care setting included in the survey.

Bereaved people's experiences of care and support

The survey included nine questions that asked about the care and support provided to bereaved people themselves. The highest-scoring question in this section related to sensitivity from healthcare staff, with 84% of participants saying that healthcare staff always engaged with them in a sensitive manner after their relative or friend died. The lowest-scoring question related to support to talk to children or young adults, with 29% of participants saying that healthcare staff did not provide enough help and support to talk to children or young adults about their relative or friend's illness.[7]

Conclusions

The findings of the first National End of Life Survey provide valuable insights into the care journeys of those who received end-of-life care during the sample period. The people who died during this period typically received care in multiple and varied settings, including hospitals, nursing homes, hospices and in their homes. It was clear that every end-of-life care journey is unique.

Most participants had confidence and trust in healthcare staff and felt that their relative or friend was always treated with respect, dignity, kindness and compassion. However, some participants said that their relative or friend's care was not as well coordinated as it should have been, and that they did not always receive help from healthcare staff as soon as they needed it. Of the settings covered in the survey, hospitals were the most common place of death. Hospices received the most positive ratings across all survey questions.

What happens next?

The HSE will use the survey findings to inform the development of quality improvement plans at national and local levels. These quality improvement plans will describe the steps that the HSE will take to address the issues highlighted by participants in the survey. Quality improvement plans will be available on www.yourexperience.ie in April 2024. Private and voluntary end-of-life care providers can use the survey results to develop plans on how they will respond to the findings. The National Care Experience Programme is engaging with organisations that represent private and voluntary providers to support them to understand and use the findings of the survey.

The Department of Health will use the information gathered to inform the development of policy in relation to end-of-life care. The findings of the survey will inform the Irish Hospice Foundation's work supporting those in receipt of end-of-life care and their families. Finally, the findings of the survey will inform national standards and HIQA's monitoring and regulation of the services included in this survey.

7 It is important to note that 56% of respondents (2,412) to this question said that they did not need help with this, or they did not have any contact with healthcare staff.

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1

About the National End of Life Survey

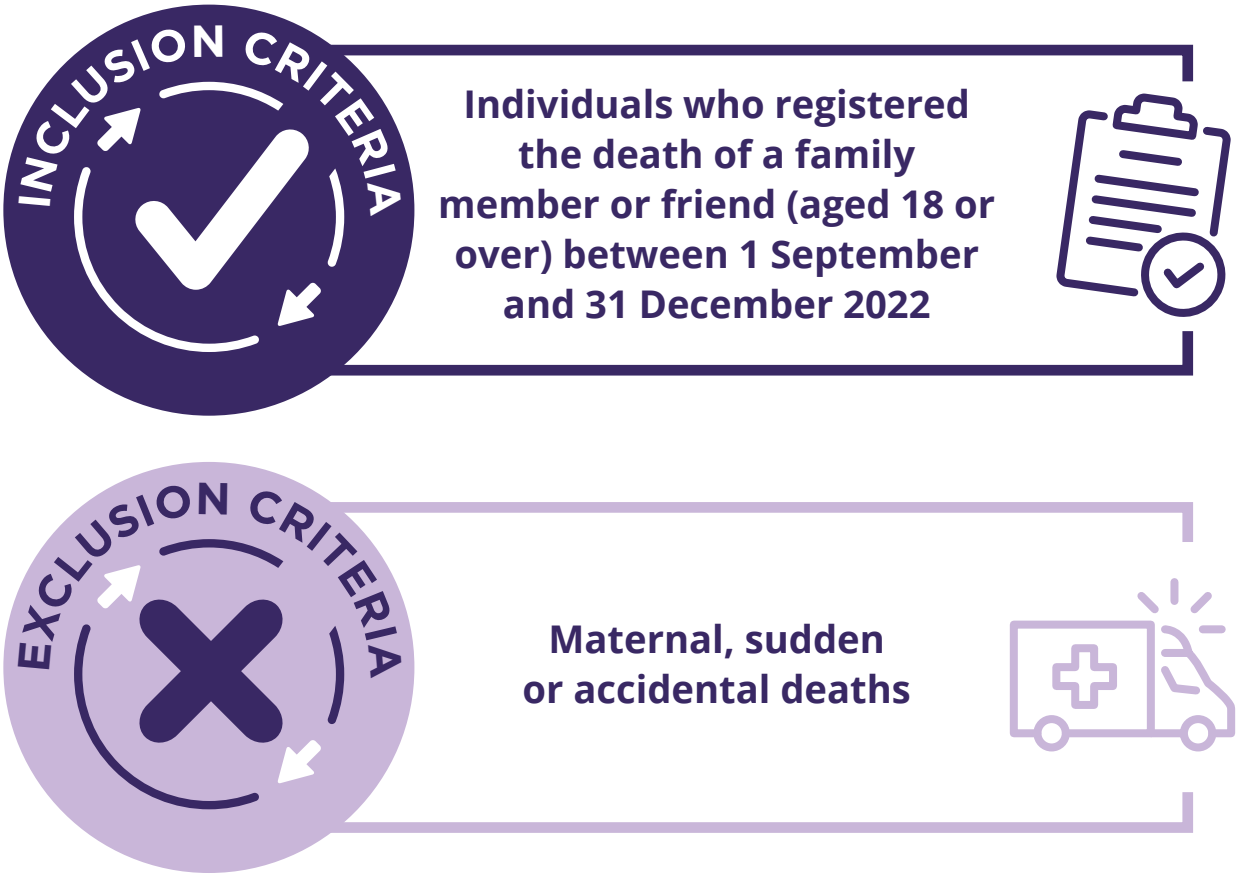
The National End of Life Survey is the first national survey asking bereaved people about the care provided to a family member or friend in the last months and days of their life. The purpose of the survey is to learn from people's experiences of end-of-life care in order to improve the services provided both to people who are dying, and to their relatives or friends.

Who was eligible to participate in the survey?

People who registered the death of a family member or friend that occurred between 1 September and 31 December 2022 were invited to participate in the survey (Figure 1.1). Sudden, maternal and child deaths were not included in the survey, as the care pathways in these circumstances are different.[8]

Eligible people were sent a survey pack in the post between March and May 2023, with the option to complete the survey online or by returning the survey questionnaire by post.

Figure 1.1 Inclusion and exclusion criteria



8 In cases where people were not invited to participate but felt they should have been, it was possible to opt in to the survey. Two people opted in to the survey in this manner.

What questions were asked in the survey?

The National End of Life Survey asked participants about the end-of-life care provided to their relatives or friends in the last months and days of life. The survey included questions on pain management, respect and dignity, emotional support, communication with healthcare staff and the provision of information. The survey questionnaire can be found in Appendix 4. The questionnaire included a total of 110 questions, of which three questions were free text, asking participants to describe their experiences in their own words.

In total, 239 people[9], including bereaved relatives, specialist palliative care staff, general practitioners, medical consultants and clinical medical directors, nursing staff based in the community, in nursing homes, in hospices and in acute hospitals, home care support staff, health and social care professionals, academic staff, policy makers, service funders and regulators were involved in developing and selecting the questions most relevant to the Irish context.(1)

The development steps are outlined below:

1. An international review of bereaved relative experience surveys identified the international experience and best practice with regard to the models and methodologies employed to deliver a National End of Life Survey.(2)
2. Focus groups involving bereaved relatives, representatives from voluntary and advocacy organisations, health and social care service staff as well as policymakers and healthcare regulators identified the key themes to be included in the survey.
3. A gap analysis was undertaken, which consisted of reviewing national standards and policies ensuring that all aspects of care that are important from an Irish context are captured.
4. A two-round Delphi study was undertaken to identify priority questions to be included in the questionnaire[10].
5. Picker Institute Europe checked the measurement and analytic quality of the questions.
6. Cognitive interviews with bereaved relatives who have used health and social care services were undertaken to assess the clarity and appropriateness of the proposed National End of Life Survey questionnaire.
7. A further review was undertaken by the National End of Life Survey advisory group members, with representatives of bereaved relatives, the Department of Health, HIQA, the HSE and special remit of organisations representing family carers, palliative and bereavement care.

9 There were 68 focus group participants, 163 people took part in the Delphi study, and eight cognitive interviews with recently bereaved people.

10 In the Delphi study, participants were asked to rate and rank potential questions for inclusion in the final questionnaire.

What care settings were included in the survey?

Bereaved people were asked about the end-of-life care provided to their relative or friend in hospitals, hospices,[11] nursing homes and the home. Figure 1.2 gives a short description of each of the care settings included in the survey.

Figure 1.2 Description of settings of care

Care at home

Experiences of care at home in the last three months of life, including homecare services, GPs and Public Health Nurses.

17 QUESTIONS

Care in a nursing home or residential care facility

Experiences of care in a nursing home or residential care facility in the last three months of life, including pain and symptom management, out of hours support and visiting.

12 QUESTIONS

Care in an acute hospital

Experiences of care in an acute hospital in the last three months of life, including pain and symptom management, out of hours support and visiting.

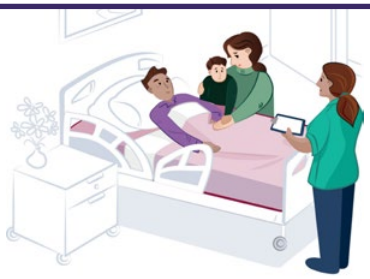
12 QUESTIONS

Care in a hospice

Experiences of care in a hospice in the last three months of life, including pain and symptom management, out of hours support and visiting.

12 QUESTIONS

11 The questionnaire asked respondents to choose from the list of the 14 specialist palliative care inpatient units. 11 responses were received for other settings and are taken into account in the below results.



Care in the last two days of life

Experiences of care in the last two days of life, including pain and symptom management, emotional, spiritual and personal care needs.

18 QUESTIONS

Care at the end of life

Experiences of care at the end of life.

7 QUESTIONS

Your experiences of care

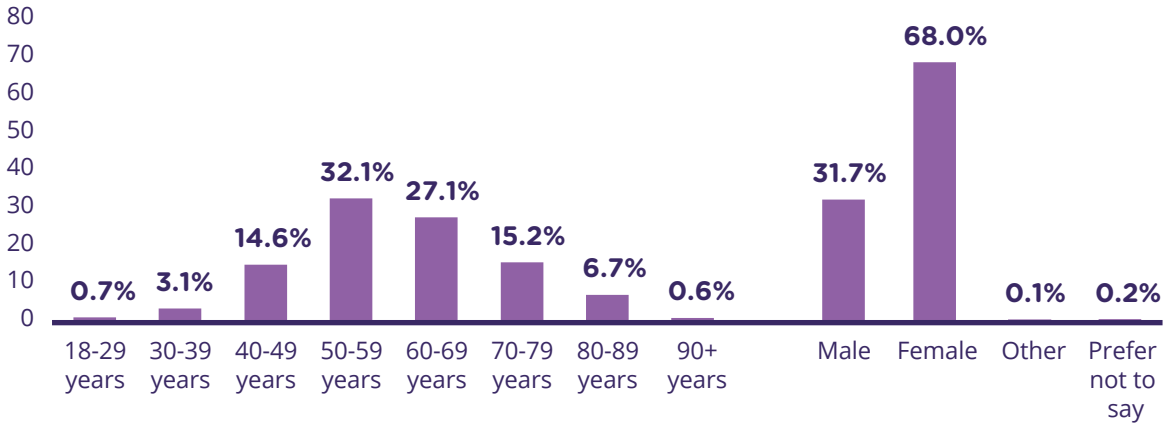
Experiences of the care and support provided to the participant in the last days of their relative or friend's life.

9 QUESTIONS

Who participated in the National End of Life Survey 2023?

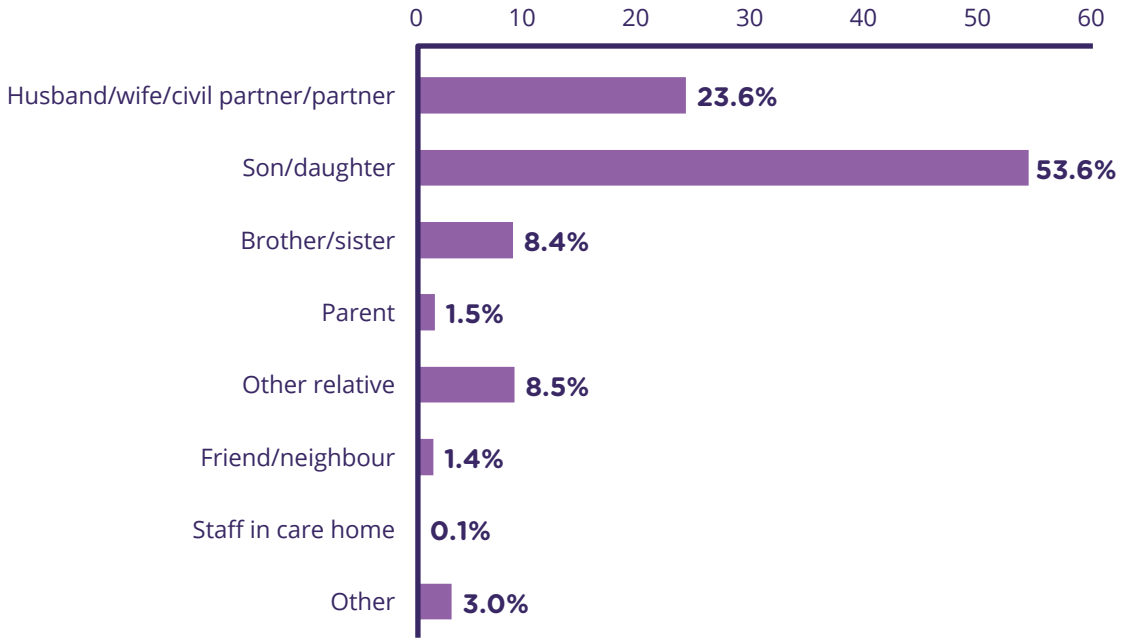
Of the 9,446 people who were invited to participate in the National End of Life Survey 2023, 4,570 returned a completed questionnaire (48.4% response rate). Of these, 31.7% (n=1,390) were male, 68.0% (n=2,981) were female, with 10 participants answering with 'Other' or 'Prefer not to say'. Over half of participants (59.2%, n=2,593) were aged between 50 and 69 years (Figure 1.3).[12]

Figure 1.3 Age and gender of participants



Most participants were adult children of the person who died (53.6%, n=2,409), while approximately a quarter (23.6%, n=1,059) were spouses or partners (Figure 1.4).

Figure 1.4 Relationship to the person who died



12 Participants who responded 'Other' (0.1% or n=3) or 'Prefer not to say' (0.2% or n=7) are not included in Figure 1.3.

The majority of people (61.8%, n=2,660) were 80 years of age or older when they died, and had been ill for at least one month (75.6%, n=3362). Figure 1.5 shows the age and gender of the people who died.[13] Figure 1.6 shows the illnesses that people who died had in their last days and hours of life, while Figure 1.7 shows how long they had been ill before they died.

Figure 1.5 Age and gender of people who died

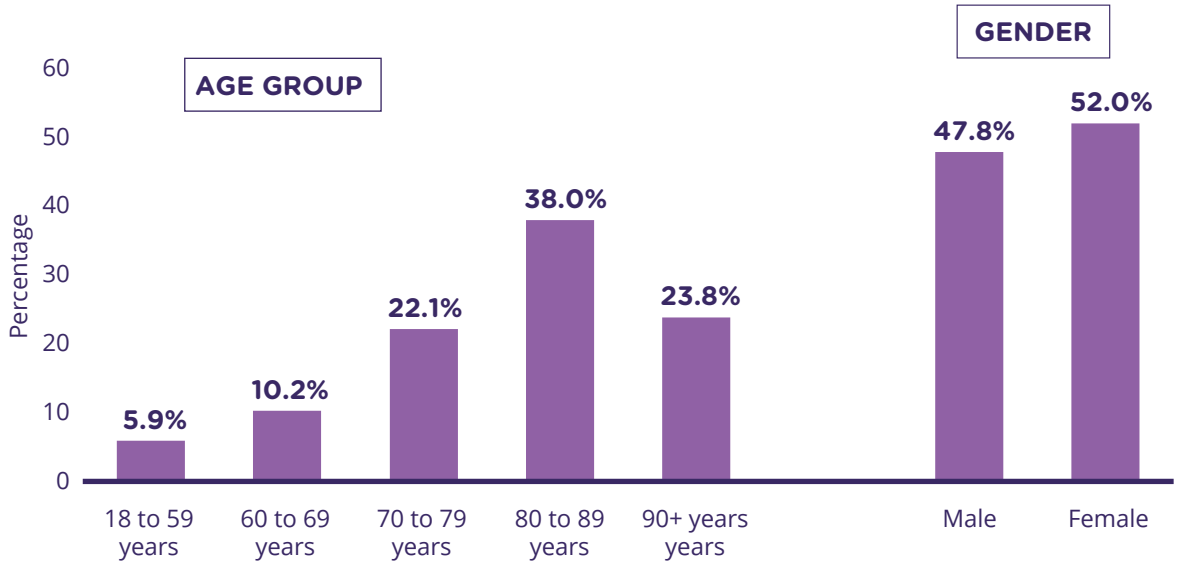
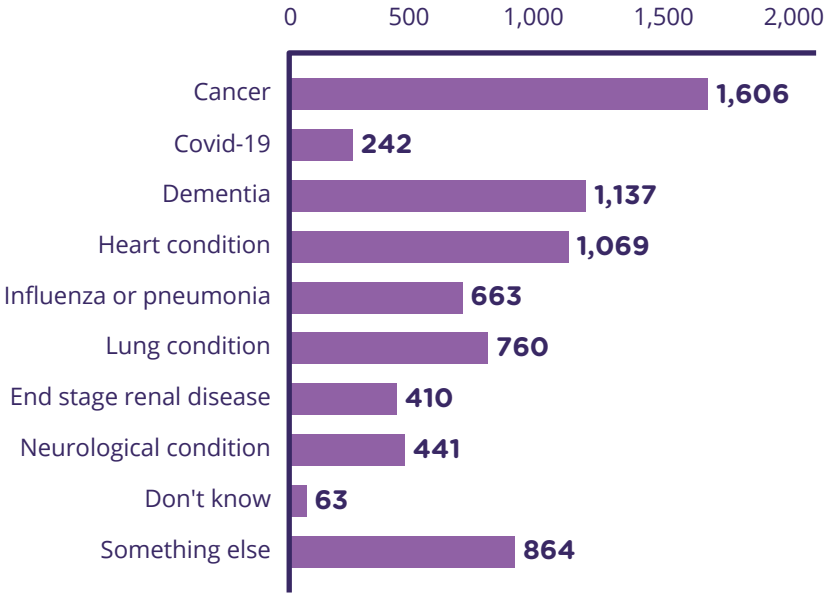
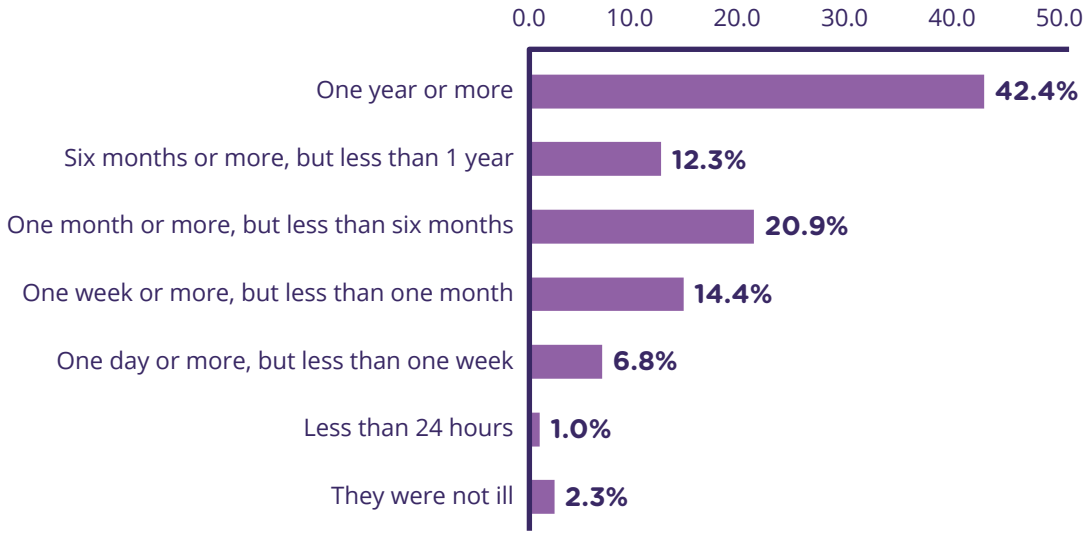


Figure 1.6 Illnesses in the last hours and days of life



13 Participants who responded 'Other' (0.1% or n=5) or 'Prefer not to say' (0.1% or n=3) are not included in Figure 1.5.

Figure 1.7 Duration of illness



Why measure the experiences of bereaved people?

The *National Standards for Residential Care Settings for Older People in Ireland* state that 'each resident continues to receive care at the end of their life which respects their dignity and autonomy and meets their physical, emotional, social and spiritual needs'.[3] In addition, the *National Standards for Safer Better Healthcare* note that people approaching end of life are particularly vulnerable and should be supported through a culture of kindness, consideration and respect.[4]

Experiences of people using health and social care services are recognised as an important indicator of healthcare quality and safety. However, there are several challenges associated with surveying people who are dying or likely to die, including significant ethical issues and the potentially frail, impaired and vulnerable condition of people at the end of life.[5, 6] Therefore, it is recommended internationally to survey bereaved relatives and friends in order to gain insights into the experiences and quality of end-of-life care.[5, 7, 8] The Office of the Ombudsman, in a report on *Developments in End of Life Care in Irish Hospitals*, suggested that 'systems should be put in place to capture the views of bereaved relatives on a regular basis'.[9] Furthermore, the *Survey of Bereaved Relatives: VOICES MaJam*, which asked bereaved relatives about their experiences of end-of-life care in the Mater Misericordiae University Hospital and St James's Hospital, recommended carrying out a national survey.[10]

The National End of Life Survey is the first national survey in Ireland to ask bereaved people about the end-of-life care provided to their relatives or friends, and will inform the development of initiatives aimed at improving the services provided both to people who are dying and to their relatives or friends.

2

In their own words

Analysis of bereaved people's comments

Three free-text questions asked participants to describe their experiences in their own words:

- **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?

In total, 9,520 comments were made in response to these free-text questions. A framework approach[11] was used to analyse the comments received in response to the open-ended questions. This approach involves multiple analysts reviewing survey comments, identifying a framework of key concepts and themes, then applying the framework across all survey comments. An analytical framework consisting of 49 codes was developed (Table 2.1). These codes were then mapped to 18 themes (Table 2.2).[14]

The framework helped to organise and systematically reduce the thousands of comments into manageable segments of information. The framework approach is suited to analysing large volumes of qualitative information and has previously been used to analyse comments made in the National Maternity Bereavement Experience Survey and the National Inpatient Experience Survey.

14 748 short comments ('yes', 'no', 'none', 'NA', 'no comment') were received across the three open-ended questions. These are included in the 'general and other comment' theme.

Table 2.1 List of comment codes

Communication – staff with staff	Feedback and complaints process
Communication – staff with deceased	Admin staff
Communication – staff with respondent	General staff
GPs	HCAs (Health Care Assistant)
Public health nurse (PHN), District/ community nurse	Ambulance service
Community health	Doctors
Homecare and home help	Involvement in patient decisions
Diagnosis and tests	Nurses
Staffing – access to specific palliative care expertise and training	Food and nutrition
Coordination of care within settings	Caring for patients with specific specialist needs
Continuity of care across care settings	Pain management
Staffing levels, availability and responsiveness	Symptom and medication management
Urgent or out of hours support	Medical needs and equipment
Access to and availability of local care	Psychosocial, emotional, spiritual and cultural support for deceased
Experience of care (Home/Community)	General quality of care
Experience of care (Hospice)	Model of care (public/private)/Private Insurance issues
ED/A&E experiences	Impact of COVID
Experience of care (Hospital)	Dignity, respect, privacy, compassion, kindness
Experience of care (Nursing Home)	Resources for respondent
Facilities – end of life (hospital/nursing home/hospice).	Personal belongings
Facilities – general (hospital/nursing home/ hospice)	Psychosocial, emotional, spiritual and cultural support for family
Ward environment	Financial and legal impacts of caring
Visiting	Timing of end-of-life care
General comments that are negative, neutral	Care at time of death
General appreciation, gratitude, a non-specific positive comment	

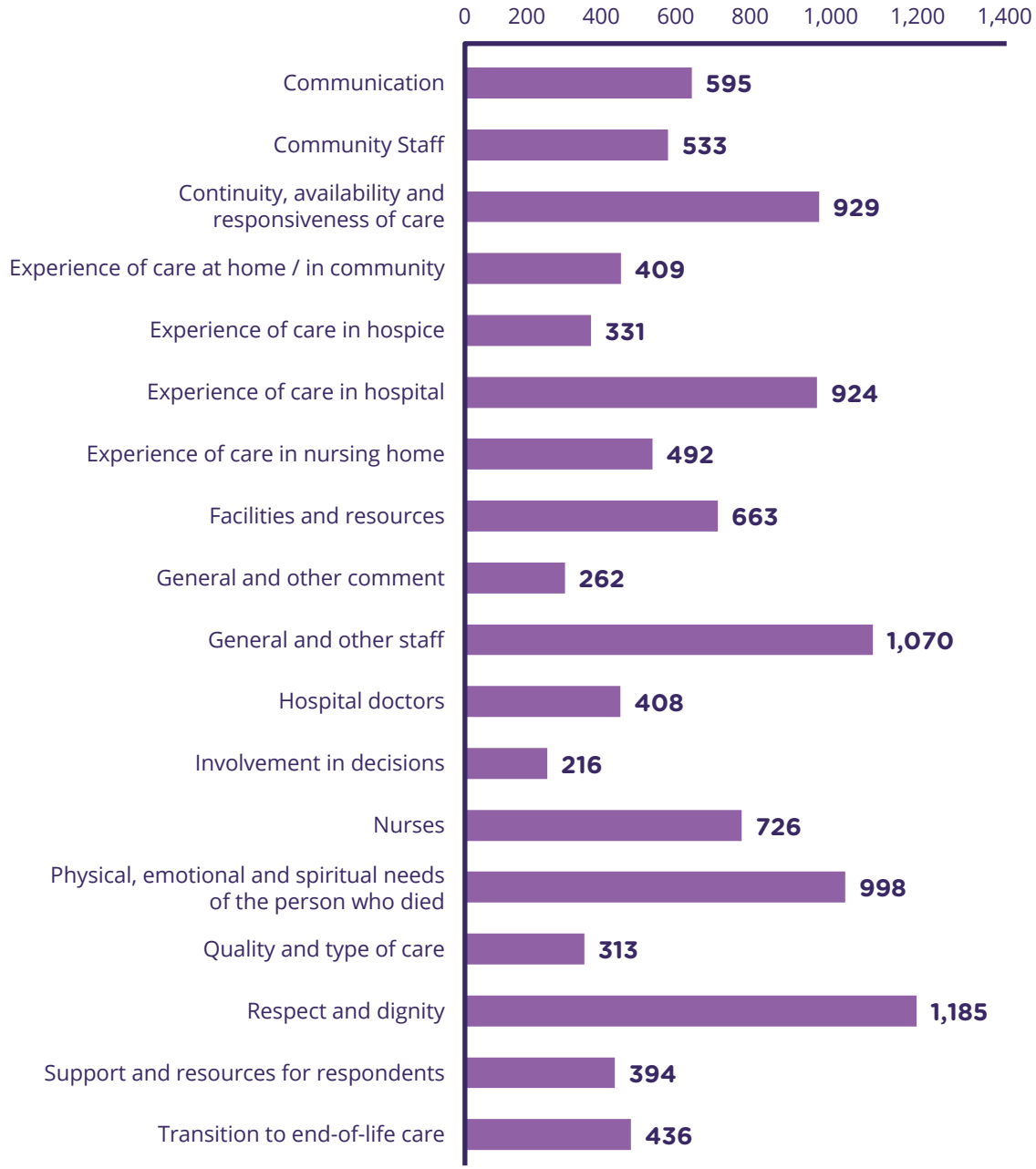
Table 2.2 List of summary themes

Communication	General and other staff
Community staff	Hospital Doctors
Continuity, availability and responsiveness of care	Involvement in decisions
Experience of care at home / in community	Nurses
Experience of care in hospice	Physical, emotional and spiritual needs of the person who died
Experience of care in hospital	Quality and type of care
Experience of care in nursing home	Respect and dignity
Facilities and resources	Support and resources for participants
General and other comment	Transition to end-of-life care

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

This question asked what was good about the care received. In total, participants made 3,573 comments in response to this question. Figure 2.1 shows the breakdown of themes covered within these comments.

Figure 2.1 Responses to Q101 broken down by theme



The most frequently occurring themes were 'Respect and dignity', 'General and other staff'[15] and 'Physical, emotional and spiritual needs of the person who died'. A selection of comments illustrating these themes is provided below.

Respect and dignity

"He was treated with dignity and respect during his time. All his wishes were considered from the time he entered the [nursing home]. He was brought out on visits, social occasions."

"Hospice was peaceful and at all times Mam was cared for to the highest standard, treated with respect, love, kindness and dignity by all. I was also treated with respect and kindness and involved in all aspects of her care. Staff were excellent and communicated clearly and available to talk at all times."

General and other staff

"The nurses were the best part of the overall experience we had as a family when we lost our loved one they did the best in an overstretched work place the cleaners were so good and all the receptionist for the doctors were ever so helpful."

"To be honest I couldn't fault the care and love my husband received in [nursing home]. I found all the staff members from nurses, carers, kitchen staff. Everyone to be so caring and loving and with a wonderful understanding and expertise, knowledge of dementia."

