



National End of Life Survey 2023

Technical Report

About the National End of Life Survey

The National End of Life Survey is part of the National Care Experience Programme — a partnership between the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health.

The National End of Life Survey is the first national survey asking bereaved relatives 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 loved ones.

Individuals 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 between March and May 2023. In total, 4,570 people took part in this survey, resulting in a response rate of 48%.

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

National End of Life Survey 2023: Technical Report

Purpose of the report

This report provides a comprehensive technical description of the model, methodology, methods and procedures implemented during the National End of Life Survey 2023. This report has been designed to provide sufficient detail for repetition, replication and review. This document does not report in detail on the survey results. The report on the survey findings can be downloaded at www.yourexperience.ie.

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1 Overview

1.1 The National End of Life Survey

The National End of Life Survey asked bereaved relatives about the care provided to a family member or friend in the last months and days of their life. 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.

Further information on the questionnaire development process can be found at www.yourexperience.ie, where you can also download a copy of the questionnaire. The survey closed on 7 July 2023. In total, 83.7% of respondents returned the survey questionnaire by post, while 16.3% of respondents filled in the survey online.

The results of the survey were published in April 2024. The national report is available at www.yourexperience.ie.

1.2 Management of the National End of Life Survey

The National Care Experience Programme is a joint initiative from the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health. HIQA, as the lead partner, contracted a managed service to administer the 2023 survey and to process the responses received. In 2023, the managed service was responsible for:

- receiving and quality assuring the list of sampled persons
- printing and distributing the questionnaire
- logging returns, opt-outs and ineligible respondents
- providing information to respondents on a dedicated survey helpline
- data processing and quality assuring survey responses
- hosting a secure back-end database to allow hospitals to view their survey results on an online reporting platform prior to the publication of the results.

1.3 Survey design

1.3.1 Survey methodology

The National End of Life Survey was based on a concurrent mixed-mode response design, which allowed participants to complete the survey online or by returning a hard copy questionnaire in the post. The mode of contact, however, was via post only. Eligible people were sent a questionnaire in the post between March and May 2023. The invitation letter provided recipients with the choice of completing the survey online or on paper.

Eligible participants who registered the death of a family member or friend that occurred between 1 September and 31 December 2022 were invited to take part in the survey. In similar surveys in other countries, people are generally contacted between three and 12 months after a bereavement.⁽¹⁾

The administration of two reminder letters was built into the survey design. Up to two reminder letters were sent to people who had not yet returned a survey. Internationally, the second reminder has been shown to increase response rates significantly.⁽²⁾

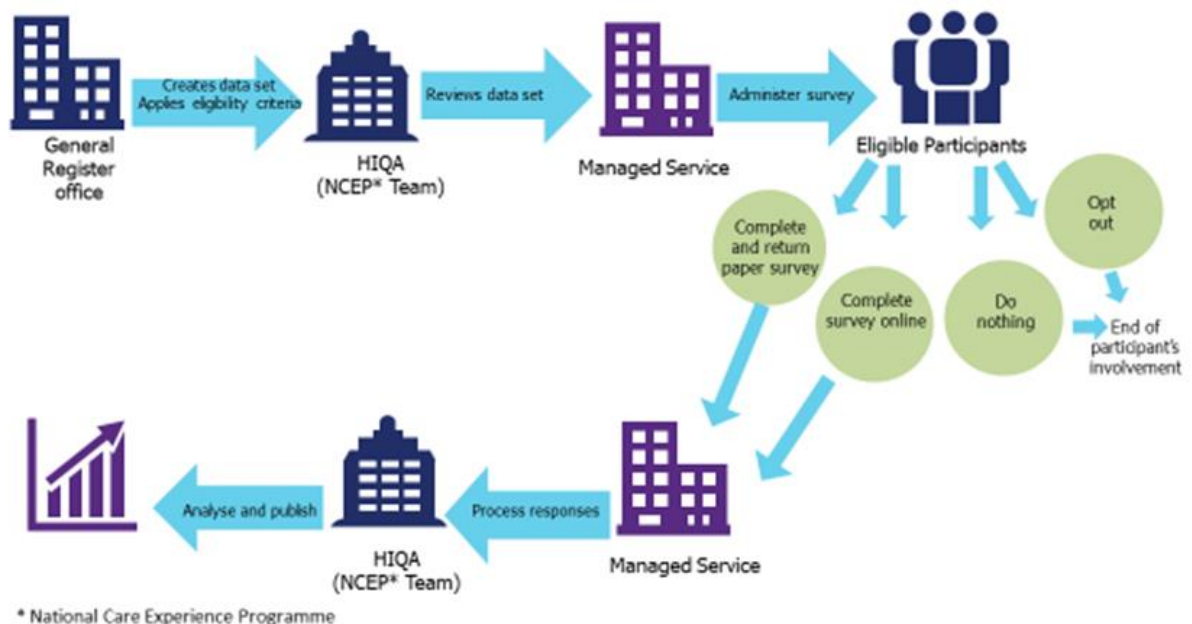
Participants could opt out of the survey by:

- calling the Freephone number
- emailing info@yourexperience.ie
- logging on to www.yourexperience.ie
- returning a blank questionnaire

The managed service processed the returned questionnaires. The data was subsequently analysed by researchers in HIQA who reported on the survey findings (see Chapter 3).

Figure 1.1 below outlines the model and design of the National End of Life Survey.

Figure 1.1 The National End of Life Survey Process



1.3.2 Sample

The sample for the National End of Life Survey comprised people who registered the death of a family member or friend that occurred between 1 September and 31 December 2022. Sudden, maternal and child deaths were not included in the survey, as the care pathways in these circumstances are different. Eligible participants were identified by the General Register Office. The General Register Office is the central repository for records relating to deaths in the Republic of Ireland.

The General Register Office securely transferred the National End of Life Survey contact dataset to the National Care Experience Programme who reviewed the dataset to ensure ineligible deaths were removed. Each death record received from the General Register Office was individually checked by the National Care Experience Programme Team to ensure they met the survey inclusion criteria. For example, sudden deaths, accidental deaths, maternal deaths, suicides and homicides were not appropriate for inclusion and were removed in order to avoid inappropriately contacting bereaved relatives.

Figure 1.2 summarises the inclusion and exclusion criteria.

Figure 1.2 Inclusion and exclusion criteria

Inclusion	Exclusion
Have registered the death of an adult family member or friend (18 years or older) within a set four month time frame, and have a postal address in the Republic of Ireland.	Sudden, unnatural and or accidental death (such as deaths from road traffic and farm accidents, suicides, poisonings).
	A maternal death (refers to deaths due to complications from pregnancy or childbirth).
	A child (under the age of 18 years old).
	Subject to an inquest, a coroner's post-mortem and or where the death was registered by a coroner.
	Registered as occurring abroad.
	Registered by a qualified informant who provided an address outside the Republic of Ireland.