Physical, emotional and spiritual needs of the person who died

"The care was very professional. The carers were excellent and very caring. Our mother enjoyed seeing them and having a little chat. Palliative care were always at the other end of the phone to assist, contact the GP etc. and ensure that Mam was doing ok."

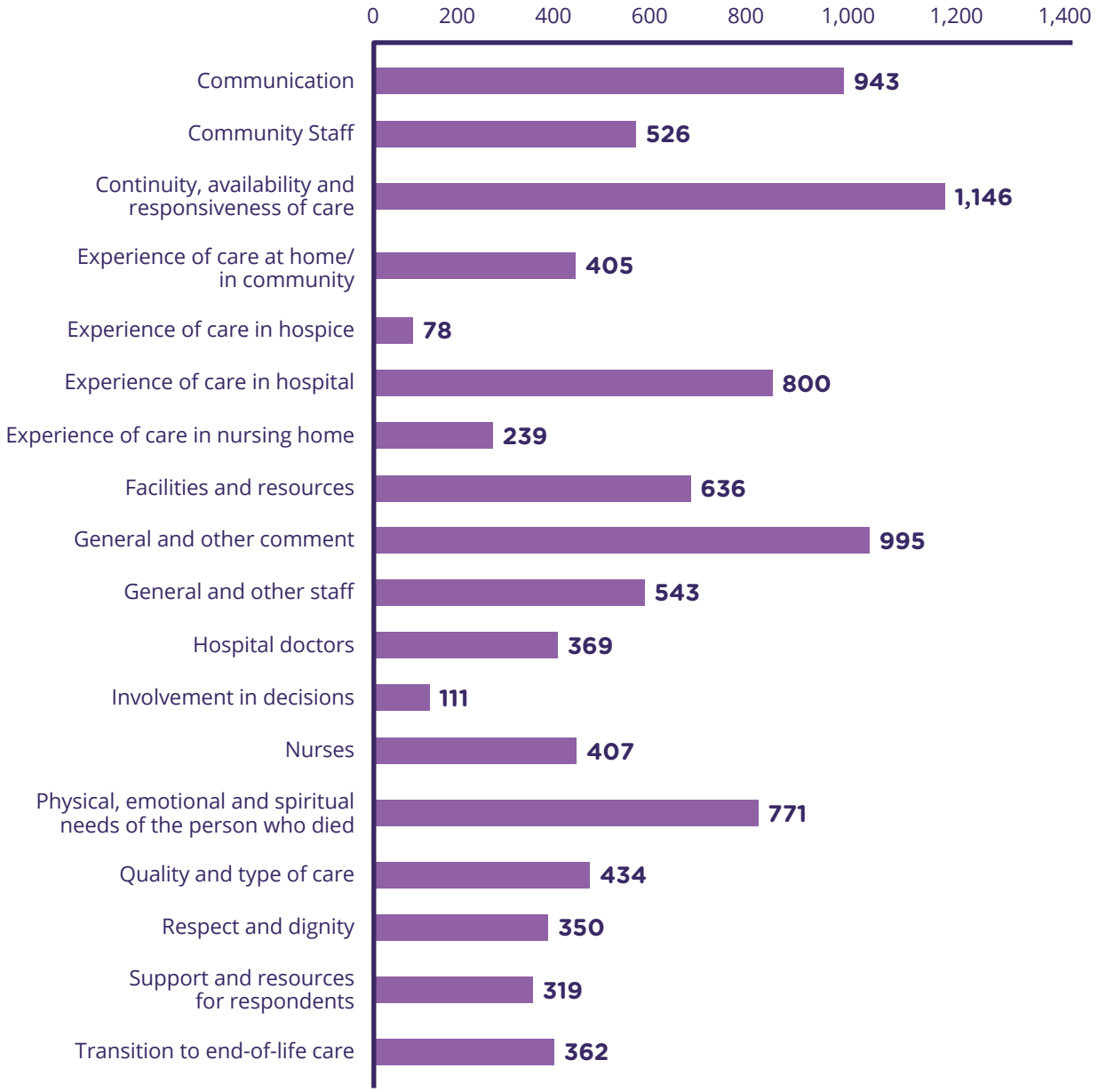
"Humanity shown by care staff. Very responsive to his religious needs."

15 Comments in this theme mentioned experiences of staff other than doctors, nurses, administrative staff, staff in the community such as cleaners, security, catering or comments referring to all staff.

Q102 Was there anything that could have been improved?

This question asked if there was anything that could be improved about the care received. In total, participants made 2,868 comments in response to this question. Figure 2.2 shows the breakdown of themes covered within these comments.

Figure 2.2 Responses to Q102 broken down by theme



For Q102, most of the comments related to the 'Continuity, availability and responsiveness of care', 'Communication' and 'General and other comment'[16] themes.

Continuity, availability and responsiveness of care

"At times, he maybe struggled with his care, because he didn't have medical care at hand. We had a carer in the house during the day, but regular scheduled medical check up by a nurse or doctor would have helped - maybe every two or three days."

"Very very poor support after-hours when a medical emergency happened after hours. Both attending resigtrar and nursing staff had poor understanding of what to do, further increasing the anxiety of my Dad and family."

Communication

"I felt communication between the doctors, nurses and myself was minimal. My brother had asked that they speak with me and keep me informed but I always had to go and look or request time to discuss. There does not seem to be anyone to liaise with me as my brother was not taking much on board."

"I wish I could have been given more information about the end of life pain relief. My partner was sedated while I wasn't there so I didn't really get a chance to say goodbye while he was conscious. I don't think we got enough information towards the end."

General and other comment

"Hospital bed which has been provided by the health board was not collected for almost 3 weeks after the death of my spouse. This caused me upset as my spouse had to stay in hospital for an extra day because bed was not available and then I had bed in my house for 3 weeks which someone else could have used."

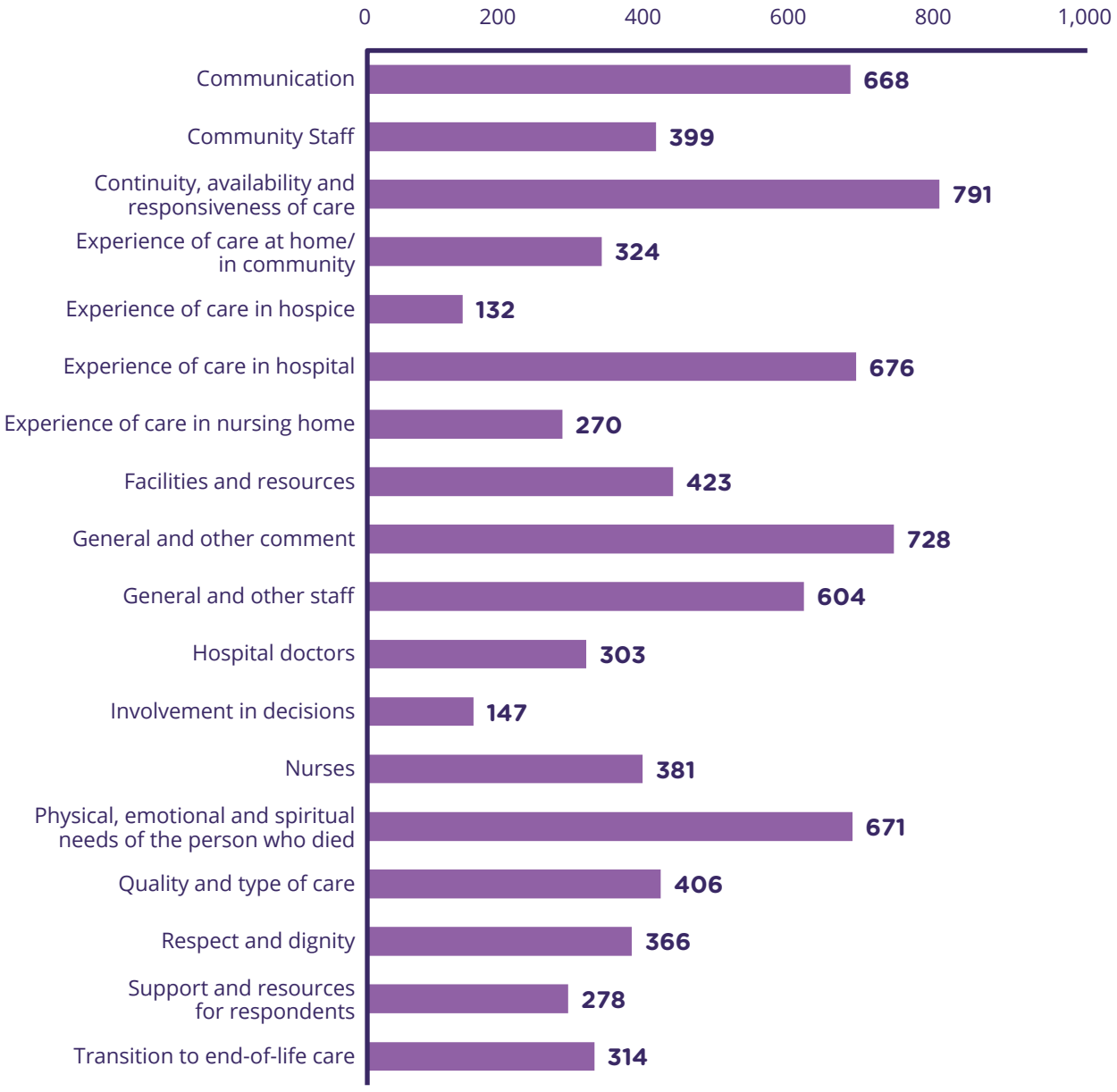
"More clarity on using health insurance or not - and what the difference really means in the particular circumstances you find yourself in, it's always vague and approached at a very vulnerable time."

16 Comments in this theme included neutral or non-specific negative comments.

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

This question asked if they had any other comments or suggestions about the care received. In total, participants made 2,304 comments in response to this question. Figure 2.3 shows the breakdown of themes covered within these comments.

Figure 2.3 Responses to Q103 broken down by theme



For Q103, most of the comments related to the 'Continuity, availability and responsiveness of care', 'Experience of care in hospital' and 'Physical, emotional and spiritual needs of the person who died' themes.

Continuity, availability and responsiveness of care

"If everyone receives this level of care at the end, it's to be commended. It felt like a co-ordinated mission by all to give my mother the most comfort and dignity during the toughest period of her life."

"I think weekend staff should familiarise themselves more with the patients they are looking after. Several times when asked at weekends the nurses etc, didn't even know the patients name, or what treatment they were getting."

Experience of care in hospital

"Visiting was very limited in the hospital setting, even though my relative could not communicate with the staff. When palliative care was mentioned, care became disjointed and my husband was embarrassed and very sad at the way he was treated and cared for."

"I would like to send my utmost appreciation to the staff at [Hospital]. They were so kind and compassionate to us and nothing was a problem."

Physical, emotional and spiritual needs of the person who died

"Dad received a lot of assistance from different health areas, Physio, OT etc. He received a hospital bed and many aids this was a great service."

"I would love to have seen more chaplaincy services. We did ask for priest after Mammy had passed away and they did phone a local priest who did come in and was so kind. Mammy was very religious and would love to have seen a chaplain each day."

3

Participants' experiences of the care provided to a family member or friend in the last three months of their life

The National End of Life Survey asked participants to describe their relative or friend's experiences of care from the last three months until their death. Similar surveys undertaken in other jurisdictions typically include questions about experiences in the weeks and months before end of life, as well as care received in the last days of life. A three month period was selected in order to provide a defined time period where those who died received care in a variety of settings. This chapter presents the results for survey questions relating to care in the last three months of life, broken down by the relevant care setting.

Care at home

"The public health nurse couldn't have been kinder, more supportive, professional and knowledgeable. He called to the house almost daily and did everything in his power to respect my mothers wishes and care for her with such compassion."

"When he came home for 6 weeks, his care was distributed to all different teams in the community. This was very hard on my husband and I. I spent all my time trying to contact them."

"Doctors' home visits should be facilitated especially for elderly with poor mobility and no transport in rural areas. I attempted to get 2 local doctors to make a home visit in the weeks before my mother went to hospital. They both refused."

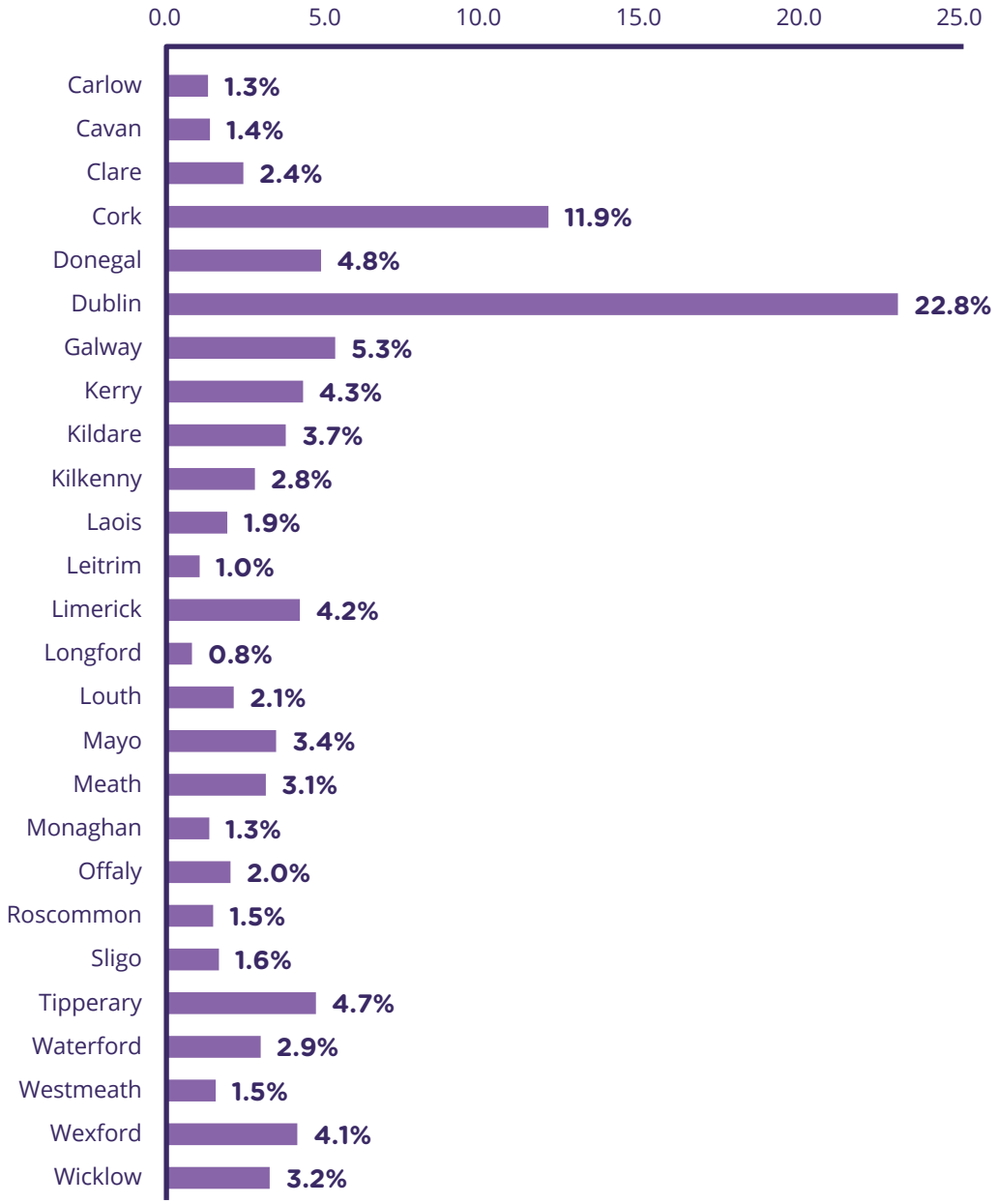
"We got good support with having equipment in place at home - hospital bed, air mattress, commode, special pressure cushion etc. The Palliative Care team had pre-ordered a lot of meds that might be needed - this was reassuring, we had them stored at home and knew there would be no panic if they were needed when chemists closed at night or weekends etc."

"My mother wanted to die at home. Hospice would have probably found it easier if she would have been admitted but they provided us with all the support we needed so that she could die at home."

"Support from the Palliative Care team in the final days was limited. They were very nice people with loads of experience and wisdom but they seemed to be very stretched. We had our final visit 2.5-3 days before he died. After that we just got telephone support."

In total, 2,525 bereaved relatives (58.5%) said that the person who died had spent time being cared for at home during the last three months of their life. Figure 3.1 shows the counties where people were cared for at home.

Figure 3.1 County of home care



Participants were asked about the services that had provided care and support at home to their relative or friend in the last three months of their life. People being cared for at home most frequently received care and support from their GP and public health nurse, followed by paid carers and community palliative care nurses. 367 participants said that the person who died did not receive care and support from any services at home (Figure 3.2).

Figure 3.2 Services providing care and support at home[17]

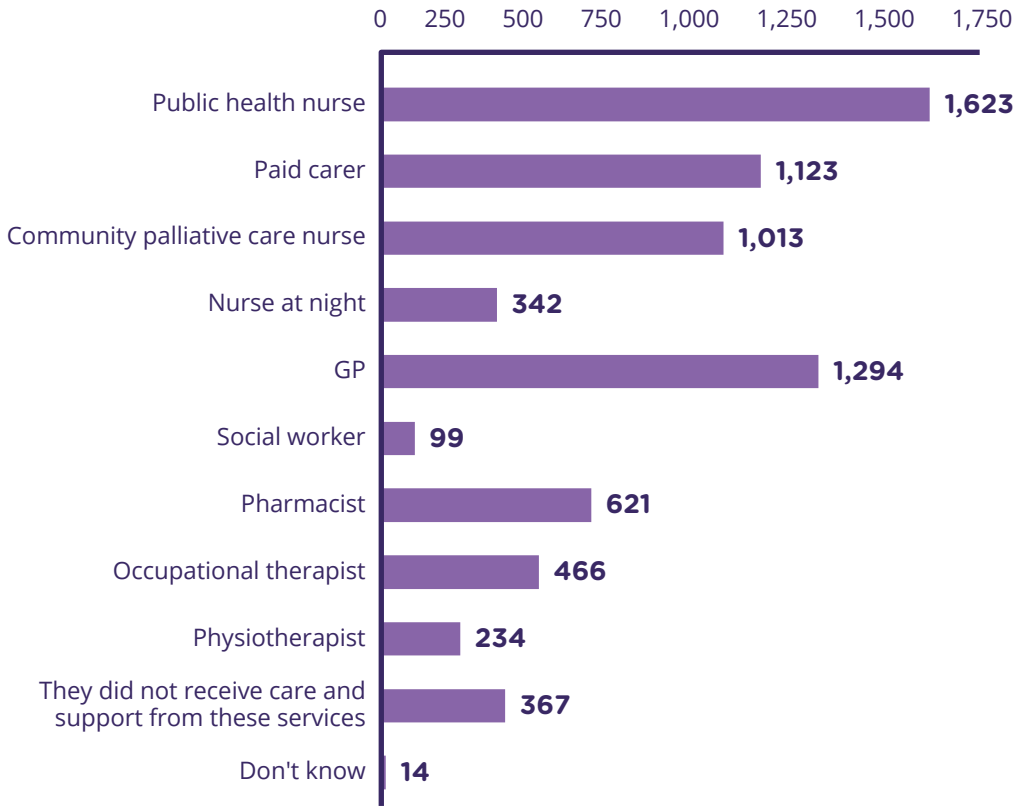


Figure 3.3 presents the results for questions on 'care at home'. The highest-scoring question concerned being treated with respect and dignity by the public health nurse, with 1,747 of 1,917 people (91.1%) saying that their relative or friend was always treated with respect and dignity by the public health nurse. The lowest-scoring question related to the availability of a GP to visit out of hours, with 579 of 1,482 people (39.1%) saying that the GP was not available to visit if their 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.

17 It was possible to select more than one response option for this question.

Figure 3.3 Scores (out of 10) for questions on 'care at home'

A total of 1,164 participants (46.1%) said that someone from a hospice, community palliative care team or other specialist palliative care service visited their relative or friend in the last three months of their life. While 42.4% (1,071) said that this was not needed, 257 bereaved relatives (10.2%) said that this was not offered.[18]

Overall experiences of care at home

In total, 78.1% of participants (1,822 of 2,332) rated the overall care that their relative or friend received from healthcare staff at home in the last three months of their life as 'good' or 'very good' (Figure 3.4). In contrast, 21.9% (510) of people rated the care received at home as 'fair to poor'.

Figure 3.4 Overall experiences of care received at home

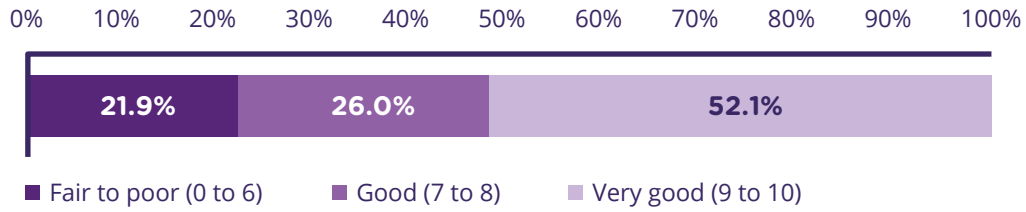
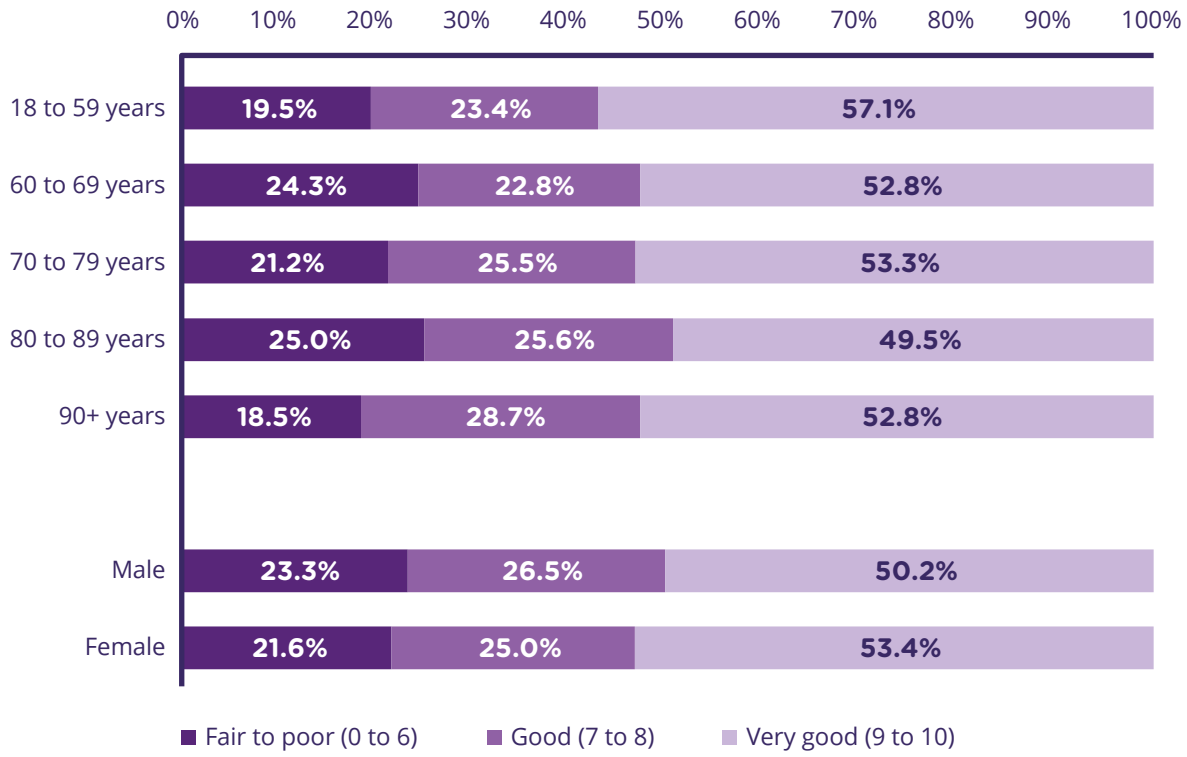


Figure 3.5 presents overall experiences of care received at home, broken down by the age and gender of the person who died.[19] In total, 76.7% of participants said that males had a 'good' or 'very good' overall experience, compared with 78.4% of females. In terms of age groups, the relatives or friends of those who died aged 90 years or older were most likely to rate the overall experience of care as 'good' or 'very good' overall.

18 A further 1.3% (33) said that they did not know.

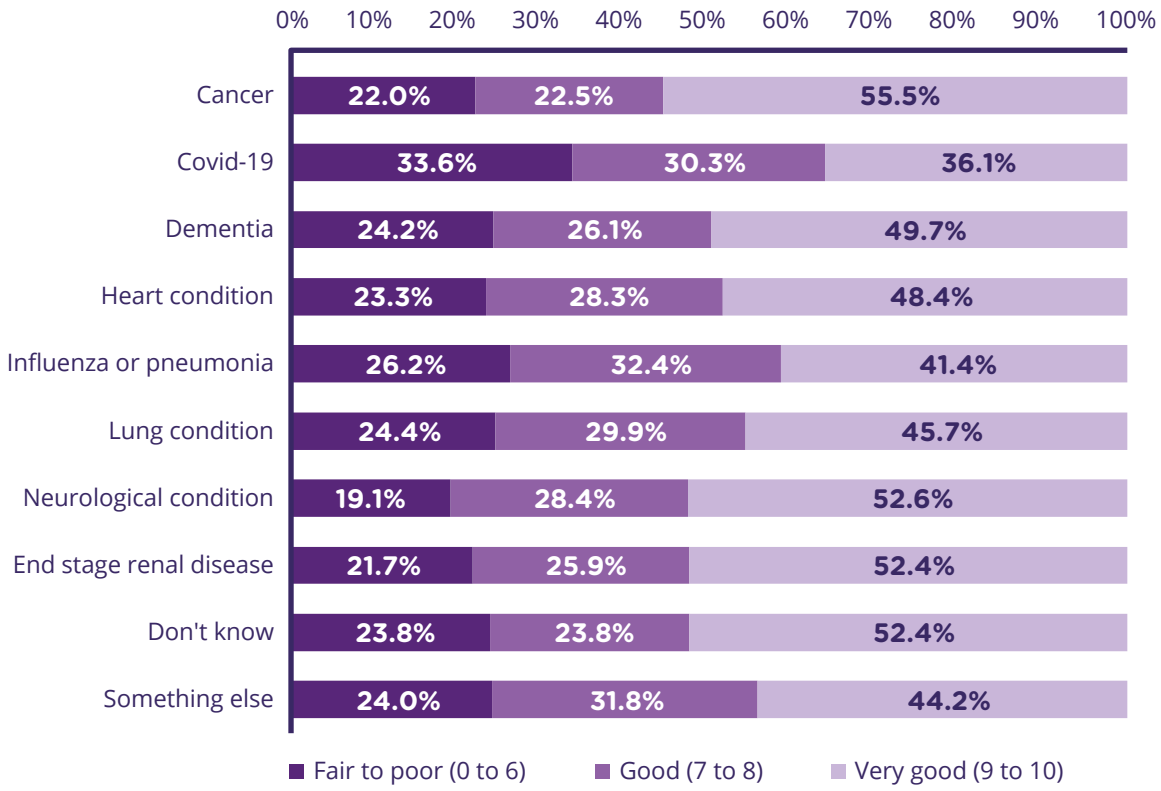
19 One respondent selected 'prefer not to say' when asked about the gender of the person who died and rated their experience as fair to poor.

Figure 3.5 Overall experiences of care received at home by age and gender of the person who died



There were some differences in participants' ratings of their overall experience of care at home depending on their illness in the last hours and days of life. Participants who said their relative had COVID-19 were most likely to report a 'fair to poor' experience (40 of 119 people or 33.6%), while those whose relative or friend had a neurological condition were least likely (41 of 215 people or 19.1%) to do so. Participants who said their relative or friend had cancer were most likely to report a 'very good' experience (593 of 1068 people or 55.5%). Figure 3.6 shows overall experiences of care at home by illnesses in the last hours and days of life.

Figure 3.6 Overall experiences of care received at home by illness



Summary of findings:
Care at home in the last three months of life

- In total, 2,525 bereaved relatives said that the person who died had spent time being cared for at home during the last three months of their life
- The highest-scoring question concerned being treated with respect and dignity by the public health nurse, with 1,747 of 1,917 people (91.1%) saying that their relative or friend was always treated with respect and dignity by the public health nurse.
- The lowest-scoring question related to the availability of a GP to visit out of hours, with 579 of 1,482 people (39.1%) saying that the GP was not available to visit if their 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.
- In total, 78.1% of participants (1,822 of 2,332) rated the overall care that their relative or friend received from healthcare staff at home in the last three months of their life as 'good' or 'very good'.

Care in a nursing home or residential care facility

"We were very pleased and happy with the treatment and care that my mother received in [nursing home]. She did not want to die in hospital and they facilitated her wishes to die in the nursing home and they exceeded our hopes and expectations with their care and compassion."

"I feel she got good care in the nursing home. Unfortunately COVID restrictions didn't allow us to visit our aunt, and she was very upset and felt isolated as she was confined to her room the week prior to her death. We were also upset by this."

"Mam went into [Nursing Home] for respite for 2 weeks. I have to say it was an awful experience for her. It took staff 40 mins to answer the bell... mam was practically immobile... The food tray was left beside mam all day. Sometimes there overnight. The room cleaner came and barely cleaned the room."

"My relative spent the last years of her life in a 'home from home' environment (nursing home). Her needs were met in every way - activities, excursions, visits from relatives at times outside of visiting hours, spiritual needs, good food and nice clean surroundings all met."

"The nursing home were very attentive to dad and nothing appeared to be a challange. They made contact with us at all times in relation to any change in his care. They had a good visiting policy in place that was user friendly to us as a family."