In total, 9,446 people were contacted and 4,570 people took part in this survey, resulting in a response rate of 48%.

1.3.3 The questionnaire

The National End of Life Survey asked bereaved relatives about the end-of-life care provided to their loved ones 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.

In total, 239 people*, including bereaved relatives, specialist palliative care staff, general practitioners, medical consultants and clinical medical directors, nursing staff based in the community, nursing homes, hospices and acute hospitals, homecare support staff, health and social care professionals, academic staff, policy-makers, funders and regulatory staff were involved in developing and selecting the questions most relevant to the Irish context.⁽³⁾

The development steps are outlined below:

1. A national review of the provision of end-of-life care services in Ireland was conducted. This included identifying and reviewing national reports, policies, pathways, guidelines, strategies and standards related to end-of-life care.
2. 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.⁽¹⁾
3. Focus groups involving bereaved relatives, representatives from voluntary and advocacy organisations, health and social care service staff as well as policy-makers and healthcare regulators identified the key themes to be included in the survey.
4. 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.
5. A two-round Delphi study was undertaken to identify priority questions to be included in the questionnaire.
6. Picker Institute Europe checked the measurement and analytic quality of the questions.
7. 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.
8. A further review was undertaken by the National End of Life Survey Programme Board members, with representatives of bereaved relatives, the Department of Health, HIQA, the HSE and special remit organisations representing family carers, palliative and bereavement care.

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

1.3.4 Ethical approval

Ethical approval for the National End of Life Survey was obtained from the Royal College of Physicians in Ireland (RCPI). This was confirmed by email from the RCPI in November 2021.

1.3.5 Data Protection Impact Assessment

A Data Protection Impact Assessment (DPIA) must be carried out to identify and mitigate risks to the privacy of data subjects prior to the processing of any personal and sensitive data. Given that the administration of the National End of Life Survey required the processing of personally identifiable information (for example, contact details and dates of birth), a DPIA was conducted in 2023 and kept under review throughout the course of the survey implementation. The DPIA Summary Report is available to download from: [https://yourexperience.ie/wp-content/uploads/2023/03/NELS_DPIA - Summary_2023_Summary_Report.pdf](https://yourexperience.ie/wp-content/uploads/2023/03/NELS_DPIA_-_Summary_2023_Summary_Report.pdf).

1.3.6 Information governance

Information governance is a means of ensuring that all data, including personal information, is handled in line with all relevant legislation, guidance and evidence-based practices. The National Care Experience Programme has developed a comprehensive information governance framework to ensure that any information it collects is handled safely and securely.

The National Care Experience Programme information governance framework comprises policies, procedures and processes covering: data protection and confidentiality, data subject access requests, record retention and destruction, security, data breach management, data quality, access control, business continuity and record management. A statement of purpose and statement of information practices detailing the information handling practices of the National End of Life Survey are available at www.yourexperience.ie/about/information-governance/.

2 Survey fieldwork

2.1 Data extraction

Data extraction refers to the sampling procedures undertaken to identify individuals eligible to participate in the survey. During the survey period, the General Register Office provided the National Care Experience Programme with details for both the deceased person and the bereaved relative (also referred to as 'qualified informant' by the General Register Office).

The General Register Office excluded the following cases prior to sharing the data with the National Care Experience Programme:

- maternal deaths
- deaths of individuals under 18 years of age
- deaths referred to or registered by the coroner
- deaths where an inquest was or is being held
- deaths registered for Irish citizens who died abroad
- deaths for qualified informants who reside abroad.

See Table 2.1 for data fields included in the contact dataset.

Table 2.1 Data fields for the contact dataset

Data of qualified informant
Forename of qualified informant
Surname of qualified informant
Address of qualified informant
Qualification of informant
Relationship of qualified informant to deceased
Data of deceased individuals
Name of Deceased
Gender of Deceased
Date of Death of Deceased
Cause(s) of death
Certified cause of death
Place of Death

Following extraction of the dataset from the General Register Office, the National Care Experience Programme information governance framework was followed to ensure that information was handled safely and securely. In order to provide additional assurance on the eligibility of all records, each one was individually checked by the National Care Experience Programme Team to ensure it met the survey inclusion criteria. For example, sudden deaths, accidental deaths, maternal deaths, suicides and homicides were not appropriate for inclusion and were removed in order to avoid inappropriately contacting bereaved relatives.

The following approach to applying the eligibility criteria and quality assuring the decisions made was adopted:

1. Firstly, two National Care Experience Programme Team members independently examined each record and highlighted any record where they were unsure if the inclusion criteria had been met. The information available for review of each case included the place of death, cause(s) of death and other underlying medical conditions, duration of illness and or diagnosis (where available in the dataset), and whether or not the case was referred to the coroner.
2. The second line of review was undertaken independently by a team member with clinical expertise to review any records highlighted by at least one reviewer as a potential exclusion or as 'unsure', and to advise on their classification.
3. All cases that were flagged by at least one of the first line reviewers were discussed at weekly case conferences where the team reached a decision on whether each case should be included or excluded. Where there was any remaining doubt over whether or not the case should be included, the team erred on the side of caution and excluded the case.
4. The Head of the Programme attended case conferences for final agreement and sign-off of outstanding records.

Adhering to agreed protocols, the National Care Experience Programme securely shared the dataset with the managed service who subsequently sent survey packs containing an invitation letter, the survey questionnaire, a freepost envelope and a Frequently Asked Questions (FAQ) document to eligible participants.

2.2 Survey administration

The survey fieldwork was carried out from 28 March to 7 July 2023. Survey invitations and questionnaires were sent to participants in March and May 2023. If no response to the survey was received, a reminder letter was issued two weeks after the initial invitation and a final reminder letter was issued four weeks after the initial invitation. Information on bereavement support and opting out of the survey was included in the survey pack and reminder letters. Participants could return their questionnaires until 7

July 2023.