"I wonder if more conversations should happen in nursing homes and with older people services about decisions when medical treatment should/or should not be made. I was very clear on my father's wish regarding DNR but never had thought I would ever be deciding whether or not he should go to hospital for treatment."

A total of 1,671 participants[20] said that their relative or friend had stayed in a nursing home or other residential care facility during the last three months of their life.

Figure 3.7 shows the length of stay in a nursing home or residential care centre. The majority of people had stayed in a nursing home or residential care facility for longer than 12 weeks (n=1,195 or 70.4%).

Figure 3.7 Length of stay in a nursing home or residential care facility

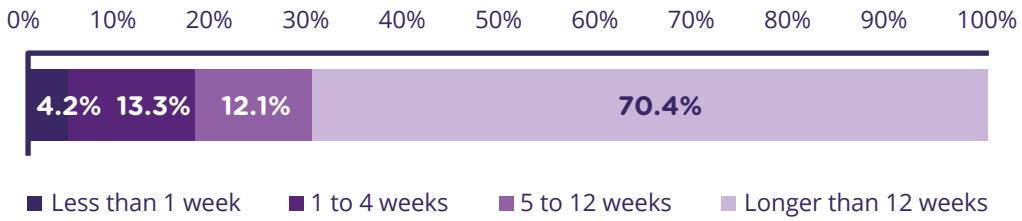
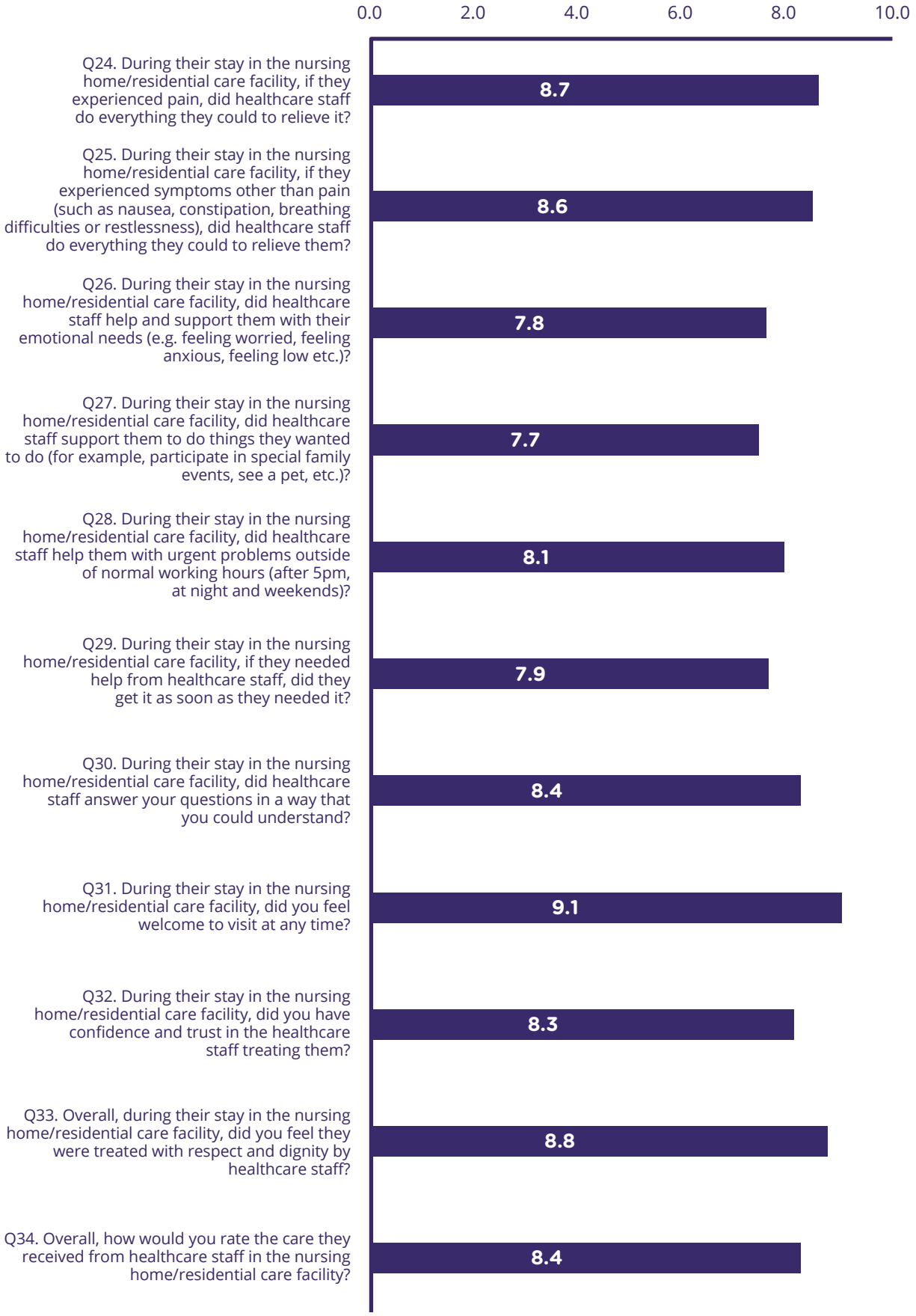


Figure 3.8 displays the results for questions on 'care in a nursing home or residential care facility'. The highest-scoring question related to participants feeling welcome to visit their relative or friend in the nursing home, with 84.8% of people (n=1,337) saying that they always felt welcome to visit at any time. The lowest-scoring question related to activity support, with 10.4% of participants (n=147) saying that healthcare staff did not support their relative or friend to do things they wanted to do (for example, participate in special family events, see a pet) during their stay in the nursing home or residential care facility.

20 A further 9 participants or 0.3% responded don't know when asked if their relative or friend stayed in a nursing home or residential care facility during the last three months of their life.

Figure 3.8 Scores (out of 10) for questions on 'Care in a nursing home or residential care facility'



Overall experiences of care in a nursing home or residential care facility

85.4% of bereaved relatives rated the overall care their relative or friend received from healthcare staff in a nursing home or residential care facility in the last three months of their life as 'good' or 'very good', with 14.6% (246 of 1,684 people) rating the care as 'fair to poor' (Figure 3.9).

Figure 3.9 Overall experience in a nursing home/residential care facility

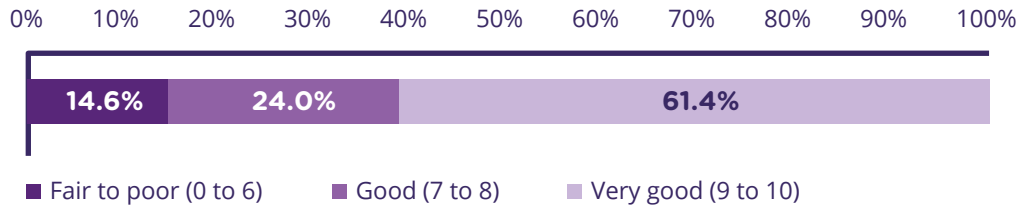


Figure 3.10 presents overall experiences of care received in a nursing home or residential care facility, broken down by the age and gender of the person who died.[21] In total, 85.1% of males and 85.6% of females had a 'good' or 'very good' overall experience. In terms of age groups, the relatives or friends of those who died aged 18 to 59 years were most likely to rate the overall experience of care as 'good' or 'very good' overall.

21 A small number of bereaved relatives selected 'Other' (n=4 responded good or very good) or 'Prefer not to say' (n=2 responded fair to poor) when asked about the gender of the person who died.

Figure 3.10 Overall experiences of care received in a nursing home or residential care facility by age and gender

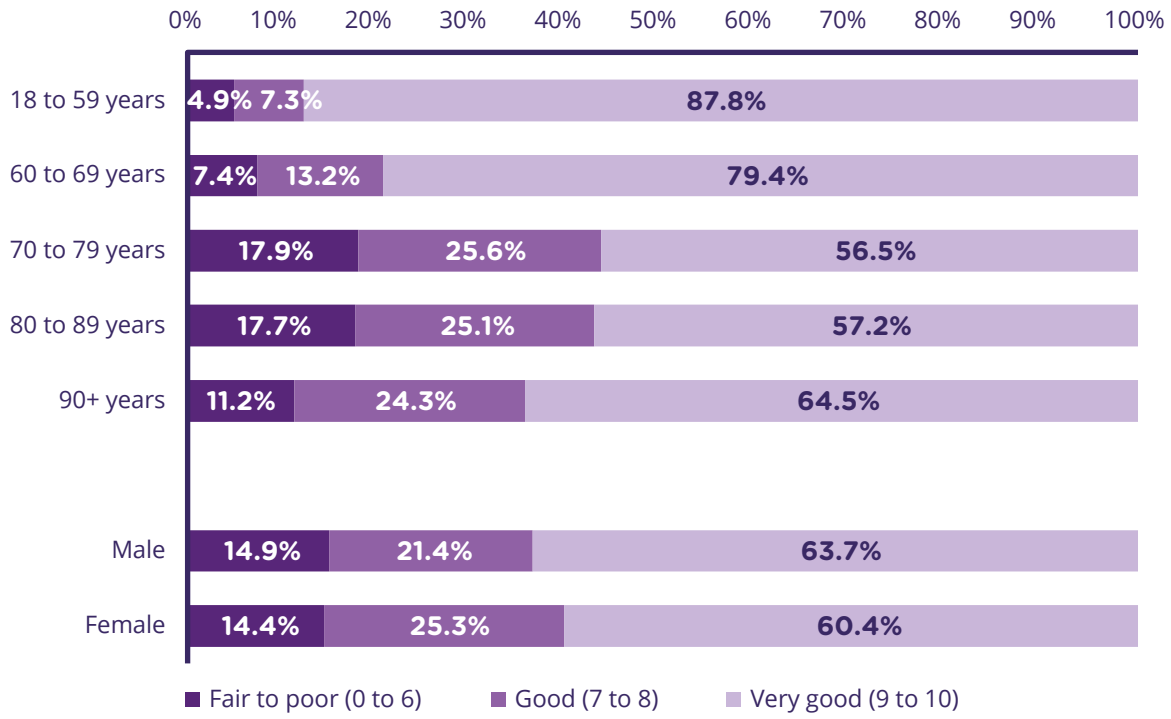


Figure 3.11 shows overall experiences of care in a nursing home or residential care by the illnesses of the person who died. Participants who did not know what illness their friend or relative had in the last hours and days of their life were most likely to report a 'fair to poor' experience (6 of 24 people or 25.0%). The next group most likely to report a 'fair to poor' experience were those whose relative or friend had a lung condition (34 of 184 people or 18.5%). Those whose relative or friend had dementia were least likely (115 of 791 people or 14.5%) to report a 'fair to poor' experience. Participants who said their relative or friend had cancer were most likely to report a 'very good' experience (198 of 300 people or 66.0%).

Figure 3.11 Overall experiences of care received in a nursing home or residential care facility by illnesses in the last hours and days of life

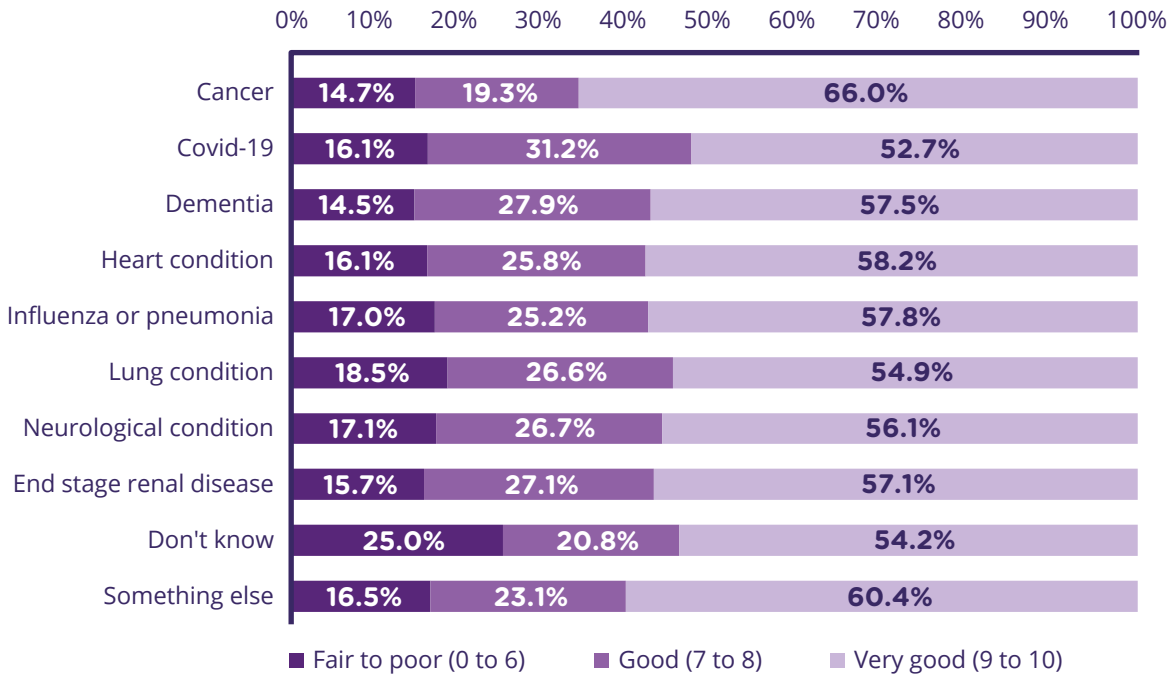
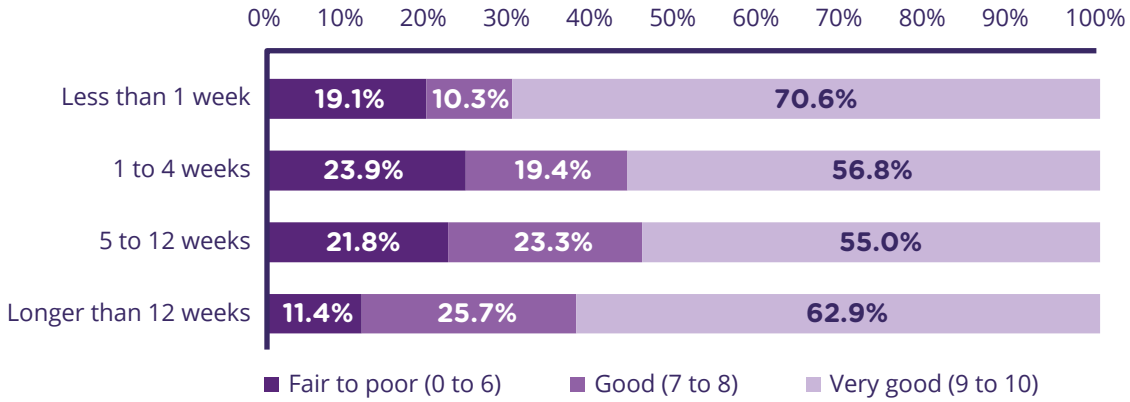


Figure 3.12 shows overall experiences by length of stay in the nursing home or residential care facility. Participants whose relative or friend spent less than one week in a nursing home or residential care setting were more likely to report a 'very good' experience (48 of 68 people or 70.6%). Participants whose relative or friend spent longer than 12 weeks in a nursing home or residential care setting were more likely to report a 'good' or 'very good' experience (1,043 of 1,177 people or 88.6%).

Figure 3.12 Overall experiences of care received in a nursing home or residential care facility by length of stay



Summary of findings:
Care in a nursing home in the last three months of life

- A total of 1,671 participants said that their relative or friend had stayed in a nursing home or residential care facility during the last three months of their life.
- The highest-scoring question related to participants feeling welcome to visit their relative or friend in the nursing home, with 84.8% of people (n=1,337) saying that they always felt welcome to visit at any time.
- The lowest-scoring question related to activity support, with 10.4% of participants (n=147) saying that healthcare staff did not support their relative or friend to do things they wanted to do (for example, participate in special family events, see a pet etc.) during their stay in the nursing home or residential care facility.
- In total, 85.4% of participants rated the overall care their relative or friend received from healthcare staff in a nursing home or residential care facility in the last three months of their life as 'good' or 'very good'.

Care in a hospital

"She was kept as comfortable as possible in the circumstances while in hospital, and prior to her final stay in hospital the medical team were open with her and answered all of her questions."

"Her stay in the hospital was unsatisfactory. Very poor communication between the staff. Overall very stressful to experience what mum went through while she was there, not given enough pain relief or care or compassion."

"I could visit at any time. Encouraged to stay overnight. He was given pain relief when needed and his position changed frequently."

"The lack of information while in the hospital setting was extremely poor and upsetting, there was no-one to talk to until my dad was being discharged."

"Nurses and care staff were excellent. They always kept us up to date on how Uncle was doing. He was made very comfortable, warm and safe. He was so well looked after by all the team."

"I will always wonder if she was in a ward instead of A&E, would she have had a more peaceful death. Instead she was very distressed and in a lot of discomfort."

A total of 2,639 people said that their relative or friend had spent time in an acute hospital during the last three months of their life.[22] Just over half of participants said that their relative or friend had been in hospital once in the last three months of their life (1,392 of 2,677, 52%), while a quarter (25.5%, 682) had been admitted twice, with 18.6% (n=498) having been admitted three or more times. 105 participants (3.9%) were not sure how many times their relative or friend had been in hospital. Over half of people had stayed in a hospital for between one and four weeks (Figure 3.13).

Figure 3.13 Length of stay in an acute hospital

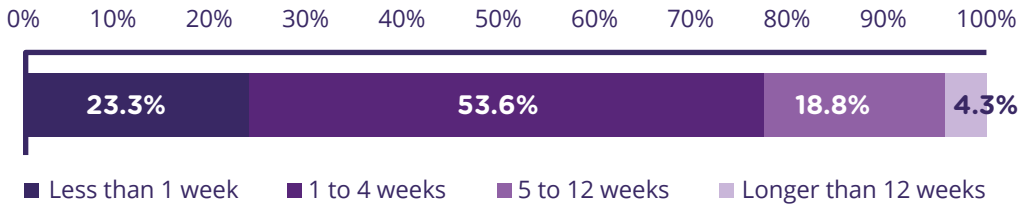


Figure 3.14 shows the average scores (out of 10) for questions on 'care in an acute hospital'. The highest-scoring questions related to pain relief and relief from other symptoms, with 64.6% of participants (1,627 of 2,520) saying that healthcare staff did everything they could to relieve their relative or friend's pain. Similarly, 64.3% of participants (1,647 of 2,561) said that healthcare staff did everything they could to relieve their relative or friend's other symptoms (such as nausea, constipation, breathing difficulties or restlessness). Further, 67.7% of people (1,850 of 2,732) said that their relative or friend was always treated with respect and dignity during their last hospital stay.

The lowest-scoring question concerned support with emotional needs, with 44.3% of people (968 of 2,737) saying that healthcare staff did not help and support their relative or friend with their emotional needs (for example feeling worried, feeling anxious, feeling low).

22 A further 15 (0.4%) did not know if their friend or relative stayed in an acute hospital.

Figure 3.14 Scores (out of 10) for questions on 'Care in an acute hospital'

Overall experiences of care in an acute hospital

In total, 71.1% of participants (1,930 of 2,716) rated the overall care that their relative or friend received in an acute hospital in the last three months of their life as 'good' or 'very good', while 28.9% (786 of 2,716) rated the care as 'fair to poor'. Figure 3.15 show overall experience of care received in an acute hospital.

Figure 3.15 Overall experience of care received in an acute hospital

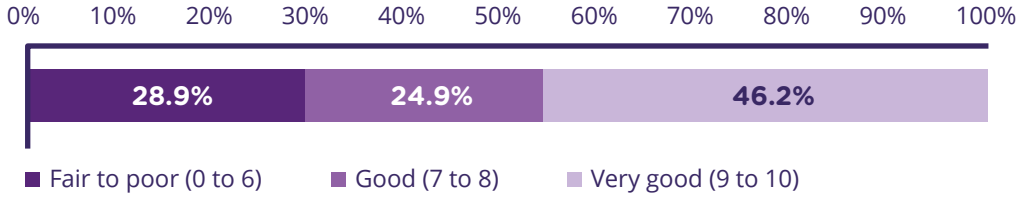
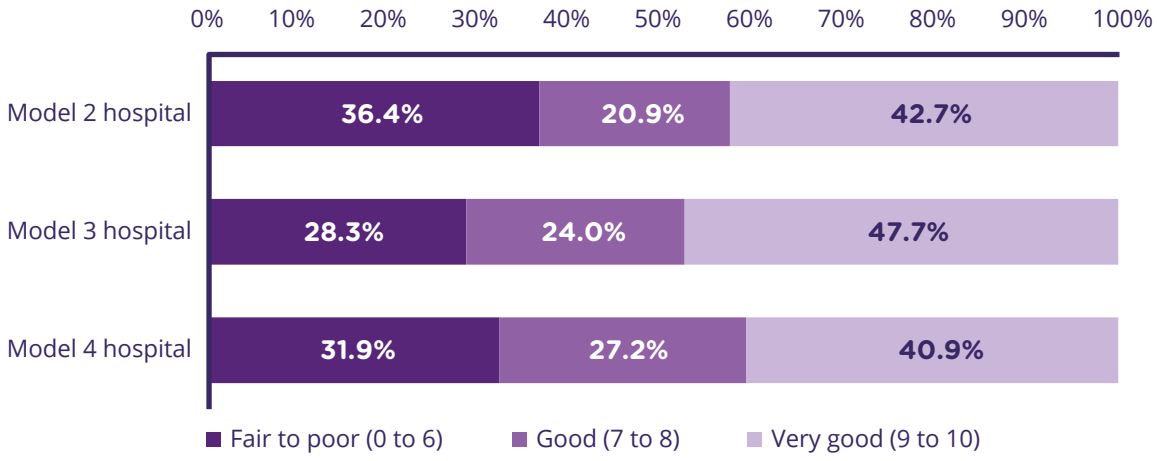


Figure 3.16 presents overall experiences of care and hospital model. The majority of participants reported a 'good' or 'very good' experience across all hospital model types[23].

Figure 3.16 Overall experience of care received and hospital model



23 Model 4 hospitals are typically large hospitals that have emergency departments and specialist services. Model 3 hospitals are medium-sized hospitals that have emergency departments but may not have similar specialist services to a Model 4 hospital. Model 2 hospitals are typically smaller and do not have emergency departments. Results for specialist elective hospitals were not compared due to insufficient number of responses.

Figure 3.17 shows overall experiences of care in acute hospitals, broken down by the age and gender of the person who died.[24] In total, 72.9% of males and 69.4% of females had a 'good' or 'very good' overall experience. In terms of age groups, the relatives or friends of those who died aged 18 to 59 years were most likely to rate the overall experience of care as 'good' or 'very good' overall.

Figure 3.17 Overall experience of care received in hospitals by age and gender

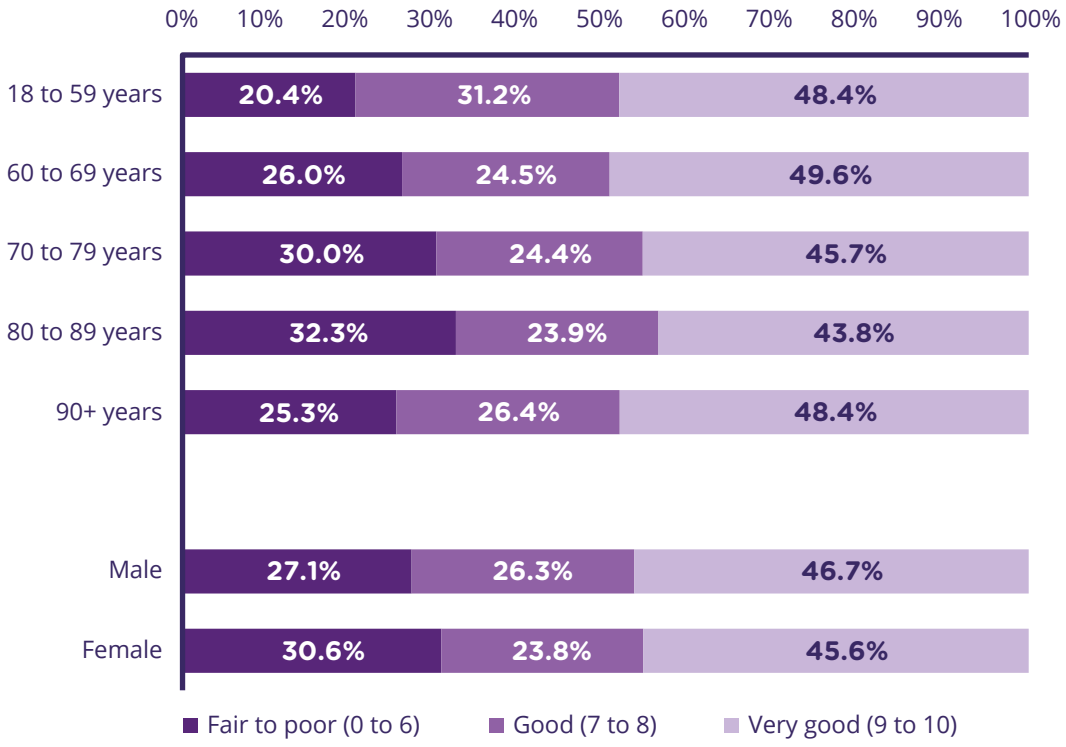


Figure 3.18 shows overall experiences of care in an acute hospital by the illnesses of the person who died. Participants who reported that their friend or relative had another illness than those listed in the last hours and days of their life were most likely to report a 'fair to poor' experience (168 of 504 people or 33.3%), while those who did not know what illness their relative or friend had were least likely (5 of 21 people or 23.8%) to do so. Participants who said their relative or friend had influenza or pneumonia were most likely to report a 'very good' experience (226 of 444 people or 50.9%).

24 A small number of bereaved relatives selected 'Other' (n=2 responded fair to poor and good) or 'Prefer not to say' (n=2 responded fair to poor and good) when asked about the gender of their relative or friend.

Figure 3.18 Overall experience of care received in hospital by illness

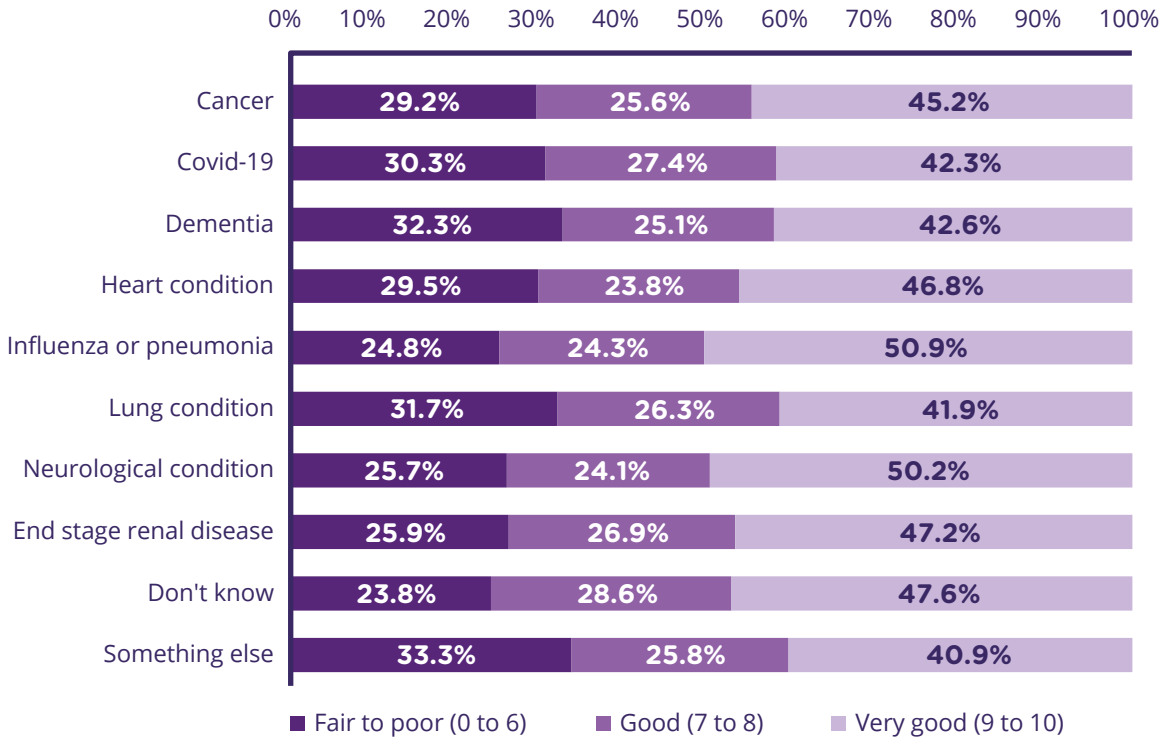
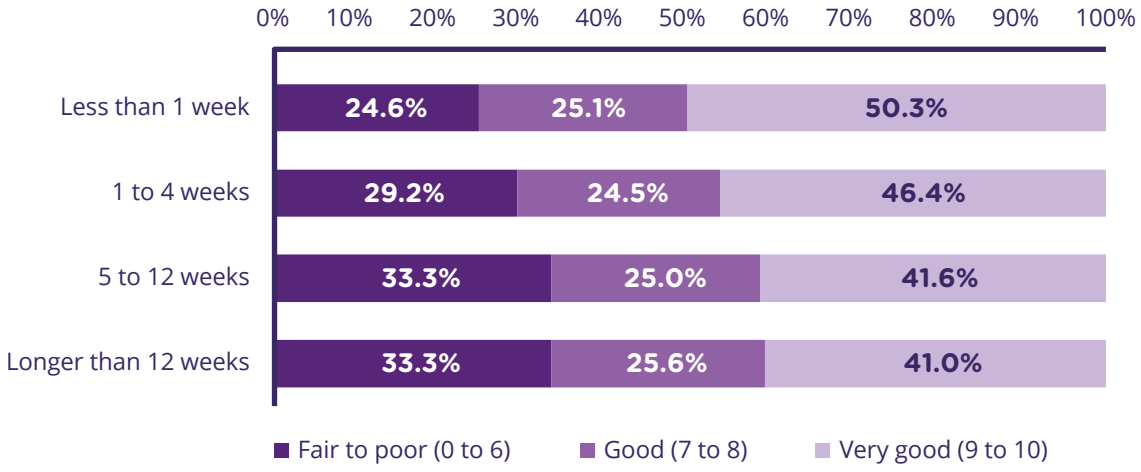


Figure 3.19 shows overall experiences by length of stay in hospital. Participants whose relative or friend spent less than one week in hospital were more likely to report a 'very good' experience (315 of 626 people or 50.3%).