2.3 Sampling and operational outcomes

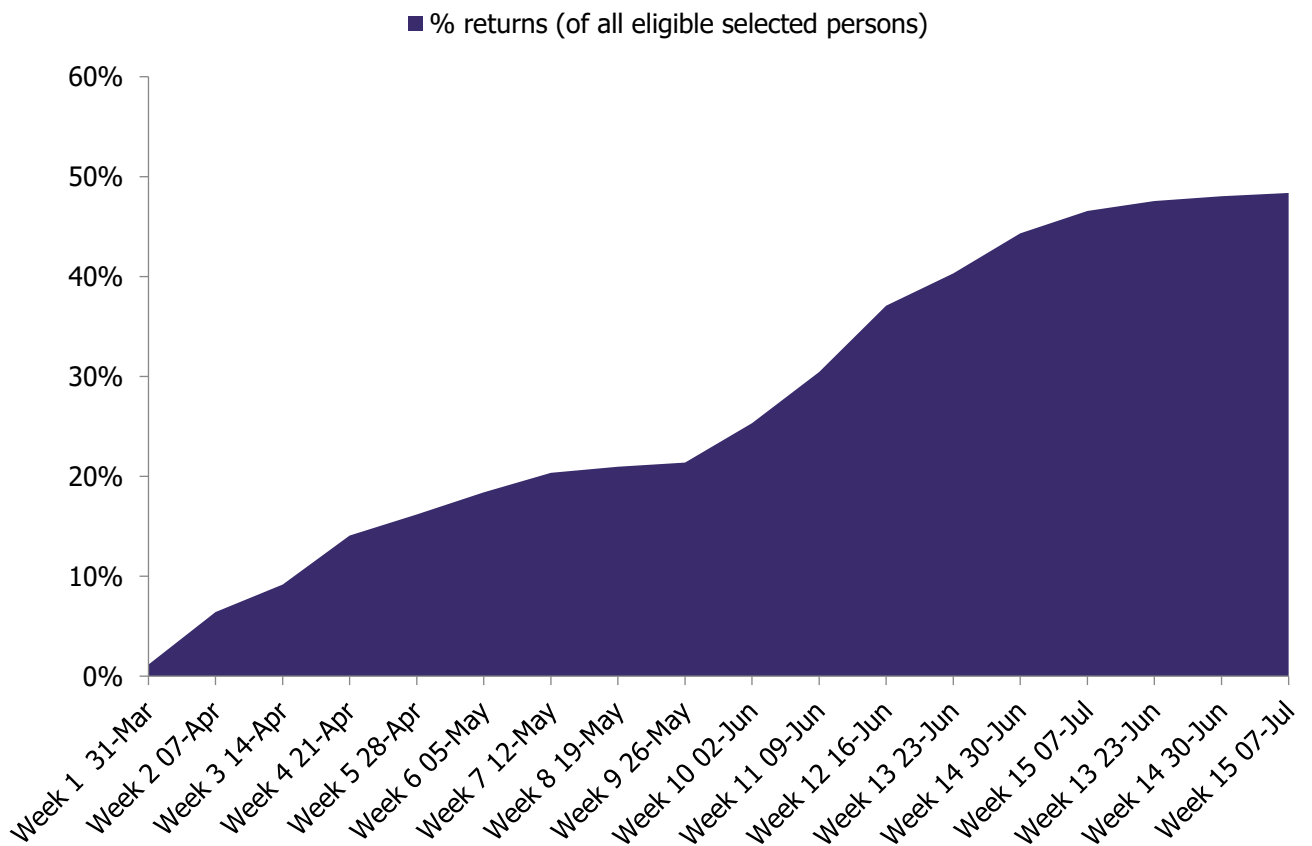
A total of 9,449 people were eligible to participate in the National End of Life Survey 2023. 408 individuals opted out of the survey. A total of 8,410 first reminder letters and 6,592 second reminder letters were sent out during the survey period. Three surveys could not be delivered to the intended recipient and were returned to the sender.

2.4 Response rates

Of the 9,449 people who were eligible to participate, 4,570 participants returned a valid survey questionnaire prior to the survey closing date of 7 July 2023, resulting in a national response rate of 48.4% (Table 2.2). 3,823 (83.7%) completed a paper copy of the survey, with 747 (16.3%) completing the survey online (Table 2.3).

Response rates were calculated by dividing the number of valid surveys received by the number of initial invitations sent. Figure 2.1 shows the cumulative response rates by week during the survey period (28 March to 7 July 2023).

Figure 2.1 Cumulative response rates by week of the survey period



Response rates according to setting of care were between 38.7% and 52.4% (see Table 2.2).

Table 2.2 Number of people invited to take part and response rates by setting of care

Group	Number invited to take part	Number of participants	Response rate (%)
National (total)	9,449	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%

As shown below in Table 2.3, the response rates for eligible male patients (48%) and eligible female respondents (49%) were similar. Response rates for the month that the death was registered in were similar.

Table 2.3 Response and non-response composition of National End of Life Survey 2023

Group		Number invited to take part	Opted out	No response	Return to sender	Completed (paper)	Completed (online)	Response rate
All respondents		9,449	408	4,468	3	3,823	747	48%
Gender	Male	4,549	220	2,146	3	1,823	357	48%
	Female	4,900	188	2,322	0	2,000	390	49%
Setting	Home	1,950	68	860	0	875	147	52%
	Hospice	913	29	428	0	382	74	50%
	Hospital	4,058	208	2,037	3	1,506	304	45%
	Nursing Home	2,409	96	1,082	0	1,017	214	51%
	Other residential care	31	1	18	0	10	2	39%
	Rehabilitation and Community Hospital	88	6	43	0	33	6	44%
Month death registered	September	2,063	92	957	2	823	189	49%
	October	2,279	109	1,078	0	919	173	48%
	November	2,272	80	1,080	0	940	172	49%
	December	2,835	127	1,353	1	1,141	213	48%

2.5 Survey operations

In addition to administering the survey and processing the responses received, the managed service was responsible for providing information to respondents on a dedicated survey helpline. During the survey period of 28 March 2023 to 7 July 2023, 353 calls were recorded by the managed service helpline operators. The highest number of calls (75, 21%) was received between 19 and 23 June (week 13 of the survey period).

The public most frequently called the Freephone helpline to opt out — a total of 139 queries (38%) were received in this regard. The helpline received 112 calls (31%) during the survey period from individuals who wished to ask survey administrators a question about the survey. Table 2.4 details the most frequent query types received and logged by operators of the helpline.

Table 2.4 Summary of query types received by the Freephone helpline

Summary of call query	Number	%
Opt out total*	139	38%
Question about survey	112	31%
Confirming survey receipt after receiving a reminder and having completed survey	69	19%
Lost questionnaire, envelope, etc.	19	5%
Upset, but did not opt out	18	5%
Concern about information	8	2%
Requesting survey in Braille	1	0.3%
Total	366	100%

*Opt out total includes opt out, not upset (98 callers) and opt out, upset (41 callers)

For 54% (n=92) and 11% (n=19) of opt outs, 'another reason' or no reason were cited as the reason for opting out respectively. Table 2.5 outlines the most frequent reasons for opting out during the National End of Life Survey.