Figure 3.19 Overall experience of care received in hospital by length of hospital stay



Summary of findings:
Care in hospital in the last three months of life

- A total of 2,639 people said that their relative or friend had spent time in an acute hospital during the last three months of their life.
- The highest-scoring questions related to pain relief and relief from other symptoms, with 64.6% of participants (1,627 of 2,520) saying that healthcare staff did everything they could to relieve their relative or friend's pain. Similarly, 64.3% of participants (1,647 of 2,561) said that healthcare staff did everything they could to relieve their relative or friend's other symptoms (such as nausea, constipation, breathing difficulties or restlessness). Further, 67.7% of people (1,850 of 2,732) said that their relative or friend was always treated with respect and dignity during their last hospital stay.
- The lowest-scoring question concerned support with emotional needs, with 44.3% of people (968 of 2,737) saying that healthcare staff did not help and support their relative or friend with their emotional needs (for example feeling worried, feeling anxious, feeling low).
- In total, 71.1% of participants (1,930 of 2,716) rated the overall care their relative or friend received in an acute hospital in the last three months of their life as 'good' or 'very good'.

Care in a hospice

"Hospice was peaceful and at all times Mam was cared for to the highest standard, treated with respect, love, kindness and dignity by all. I was also treated with respect and kindness and involved in all aspects of her care. Staff were excellent and communicated clearly and available to talk at all times."

"[Hospice] was excellent and could not be faulted in any way, however, it took far too long to get a bed there."

"In the hospice there is a family suite with kitchenette, beds etc. but it is being used for storage - not for family as it was intended - big waste."

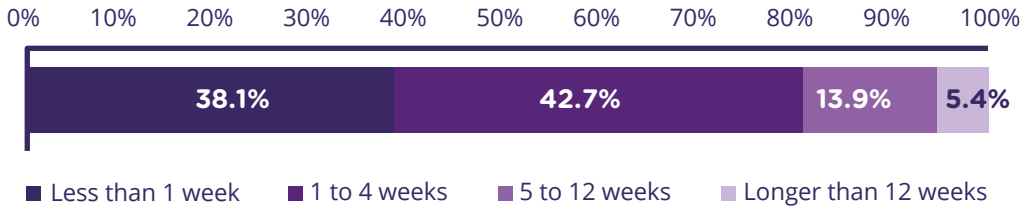
"The level of care, support and sensitivity towards both patient and family was beyond all expectations in the hospice... Wonderful people each and every one of them with exceptional empathy, skills and a depth of both knowledge and ability to genuinely care for and support the most vulnerable of people day in day out. Thanks to all."

"Owing to the underlying mental health needs of the person who died, hospice staff made every effort to understand and learn more about these needs, so compassionate and professional."

"For [hospice] wasn't advised what was needed to get death certificate. I felt hospice could have posted out the form required to get death cert. Unnecessary to have to go back to hospice to get the form. Had I known about pet visit - this would have been good."

In total, 540 participants said that their relative or friend had spent time in a hospice during the last three months of their life. Figure 3.20 shows the length of stay in a hospice.[25] The majority of people (42.7%, 231 of 541) had stayed in a hospice for four weeks or less.

Figure 3.20 Length of stay in a hospice



Questions on 'care in a hospice' received the most positive ratings on the survey. Figure 3.21 shows the average scores (out of 10) for questions on 'care in a hospice'. The highest-scoring question related to being treated with respect and dignity, with 96.3% of participants (523 of 543) saying that their relative or friend was always treated with respect and dignity by healthcare staff during their hospice stay.

The lowest-scoring question was Q53, with 6.5% of participants (25 of 383) saying that healthcare staff did not support their relative or friend to do things they wanted to do (for example, participate in special family events, see a pet) during their hospice stay.

25 Five participants (0.2%) did not know if their relative or friend spent time in a hospice.

Figure 3.21 Scores (out of 10) for questions on 'Care in a hospice'

Overall experiences of care in a hospice

Figure 3.22 shows the overall experience of care received in a hospice. In total, 91.5% of participants (494 of 540) rated the care that their relative or friend received in the hospice as 'very good', with 2.6% (14 of 540) rating it as 'fair to poor'.

Figure 3.22 Overall experience of care received in a hospice

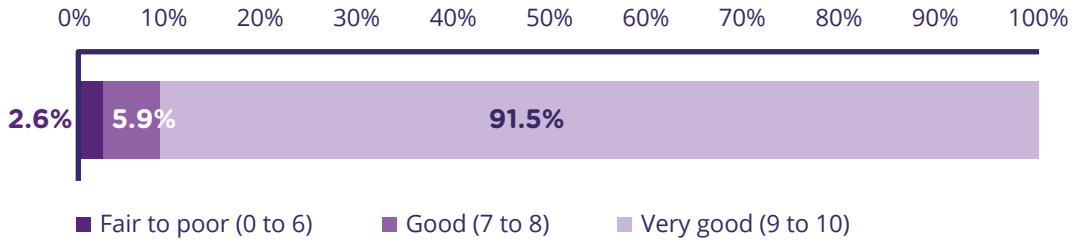
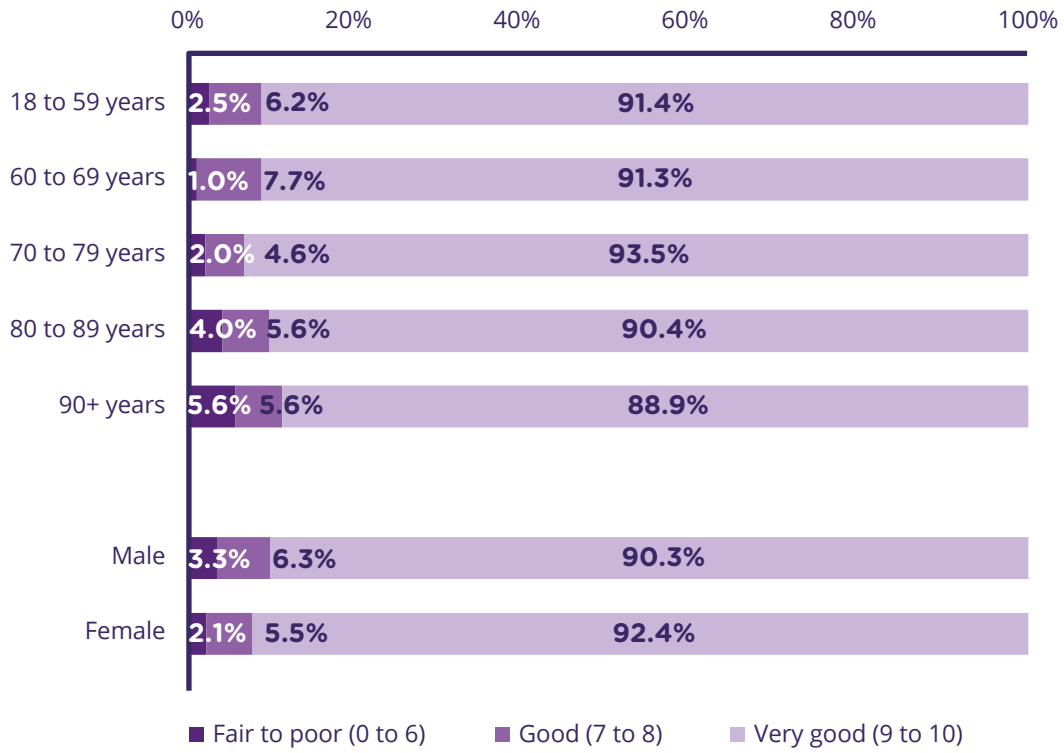


Figure 2.23 shows overall experiences of care in a hospice, broken down by the age and gender of the person who died.[26] In total, 96.6% of males and 97.9% of females had a 'good' or 'very good' overall experience. In terms of age groups, the relatives or friends of those who died aged 60 to 69 years were most likely to rate the overall experience of care as 'good' or 'very good' overall.

Figure 3.23 Overall experience of care received in a hospice by age and gender



26 One participant selected 'Other' when asked about the gender of the person who died.

Figure 3.24 shows the overall experiences of care in a hospice by the illnesses of the person who died. Participants who reported that their friend or relative had influenza or pneumonia in the last hours and days of their life were most likely to report a 'fair to poor' experience (three of 20 people or 15.0%). Participants whose relative or friend had a neurological condition were the next group most likely to report a 'fair to poor' experience (three of 35 people or 8.6%). All participants who said their relative or friend had COVID-19 reported a 'very good' experience of care in a hospice (11 of 11 people or 100%). All participants who did not know what illness their relative or friend had in the last hours and days of life also reported a 'very good' experience of care in a hospice (two of two people or 100%). Almost all participants whose relative or friend had end stage renal disease reported a 'very good' experience (24 of 25 people or 96.0%).

Figure 3.24 Overall experience of care received in hospices by illness

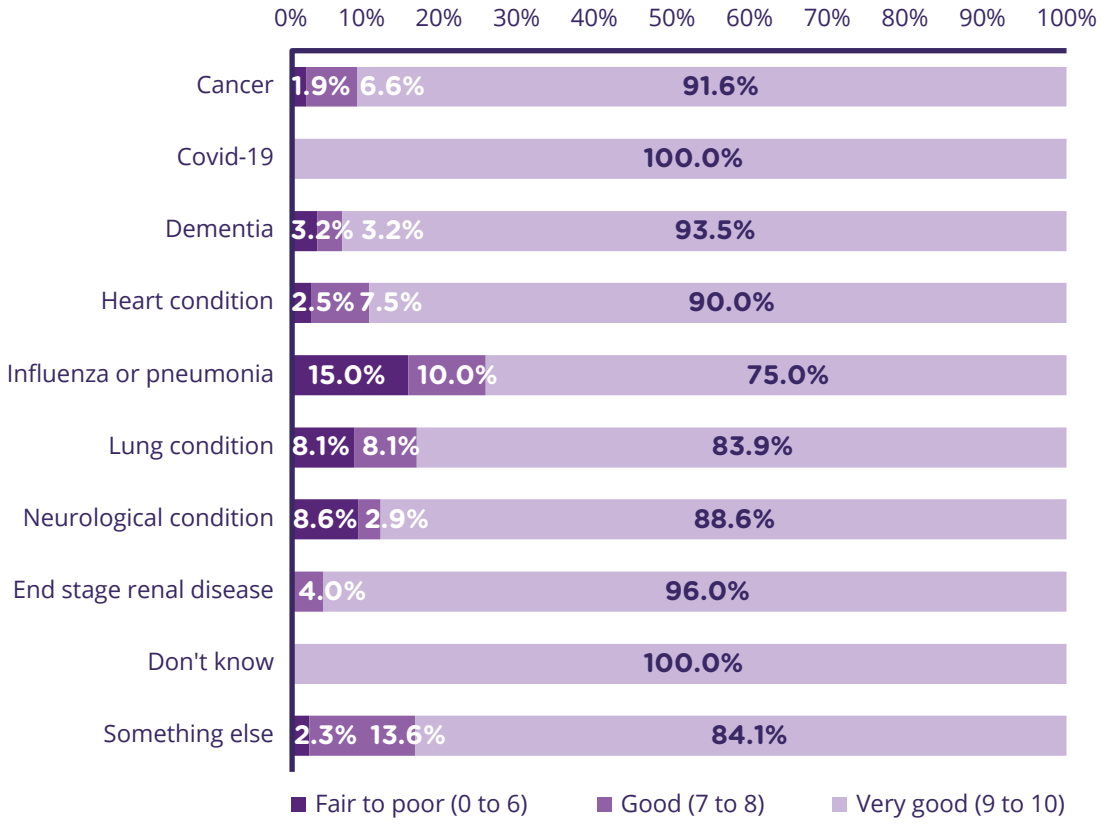
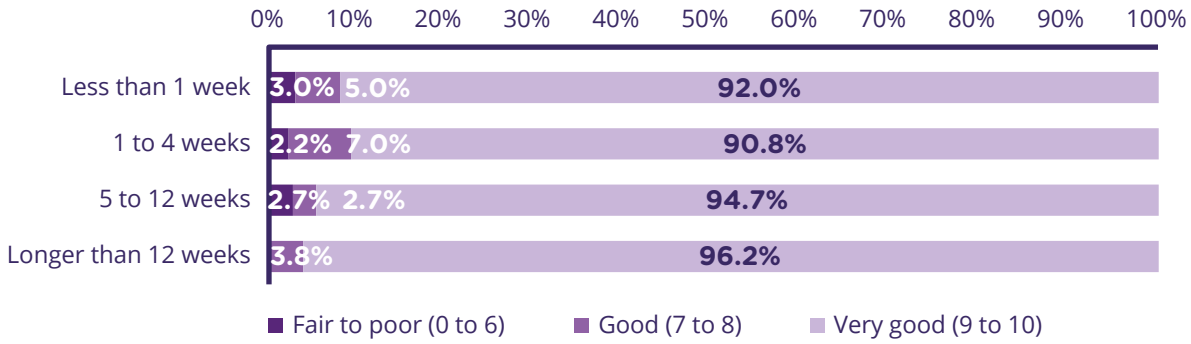


Figure 3.25 Overall experience of care received in hospices by length of stay



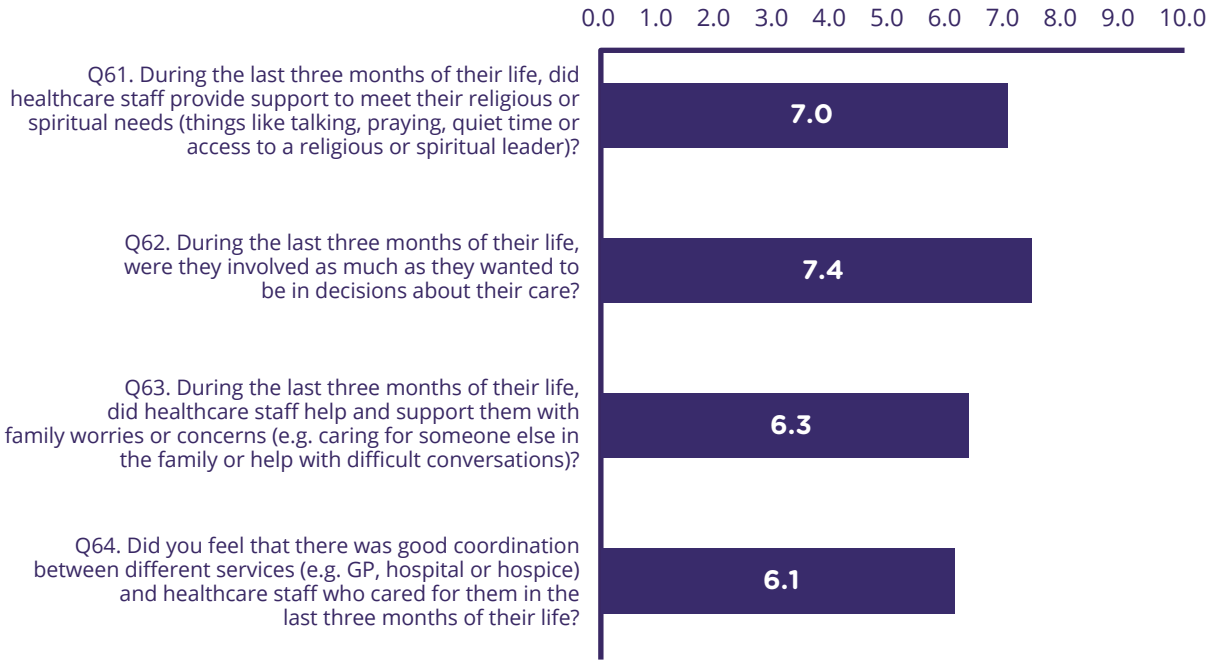
Summary of findings:
Care in a hospice in the last three months of life

- In total, 540 participants said that their relative or friend had spent time in a hospice during the last three months of their life.
- The highest-scoring question related to being treated with respect and dignity, with 96.3% of bereaved relatives (523 of 543) saying that their relative or friend was always treated with respect and dignity by healthcare staff during their hospice stay.
- The lowest-scoring question was Q53, with 6.5% of participants (25 of 383) saying that healthcare staff did not support their relative or friend to do things they wanted to do (for example, participate in special family events, see a pet) during their hospice stay.
- In total, 97.4% of participants (526 of 540) rated the care that their relative or friend received in the hospice as 'good' or 'very good'.

Overall care in the last three months

Four questions on the survey asked about the overall care that the person who died received in the last three months of life. Figure 3.26 shows the average score (out of 10) for these questions. The highest-scoring question related to involvement in decisions about their care, with 57.9% of participants (1,817 of 3,136) saying that their relative or friend was definitely involved as much as they wanted to be in decisions about their care, with 32.1% (1,006 of 3,136) involved 'to some extent'.[27] The lowest-scoring question concerned coordination between services, with 23.9% of people (892 of 3,739) saying that they did not feel there was good coordination between the different services and healthcare staff who cared for their relative or friend in the last three months of their life.

Figure 3.26 Scores (out of 10) for questions on overall care in the last three months



27 This does not include 941 participants who selected 'they did not want to be involved or were not able to be involved' and 89 who selected 'don't know'.

4

Participants' experiences of the care provided to a family member or friend at the end of life

This chapter presents the results for survey questions relating to care in the last two days of life, broken down by the relevant care setting. The questions in this section focused specifically on care in the last two days and at the end of life.

Experiences of care in the last two days of life

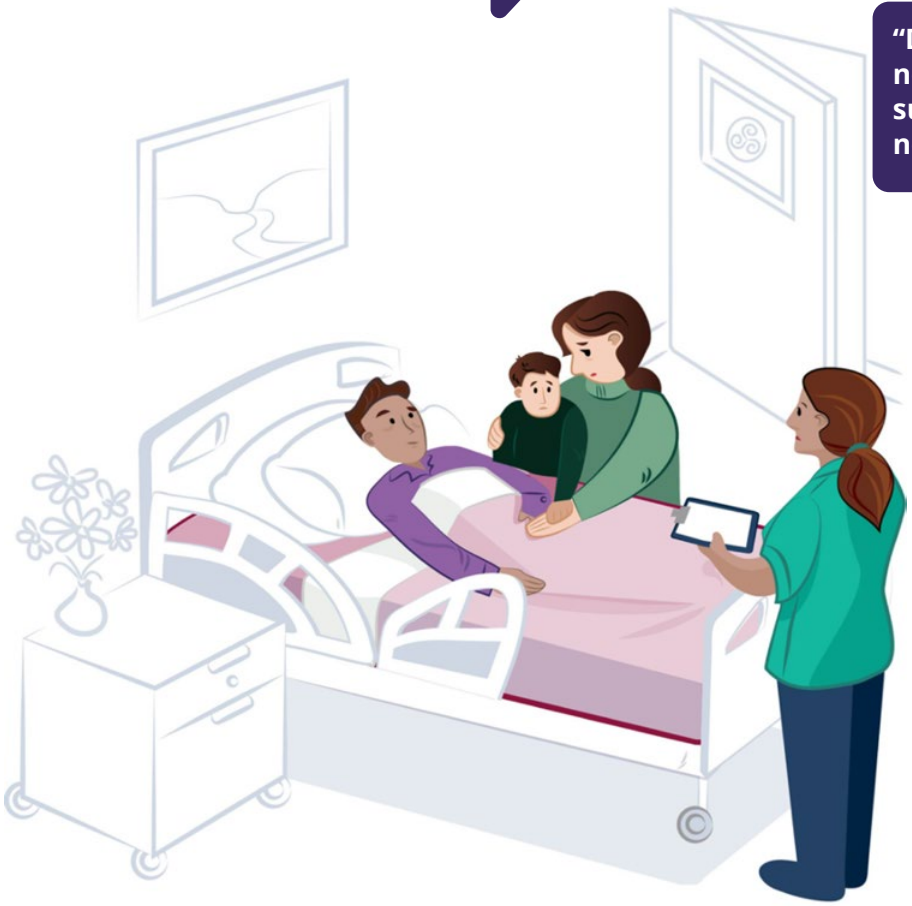
"I am grateful to the experienced home help who saw my mother was suffering pain, and got the district nurse to arrange a palliative care nurse to come and Doc to prescribe morphine in the last 2 days of my mother's life."

"We felt that the 'box' containing the medicines administered during the last stage of life was initiated very quickly. The function of the medicines were explained, but the full range of possible effects was not. As soon as the medicines were administrated the patient 'went to sleep' and there was no further communication."

"Dad was moved to a private room for the last days but considering how sick he was, I felt this should have happened sooner."

"Mum was made comfortable in her last few days."

"Due to the holiday season the normal level of contact and support in the last few days was not available."

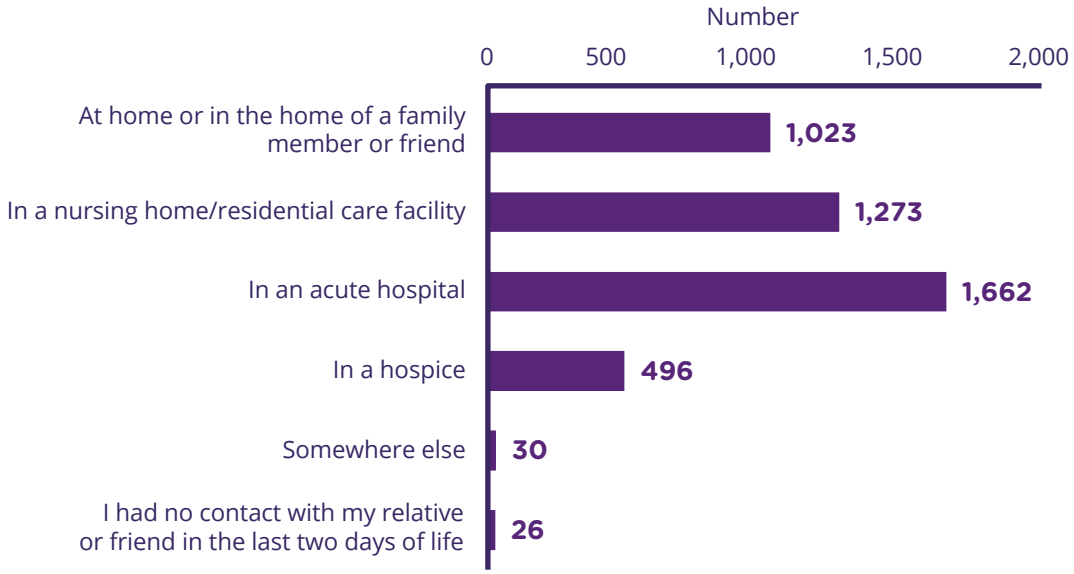


"It was as though we were all in the sitting room at home, purely because the staff enabled and facilitated this visit. I am so grateful that it happened because I knew it was the one thing Daddy didn't get a chance to do before he became too ill."

Location of care in the last two days

During the last two days of their life, 23.1% of people who died (n=1,023) were cared for at home, 28.7% (n=1,273) in a nursing home or other residential care facility, while 37.5% (n=1,662) were cared for in an acute hospital. A further 11.2% (n=496) were cared for in a hospice and 0.7% (n=30) were cared for somewhere else. Figure 4.1 shows the location of care in the last two days of life.

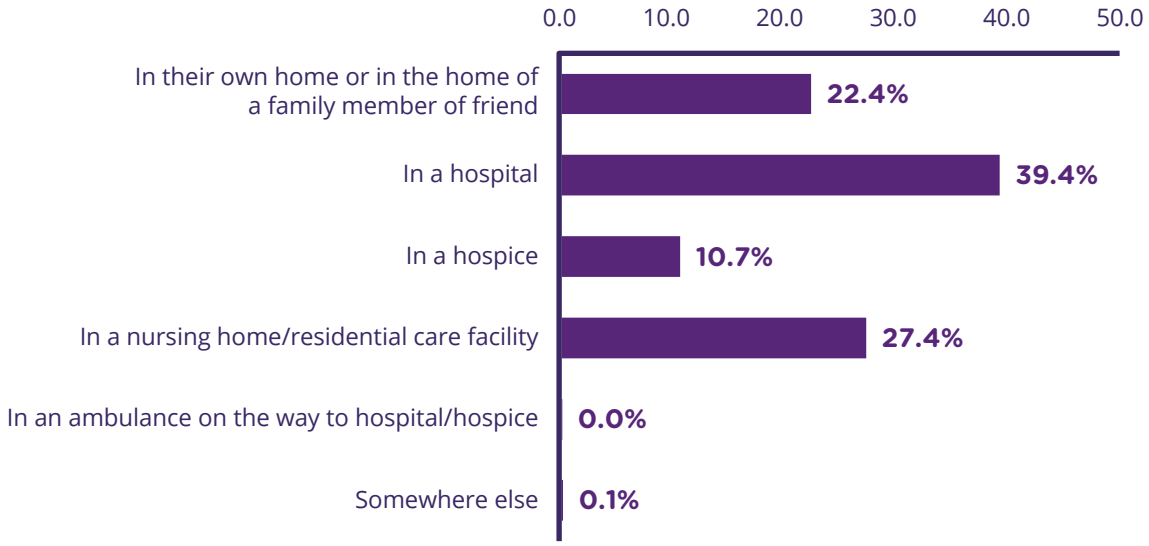
Figure 4.1 Location of care in the last two days of life



Place of death

Participants were also asked where their relative or friend died. Around two in five people were in a hospital when they died (1,799 of 4,570, 39.4%), while around one in five people were in their own home or in the home of a family member or friend. 10.7% of people (n=487) died in a hospice, and 27.4% (n=1,251) died in a nursing home or other residential care facility. A small number of people died in an ambulance on the way to a hospital or hospice (n=2 or 0.04%) or somewhere else (n=6 or 0.1%). Figure 4.2 shows the place of death.

Figure 4.2 Place of death



The places of death reported by survey participants align closely with the figures recorded by the General Register Office during the survey period, shown in Table 4.1.

Table 4.1 Place of death recorded by General Register Office

	N	%
Home	1,950	20.6%
Hospital	4,058	42.9%
Hospice	913	9.7%
Nursing Home and other residential settings	2,528	26.8%
Total	**9,449**	**100.0%**

Experiences of care at home in the last two days of life

"My Mum was lucky to be able to stay at home for the final days of her life. Between our GP, our live-in care from agency and the [hospice] palliative care team my Mum got the best treatment possible and was as happy and comfortable, pain free until she closed her eyes for the final time."

"Unfortunately, the timing of my husband's last few days were over the Christmas period and when I contacted the Palliative Care Unit for help over the last day, there was nobody there to help."

"The support from the palliative care nurse and the night nurse in the last few days to my mammy was phenomenal, their care and compassion will never be forgotten."

"Palliative care drugs had to be collected from pharmacy each day in the last few days. We were ok as there was 3 of us but would have been very difficult if on your own or further from town."

"When home help came to mum, at the beginning, help with showering was not on her care plan and was never put on it. Palliative care nurse was unavailable at the weekends."

"It was great to get her home and pass away peacefully in her own bed, surrounded by her family. The carers who came into her everyday from [homecare provider] went above and beyond in her final days. Palliative Care Team were brilliant as they listened to me and understood me."

In total, 1,023 people were cared for at home during the last two days of their life, while 1,025 people died at home. This section presents findings broken down both by where care was received in the last two days of life, and also by where people died.

70.0% of participants (673 of 962) said that their relative or friend was visited by a member of the hospice, palliative care team or other specialist palliative care service in the last two days of their life.

32.7% of participants (294 of 900), whose relative died at home, said that their relative or friend was told by a healthcare professional that they were likely to die; 53.8% (n=484) said that the person was not told and 122 (13.56%) said that they did not know. While 67.6% of bereaved relatives (607 of 898) indicated that healthcare staff talked to them about what to expect when their relative or friend was dying, 24.3% (n=218) said that healthcare staff did not talk to them about what to expect.[28] 71.5% of participants (264 of 369) said that a discussion about what to expect when their relative was dying would have been helpful.

Of 893 people, 882 (98.8%) felt that their relative died in the right place, while three (0.3%) thought that their relative did not die in the right place.[29]

Figure 4.3 shows the average scores (out of 10) for questions on care provided at home in the last two days of life, compared to the national average[30]. The highest-scoring question related to kindness and compassion from healthcare staff, with 94.6% of bereaved relatives (742 of 784) saying that their relative or friend was always treated with kindness and compassion during the last two days of their life.