Table 2.5 Most frequent reason for opting out

Summary of call query	Number	%
Another reason	91	63%
I prefer not to say	13	9%
The deceased did not need and or avail of end-of-life care in the last months and days of life	9	6%
I do not have time	8	6%
I am not a relative of the deceased	2	1%
I don't know about the care provided to the deceased	5	3%
I have difficulty reading or completing the survey (for example, sight difficulties)	6	4%
I am too ill	5	3%
I never take part in surveys of any kind	3	2%
I do not like the invitation letter	2	1%
The survey is not available in my first language	1	0.7%
Total	145	100%

2.6 Data retention and destruction

Contact details of bereaved relatives and details about their deceased relative were used to distribute the questionnaire and to determine eligibility to participate in the survey. Names and addresses were deleted at the close of the survey period. Hard copies of the survey questionnaire were destroyed once all answers had been coded and correctly uploaded to the response file.

3 Data processing, analysis and reporting

3.1 Data processing and steps

Completed questionnaires were received both online and in paper form. All completed (paper) questionnaires were returned by participants to the managed service where they were opened, date stamped, punched and coded. Data was entered into a customised data entry form developed in Askia software. The form was designed to quality assure the data upon entry. For example, data entry staff could not progress to the next field if an incorrect survey code (ID) was entered. Similarly, out-of-range values were not permitted for any of the numeric fields. The processing of paper questionnaires concluded in July 2023.

The National End of Life Survey website allowed patients to input their eight digit code[†] and complete the survey online. Similar to the paper-based survey, invalid survey codes (IDs) were not permitted on login (an error message appeared asking the user to enter their code again), and the routing in the questionnaire was programmed into the online survey design.

To prepare the data for analysis and reporting, scoring (see section 3.3.2) and a number of post-entry recodes were applied to the survey response file (using stata 17).

The age of the person who died was collapsed into five categories of age groups (18–59, 60–69, 70–79, 80–89, 90 or older).

The questions on overall experience (Question 21, Question 34, Question 47, Question 60, Question 91 and Question 100 were rated 0–10) were collapsed into three groups: very good (score of 9–10), good (7–8), and fair to poor (0–6).

3.2 Mapping survey questions

For analytic and reporting purposes, questions were grouped into 'stages of care' along the person who died and their relative or friends' journey. Figure 3.1 provides a brief description of the stages of care and specifies the number of questions corresponding to each stage of care. Filter questions (that is, questions with the main purpose of routing respondents to the next applicable question) were excluded from this categorisation. Questions on demographics and the three open-ended questions were also excluded. Appendix 1 shows how individual questions map to the stages of care.

[†] Eligible participants received a unique eight digit survey code, which was provided to them in the initial invitation and subsequent reminder letters.

Figure 3.1 Description of stages of care



3.3 Quantitative methodology

This section explains how the stage of care scores were calculated and describes the quality assurance of the survey data.

3.3.1 Question scores

To calculate scores for the stages of care described in Section 3.2, the responses to the questions making up these stages of care were assigned a score using methods equivalent to those used in the UK by the Care Quality Commission (CQC).⁽⁴⁾ The scores

applied to each of these questions are shown in Appendix 1. Figure 3.2 is an example of how response options were converted into scores. 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 total, 77 questions were scored in this way.

In the example below, 'No' was given a score of 0, 'Yes, sometimes' was given a score of 5 and 'Yes, always' 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.

Figure 3.2 Example of a scored question

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

1	10	Yes, always
2	5	Yes, sometimes
3	0	No
4	M	They did not see the public health nurse

Table 3.1 below shows how scores were calculated for a specific question in the survey. In this example, the scores of five respondents are presented. The score for Question 7 (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 Question 7 is 6 out of 10.

Table 3.1 Sum of scores for Q7 based on five respondents

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

3.3.2 Stages of care scores

A stage of care score was generated for each respondent with one or more 'scorable' responses on items making up a stage, by calculating the average of all scored items within that stage. Stage of care scores ranged from 0 to 10, with higher scores indicating a more positive experience. Table 3.2 shows an example of the original and scored data for the 'care in last three months' stage of care. The 'care in last three months' stage of care score is calculated as the average of the scored responses for the three items included in this stage. Please see Appendix 1 for the wording and response options for the questions shown in Table 3.2.

Table 3.2 Example of scored responses for the 'care in last three months' stage of care

Original responses				Scored responses				Care in the last three months stage score
Q61	Q62	Q63	Q64	RQ61	RQ62	RQ63	RQ64	
1	1			10	10			10
1	2	2	2	10	5	5	5	6.25
1	1	3	3	10	10	0	0	5
2	2	4		5	5			5
4	4	4						[Missing]

3.3.3 Comparison of groups

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.

3.3.4 Quality assurance of quantitative data

Insofar as possible, quality assurance was built into the design of the data capture for the paper-based survey responses. The managed service verified 202 of 3,562 (6%) paper-based surveys through double entry using the Askia software.

Frequency checks on the merged (paper and online) survey data also confirmed that the rate of missing data on the individual survey questions was in the low range, that is, there was no substantial evidence of 'survey fatigue', whereby rates of missing responses would be higher for questions appearing later in the questionnaire. For example, missing responses averaged 2.1% for Q1-Q3 compared with 4.1% for Q104-Q106.

3.4 Qualitative methodology

This section describes the processing of the qualitative data collected via the survey questionnaire, that is, responses to the last three (open-ended) questions:

- 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?

Table 3.3 shows the number of responses received for each question by gender, age group, route of admission and response mode (paper or online).

Table 3.3 Number of responses received for Q101, Q102 and Q103 by gender, age group, and response mode[‡]

	Q101	Q102	Q103
Male (respondent)	1,051	938	731
Female (respondent)	2,419	2,206	1,822
Other (respondent)	2	2	1
Prefer not to say (respondent)	7	7	6
Age 18–29 (respondent)	27	27	22
Age 30–39 (respondent)	114	108	91
Age 40–49 (respondent)	536	504	407
Age 50–59 (respondent)	1,134	1,059	849
Age 60–69 (respondent)	939	823	669
Age 70–79 (respondent)	480	416	339
Age 80–89 (respondent)	227	198	164
Age 90+ (respondent)	18	14	14
Male (person who died)	1,629	1,508	1,213
Female (person who died)	1,822	1,623	1,325
Other (person who died)	5	3	2
Prefer not to say (person who died)	3	3	2
Age 18–59 (person who died)	198	183	150
Age 60–69 (person who died)	345	316	257
Age 70–79 (person who died)	751	684	555
Age 80–89 (person who died)	1,312	1,192	946
Age 90 or older (person who died)	811	720	597
Paper	2,974	2,666	2,180
Online	634	598	471

[‡] The number of responses is based on responses to the demographic questions of the survey. Please note differences exist between participants' responses and the data extract.

3.4.1 Anonymisation of qualitative data

All qualitative responses were anonymised. Whether on paper or online, the same set of procedures was followed. The overarching principle guiding these procedures was the protection of the anonymity of individuals, including respondents, the person who died, and staff members. The redaction guidelines can be found in Appendix 2.

3.4.2 Developing thematic codes for the qualitative data

The framework method was used to analyse and manage the wealth of information provided in participants' comments.⁽⁵⁾ All comments received in response to Q101 (Overall what was good about the care your relative or friend received?), Q102 (Was there anything that could have been improved?) and Q103 (Do you have any other comments or suggestions about the care your relative or friend received?) were analysed and multi-coded using 48 codes, as shown in Table 3.4.

Table 3.4 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	HCA's (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	

An analytical framework consisting of 20 themes was then developed, with the 48 codes mapped to these 18 themes (see Table 3.5). This framework helped organise and systematically reduce the thousands of participants' comments into manageable chunks of information.⁽⁵⁾

Table 3.5 List of summary themes

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

3.5 Treatment of duplicates

Duplicates could occur within the National End of Life Survey data in two ways: the first was within the data extracts and the second was within the survey responses, whereby a respondent may have opted to complete a survey online as well as on paper.

The vast majority of duplicates within the data extracts were identified and removed as part of the quality assurance processes. Duplicates in the survey response file could not occur as the system did not permit entry of a record with a survey ID which was already in the online survey response set. In this sense, a duplicate is defined as a paper-based response that already appeared in the online file. The record in the duplicate set with the older time stamp was the one retained in the final dataset. There were seven duplicate questionnaires.

3.6 Quality assurance of qualitative data

The following processes assured the quality of this data:

- regular audits of paper-based responses against the data entered online confirmed high levels of accuracy in the transcription of the handwritten comments to the online system.
- the National End of Life Survey Team at HIQA reviewed all comments to check that they had been anonymised in accordance with the agreed redaction protocols. Only then was the data released to the online reporting facility for individual sites to review (also refer to section 3.7).
- 3% of responses were selected for blind double-coding. Responses were selected at a random starting point, followed by every 33rd comment, in order to achieve the set quota. Where necessary, codes were edited or additional codes added in order to ensure that the coding was as comprehensive as possible.

3.7 Publication of national results

In April 2024, the National End of Life Survey Team published a national report based on the findings of the survey. Tableau data visualisation was embedded at www.yourexperience.ie and allows site visitors to further examine the results. It should be noted that personnel working in services and other stakeholders had been granted access to a 'real-time' online reporting platform where they could view their performance in the survey as the data was being processed. Access to this information prior to the publication of reports allows settings to be proactive and to identify opportunities for improvement at an early stage.

The national report was designed to:

- provide a clear description of the key features of end-of-life care at national and local levels, pointing to areas of good experience and areas needing improvement in the system.
- together with other data and information sources, provide a robust basis for the development of quality improvement plans at national and setting of care level.
- together with other data and information sources, enable the identification of policy priorities at the national level.
- provide a basis for benchmarking progress over time following future surveys.

All published reports are available at www.yourexperience.ie.

3.8 Survey findings, quality improvement and next steps

Services that participated in the survey have been invited to share initiatives they have undertaken in response to the findings of the survey. These will be shared on www.yourexperience.ie.

The HSE has used the survey results to develop quality improvement plans at national and local levels. These quality improvement plans describe the steps that will be taken to address the findings of the survey and improve end of life care. The quality improvement plans are available from www.yourexperience.ie.

The Department of Health will continue to use the information gathered to inform the development of policy and strategy in relation to end-of-life care.

Finally, the findings of the survey will inform HIQA's approach to the monitoring, regulation and setting standards for end-of-life care.

A lessons learned exercise was conducted by the National Care Experience Programme Team. The findings of this process will inform the next iteration of the National End of Life Survey.

The National Care Experience Programme Steering Group determines the frequency of all surveys. The group will agree on the most appropriate time to conduct this survey again, which will allow us to understand what changes to service and practice, based on the National End of Life Survey, have effectively improved the experience for people who are dying and their loved ones.

4 International comparisons

4.1 Comparisons with international data

Surveys of end-of-life care have been carried out in a number of countries, using a wide variety of approaches and survey tools.

A summary of the approaches taken in the United States of America, England, New Zealand and Japan, and how these compare with the National End of Life Survey approach is provided in Table 4.1. Further detail on the surveys carried out in these and other jurisdictions is provided in the International Review of End of Life Surveys.⁽¹⁾

A comparison of results in Ireland and the 2015 VOICES survey conducted in England is provided in Table 4.2. Comparing experiences across jurisdictions is challenging due to variations in health service provision, differences in survey instruments and methodology, as well as cultural differences in how encounters with the health service are perceived and reported.⁽⁶⁾ Comparisons of survey results across jurisdictions should therefore be made with caution. Nevertheless, there are some common aspects in survey approaches between other jurisdictions and Ireland and comparisons of results on similar questions can be useful.

Comparisons are only made for questions with similar wording and response options. In Table 4.2, questions are numbered and ordered according to where they appear in the National End of Life Survey. These questions are numbered and categorised differently in the 2015 VOICES survey.

Table 4.1 Overview of end of life surveys in other jurisdictions

Jurisdiction	Survey information	Differences from National End of Life Survey approach
United States of America	<p><i>Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice survey</i></p> <p>Domains measured:</p> <ul style="list-style-type: none"> ▪ Communication with family ▪ Getting timely help ▪ Treating the patient with respect ▪ Emotional and spiritual support ▪ Help for pain and symptoms ▪ Training family to care for patient ▪ Rating of hospice ▪ Willingness to recommend this hospice 	<p>Measures the quality of care provided by hospice care teams in all settings.</p> <p>Data collection is initiated two months following the month of the person's death.</p> <p>Survey mode is via mail or telephone.</p> <p>Hospices that have 50 or more survey-eligible patient/family caregiver pairs in a reference year are required to participate.</p>