The lowest-scoring question related to religious and spiritual needs, with 39.8% of people (159 of 399) saying that healthcare staff did not provide support to meet their relative or friend's religious or spiritual needs during the last two days of their life.[31]

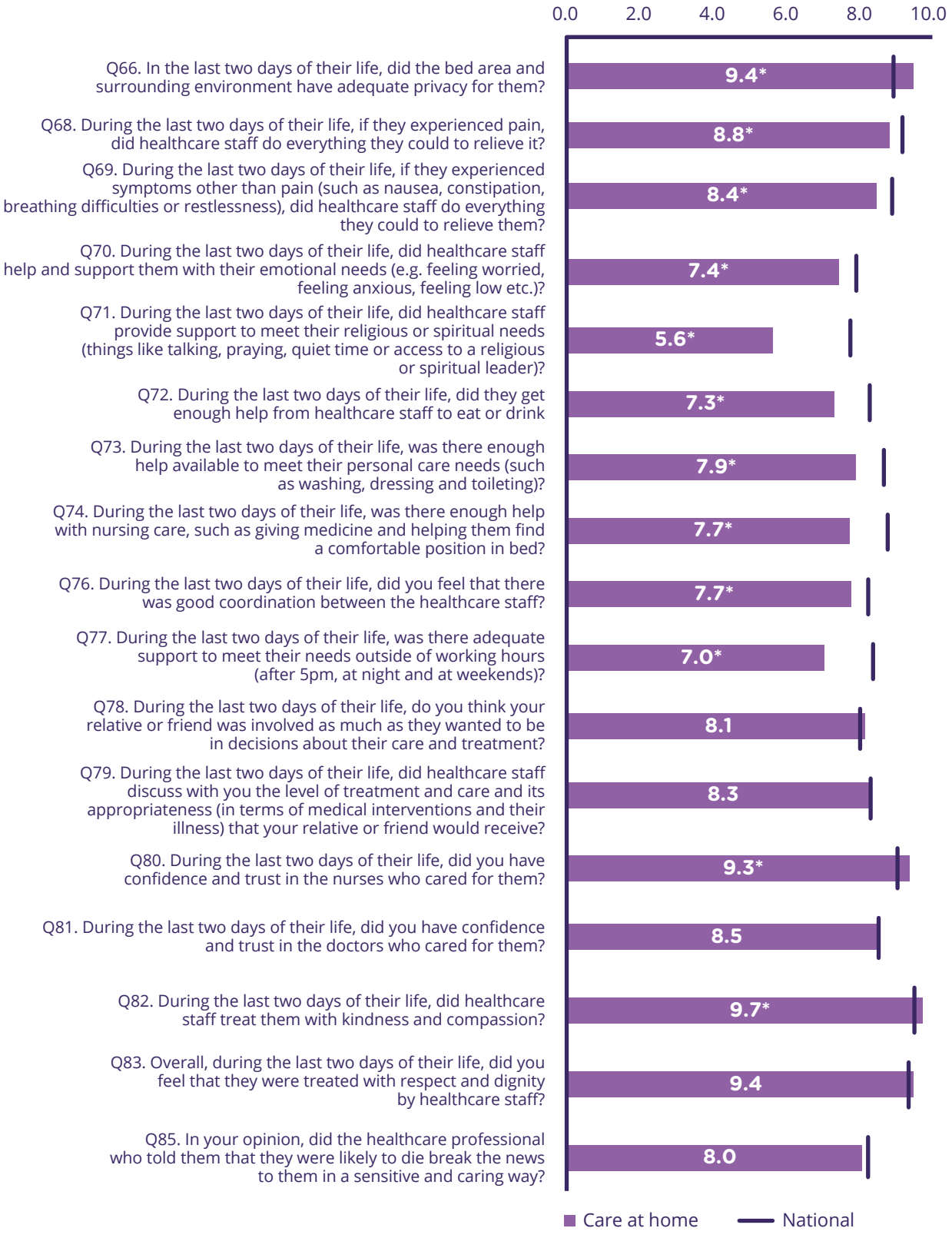
28 73 respondents (8.1%) selected the response option 'not applicable – they died unexpectedly'.

29 A further 8 respondents (0.9%) were not sure.

30 The national average relates to the score across all settings.

31 476 (54.4%) of respondents selected 'they did not need help with this'.

Figure 4.3 Scores (out of 10) for questions on care provided at home in the last two days of life



*denotes a statistically significant difference from the national average.

Summary of findings:
Care at home in the last two days of life

- In total, 1,025 participants said that their relative or friend died at home.
- The highest-scoring question related to kindness and compassion from healthcare staff, with 94.6% of bereaved relatives (742 of 784) saying that their relative or friend was always treated with kindness and compassion during the last two days of their life.
- The lowest-scoring question related to religious and spiritual needs, with 39.8% of people (159 of 399) saying that healthcare staff did not provide support to meet their relative or friend's religious or spiritual needs during the last two days of their life.

Experiences of care in a nursing home in the last two days of life

"He was allowed to remain in a private room with lots of space for family members to stay. He got pain relief and nausea relief as soon as we requested. Family were allowed to stay at his bedside 24/7 for the last few days."

"The care given by the clinical nurse manager and nurse who she knew on the last day was excellent. However, she did not have a prescription for enough morphine on the morning of her death which caused her great distress as she kept waking up. The CNM had to get on the phone to get the prescription."

"While a priest was called and attended in the days before she died we were told that a priest couldn't be called after she died. This may have been timing ([December]) but it would love been nice to have had a chaplain available."

"In last two days of life everything possible was done to make him comfortable and pain free. All family were there when he died."

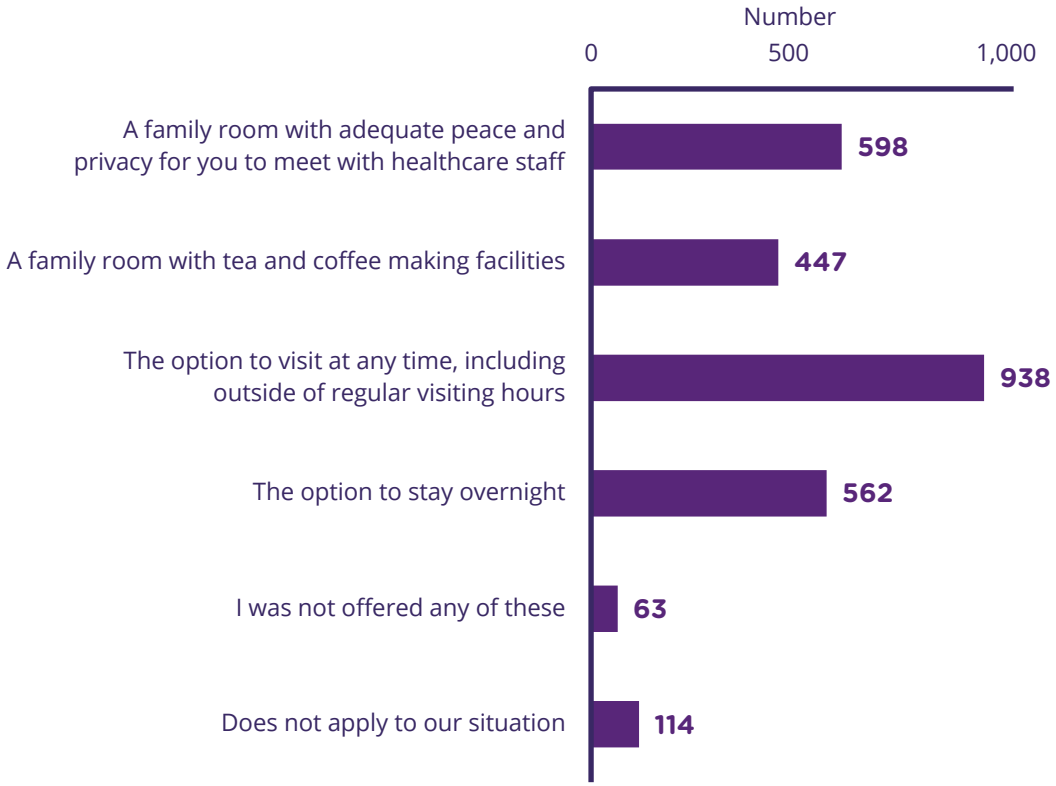
"Proper communication in the last days of Mum's life. It seemed the [management staff] or staff do not have a standard policy for dealing with families in the end of life stage. It has caused unnecessary upset."

"Staff... did everything they possibly could to make our very difficult and sad time with our mum/wife as easy and comfortable as possible. Each and every staff member went out of their way to help our mum/wife to help us as a family."

In total, 1,273 people were cared for in a nursing home or residential care facility during the last two days of their life, while 1,251 people died in a nursing home or residential care facility. This section presents findings broken down both by where care was received in the last two days of life, and also by where people died.

During the last two days of their relative or friend's life, 598 participants said that they were offered a family room with adequate privacy to meet with healthcare staff, while 447 said that they were offered a family room with tea and coffee making facilities. 562 participants said that they were offered the option to stay overnight, while 938 said that they were offered the option to visit at any time, including outside of regular visiting hours. Finally, 63 participants said that they were not offered any of these facilities (Figure 4.4).[32]

Figure 4.4 Facilities offered in the last two days of life in a nursing home



32 A further 114 bereaved relatives said that the question did not apply to their situation. It was possible to select multiple options in response to this question.

37.7% of participants (459 of 1,217) said that their relative or friend was visited by a member of the hospice, palliative care team or other specialist palliative care service in the last two days of their life.

90.4% of people (n=1,066), whose relative or friend died in a nursing home, said that their relative or friend died in a single room, while 9.2% (n=109) said that their relative did not die in a single room. Of 1,192 people, 1,063 (89.2%) felt that their relative died in the right place, while 55 (4.6%) thought that their relative did not die in the right place.

12.2% of participants (140 of 1,148) said that their relative or friend was told by a healthcare professional that they were likely to die, 57.5% (n=660) said that the person was not told and 30.3% (n=348) said that they did not know. While 63.5% of bereaved relatives (733 of 1,154) indicated that healthcare staff talked to them about what to expect when their relative or friend was dying, 27.5% (n=317) said that healthcare staff did not talk to them about what to expect. 65.5% of participants (298 of 455) said that a discussion about what to expect when their relative was dying would have been helpful.

Figure 4.5 shows the average scores (out of 10) for questions on care provided in nursing homes in the last two days of life, compared to the national average. The highest-scoring question related to kindness and compassion from healthcare staff, with 91.9% of participants (1,067 of 1,161) saying that their relative or friend was always treated with kindness and compassion by healthcare staff during the last two days of their life.

The lowest-scoring question related to involvement in decisions, with 6.5% of people 26 of 397) saying that their relative or friend was not as involved as they wanted to be in decisions about their care and treatment during the last two days of their life.

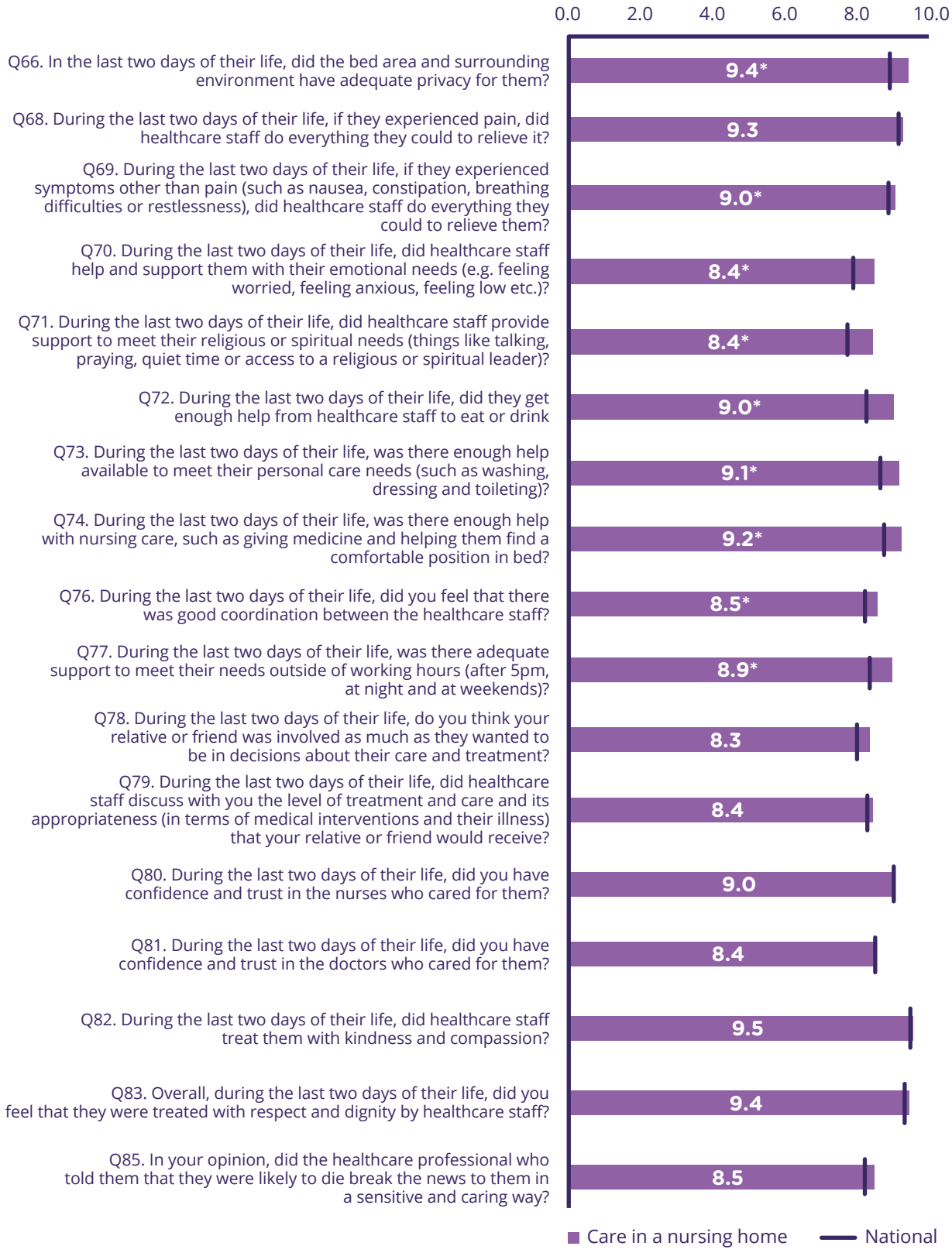
33 A further one participant selected 'they did not die in a healthcare setting' and four selected 'don't know'.

34 A further 74 respondents (6.2%) were not sure.

35 104 respondents (9.0%) selected the response option 'not applicable – they died unexpectedly'.

36 This does not include 744 respondents who selected the response option 'they were not able to be involved in decisions at this time' and 26 who selected 'don't know'.

Figure 4.5 Scores (out of 10) for questions on care provided in a nursing home in the last two days of life



*denotes a statistically significant difference from the national average.

Summary of findings:
Care in a nursing home in the last two days of life

- In total, 1,251 participants said that their relative or friend died in a nursing home or residential care facility.
- The highest-scoring question related to kindness and compassion from healthcare staff, with 91.9% of bereaved relatives (1,067 of 1,161) saying that their relative or friend was always treated with kindness and compassion by healthcare staff during the last two days of their life.
- The lowest-scoring question related to involvement in decisions, with 6.5% of people (26 of 397) saying that their relative or friend was not as involved as they wanted to be in decisions about their care and treatment during the last two days of their life.

Experiences of care in hospital in the last two days of life

"My brothers slept in the room with him during his last week and the whole family stayed for his last two nights. The nursing staff and doctors allowed us to be there and create our own family space. Despite it being an active ward and very busy at times, we never felt we shouldn't have been there. It was a very comforting for him and us. We knew he got the best of care."

"We had no communication in the last 24 hours and were totally not allowed to visit until the last 2-3 hours of our mum's life."

"It was the weekend - he got delayed being admitted in A and E. A Doctor told me on the Friday morning he would most likely receive palliative care straight away. By the time he got a bed there was not palliative care staff over the weekend. He died Sunday night. We had to beg for him to receive pain relief all weekend - he was in awful pain and discomfort for 3 days - I will never forget watching him struggle."

"My mother was... treated with the utmost dignity, and professionalism at all times. This care was second to none. We shall always appreciate their kindness and care towards our mother and to ourselves."

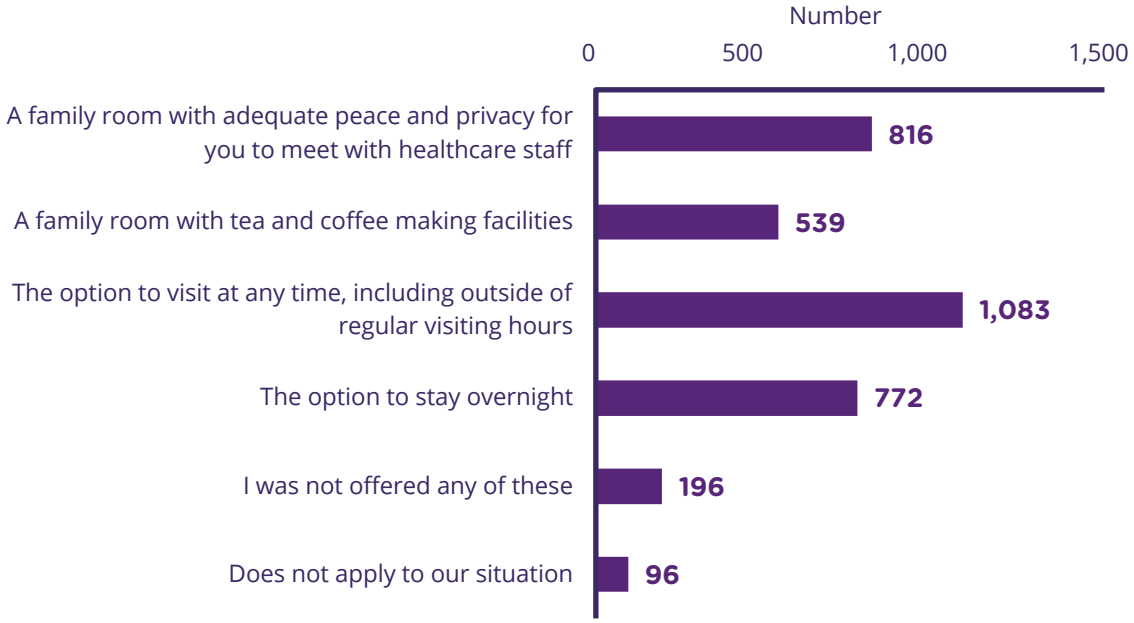
"Dad had excellent care from the Oncology team throughout his long illness. Unfortunately, in his last weeks he was sent to a general ward rather than Oncology ward where the care was not at the same level."

"The care was good, it was an intensive care situation. We had not experienced before, so we trust that the level of care was good."

In total, 1,662 people were cared for in hospital during the last two days of their life, while 1,799 people died in hospital. This section presents findings broken down both by where care was received in the last two days of life, and also by where people died.

During the last two days of their relative or friend's life, 816 participants said that they were offered a family room in the hospital with adequate privacy to meet with healthcare staff, 539 said that they were offered a family room with tea and coffee making facilities. 772 participants said that they were offered the option to stay overnight, 1,083 said that they were offered the option to visit at any time, including outside of regular visiting hours. Finally, 196 participants said that they were not offered any of these facilities (Figure 4.6).[37]

Figure 4.6 Facilities offered in the last two days of life in a hospital



37 A further 96 bereaved relatives said that the question did not apply to their situation.

55.7% of participants (951 of 1,706) said that their relative or friend was visited by a member of the hospice, palliative care team or other specialist palliative care service in the last two days of their life. 17.7% (n=302) said that they did not know if their relative or friend was visited by a member of the hospice, palliative care team or other specialist palliative care service in the last two days of their life.

80.0% of people (1,360 of 1,701), whose relative or friend died in a hospital, said that their relative or friend died in a single room, while 19.1% (n=324) said that their relative did not die in a single room.[38] Of 1,720 people, 1,288 (74.9%) felt that their relative or friend died in the right place, while 284 (16.5%) thought that their relative did not die in the right place.[39] Notably, 81% of those whose relative or friend died in a single hospital room said that they died in the right place, compared with 51% of those whose relative or friend did not die in a single room.

24.5% of participants (417 of 1,702) said that their relative or friend was told by a healthcare professional that they were likely to die; 819 (48.1%) said that the person was not told and 466 (27.4%) said that they did not know. While 62.6% of bereaved relatives (1,057 of 1,688) indicated that healthcare staff talked to them about what to expect when their relative or friend was dying, 29.0% (n=489) said that healthcare staff did not talk to them about what to expect.[40] 76.3% of participants (572) said that a discussion about what to expect when their relative was dying would have been helpful.

Figure 4.7 shows the average scores (out of 10) for questions on care provided in hospitals in the last two days of life. The highest-scoring question related to kindness and compassion from healthcare staff, with 86.4% of bereaved relatives (1,454 of 1,682) saying that their relative or friend was always treated with kindness and compassion by healthcare staff during the last two days of their life.

The lowest-scoring question related to emotional needs, with 15.6% of people (156 of 1,002) saying that healthcare staff did not help and support their relative or friend with their emotional needs (for example, feeling worried, feeling anxious, feeling low).[41]

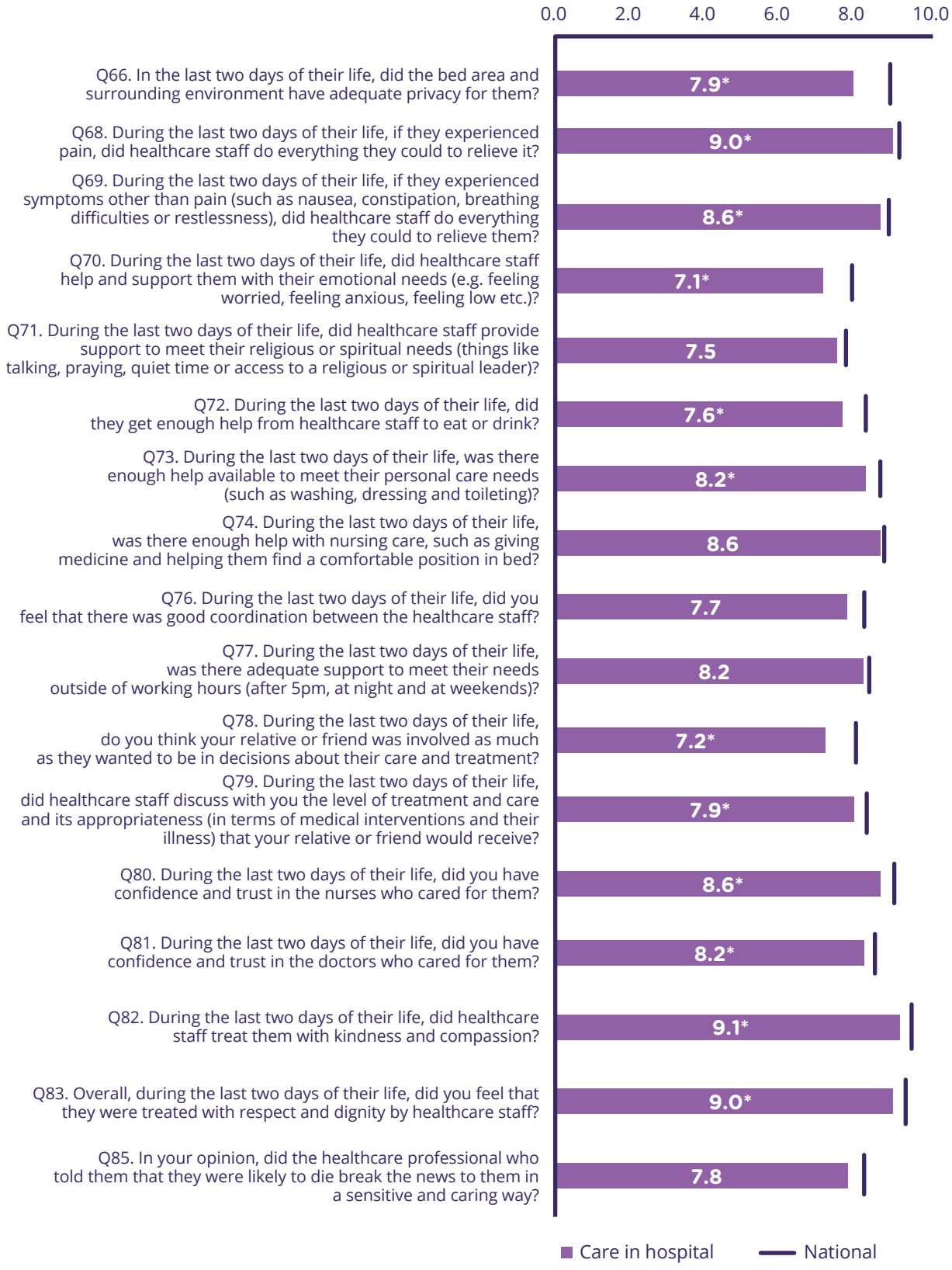
38 A further two answered 'they did not die in a healthcare setting' and 15 answered ' don't know'.

39 A further 148 respondents (8.6%) were not sure.

40 142 respondents (8.4%) selected the response option 'not applicable – they died unexpectedly'.

42 This does not include 542 respondents who answered 'they did not need help with this' and 188 respondents who answered 'don't know'.

Figure 4.7 Scores (out of 10) for questions on care provided in a hospital in the last two days of life



*denotes a statistically significant difference from the national average.

Summary of findings:
Care in hospital in the last two days of life

- In total, 1,799 participants said that their relative or friend died in hospital.
- The highest-scoring question related to kindness and compassion from healthcare staff, with 86.4% of bereaved relatives (1,454 of 1,682) saying that their relative or friend was always treated with kindness and compassion by healthcare staff during the last two days of their life.
- The lowest-scoring question related to emotional needs, with 15.6% of people (156 of 1,002) saying that healthcare staff did not help and support their relative or friend with their emotional needs (for example feeling worried, feeling anxious, feeling low).

Experiences of care in a hospice in the last two days of life

"The empathy and compassion shown by the staff of [Hospice] was second to none. The palliative care team were excellent. We were given a family room and everything was done to make our mum was comfortable and free of pain during her last days."

"The hospice did not like her grandchildren visiting which was really sad considering the joy that they gave her."

"My husband felt very comfortable in the hospice and admired the way the hospice was run, and benefitted from the kindness and professionalism of all staff involved. Genuinely, it was a wonderful place."

"The decision to place him in a Hospice was taken very late and he died in less than 24 hours. The Family would strongly have been of the view that he should have been moved earlier which would have made his last days more comfortable."

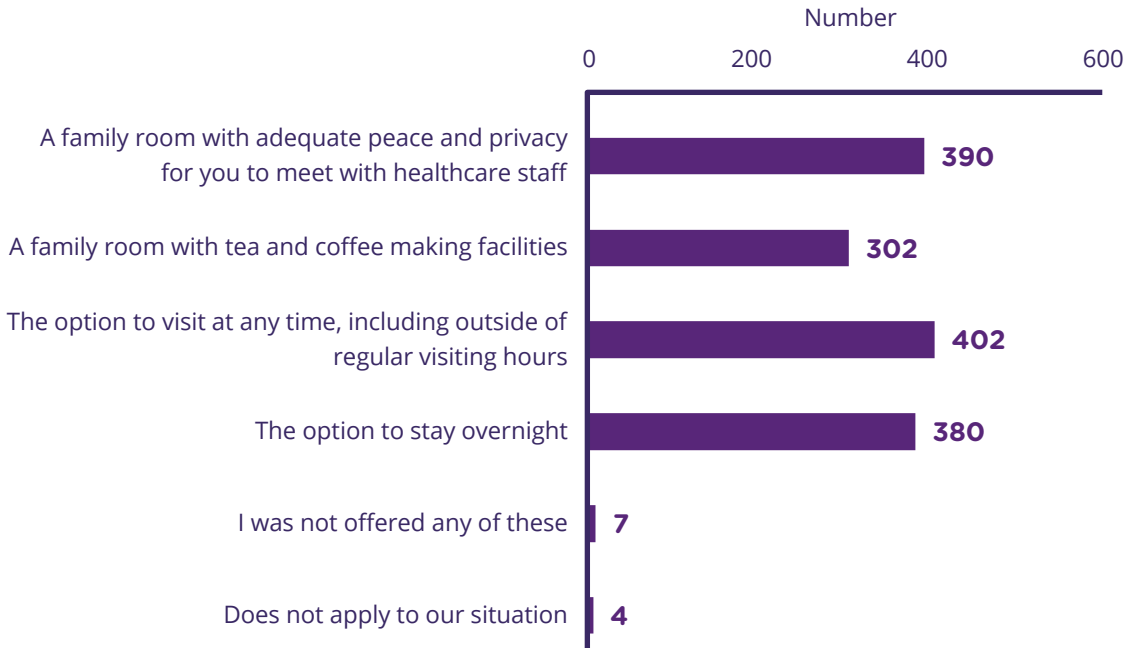
"The staff in the hospice do an amazing job, however she was in a shared ward during the last week of her life with little privacy. They did their best with screens etc but it wasn't great. Especially after she had been given a lovely private room on admission to the hospice but moved to shared ward after 2 days. which is difficult to understand given that they knew her time was short."

"The best support my Dad received was in [hospice]. They were kind and supportive, right down to the catering staff. My dad's room was lovely and we were able to bring personal items in so it felt more homely. We were able to visit whenever we wanted and stay overnight in his room which allowed us to spend the last days with him as he declined so quickly."

In total, 496 people were cared for in a hospice during the last two days of their life, while 487 people died in a hospice. This section presents findings broken down both by where care was received in the last two days of life, and also by where people died.

During the last two days of their relative or friend's life, 390 participants said that they were offered a family room with adequate privacy to meet with healthcare staff, while 302 said that they were offered a family room with tea and coffee making facilities. 380 bereaved relatives said that they were offered the option to stay overnight, while 402 said that they were offered the option to visit at any time, including outside of regular visiting hours. Finally, seven participants said that they were not offered any of these facilities (Figure 4.8).[42]

Figure 4.8 Facilities offered in the last two days of life in a hospice



42 A further four bereaved relatives said that the question did not apply to their situation.

97.3% of people (464 of 477) said that their relative or friend died in a single room, while 11 (2.3%) said that their relative did not die in a single room.[43]

52.5% of participants (245 of 467) said that their relative or friend was told by a healthcare professional that they were likely to die; 115 (24.6%) participants said that the person was not told and 107 (22.9%) said that they did not know. While 83.0% of participants (386 of 465) indicated that healthcare staff talked to them about what to expect when their relative or friend was dying, 70 participants (15.1%) said that healthcare staff did not talk to them about what to expect.[44] 127 participants (76%) said that a discussion about what to expect when their relative was dying would have been helpful.