<p>United States of America</p>	<p><i>The Bereaved Family Survey (BFS)</i></p> <p>Domains measured:</p> <ul style="list-style-type: none"> ▪ interactions with staff ▪ communication with family members about the patient's condition and timing of death ▪ management of the patient's hygiene and pain ▪ provision of emotional support before and after death and anxiety at end of life ▪ spiritual support ▪ information provided on burial and funeral benefits, benefits for surviving spouses and dependents ▪ overall rating of care in final month of life. 	<p>Sample is family members of military veterans only.</p> <p>Administered to family members of people who have died in inpatient settings such as nursing home, freestanding hospice inpatient units and acute care hospitals.</p> <p>Asks bereaved family members about the last month of their loved one's life.</p>
<p>England</p>	<p><i>National Survey of Bereaved People (VOICES) 2015</i></p> <p>Domains measured:</p> <ul style="list-style-type: none"> ▪ communication ▪ information on care planning ▪ overall experience ▪ pain and symptom management ▪ spiritual and psychosocial care ▪ caregiver support ▪ personal care ▪ provision of fluid ▪ nutrition ▪ demographic information including free text questions 	<p>Since 2012, deaths were selected from those which occurred between January and April to limit any seasonal change in the annual death register.</p> <p>Deaths where the death had occurred "elsewhere" than the designated locations (home, care home, hospital or hospice) were excluded.</p> <p>To ensure a representative sample of deaths, the sample was stratified by cause of death, place of death and geographic spread.</p> <p>Focused on last three months and last three days of life.</p>
<p>England</p>	<p><i>The National Care of the Dying Audit for Hospitals (NCDAH)</i> (from 2013-2016) and <i>National Audit of Care at the End of Life (NACEL)</i> (2017 to date)</p> <p>Domains measured:</p> <ul style="list-style-type: none"> ▪ symptom management including pain ▪ emotional support ▪ spiritual support ▪ care provided by staff 	<p>The surveys capture the experience of care at a local healthcare provider level, as part of a wider audit structure.</p> <p>Timeframe for audit varies.</p> <p>NACEL can be completed online or via a designated helpline.</p> <p>Setting is acute and community hospitals. From 2021 mental health inpatient units are included.</p>

	<ul style="list-style-type: none"> ▪ communication ▪ hospital environment. 	Focuses on last admission to hospital.
New Zealand	<p><i>Survey of Bereaved People (VOICES) conducted in the Auckland District Health Board in 2017</i></p> <p>Outputs reported on are end-of-life experience of people who died, examining the last three months of life, including:</p> <ul style="list-style-type: none"> ▪ services provided by general practitioners ▪ hospice ▪ district nursing ▪ urgent care ▪ aged residential care ▪ inpatient hospital care 	<p>Conducted in one district only.</p> <p>Survey can be completed via post, phone or in person.</p> <p>Bereaved relatives received the survey pack 6 to 12 months following the death of the person.</p>
New Zealand	<p><i>VOICES: South Island pilot survey of bereaved people</i>, which surveyed bereaved relatives from the five district health boards on behalf of the South Island Alliance, on the South Island of New Zealand in 2018</p> <p>In addition to the outputs reported in the VOICES above, this survey also reported on:</p> <ul style="list-style-type: none"> ▪ nature and extent of physical and psychological symptoms experienced in the last three months of life and predictors of unmet symptoms. ▪ the proportion of patients accessing community and hospital specialist palliative care services in the last three months of life, and predictors of the use of specialist palliative care services. ▪ overall experience of care delivered in the last three months of life from the family/whānau perspective. ▪ the role of ethnicity and culture in determining end of life experience. 	<p>Included sudden deaths as the study did not have access to the National Health Index database from all district health boards.</p> <p>Data collection was initiated at least three months after the person's death.</p> <p>Mode of completion was either by mail, online, by telephone, by Skype or face-to-face interview.</p>

Japan	<p><i>Japan Hospice and Palliative Care Evaluation (J-HOPE) surveys</i></p> <p>Domains measured include:</p> <ul style="list-style-type: none"> ▪ help with decision making for patient ▪ help with decision making for family ▪ physical care by physician ▪ physical care by nurse ▪ psychoexistential care ▪ environment ▪ cost of care ▪ availability of care ▪ coordination of care ▪ family burden 	<p>The 2018 iteration surveyed acute hospitals, palliative care units and home.</p> <p>Participating institutions identified up to 80 potential respondents that met the inclusion criteria.</p> <p>Participants were included if their loved one died of cancer and the deceased person and bereaved person were aged 20 years or over (the definition of an adult in Japan).</p> <p>Participants were included if their loved one received palliative care for more than three days.</p> <p>Data collection was initiated at least three months following their loved one's death.</p>
Japan	<p><i>National Mortality follow back survey of bereaved relatives</i> conducted in 2018</p> <p>The questionnaire consisted of 150 questions, measuring a number of areas including:</p> <ul style="list-style-type: none"> ▪ domains identified by Japanese people as important in a good death ▪ domains of care ▪ caregiver burden 	<p>One objective of the survey was to examine respondents' acceptability of this method of survey.</p> <p>Participants were eligible if they and their loved one were aged 20 years or over.</p> <p>Data collection was initiated 13-25 months following the person's death (due to the availability of data from the Japanese vital statistics agency).</p> <p>The sample included people who died from one of the following five causes of death: cancer, heart disease, cerebrovascular disease, pneumonia, renal failure.</p>

Table 4.2 Comparison of response rate and question with results from England (2015 VOICES survey)

	Ireland 2023	England (2015 VOICES) [§]
Response rate	48%	43%
Response rate by place of death	Home: 52% Hospital: 45% Nursing Home: 51% Hospice: 50%	Home: 42% Hospital: 41% Care Home: 48% Hospice: 48%
Gender of deceased (female %) response rate	49%	44%
Age of deceased at death (%>80 years)	62%	66%
Q3: How long had they been ill before they died?	They were not ill - they died suddenly: 2% Less than 24 hours: 1% One day or more but less than one week: 7% One week or more but less than one month: 14% One month or more but less than six months: 21% Six months or more but less than one year: 12% One year or more: 42%	He/she was not ill - he/she died suddenly: 8% Less than 24 hours: 1% One day or more but less than one week: 5.1% One week or more but less than one month: 11% One month or more but less than six months: 20% Six months or more but less than one year: 11% One year or more: 44%
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? (% yes, definitely)	76%	58%*
Q90. On balance, do you think that they died in the right place? (% yes)	91%	77%*

*weighted percentage

[§] The results of the 2015 VOICES survey conducted in England can be downloaded from <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/datasets/nationalsurveyofbereavedpeoplevoices>

5 References

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Appendix 1

National End of Life Survey question wording, response options, corresponding scores and mapping to stages of care

Question	Wording	Response options with corresponding scores in parentheses	Stage of Care
Q06	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?	Yes, always (10); Yes, sometimes (5); No (0); They did not need a home visit from the public health nursing team (M); Don't know (M)	Care at home
Q07	Overall, did you feel they were treated with respect and dignity by the public health nurse?	Yes, always (10); Yes, sometimes (5); No (0); They did not see the public health nurse (M)	Care at home
Q08	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?	Yes, always (10); Yes, sometimes (5); No (0); They did not need a home visit from the GP (M); Don't know (M)	Care at home
Q09	Overall, did you feel your relative or friend was treated with respect and dignity by their GP in the last three months of their life?	Yes, always (10); Yes, sometimes (5); No (0); They did not need see their GP (M); Don't know (M)	Care at home
Q10	If your relative or friend wanted to talk to the GP about their condition, treatment or tests, did they have an opportunity to do so?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not want to talk to the GP (M); Don't know (M)	Care at home
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	Yes, always (10); Yes, sometimes (5); No (0); They did not need a home visit from their GP (family doctor) or the GP out of hours service (M); Don't know (M)	Care at home