Of 476 people, 447 (93.9%) felt that their relative died in the right place, while 10 (2.1%) thought that their relative did not die in the right place.[45]

Figure 3.8 shows the average scores (out of 10) for questions on care provided in a hospice in the last two days of life. The highest-scoring questions related to kindness and compassion and pain management. 98.3% of bereaved relatives (464 of 472) said that their relative or friend was always treated with kindness and compassion by healthcare staff during the last two days of their life. 97.4% (450 of 462) said that healthcare staff did everything they could to manage their relative or friend's pain.

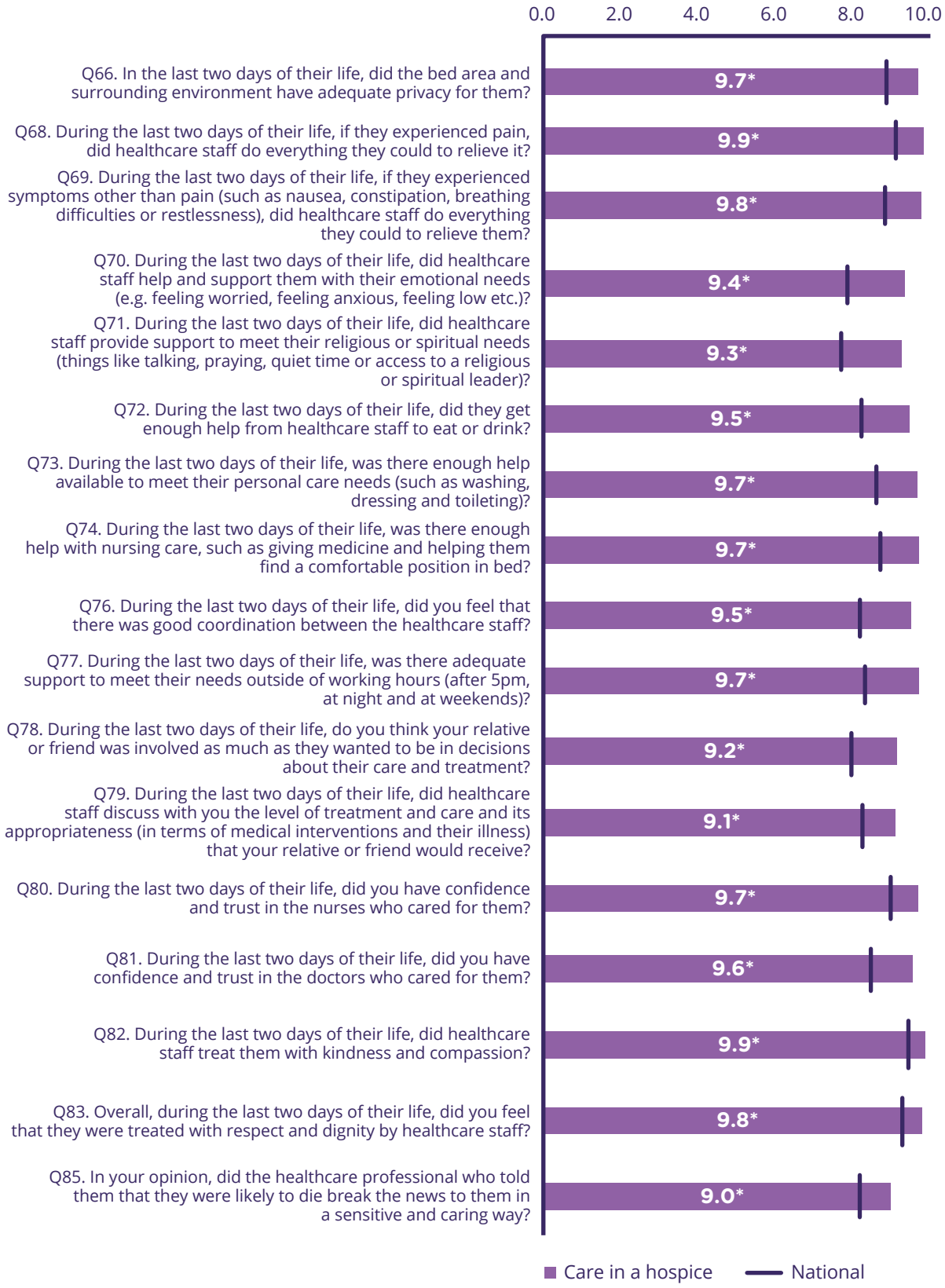
The lowest-scoring question was Q85, with 6.4% (15 of people 236) saying that the healthcare staff who told their relative or friend that they were likely to die did not do so in a sensitive and caring way.

43 Two participants responded 'they did not die in a healthcare setting'.

44 Nine respondents (1.9%) selected the response option 'not applicable – they died unexpectedly'.

45 A further 19 respondents (4.0%) were not sure.

Figure 4.9 Scores (out of 10) for questions on care provided in a hospice in the last two days of life



*denotes a statistically significant difference from the national average.

Summary of findings:
Care in a hospice in the last two days of life

- In total, 487 participants said that their relative or friend died in a hospice.
- The highest-scoring questions related to kindness and compassion and pain management. 98.3% of bereaved relatives (464 of 472) said that their relative or friend was always treated with kindness and compassion by healthcare staff during the last two days of their life. 97.4% (450 of 462) said that healthcare staff did everything they could to manage their loved one's pain.
- The lowest-scoring question was Q85, with 6.4% (15 of people 236) saying that the healthcare staff who told their relative or friend that they were likely to die did not do so in a sensitive and caring way.

Overall experiences of care at the end of life

"The staff team in [hospital] were amazing. They communicated so well with us and included us in decisions on my father's care in the final days and hours of his life. There was space and time given to us. We spent the last 24 hrs at my dad's side even in the HDU dept. So caring, so considerate, so good."

"Visitors should not be denied, our father died alone. We all feel very sad about this. The emergency department was not fit for purpose at this time, it was totally overwhelmed... If my father had a bed in a ward, we would have been able to visit him."

"Hospital staff in the last hours were amazing individuals. Hugely understanding of our situation, very compassionate, kind, supportive - fantastic individuals."

"The last 24 hours were unnecessarily stressful and we would have welcomed more medical intervention to assist with Mum's passing. We had to negotiate pain relief with palliative when the outcome was inevitable."

"1. No home help at weekends. 2. Nurse only called once a week and twice the week mum died. Over a 5 week period of end of life. 3. No palliative care available. 4. No overnight help to family."

"The nursing home were very respectful when dad died. They gave us use of the family/tv room and allowed us and our family spend as much time as we wanted to with dad. I noticed the circle of life sign on his door and at reception too."

Overall experiences of care at the end of life

Participants were asked to rate the overall care that their relative or friend received at the end of their life on a scale from 0 (very poor care) to 10 (very good care). In total, 73.7% of participants (3,145 of 4,265) rated the care their relative or friend received at the end of their life as 'very good', 15.2% (648) rated it as 'good' (score of 7-8), while 11.1% (472) said that their relative received 'fair to poor' care (score of 0-6) (Figure 4.10).

Figure 4.10 Overall experience of care at the end of life

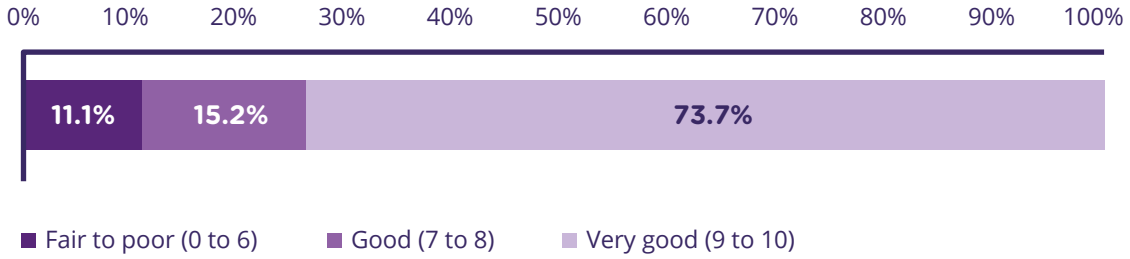
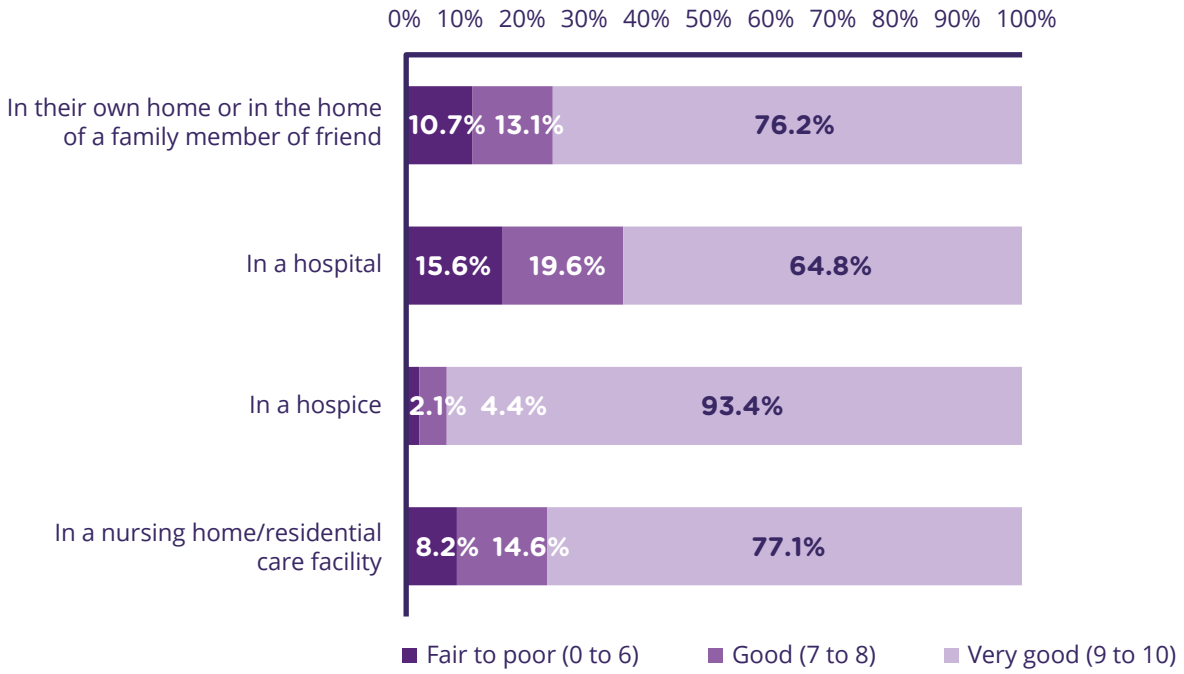


Figure 4.11 shows overall experiences of care at the end of life, broken down by place of death.[46] The most positive ratings of overall care at the end of life were from bereaved relatives of people who died in a hospice, with 93.4% of people (442 of 473) rating the overall care that their relative or friend received in a hospice at the end of their life as 'very good'.

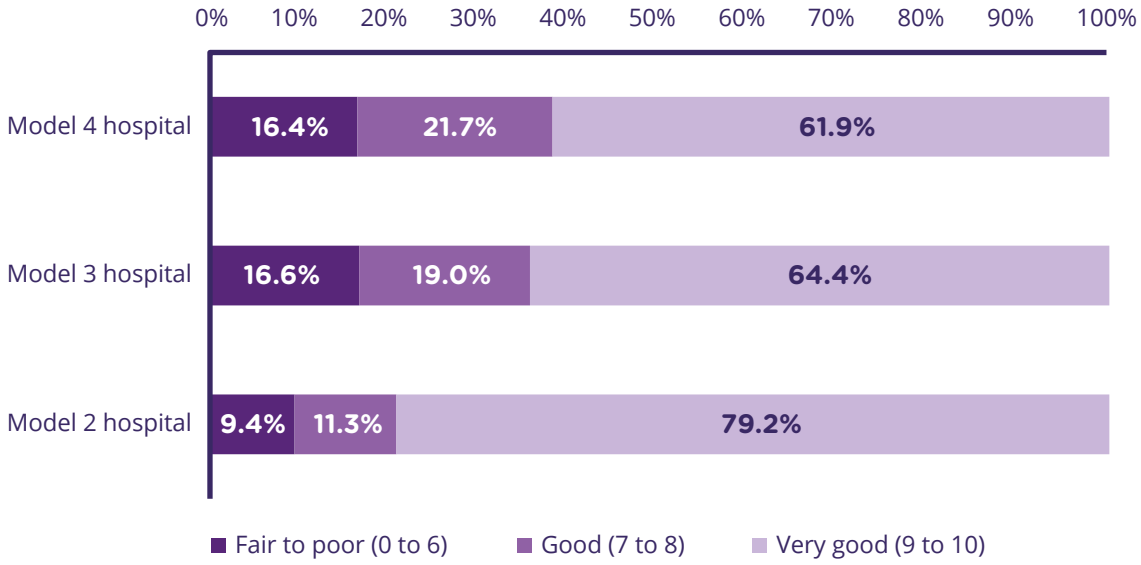
Figure 4.11 Overall experiences of care at the end of life by place of death



46 This does not include a small number of participants who responded 'in an ambulance on the way to hospital/hospice' (n=2) and 'somewhere else' (n=6).

Figure 4.12 presents overall experiences of care at the end of life and hospital model for people who died in a hospital.[47] 79.2% (42 of 53) of participants whose relative or friend died in a model two hospital reported a 'very good' experience of care at end of life.

Figure 4.12 Overall experiences of care at the end of life and hospital model



47 One participant responded that their relative or friend died in a specialist elective hospital.

Figure 4.13 shows overall experiences by age and gender of the person who died.[48] In total, 87.4% of males and 90.1% of females had a 'good' or 'very good' overall experience. In terms of age groups, the relatives or friends of those who died aged 18 to 59 years were most likely to rate the overall experience of care as 'good' or 'very good' overall.

Figure 4.13 Overall experiences of care at the end of life by age and gender

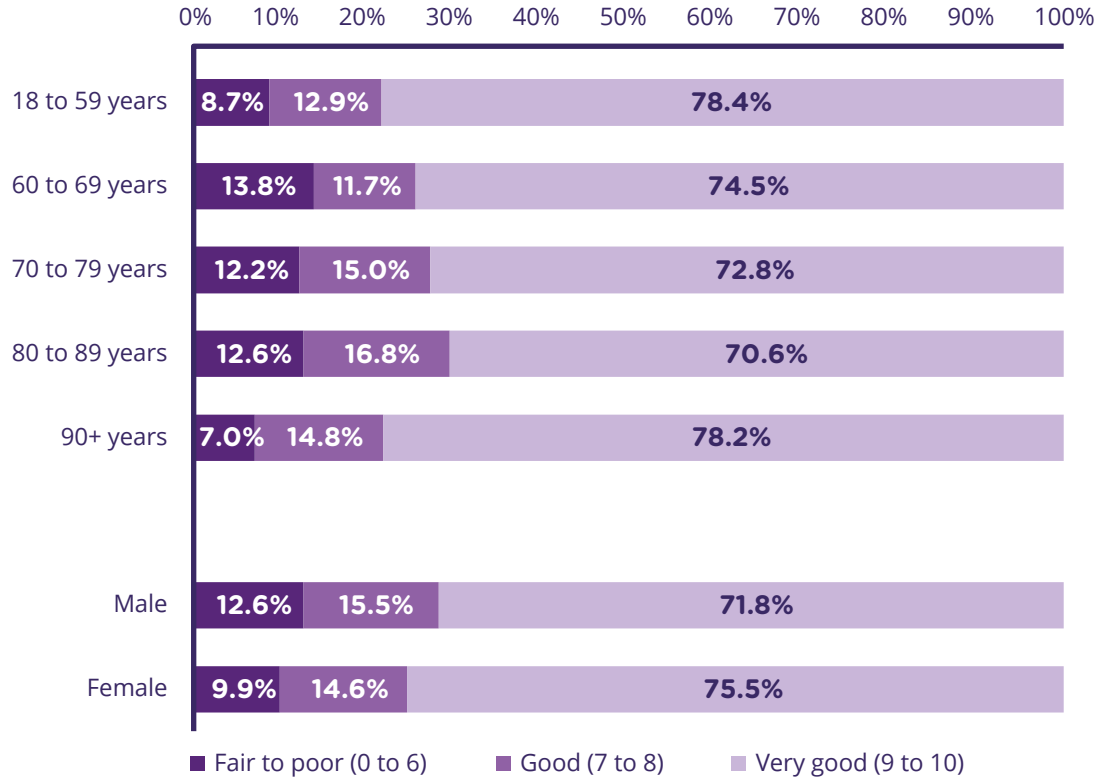
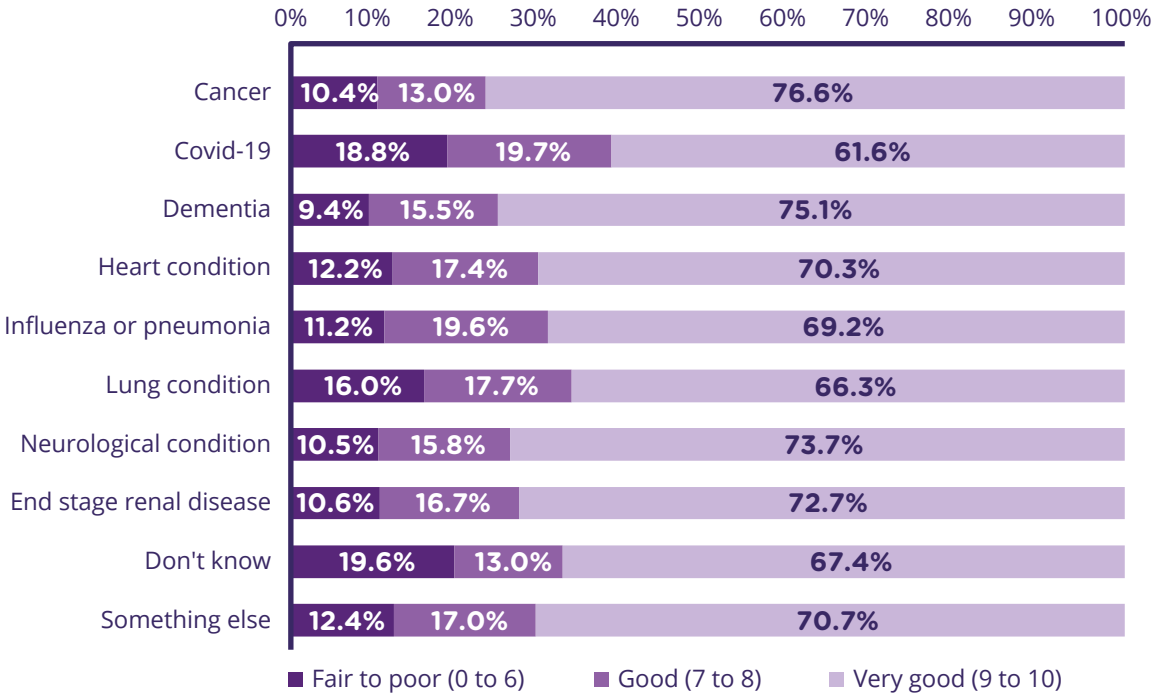


Figure 4.14 shows overall experiences of care at the end of life by the illnesses of the person who died. Participants who did not know what illness their friend or relative had in the last hours and days of their life were most likely to report a 'fair to poor' experience (9 of 46 people or 19.6%), while those whose relative or friend had dementia were least likely (102 of 1,086 people or 9.4%) to do so. Participants who said their relative or friend had cancer were most likely to report a 'very good' experience (1,157 of 1,510 people or 76.6%).

48 A small number of bereaved relatives selected 'Other' (n=4 selected 'good' or "very good experience) or 'Prefer not to say' (n=3 selected good) when asked about the gender of the person who died.

Figure 4.14 Overall experiences of care at the end of life by illness



5

Participants' experiences of the care and support provided to them in the last days of their relative or friend's life

Participants' experiences of the care and support provided to them in the last days of their relative or friend's life

"The staff could not do enough for you. During the last days of my Dad's life they provided us with beds to stay with him overnight. They provided refreshments many times throughout the days. They treated my Dad with respect and dignity and then updated us all the time on his conditions."

"GP services should be more involved with their elderly patients in helping family members to source services that are available. Dealing with elderly parents is a very new process to family members."

"The doctors' communication with family was poor. They did not advise us that my Dad was so ill and was at end of life and I feel they knew his prognosis and did not communicate this to us until the very end, which led to our family being in shock and not being able to say everything we wanted to say to our dad before he died."

"The staff at [hospital] were exceptional. The care that Dad received was second to none. As a family we were treated with compassion and respect. We were given space and time to spend Dad's final days with him as a family which is something we will always be grateful for."

"All the staff and doctors were very helpful. They showed us empathy and kindness. They explained the supports available. They were understanding and responsive to all our requests. They showed my Dad and our family the respect and understanding we needed."

"We feel we didn't get enough support e.g. offer any counselling."

Participants were asked about their experiences of the care and support provided to them by healthcare staff in the last days of their relative or friend's life, and after they had died. Figure 5.1 shows the average scores (out of 10) for questions on the participants' own experiences of care and support provided by healthcare staff. The highest-scoring question related to sensitivity from healthcare staff, with 84.3% of participants (3,546 of 4,329) saying that healthcare staff always engaged with them in a sensitive manner after their relative or friend died. The lowest-scoring question related to support to talk to children or young adults, with 29.0% of participants (542 of 1,871) saying that healthcare staff did not provide enough help and support to talk to children or young adults about their relative or friend's illness.[49]

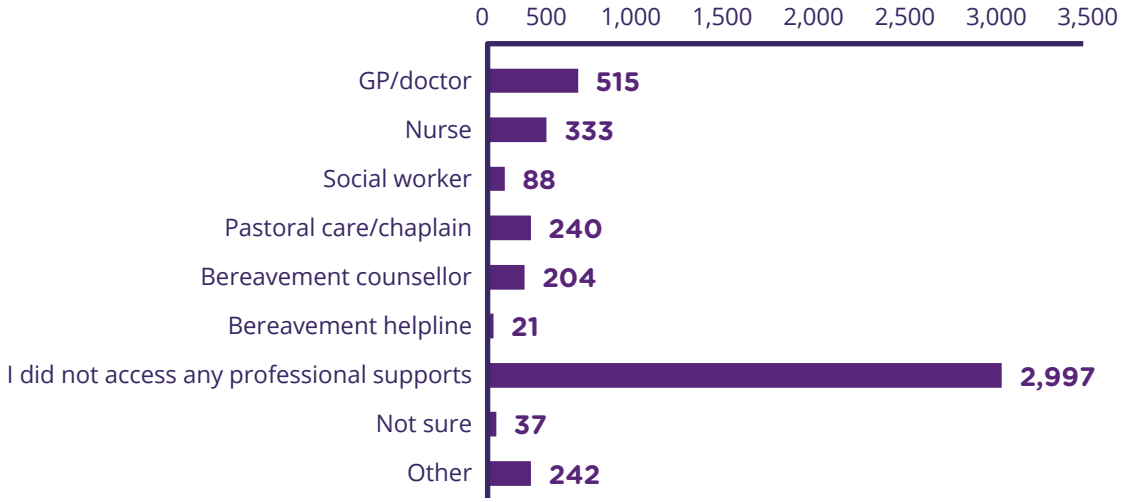
Figure 5.1 Scores (out of 10) for questions on bereaved relatives' experiences of care and support

49 This does not include 1,296 respondents who selected 'not applicable, I did not have any contact with healthcare staff' and 1,116 respondents who selected 'I did not need help with this'.

Sources of support

The majority of participants (64.1%) said that they did not access any professional supports after their relative or friend died (2,997 of 4,677). Of those who did access support, 515 (11.0%) participants received support from GPs, 333 (7.1%) from nurses, 88 (1.9%) from social workers, and 240 (5.1%) from pastoral care or a chaplain. A further 204 (4.4%) received support from a bereavement counsellor or a bereavement helpline (Figure 5.2).

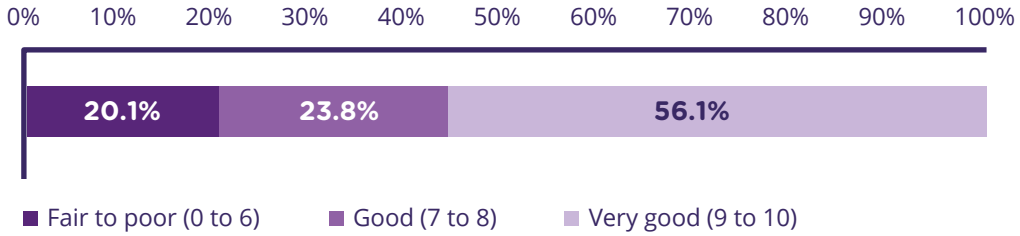
Figure 5.2 Supports accessed by bereaved relatives after their relative or friend died[50]



Overall experiences of care and support

Participants rated the overall care and support they received on a scale from 0 (very poor care and support) to 10 (very good care and support). 56.1% (n=2,325) of participants said that they received 'very good' care and support (score of 9-10), 23.8% (n=988) 'good' care and support (score of 7-8), with 20.1% (n=831) saying that they received 'fair to poor' care and support (score of 0-6) (Figure 5.3).

Figure 5.3 Bereaved relatives' overall experiences of care and support



50 Participants could select more than one response option for this question.

Figure 5.4 shows participants' overall experiences of care and support, broken down by their age and gender.[51] In total, 84.4% of males had a 'good' or 'very good' overall experience of care and support, compared with 78.0% of females. In terms of age groups, participants aged 18-29 years were most likely to report a 'fair to poor' experience (9 of 31 people or 29.0%), while participants aged 90+ years were most likely to report a 'very good' experience (14 of 20 people or 70.0%).

Figure 5.4 Participants' overall experiences of care and support by age and gender

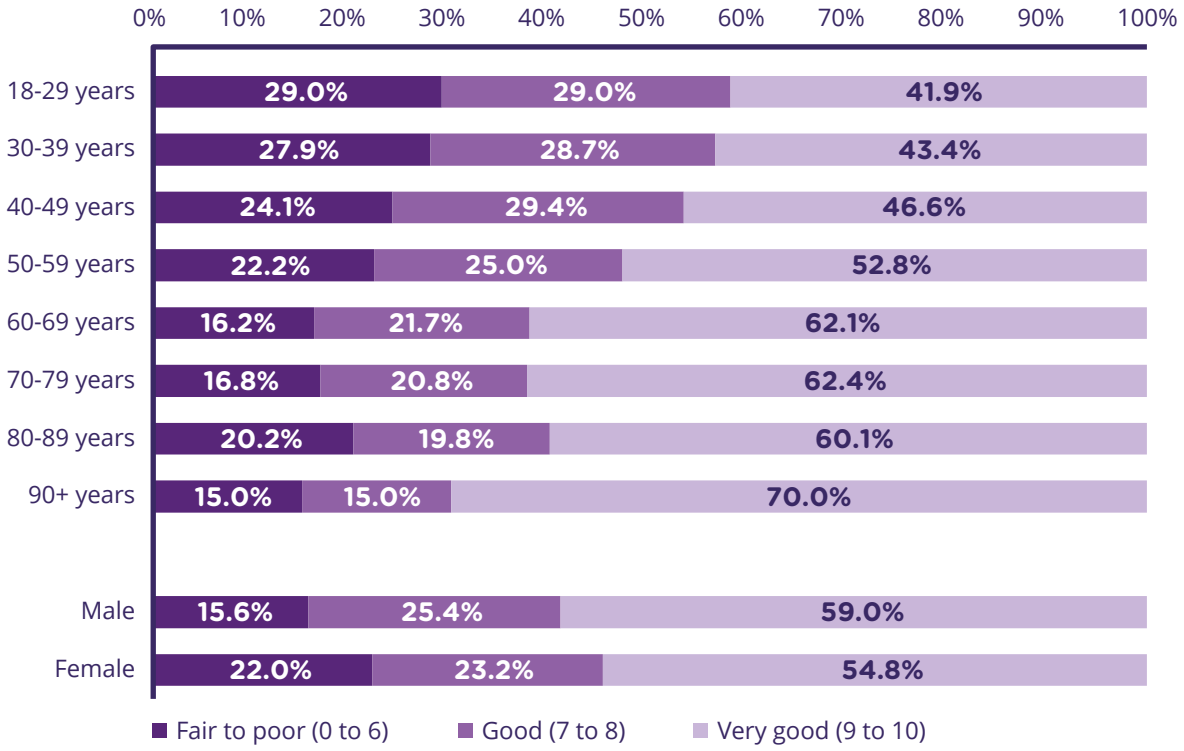


Figure 5.5 shows participants' overall experiences of care and support by their relationship to the person who died.