	hours (after 5pm, at night and weekends) were they available to visit?		
Q13	While at home, did healthcare staff help and support them with accessing additional equipment for their home, or making minor adaptations to their home?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need additional equipment or adaptations to the home (M); Don't know (M)	Care at home
Q14	While at home, if they experienced pain, did healthcare staff do everything they could to relieve it?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not have any pain (M)	Care at home
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?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need help with this (M)	Care at home
Q16	While at home, did healthcare staff help and support them with their emotional needs (e.g. feeling worried, feeling anxious, feeling low, etc.)?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need help with this (M); Don't know (M)	Care at home
Q17	While at home, if they needed help from healthcare staff, did they get it as soon as they needed it?	Yes, always (10); Yes, sometimes (5); No (0); They did not need any help from healthcare staff (M)	Care at home
Q18	Overall, while they were at home, did healthcare staff answer any questions you had in a way that you could understand?	Yes, always (10); Yes, sometimes (5); No (0); I didn't have any questions (M)	Care at home
Q19	Overall, while they were at home, did you have confidence and trust in the healthcare staff treating them?	Yes, always (10); Yes, sometimes (5); No (0)	Care at home

Q20	While at home, did the healthcare staff give you enough help and support to care for them?	Yes, definitely (10); Yes, to some extent (5); No (0); I did not need help with this (M); Don't know (M)	Care at home
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?	They received very poor care (0) to they received very good care (10)	Care at home
Q24	During their stay in the nursing home/residential care facility, if they experienced pain, did healthcare staff do everything they could to relieve it?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not have any pain (M); Don't know (M)	Care in a nursing home
Q25	During their stay in the nursing home/residential care facility, if they experienced symptoms other than pain (such as nausea, constipation, breathing difficulties or restlessness), did healthcare staff do everything they could to relieve them?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not have any symptoms (M); Don't know (M)	Care in a nursing home
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.)?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need support (M); Don't know (M)	Care in a nursing home
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)?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need help with this (M); Don't know (M)	Care in a nursing home

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?	Yes, always (10); Yes, sometimes (5); No (0); Don't know (M)	Care in a nursing home
Q30	During their stay in the nursing home/residential care facility, did healthcare staff answer your questions in a way that you could understand?	Yes, completely (10); Yes, to some extent (5); No (0); I didn't have any questions (M)	Care in a nursing home
Q31	During their stay in the nursing home/residential care facility, did you feel welcome to visit at any time?	Yes, always (10); Yes, sometimes (5); No (0); I wasn't allowed due to visiting restrictions (M)	Care in a nursing home
Q32	During their stay in the nursing home/residential care facility, did you have confidence and trust in the healthcare staff treating them?	Yes, always (10); Yes, sometimes (5); No (0)	Care in a nursing home
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?	Yes, always (10); Yes, sometimes (5); No (0)	Care in a nursing home
Q34	Overall, how would you rate the care your relative or friend received from healthcare staff in the nursing home/residential care facility?	They received very poor care (0) to they received very good care (10)	Care in a nursing home
Q38	During their last stay in hospital, if they experienced pain, did healthcare staff do everything they could to relieve it?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need have any pain (M); Don't know (M)	Care in an acute hospital

Q39	During their last stay in hospital, if they experienced symptoms other than pain (such as nausea, constipation, breathing difficulties or restlessness), did healthcare staff do everything they could to relieve them?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need have any symptoms (M); Don't know (M)	Care in an acute hospital
Q40	During their last stay in hospital, did healthcare staff help and support them with their emotional needs (e.g. feeling worried, feeling anxious, feeling low, etc.)?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need have any symptoms (M); Don't know (M)	Care in an acute hospital
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)?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need help with this (M); Don't know (M)	Care in an acute hospital
Q42	During their last stay in hospital, if they needed help from healthcare staff, did they get it as soon as they needed it?	Yes, always (10); Yes, sometimes (5); No (0); They did not need help (M); Don't know (M)	Care in an acute hospital
Q43	During their last stay in hospital, did healthcare staff answer your questions in a way that you could understand?	Yes, completely (10); Yes, to some extent (5); No (0); I didn't have any questions (M); I wasn't there (M)	Care in an acute hospital
Q44	During their last stay in hospital, did you feel welcome to visit at any time?	Yes, always (10); Yes, sometimes (5); No (0); Not applicable (M); I wasn't allowed due to visiting restrictions (M)	Care in an acute hospital
Q45	During their last stay in hospital, did you have confidence and trust in the healthcare staff treating them?	Yes, always (10); Yes, sometimes (5); No (0)	Care in an acute hospital

Q46	Overall, during their last stay in hospital, did you feel they were treated with respect and dignity by healthcare staff?	Yes, always (10); Yes, sometimes (5); No (0)	Care in an acute hospital
Q47	Overall, how would you rate the care your relative or friend received in the hospital?	They received very poor care (0) to they received very good care (10)	Care in an acute hospital
Q50	During their stay in the hospice, if they experienced pain, did healthcare staff do everything they could to relieve it?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not have any pain (M); Don't know (M)	Care in a hospice
Q51	During their stay in the hospice, if they experienced symptoms other than pain (such as nausea, constipation, breathing difficulties or restlessness), did healthcare staff do everything they could to relieve them?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not have any symptoms (M); Don't know (M)	Care in a hospice
Q52	During their stay in the hospice, did healthcare staff help and support them with their emotional needs (e.g. feeling worried, feeling anxious, feeling low, etc.)?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need help with this (M); Don't know (M)	Care in a hospice
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.)?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need support (M); Don't know (M)	Care in a hospice
Q54	During their stay in the hospice, did healthcare staff provide help with urgent problems outside of normal working hours	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need help with this (M); Don't know (M)	Care in a hospice