51 A small number of participants selected 'Other' (n=4) or 'Prefer not to say' (n=3) when asked about their gender.

Figure 5.5 Participants' overall experiences of care and support by relationship to the person who died[52]

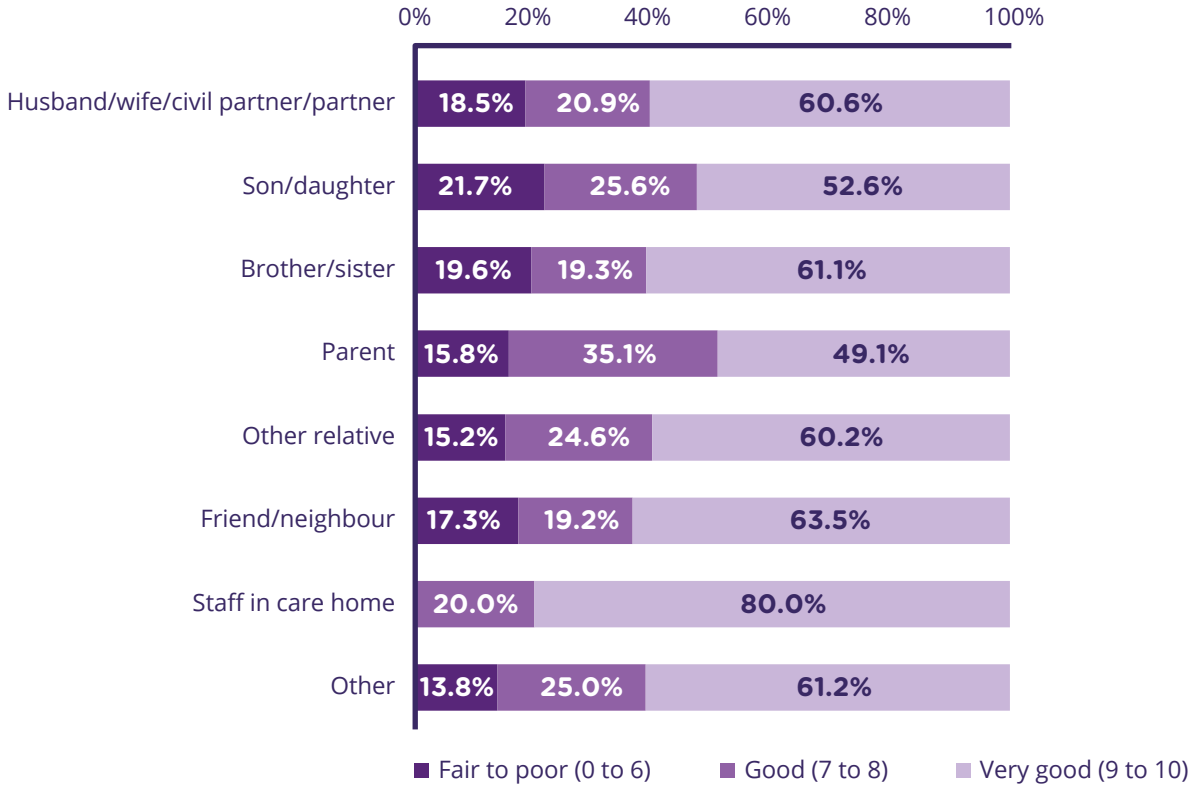


Figure 5.6 shows participants' overall experiences of care and support by the illnesses of the person who died. Participants who did not know what illness their friend or relative had in the last hours and days of their life were most likely to report a 'fair to poor' experience (14 of 47 people or 29.8%), while those whose relative or friend had a neurological condition were least likely (73 of 402 people or 18.2%) to do so. Bereaved relatives who said their relative or friend had a neurological condition (237 of 402 people or 59.0%) or cancer (874 of 1,484 people or 58.9%) were most likely to report a 'very good' experience of care and support.

52 For 'Son/daughter' responses, this means the survey participant was the son or daughter of the person who died. In addition 'Parent' means the participant was the parent of the person who died. In five cases, care home staff registered the death and responded to the survey.

Figure 5.6 Participants' overall experiences of care and support by illness

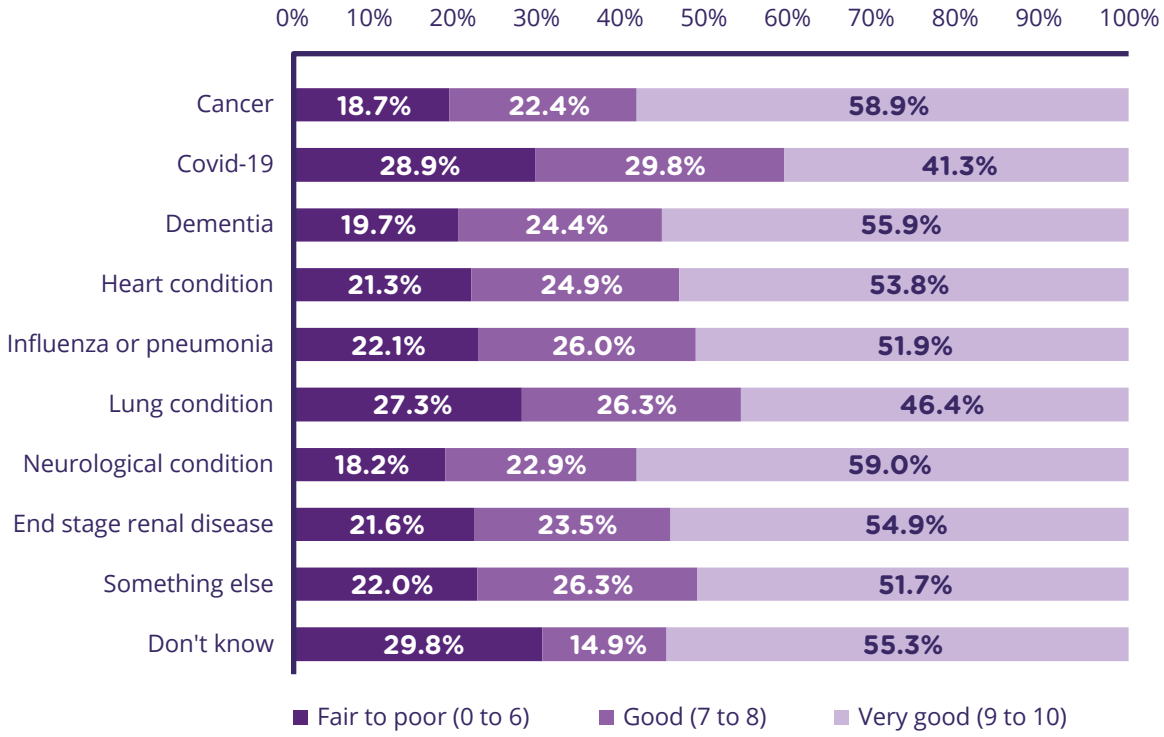
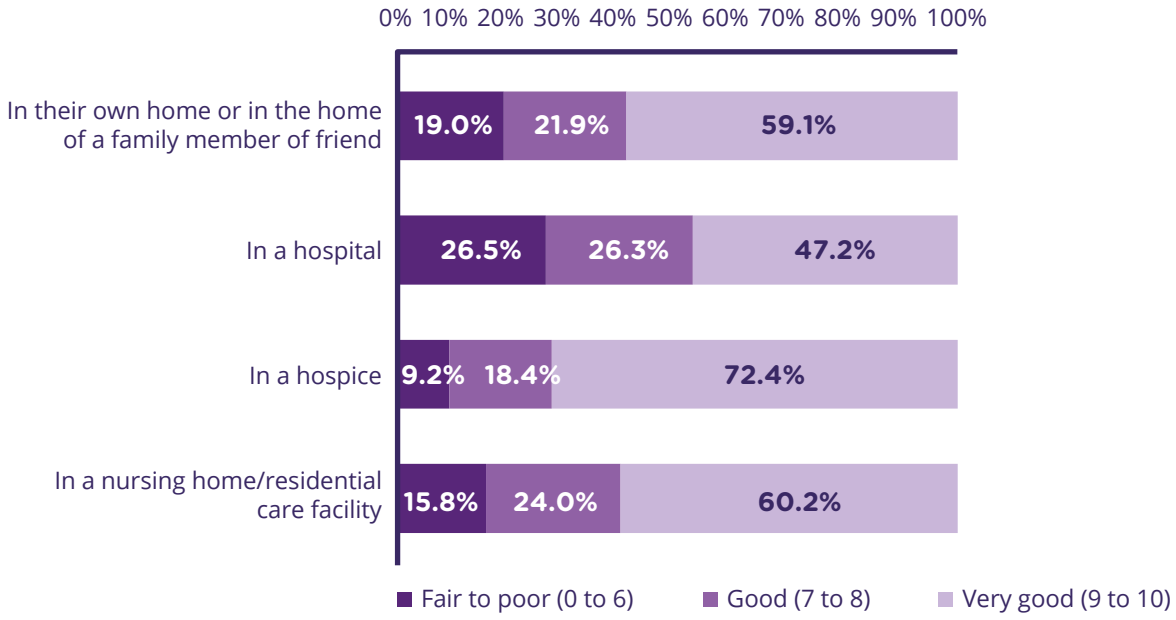


Figure 5.7 shows participants' overall experiences of care and support by place of death. The most positive ratings of overall experience of care and support for participants were from bereaved relatives or friends of people who died in a hospice, with 72.4% of people (323 of 446) rating the overall care and support received in a hospice as 'very good'.

Figure 5.7 Participants' overall experiences of care and support by place of death



6

Coordination of care across settings

The survey asked about the experiences of people who received care or died in various settings including hospitals, nursing homes, hospices and in their homes. In many cases, the people who died received care across more than one of these settings in the last months and days of their lives. While it is not possible to definitively map all movements between these settings and services, this chapter provides an overview of the typical journeys experienced in the last months and days of life.

It was evident that participants' relatives and friends typically received care in more than one setting in their last months and days. Table 6.1 shows that of the 4,570 survey responses, 7,375 settings of care were described, indicating that those who died received care in approximately 1.6 settings on average. More than half of survey respondents indicated that their relative or friend had received care in hospital in the last three months, followed by care at home as the next most frequently identified care setting.

Table 6.1 Settings where people received care in the last three months

Setting	Number of responses
Home	2,525
Nursing home	1,671
Hospital	2,639
Hospice	540
Total	**7,375**

Question 88 asked participants where their relative or friend died, with the results shown in Table 6.2. The most common place of death was a hospital (39.4%), followed by a nursing home, home and hospice.

Table 6.2 Place of death[53]

Setting	Number of responses	Percentage
Home	1,025	22.4%
Nursing home	1,251	27.4%
Hospital	1,799	39.4%
Hospice	487	10.7%
Other settings	8	0.2%
Total	**4,570**	**100.0%**

When broken down further, it is possible to see the link between settings where care was received in the last three months and place of death, as shown in Table 6.3. It was notable that 85.7% of the 540 people who accessed hospice care in the last three months of their life subsequently died in a hospice. In addition, 71.6% of the 1,671 people who received nursing home care in the last three months of their life, subsequently died in a nursing home. While Table 6.3 does not fully demonstrate the complexity and variety of services and settings where care was received in the last months and days of life, it does demonstrate numerous routes taken by people when receiving end-of-life care.

Table 6.3 Place of death, compared by settings where care was received in the last three months of life

Last three months – care received	N	Place of death	N	%
Home	2,525	Home	951	37.7%
		Nursing home	158	6.3%
		Hospital	1,074	42.5%
		Hospice	338	13.4%
Nursing Home	1,671	Home	47	2.8%
		Nursing home	1,197	71.6%
		Hospital	337	20.2%
		Hospice	87	5.2%
Hospital	2,639	Home	420	15.9%
		Nursing home	386	14.6%
		Hospital	1,513	57.3%
		Hospice	315	11.9%
Hospice	540	Home	37	6.9%
		Nursing home	18	3.3%
		Hospital	22	4.1%
		Hospice	463	85.7%

Question 64 asked participants if they felt that there was good coordination between the different services and staff that cared for their relative or friend in the last three months of their life. In total, 1,699 participants (45.4%) answered that there 'definitely' was good coordination between the services and staff, 1,148 (30.7%) answered 'to some extent', with 892 (23.9%) answering 'no'[54]. Question 76 asked if there was good coordination between healthcare staff in the last two days, with 3,007 participants (73.6%) saying that there was 'definitely' good coordination.

Participants' comments also described their experiences of the coordination between the various services, settings and professionals involved in end–of-life care. Table 6.4 shows the responses relating to the continuity, availability and responsiveness of care, across each of the three free-text survey questions.

Table 6.4 Number of comments relating to continuity, availability and responsiveness of care

Question	No. of relevant comments
Q101. Overall, what was good about the care your relative or friend received?	929
Q102. Was there anything that could have been improved?	1,146
Q103. Do you have any other comments or suggestions about the care your relative or friend received?	791

54 437 participants said that the question was not relevant to their situation or they didn't know.

Examples of comments relating to continuity, availability and responsiveness of care

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

"Her care was at home by family paid carers and with visits from public health nurses and one palliative care nurse on final days. I couldn't have wished for better. Her GP was always available."

"My father died at home aged 93. It was a miracle he got home for the last 2 weeks of his life after 6 weeks in hospital and that was down to the support staff, doctors/nurses in rehab or the incredible home helpers, OC therapist and the PHN/GP, hospice nurses in the last 3 days."

Q102. **Was there anything that could have been improved?**

"Communication and support around discharge plan from hospital was very poor. There appeared to be no communication between the various services. This needs to be addressed."

"Co-ordination between nurses, carers, doctors and consultants. We found this aspect to be scandalous. Nobody knew what the other 'team' was doing etc. Different staff gave different information."

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

"All in all we as a family were very happy with the overall care of our Mam. She died at home very peacefully thanks to the hospice nurses and comfortably due to hospital bed at home which was fantastic. All her needs and requests were honoured between the Public Health Nurse/Care Team and hospice care at home."

"The main problem seems to be the lack of palliative care teams/staff at weekends - Also lack of communication between parts of HSE. Dad was actually in a palliative care room in the HSE nursing home/unit. He could have stayed there (if it wasn't weekend). He ended up going across the road to the hospital in an ambulance and waiting in that ambulance (then put in another ambulance) before eventually getting in to A&E. We then had to listen to staff tell us palliative care staff will be in Monday - he struggled on with whatever they gave him until Sunday night."

Conclusion

In total, 4,570 bereaved family members and friends participated in the first National End of Life Survey. Participants shared their experiences of the care their relative or friend received in the last months and days of their life, including the care they received at home, in a nursing home or residential care facility, in hospital and in a hospice. It was clear that the people who died experienced a variety of pathways of care, involving multiple care settings and services in the last months and days of their lives.

While most participants (89%) rated the overall care that their relative or friend received as 'good' or 'very good' and highlighted positive aspects of the care they received, a number of areas for improvement were also identified. When asked to describe in their own words what could be improved, participants highlighted issues relating to the continuity, availability and responsiveness of care; and a desire for clearer and more consistent communication. Other areas for improvement included the need for healthcare staff to provide help as soon as the person who died needed it, as well as help and support with their emotional needs (such as feeling worried, feeling anxious, feeling low). In addition, participants said that they were not given enough help and support by healthcare staff to talk to children or young adults about their relative or friend's illness.

Participants also highlighted numerous areas of positive experience in their relative or friends' care. For example, participants highlighted the respect and dignity with which their relative or friend was treated. In addition, a large number of comments praised staff for the care they provided, as well as the physical, spiritual and emotional support that was made available. Most participants had confidence and trust in the healthcare staff caring for their relative or friend, and said that they were treated with respect and dignity and with kindness and compassion in the last two days of their life. In addition, participants felt that staff did everything they could to help manage their relative or friends' symptoms (such as nausea, constipation, breathing difficulties or restlessness), and explained their relative or friend's condition and care in a way they themselves could understand.

The survey included people who received care or died in various settings including hospitals, nursing homes, hospices and in their homes. In many cases, the people who died received care across more than one of these settings in the last months and days of their lives. Just under 40% of participants said that their relative or friend had died in a hospital, followed by 27% who died in a nursing home or residential care facility, 22% who died at home, and 11% who died in a hospice[55]. Participants whose relative or friend died in a hospice were more likely to rate their end-of-life care as 'good' or 'very good' (98%), when compared with a nursing home (92%), hospital (84%) or those who died at home (89%). There were a number of notable differences in responses to questions based on where the person died. For example, participants whose relative or friend died at home were most likely to say that they had died 'in the right place' (99%), compared with 94% for hospices, 89% for nursing homes and 75% for hospitals.

55 In total, eight participants said that their relative or friend died in an ambulance or 'somewhere else'.

In addition, participants were most likely to say they always felt welcome to visit their relative or friend in a hospice at any time in the last three months (95%), compared with a nursing home (81%) or a hospital (58%). When asked about visiting hospitals and other healthcare settings in the last two days of their relative or friend's life, most participants said they were given the option to visit at any time, including outside of regular visiting hours.

Two survey questions asked about coordination in the last months and days of life. Question 64 asked participants if they felt there was good coordination between the different services and staff that cared for their relative or friend in the last three months of their life. In total, 1,699 participants (45%) answered that there 'definitely' was good coordination between the services and staff. Question 76 asked if there was good coordination between healthcare staff in the last two days, with 3,007 participants (74%) saying that there was 'definitely' good coordination.

The survey included nine questions that asked about the care and support provided to participants themselves. The highest-scoring question in this section related to sensitivity from healthcare staff, with 84% of participants saying that healthcare staff always engaged with them in a sensitive manner after their relative or friend died. The lowest-scoring question related to support to talk to children or young adults, with 29% of participants saying that healthcare staff did not provide enough help and support to talk to children or young adults about their relative or friend's illness.[56]

In conclusion, participants in the first National End of Life Survey highlighted some areas of good care, as well as areas requiring improvement. Most participants always had confidence and trust in healthcare staff and felt that their relative or friend was always treated with respect and dignity and kindness and compassion. However, some participants said that their relative or friend's care was not as well coordinated as it should have been, and that they did not always receive help from healthcare staff as soon as they needed it. Of the settings covered in the survey, hospitals were the most common place of death. Hospices received the most positive ratings across all survey questions.

What happens next?

The HSE will use the survey findings to inform the development of quality improvement plans at national and local levels. These quality improvement plans will describe the steps that the HSE will take to address the issues highlighted by participants in the survey. Quality improvement plans will be available on www.yourexperience.ie in April 2024. Private and voluntary end-of-life care providers can use the survey results to develop plans on how they will respond to the findings. The National Care Experience Programme is engaging with organisations that represent private and voluntary providers to support them to understand and use the findings of the survey.

The Department of Health will use the information gathered to inform the development of policy in relation to end-of-life care. Finally, the findings of the survey will inform national standards and HIQA's monitoring and regulation of the services included in this survey.

56 It is important to note that 56% of respondents (2,412) to this question said that they did not need help with this, or they did not have anyway contact with healthcare staff.

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Appendices

Appendix 1:

Membership of the National End of Life Survey governance groups

Steering group:

Angela Fitzgerald (Chair)	Chief Executive Officer, HIQA
Rachel Flynn	Director of Health Information and Standards, HIQA
Sean Egan	Director of Healthcare Regulation, HIQA
Mary McGeown	Principal Officer, Department of Health
Niamh Bernard	Principal Officer, Acute Hospital Oversight and Performance Division, Department of Health
Laura Casey	Principal Officer, Older Persons Policy Development, Department of Health
Roisin O'Leary	Patient Representative, Sage Advocacy
Mervyn Taylor	Management Lead, Sage Advocacy
Iolo Eilian	Assistant National Director, Patient and Service User Engagement, HSE
Joanne Condon	National Manager, National Advocacy Service
Georgina Cruise	National Manager, Patient Advocacy Service
Margaret Brennan	Assistant National Director Quality And Patient Safety Lead Acute Operations, HSE
David Walsh	National Director Community Operations, HSE
Joe Ryan	National Director, Operational Performance and Integration, HSE
Fidelma Browne	Assistant National Director Communications Strategy, HSE
Marty Whelan	Head of Communications and Stakeholder Engagement, HIQA
Orla Healy	National Clinical Director, Quality and Patient Safety, HSE
John Farrelly	Chief Executive Officer, Mental Health Commission

National End of Life Advisory Group:

Rachel Flynn	Director of Health Information and Standards, HIQA
Tracy O' Carroll	Deputy Director of the National Care Experience Programme, HIQA
Geraldine Ryan	Regional Manager, Healthcare Regulation, HIQA
Ciaran Browne	National Lead Acute Hospital Services, HSE
Mila Whelan	Interim Senior Operations Manager Patient and Service User Experience Unit, HSE
Margaret McKiernan	Director of Nursing, Mercy University Hospital Cork, Chair of Hospice Friendly Hospitals Acute Hospitals Network
Siobhan Murphy	Director of Healthcare, Irish Hospice Foundation
Anna De Siún	Acting Head of Carer Supports, Family Carers Ireland
Paula Pinto	Programme Manager – Policy and Engagement, All Ireland Institute for Hospice and Palliative Care
Deirdre Hyland	Patient Safety Surveillance Officer, National Patient Safety Office, Department of Health
Rory Egan	Assistant Principal Officer, Older Persons Strategy Unit, Department of Health
Maurice Dillon	National Lead for Palliative Care, Operations Planning HSE

National End of Life Survey Project Team:

Tracy O' Carroll	Deputy Director of the National Care Experience Programme, HIQA
Conor Foley	Senior Analyst, National Care Experience Programme, HIQA
Diarmuid Ó Coimín*	Project Lead, National Care Experience Programme, HIQA
Donnacha O'Ceallaigh	Project Lead, National Care Experience Programme, HIQA
Daniela Rohde**	Analyst, National Care Experience Programme, HIQA
Alice Reetham	Project Officer, National Care Experience Programme, HIQA
Ellie Marley	Project Officer, National Care Experience Programme, HIQA
Ella Tuohy	Research Officer, National Care Experience Programme, HIQA
Geneviéve Ruiz-O'Sullivan	Research Officer, National Care Experience Programme, HIQA
Anna Maria Verling***	Project Lead, National Care Experience Programme, HIQA

*until December 2021

**until September 2023

***until May 2023

Appendix 2:

Who took part in the National End of Life Survey 2023?

People invited to take part

In total, 9,449 people met the eligibility criteria for the National End of Life Survey 2023 and were invited to participate.[57] A total of 408 people opted out of the survey. In total, 4,570 people returned a valid survey. This represents a national response rate of 48.4%.

The group whose relative or friend died at home had the highest response rate, with 52.4% of patients returning a questionnaire.

Table A shows the number of people eligible and invited to participate in the National End of Life Survey. It also indicates how many people took part and gives the corresponding response rate for each setting of care.

Table A. Number of people invited to participate, response numbers and response rate by setting of care

Group	Number invited to take part	Number of participants	Response rate (%)
National (total)	9,446	4,570	48.4%
Home	1,950	1,022	52.4%
Hospice	913	456	50.0%
Hospital	4,058	1,810	44.6%
Nursing Home	2,409	1,231	51.1%
Other residential care	31	12	38.7%
Rehabilitation and Community Hospital	88	39	44.3%

Characteristics of survey respondents

To get a better understanding of who participated in the National End of Life Survey, the questionnaire included demographic questions. This information was important to establish if the people who responded to the survey represented all sections of society.

Of the respondents, 31.7% were male and 68.0% were female. People aged 50 to 59 years accounted for 32.1% of survey respondents, with 27.1% aged 60 to 69 years. The vast majority of respondents (96.1%) indicated having a white, Irish ethnic background. Tables B summarises the characteristics of the survey respondents by sex, age and ethnic group.

57 There were three 'return to sender' invitations, leaving the eligible sample at 9,446.

Table B. Respondent characteristics nationally by sex, age and ethnic group

Group Sex	Number of participants	Percentage (%)
Males	1,390	31.7
Females	2,981	68.0
Other	3	0.1
Prefer not to say	7	0.2
Age group		
18-29 years	32	0.7
30-39 years	136	3.1
40-49 years	638	14.6
50-59 years	1406	32.1
60-69 years	1187	27.1
70-79 years	666	15.2
80-89 years	293	6.7
90+ years	25	0.6
Ethnic group*		
Irish	4,215	96.1
Irish traveller	2	0.1
Roma	2	0.1
Any other white background	142	3.2
African	2	0.1
Chinese	1	0.02
Indian/Pakistani/Bangladeshi	5	0.1
Any other Asian background	3	0.1
Arabic	1	0.02
Mixed	2	0.1
Other	11	0.3

*199 did not indicate an ethnic group

Of the people who died, 47.8% were male and 52.0% were female. People aged 80 to 89 years accounted for 38.0% of survey respondents, with 23.8% aged 90 years or older. The vast majority of respondents (95.6%) indicated the person that died had a white, Irish ethnic background. Tables C summarises the characteristics of the person who died by sex, age and ethnic group.

Table C. Characteristics nationally by sex, age and ethnic group of the person who died

Group Sex	Number of participants	Percentage (%)
Males	2,085	47.8
Females	2,266	52.0
Other	5	0.1
Prefer not to say	3	0.1
Age group		
18 to 59 years	253	5.9
60 to 69 years	441	10.2
70 to 79 years	951	22.1
80 to 89 years	1,634	38.0
90+ years	1,026	23.8
Ethnic group*		
Irish	4,180	95.6
Irish traveller	1	0.02
Any other white background	155	3.6
African	4	0.1
Any other Black background	2	0.1
Chinese	1	0.02
Indian/Pakistani/Bangladeshi	5	0.1
Any other Asian background	3	0.1
Arabic	1	0.02
Mixed	2	0.1
Other	17	0.4

*74 people did not indicate an ethnic group

Table D summarises the illness, duration of illness and medical card status of the person who died.

Table D. Characteristics nationally by illness, duration of illness and medical card status of the person who died

Group Illnesses in the last days and months of life*	Number of participants	Percentage (%)
Cancer	1,606	35.1
Covid-19	242	5.3
Dementia	1,137	24.9
Heart condition	1,069	23.4
Influenza or pneumonia	663	14.5
Lung condition	760	16.6
Neurological condition	441	9.7
End stage renal disease	410	9.0
Don't know	63	1.4
Something else	864	19.0
Duration of illness**		
They were not ill	103	2.3
Less than 24 hours	43	1.0
One day or more, but less than one week	302	6.8
One week or more, but less than one month	639	14.4
One month or more, but less than six months	931	20.9
Six months or more, but less than 1 year	546	12.3
One year or more	1,885	42.4

*Some people selected more than one illness

**121 respondents did not answer this question

Appendix 3:

A technical note on analyses and interpretation

Preliminary note

Please note that values in figures do not always add up to 100% exactly. This is due to rounding.

Scoring methodology

The scores for the stages of care were calculated by grouping survey questions into eight stages of care: care at home, care in a nursing home, care in an acute hospital, care in a hospice, care in last three months, care in last two days, care at end of life and experience of care and support. Scores are presented for individual questions making up a stage of care. The responses to all questions in each stage were also summarised to form overall scores ranging from 0-10. [14]

The National End of Life Survey scoring methodology is based on the methodology used in the National Inpatient Experience Survey, which was in turn based on the approach used by the Care Quality Commission on behalf of the National Health Service (NHS) in England.

It should be noted that only evaluative questions could be scored, that is questions that assessed an actual experience of care. Routing or demographic questions were not scored. More 'positive' answers were assigned higher scores than more 'negative' ones. In the example, 'No' was given a score of 0, 'Yes, to some extent' was given a score of 5 and 'Yes, definitely' was given a score of 10. The last response option, 'They did not see the public health nurse' was categorised as 'missing'. It was not scored as it cannot be evaluated in terms of best practice.

The table below shows how scores were calculated for a specific question. In this example, the scores of five respondents are presented. The score for Q7 is calculated by adding the scores in the right-hand column (10+10+5+0+5), before dividing them by the number of people who responded to this question (30/5=6). Thus, the average score for Q7 is 6 out of 10.

Table E. Example of a scored question in the 2023 survey

Q7. Overall, did you feel they were treated with respect and dignity by the public health nurse?	
Respondent	**Score**
1	10
2	10
3	5
4	0
5	5
Sum of scores	**30**

Scores for the stages of care (scales) were constructed by calculating the average scores for all questions belonging to that stage.

Comparing groups

When is a difference a 'real' difference?

Statistical tests were carried out to examine if there were significant differences from the national average.

A 'z-test' was used to compare care experience data at the 99% confidence level. A z-test is a statistical test used to examine whether two population mean scores are different when the variances are known and the sample size is large. A statistically significant difference means it is very unlikely that results were obtained by chance alone if there was no real difference. Therefore, when a score is 'higher than' or 'lower than' the national average, this is highly unlikely to have occurred by chance.

Survey analysis and reporting

The survey data was analysed by the National End of Life Survey team, part of the National Care Experience Programme based in the Health Information and Quality Authority (HIQA).

Quantitative survey data was analysed using the statistical package Stata 17.

The responses to the open-ended questions were transcribed and anonymised. All references to dates, names, places and nationalities were removed from comments before they were thematically analysed and coded.

Areas of good care and areas needing improvement

Identifying higher and lower-scoring questions

This section lists the areas where participants reported good care experiences, and details those areas where there is the most room for improvement. Questions with higher average scores out of 10 and a stronger relationship with overall experiences of care are areas of good care experience. Questions with lower scores out of 10 and stronger relationships with overall experiences of care are areas needing improvement. The list includes the relevant question number and setting or questionnaire section for each area.

The figures below show the average score out of 10 for each question on the survey, and how strong a relationship it has with participants' overall experience. The vertical axis shows the correlation of each question with overall experience, the horizontal axis shows each question's score out of 10.

Questions with high average scores out of 10 and a strong relationship with overall experience are highlighted in blue. Questions with lower scores out of 10 and strong relationships with overall experience are highlighted in purple.

Figure A shows the average score out of 10 for each question on the survey on care at home, and how strong a relationship it has with participants' overall experience of care at home.

Figure A. Overall care at home experience map

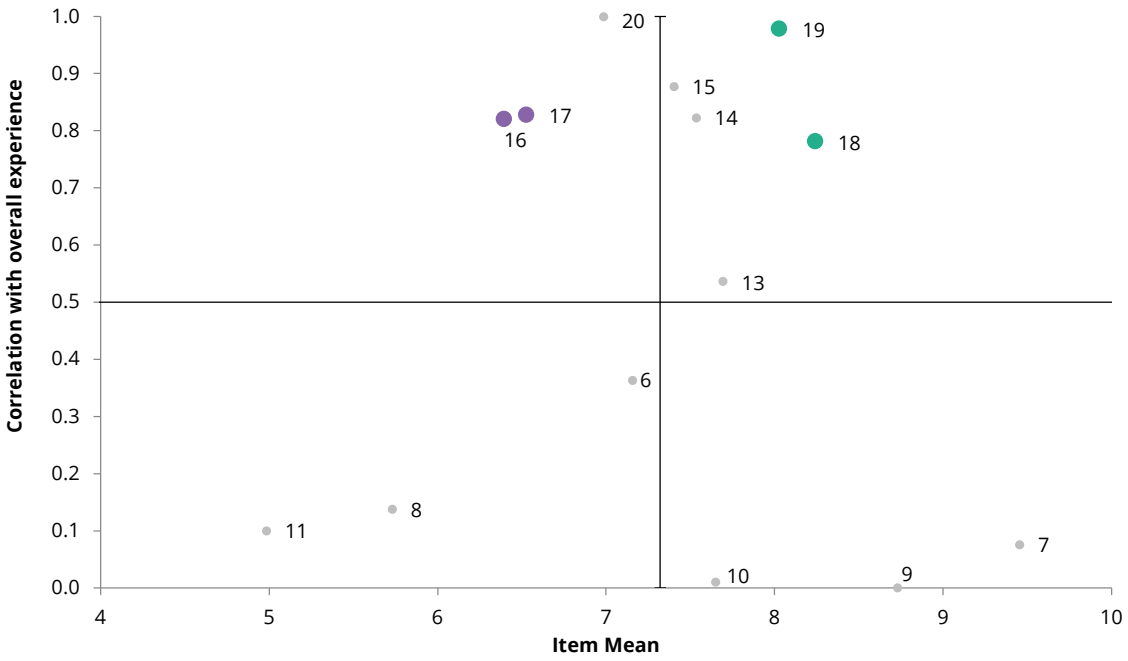


Figure B shows the average score out of 10 for each question on the survey on care in a nursing home or other residential centre, and how strong a relationship it has with participants' overall experience of care in a nursing home or other residential centre.

Figure B. Overall care in a nursing home or other residential centre experience map

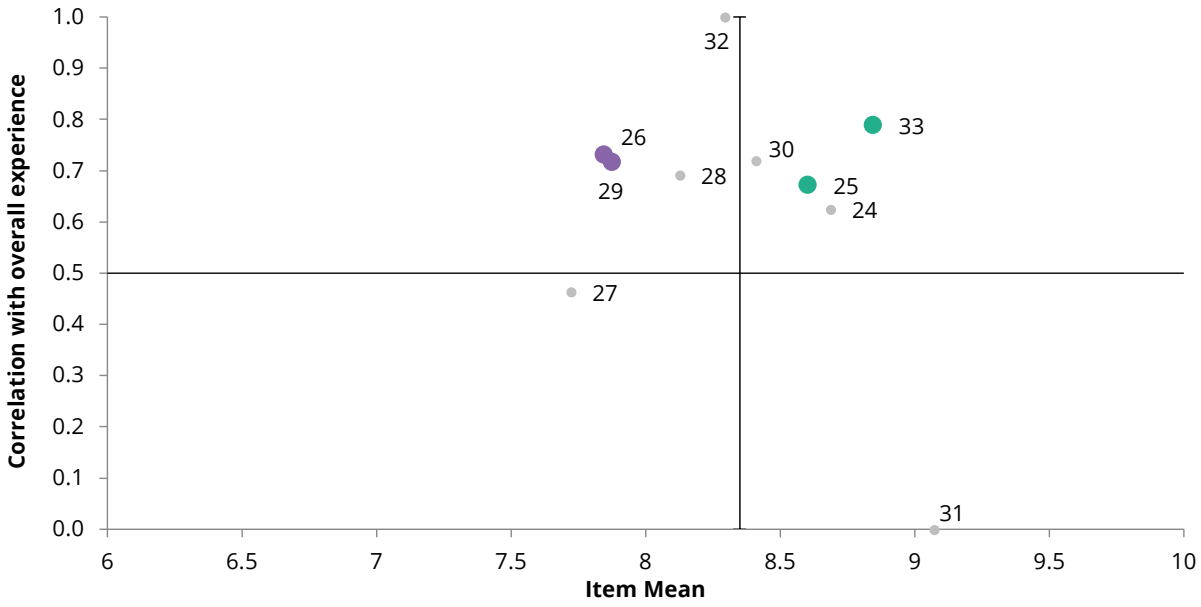


Figure C shows the average score out of 10 for each question on the survey on care in an acute hospital, and how strong a relationship it has with participants' overall experience of care in an acute hospital.

Figure C. Overall care in an acute hospital experience map

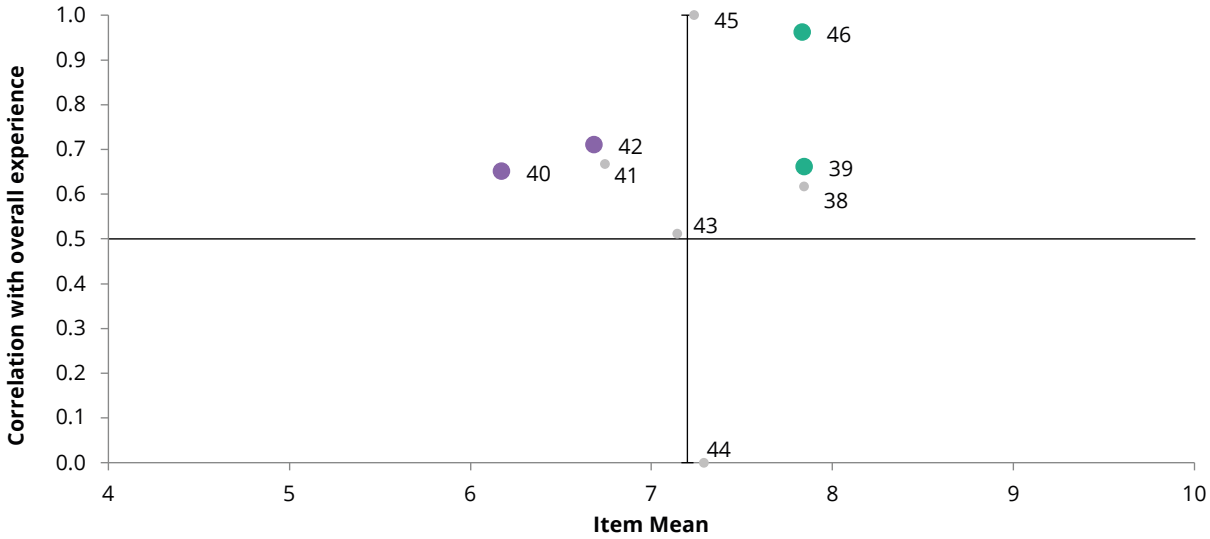


Figure D. Overall care in a hospice experience map

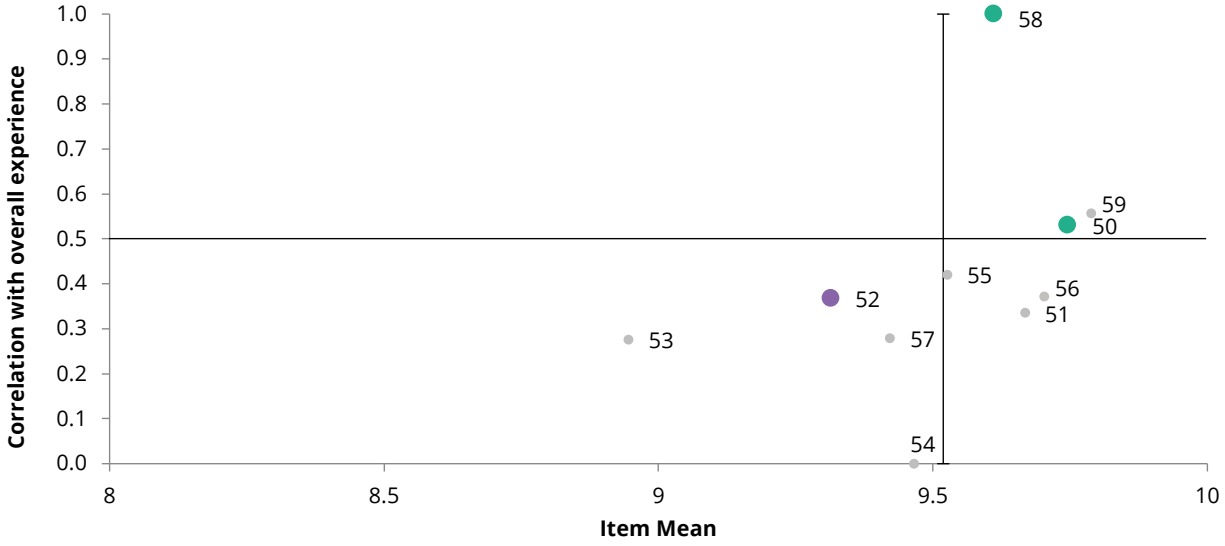


Figure E shows the average score out of 10 for each question on the survey on care in the last two days, and how strong a relationship it has with participants' overall experience of care in the last two days.

Figure E. Overall care in the last two days experience map

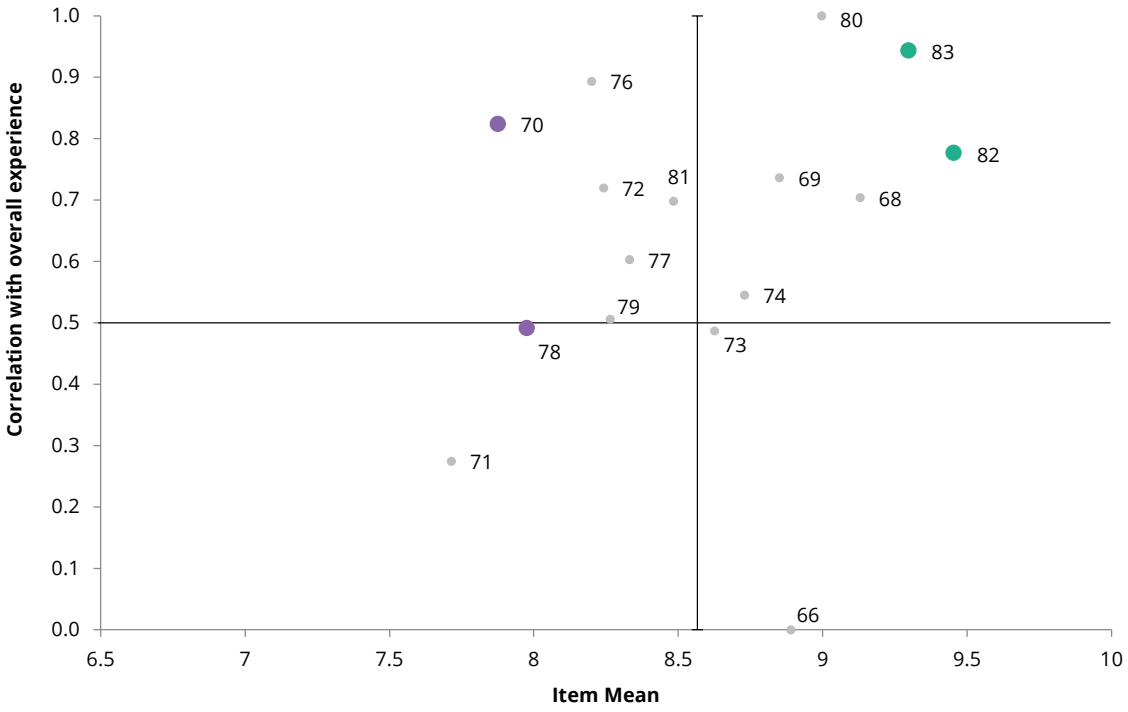
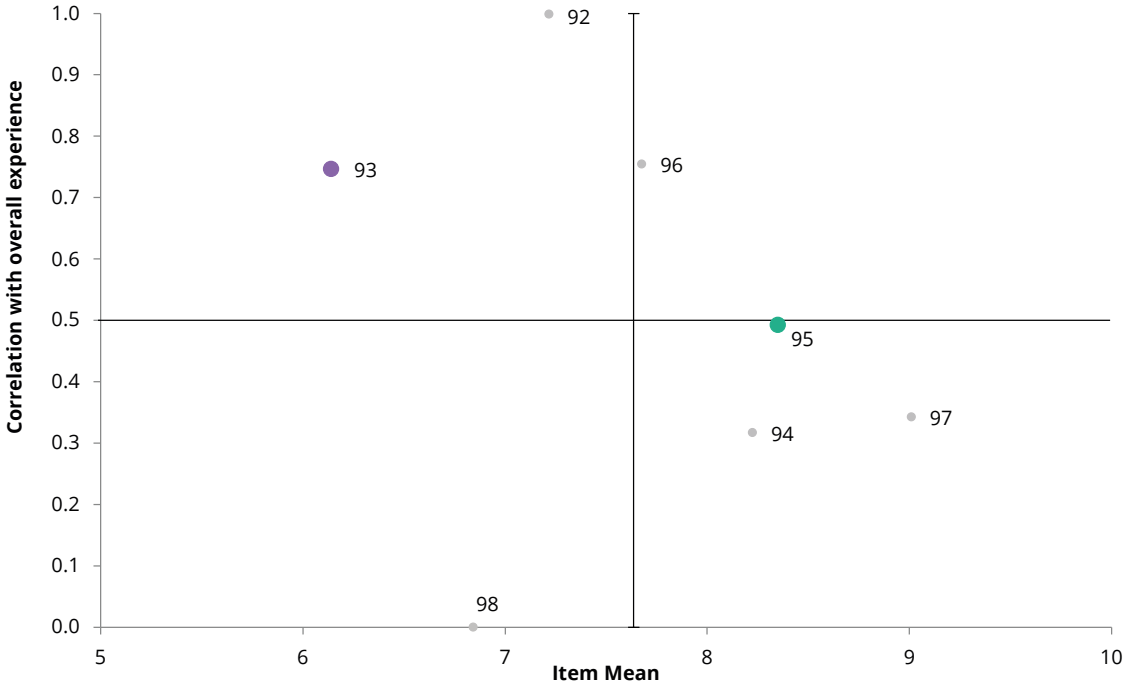


Figure F shows the average score out of 10 for each question on the survey on respondent experiences of care and support, and how strong a relationship it has with participants' overall experience of care in the last two days.

Figure F. Overall respondent experiences of care and support experience map



Areas of good care experience

Care at home

Staff answering questions | Q18

Of the 2,173 people who answered this question, 1,556 (71.6%) said that healthcare staff always answered their questions in a way they could understand while their relative or friend was being cared for at home. The average score for this question was 8.24 out of 10.

Confidence and trust in staff | Q19

Of the 2,386 people who responded to this question, 1,630 (68.3%) said that they always had confidence and trust in the healthcare staff treating their relative or friend while they were being cared for at home. The average score for this question was 8.03 out of 10.

Care in a nursing home or other residential care

Symptom management | Q25

Of the 1,619 people who responded to this question, 1,225 (75.7%) said that healthcare staff always did everything they could if their relative or friend experienced symptoms other than pain (such as nausea, constipation, breathing difficulties or restlessness). The average score for this question was 8.60 out of 10.

Treated with respect and dignity | Q33

Of the 1,692 people who answered this question, 1,363 (80.6%) said that their relative or friend was always treated with respect and dignity by healthcare staff during their stay in the nursing home or residential care facility. The average score for this question was 8.84 out of 10.

Care in an acute hospital

Symptom management | Q39

Of the 2,561 people who responded to this question, 1,647 (64.3%) said that healthcare staff always did everything they could to if their relative or friend experienced symptoms other than pain (such as nausea, constipation, breathing difficulties or restlessness). The average score for this question was 7.85 out of 10.

Treated with respect and dignity | Q46

Of the 2,732 people who responded to this question, 1,850 (67.7%) said that their relative or friend was always treated with respect and dignity by healthcare staff during their last stay in hospital. The average score for this question was 7.84 out of 10.

Care in a hospice

Confidence and trust in staff | Q58

Of the 540 people who responded to this question, 505 (93.5%) said that they always had confidence and trust in the healthcare staff treating their relative or friend during their stay in the hospice. The average score for this question was 9.61 out of 10.

Treated with respect and dignity | Q59

Of the 543 people who responded to this question, 523 (96.3%) said that their relative or friend was always treated with respect and dignity by healthcare staff during their stay in the hospice. The average score for this question was 9.79 out of 10.

Care in the last two days

Treated with kindness and compassion | Q82

Of the 4,106 people who responded to this question, 3,734 (90.9%) said that healthcare staff always treated their relative or friend with kindness and compassion during the last two days of their life. The average score for this question was 9.46 out of 10.

Treated with respect and dignity | Q83

Of the 4,233 people who responded to this question, 3,773 (89.1%) said that their relative or friend was always treated with respect and dignity by healthcare staff during the last two days of their life. The average score for this question was 9.30 out of 10.

Participants' experiences of care and support

Explanation of condition and care | Q95

Of the 4,044 people who responded to this question, 3,018 (74.6%) said that healthcare staff definitely explained their relative or friend's condition and care in a way they themselves could understand. The average score for this question was 8.35 out of 10.

Areas needing improvement

Care at home

Help and support with emotional needs | Q16

Of the 1,803 people who responded to this question, 355 (19.7%) said that healthcare staff did not help and support their relative or friend with their emotional needs (e.g. feeling worried, feeling anxious, feeling low etc.) while they were at home. The average score for this question was 6.39 out of 10.

Help from healthcare staff when needed | Q17

Of the 2,158 people who responded to this question, 381 (17.7%) said that their relative or friend did not get help from healthcare staff as soon as they needed it while at home. The average score for this question was 6.52 out of 10.

Care in a nursing home or other residential care

Help and support with emotional needs | Q26

Of the 1,515 people who responded to this question, 103 (6.8%) said that healthcare staff did not help and support their relative or friend with their emotional needs (for example feeling worried, feeling anxious, feeling low) during their stay in the nursing home or residential care facility. The average score for this question was 7.85 out of 10.

Help from healthcare staff when needed | Q29

Of the 1,552 people who responded to this question, 111 (7.2%) said that their relative or friend did not get help from healthcare staff as soon as they needed it during their stay in the nursing home or residential care facility. The average score for this question was 7.88 out of 10.

Care in an acute hospital

Help and support with emotional needs | Q40

Of the 2,185 people who responded to this question, 454 (20.8%) said that healthcare staff did not help and support their relative or friend with their emotional needs (for example feeling worried, feeling anxious, feeling low) during their last stay in hospital. The average score for this question was 6.18 out of 10.

Help from healthcare staff when needed | Q42

Of the 2,485 people who responded to this question, 417 (16.8%) said that their relative or friend did not get help from healthcare staff as soon as they needed it during their last stay in hospital. The average score for this question was 6.69 out of 10.

Care in a hospice

Help and support with emotional needs | Q52

Of the 480 people who responded to this question, 7 (1.5%) said that healthcare staff did not help and support their relative or friend with their emotional needs (for example feeling worried, feeling anxious, feeling low) during their hospice stay. The average score for this question was 9.31 out of 10.

Care in the last two days

Help and support with emotional needs | Q70

Of the 2,568 people who responded to this question, 278 (10.8%) said that healthcare staff did not help and support their relative or friend with their emotional needs (for example feeling worried, feeling anxious, feeling low) during the last two days of their life. The average score for this question was 7.88 out of 10.

Coordination between healthcare staff | Q76

Of the 4,088 people who responded to this question, 391 (9.6%) said that there was poor coordination between healthcare staff during the last two days of their relative or friend's life. The average score for this question was 8.20 out of 10.

Participants' experiences of care and support

Help and support to talk to children or young adults | Q93

Of the 1,871 people who responded to this question, 542 (29.0%) said that they were not given enough help and support by healthcare staff to talk to children or young adults about their relative or friend's illness. The average score for this question was 6.14 out of 10.

Appendix 4:

The 110 questions were developed by 239 people, including bereaved relatives and friends, specialist palliative care staff, general practitioners, medical consultants and clinical medical directors, nursing staff based in the community, nursing homes, hospices and acute hospitals, home care support staff, health and social care professionals, academic staff, policy makers, funders and regulatory staff were involved in. Further information on the questionnaire development process can be found on yourexperience.ie.

NATIONAL END OF LIFE SURVEY QUESTIONNAIRE

National End of Life Survey

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 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:

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

HSE

An Roinn Sláinte
Department of Health

Irish Hospice Foundation

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 have been impacted by any issues with regard to end-of-life care and would like information or support, or if you would like to provide feedback on the care provided to your loved ones, you can do so by contacting the Patient Advocacy Service on 0818 293 003 or at info@patientadvocacyservice.ie. For more information, please visit 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. ☐ 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 one year
7. ☐ One year or more

Q4a. Did they spend any time being cared for at home during the last three months of life?

1. ☐ Yes → **GO TO Q4b.**
2. ☐ No, they were in a hospital, hospice, nursing home or a residential care facility for the whole three months → **GO TO Q22a.**

Q.4b Please write the name of the town/village and county where they were cared for at home:

Town/village:

County:

1. ☐ Carlow
2. ☐ Cavan
3. ☐ Clare
4. ☐ Cork
5. ☐ Donegal
6. ☐ Dublin
7. ☐ Galway
8. ☐ Kerry
9. ☐ Kildare
10. ☐ Kilkenny
11. ☐ Laois
12. ☐ Leitrim
13. ☐ Limerick
14. ☐ Longford
15. ☐ Louth
16. ☐ Mayo
17. ☐ Meath
18. ☐ Monaghan
19. ☐ Offaly
20. ☐ Roscommon
21. ☐ Sligo
22. ☐ Tipperary
23. ☐ Waterford
24. ☐ Westmeath
25. ☐ Wexford
26. ☐ Wicklow

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 Q22a.

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 Q22a.**
11. ☐ Don't know **→GO TO Q22a.**

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 their 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
5. ☐ Don't know

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?

1. ☐ Yes, always
2. ☐ Yes, sometimes
3. ☐ No
4. ☐ They did not see their GP
5. ☐ 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?

1. ☐ Yes, definitely
2. ☐ Yes, to some extent
3. ☐ No
4. ☐ They did not want to talk to the GP
5. ☐ 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?

1. ☐ Yes, always
2. ☐ Yes, sometimes
3. ☐ No
4. ☐ They did not need a home visit from their GP (family doctor) or the GP out of hours service
5. ☐ 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?

1. ☐ Yes
2. ☐ No, this was not needed
3. ☐ No, this was not offered
4. ☐ 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?

1. ☐ Yes, definitely
2. ☐ Yes, to some extent
3. ☐ No
4. ☐ They did not need additional equipment or adaptations to the home
5. ☐ Don't know

Q14. While at home, 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

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 your relative or friend 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 Q35a.

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

Q22a. Did your relative or friend stay in a nursing home/residential care facility at any time during the last three months of their life?

1. ☐ Yes, they stayed in a nursing home/residential care facility
2. ☐ No → **GO TO Q35a.**
3. ☐ Don't know → **GO TO Q35a.**

Q22b. Please write the name of the nursing home/residential care facility and the county it is located in the space below:

Name of nursing home/residential care facility:

County:

1. ☐ Carlow
2. ☐ Cavan
3. ☐ Clare
4. ☐ Cork
5. ☐ Donegal
6. ☐ Dublin
7. ☐ Galway
8. ☐ Kerry
9. ☐ Kildare
10. ☐ Kilkenny
11. ☐ Laois
12. ☐ Leitrim
13. ☐ Limerick
14. ☐ Longford
15. ☐ Louth
16. ☐ Mayo
17. ☐ Meath
18. ☐ Monaghan
19. ☐ Offaly
20. ☐ Roscommon
21. ☐ Sligo
22. ☐ Tipperary
23. ☐ Waterford
24. ☐ Westmeath
25. ☐ Wexford
26. ☐ Wicklow

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

1. ☐ Less than one week
2. ☐ One to four weeks
3. ☐ Five to 12 weeks
4. ☐ 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?

1. ☐ Yes, definitely
2. ☐ Yes, to some extent
3. ☐ No
4. ☐ They did not have any pain
5. ☐ 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?

1. ☐ Yes, definitely
2. ☐ Yes, to some extent
3. ☐ No
4. ☐ They did not have any symptoms
5. ☐ 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.)?

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

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 your relative or friend 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 usually has an emergency department or an urgent care centre, and provides services for inpatients, outpatients and day-case treatments). 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 Q48a.

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.

Q35a. Did your relative or friend stay in an acute hospital at any time during the last three months of their life?

1 ☐ Yes, they stayed in an acute hospital
2 ☐ No → **GO TO Q48a.**
3 ☐ Don't know → **GO TO Q48a.**

Q35b. Please write the name of the last acute hospital in the space below:

Name of acute hospital:

County:

1 ☐ Carlow
2 ☐ Cavan
3 ☐ Clare
4 ☐ Cork
5 ☐ Donegal
6 ☐ Dublin
7 ☐ Galway
8 ☐ Kerry
9 ☐ Kildare
10 ☐ Kilkenny
11 ☐ Laois
12 ☐ Leitrim
13 ☐ Limerick
14 ☐ Longford
15 ☐ Louth
16 ☐ Mayo
17 ☐ Meath
18 ☐ Monaghan
19 ☐ Offaly
20 ☐ Roscommon
21 ☐ Sligo
22 ☐ Tipperary
23 ☐ Waterford
24 ☐ Westmeath
25 ☐ Wexford
26 ☐ Wicklow

Q36. How long was their last hospital stay?

1 ☐ Less than one week
2 ☐ One to four weeks
3 ☐ Five to 12 weeks
4 ☐ Longer than 12 weeks

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

1 ☐ Once
2 ☐ Twice
3 ☐ Three or more times
4 ☐ Not sure

Q38. During their last stay in hospital, 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 ☐ 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?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ They did not have any symptoms
5 ☐ 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.)?

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

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
5 ☐ I wasn't there

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 your relative or friend 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 or friend 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.

Q48a. Did your relative or friend stay in a hospice at any time during the last three months of their life?

1 ☐ Yes
2 ☐ No → **GO TO Q61.**
3 ☐ Don't know → **GO TO Q61.**

Q48b. Which hospice did they stay at?

1 ☐ Donegal Hospice
2 ☐ Galway Hospice Foundation
3 ☐ Kerry Hospice
4 ☐ Marymount University Hospital and Hospice, Cork
5 ☐ Mayo Hospice
6 ☐ Milford Care Centre, Limerick
7 ☐ North West Hospice, Sligo
8 ☐ Our Lady's Hospice - Blackrock Hospice, Dublin
9 ☐ Our Lady's Hospice - Wicklow Hospice
10 ☐ Our Lady's Hospice - Harold's Cross, Dublin
11 ☐ South East Palliative Care Centre, Waterford
12 ☐ St Brigid's Hospice, Kildare
13 ☐ St Francis Hospice, Blanchardstown, Dublin
14 ☐ St Francis Hospice, Raheny, Dublin

Q49. How long was their last hospice stay?

1 ☐ Less than one week
2 ☐ One to four weeks
3 ☐ Five to 12 weeks
4 ☐ 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?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ They did not have any pain
5 ☐ 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?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ They did not have any symptoms
5 ☐ 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.)?

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

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 your relative or friend 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 your relative or friend's 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
- 5 ☐ Don't know

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 (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, was your relative or friend 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 and provides services for inpatients, outpatients and day-case treatments)
4. ☐ In a hospice
5. ☐ Somewhere else
6. ☐ I had no contact with my relative or friend in the last two days of life → **GO TO Q101.**

Q66. During 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
5. ☐ Does not apply to our situation

Q67. During 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
5. ☐ I was not offered any of these
6. ☐ 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. ☐ Don't know

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

Q70. 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

Q71. 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

Q72. 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

Q73. 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

Q74. 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

Q75. During the last two days of their life, did a member of the hospice, 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

Q77. During the last two days of their life, was there adequate support to meet their needs outside of normal 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 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. Was your relative or friend 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.**
2 ☐ No →**GO TO Q87.**
3 ☐ 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 your relative or friend die?

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

Name of Town:

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 →**GO TO Q90.**

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 a single room?

1 ☐ Yes
2 ☐ No
3 ☐ They did not die in a healthcare setting
4 ☐ Don't know

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

1 ☐ Yes
2 ☐ No
3 ☐ Not sure

Q91. Overall, how would you rate the care your relative or friend 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 to my situation

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 to my situation

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 to my situation

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

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ Not applicable to my situation

Q96. During the last days of their life, did <u>you</u> 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 to my situation

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 to my situation

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

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need this information
5 ☐ Not applicable to my situation

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

(Tick all that apply)

1 ☐ GP/doctor
2 ☐ Nurse
3 ☐ Social worker
4 ☐ Pastoral care or healthcare chaplain
5 ☐ Bereavement counsellor
6 ☐ Bereavement helpline
7 ☐ I did not access any professional supports
8 ☐ Not sure
9 ☐ 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?

1 ☐ Male
2 ☐ Female
3 ☐ Other
4 ☐ Prefer not to say

Q105. How old are you?

1 ☐ 18-29 years
2 ☐ 30-39 years
3 ☐ 40-49 years
4 ☐ 50-59 years
5 ☐ 60-69 years
6 ☐ 70-79 years
7 ☐ 80-89 years
8 ☐ 90 + years

Q106. What is your ethnic or cultural background?

(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 ☐ Arab
11 ☐ Mixed, please specify:

12 ☐ Other, please write your ethnic group here:

Q107. Your relative/friend was:

1 ☐ Male
2 ☐ Female
3 ☐ Other
4 ☐ Prefer not to say

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 ☐ Arab
11 ☐ Mixed, please specify:

12 ☐ Other, please write their 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 who died have:**

(Tick all that apply)

1. ☐ A medical card
2. ☐ A GP visit card
3. ☐ Private health insurance
4. ☐ None of the above
5. ☐ Don't know

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 Freephone HSE/Irish Hospice Foundation bereavement support freephone service on 1800 80 70 77 to talk to a bereavement support volunteer. The Freephone service is available from 10am to 1pm, Monday to Friday. You can also contact Samaritans 24 hours a day, 7 days a week on Freephone 116 123 or by emailing jo@samaritans.ie.

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.

Notes

Notes

National End of Life Survey

@CareExperience

www.yourexperience.ie

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

HSE

An Roinn Sláinte
Department of Health

Irish Hospice Foundation