	(after 5pm, at night and weekends)?		
Q55	During their stay in the hospice, if they needed help from healthcare staff, did they get it as soon as they needed it?	Yes, always (10); Yes, sometimes (5); No (0); They did not need help (M); Don't know (M)	Care in a hospice
Q56	During their stay in the hospice, did you feel welcome to visit at any time?	Yes, always (10); Yes, sometimes (5); No (0); I wasn't allowed due to visiting restrictions (M)	Care in a hospice
Q57	During their stay in the hospice, did healthcare staff answer your questions in a way that you could understand?	Yes, completely (10); Yes, to some extent (5); No (0); I didn't have any questions (M)	Care in a hospice
Q58	During their stay in the hospice, did you have confidence and trust in the healthcare staff treating them?	Yes, always (10); Yes, sometimes (5); No (0)	Care in a hospice
Q59	Overall, during their stay in the hospice, did you feel they were treated with respect and dignity by healthcare staff?	Yes, always (10); Yes, sometimes (5); No (0)	Care in a hospice
Q60	Overall, how would you rate the care your relative or friend received in the hospice?	They received very poor care (0) to they received very good care (10)	Care in a hospice
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)?	Yes, always (10); Yes, sometimes (5); No (0); They did not need support with this (M); Don't know (M)	Care in last three months
Q62	During the last three months of their life, were they involved as much as	Yes, definitely (10); Yes, to some extent (5); No (0); They did not want to be involved or were not	Care in last three months

	they wanted to be in decisions about their care?	able to be involved (M); Don't know (M)	
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)?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need help with this (M); Don't know (M)	Care in last three months
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?	Yes, definitely (10); Yes, to some extent (5); No (0); Not relevant to our situation (M); Don't know (M)	Care in last three months
Q66	During the last two days of their life, did the bed area and surrounding environment have adequate privacy for them?	Yes, definitely (10); Yes, to some extent (5); No (0); I was not with them in the last two days (M); Does not apply to our situation (M)	Care in last two days
Q68	During the last two days of their life, if they experienced pain, did healthcare staff do everything they could to relieve it?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not have any pain (M); Don't know (M)	Care in last two days
Q69	During the last two days of their life, if they experienced symptoms other than pain (such as nausea, constipation, breathing difficulties or restlessness), did healthcare staff do everything they could to relieve them?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not have any symptoms (M)	Care in last two days
Q70	During the last two days of their life, did healthcare staff help and support them with their emotional	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need help with this (M); Don't know (M)	Care in last two days

	needs (e.g. feeling worried, feeling anxious, feeling low etc.)?		
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)?	Yes, always (10); Yes, sometimes (5); No (0); They did not need help with this (M); Don't know (M)	Care in last two days
Q72	During the last two days of their life, did they get enough help from healthcare staff to eat or drink?	Yes, always (10); Yes, sometimes (5); No (0); They did not want help (M); They were not able to eat or drink (M); Don't know (M)	Care in last two days
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)?	Yes, definitely (10); Yes, to some extent (5); No (0); They did not need help with personal care needs (M)	Care in last two days
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?	Yes, definitely (10); Yes, to some extent (5); No (0); Don't know (M)	Care in last two days
Q76	During the last two days of their life, did you feel that there was good coordination between the healthcare staff?	Yes, definitely (10); Yes, to some extent (5); No (0); Don't know (M)	Care in last two days
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)?	Yes, always (10); Yes, sometimes (5); No (0); Don't know (M)	Care in last two days
Q78	During the last two days of their life, do you think your relative or friend was involved as much as they	Yes, definitely (10); Yes, to some extent (5); No (0); They were not able to be involved in decisions at this time (M); Don't know (M)	Care in last two days

	wanted to be in decisions about their care and treatment?		
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?	Yes, definitely (10); Yes, to some extent (5); No (0); Does not apply to our situation (M)	Care in last two days
Q80	During the last two days of their life, did you have confidence and trust in the nurses who cared for them?	Yes, always (10); Yes, sometimes (5); No (0); Does not apply to our situation (M)	Care in last two days
Q81	During the last two days of their life, did you have confidence and trust in the doctors who cared for them?	Yes, always (10); Yes, sometimes (5); No (0); Does not apply to our situation (M)	Care in last two days
Q82	During the last two days of their life, did healthcare staff treat them with kindness and compassion?	Yes, always (10); Yes, sometimes (5); No (0); Does not apply to our situation (M)	Care in last two days
Q83	Overall, during the last two days of life, did you feel that they were treated with respect and dignity by healthcare staff?	Yes, always (10); Yes, sometimes (5); No (0)	Care in last two days
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?	Yes, definitely (10); Yes, to some extent (5); No (0); Don't know (M)	Care at the end of life
Q91	Overall, how would you rate the care your relative or friend received at the end of their life?	They received very poor care (0) to they received very good care (10)	Care at the end of life

Q92	Looking back over the last days of their life, were you given enough emotional help and support by healthcare staff?		Care at the end of life
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?	Yes, definitely (10); Yes, to some extent (5); No (0); I did not need help with this (M); Not applicable to my situation (M)	Care at the end of life
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?	Yes, definitely (10); Yes, to some extent (5); No (0); Not applicable to my situation (M)	Care at the end of life
Q95	During the last days of their life, did healthcare staff explain their condition and care in a way that you could understand?	Yes, definitely (10); Yes, to some extent (5); No (0); Not applicable to my situation (M)	Care at the end of life
Q96	During the last days of their life, did you feel you had enough time to discuss their care and treatment with healthcare staff?	Yes, definitely (10); Yes, to some extent (5); No (0); Not applicable to my situation (M)	Care at the end of life
Q97	After your relative or friend died, did healthcare staff engage with you in a sensitive manner?	Yes, definitely (10); Yes, to some extent (5); No (0); Not applicable to my situation (M)	Care at the end of life
Q98	Did healthcare staff give you practical information on what to do after your relative or friend died, including information on registering their death?	Yes, definitely (10); Yes, to some extent (5); No (0); I did not need this information (M); Not applicable to my situation (M)	Care at the end of life
Q100	Overall, and taking all services into account, how would you rate the care and support you received?	I received very poor care and support (0) to I received very good care and support (10)	Care at the end of life

Appendix 2

National End of Life Survey redaction guidelines

Example	Recommended redaction
Relationship to deceased person My dad, my sister etc.	No redaction
Name of deceased person My sister Mary John was in the hospice	My sister [Name] [Name] was in the hospice
Age At 89 years old...	No redaction
Names and titles Dr., Mr., Prof. James, Mary, Nurse Pat, Nurse O'Brien	Dr. [Name] Mr. [Name] Prof. [Name] [First Name] Nurse [Name]
Gender Male (Nurse), male care assistant	No redaction
Specialist healthcare professionals Senior nurse, renal nurse, oncologist	No redaction
General categories of healthcare specialists (plural) The nurses, doctors, consultants	No redaction
Specific categories of healthcare specialists Anaesthetist, physio, dietician	No redaction
Specific grades of healthcare professional Junior doctor, intern, CNM etc.	No redaction
Dates, days, times Monday, Tues etc., weekend, bank holiday weekend, waiting between 7 and 9.30, May, October etc., September 2022 24 May 2022 October bank holiday	No redaction [May] 2022 [October]
Departments & wards Emergency department, operating theatre, cancer ward, recovery, ICU/CCU, AMAU (acute medical assessment unit), heart and lung transplant unit Ward name (St James's Ward)	No redaction No redaction
Religions, nationality Muslim doctor, Indian, Pakistani, etc. Generic use of term like foreign	[Rel] [Nat] [eth] No redaction
Hospital, hospice or nursing home names In the Mater Private, Mayo Hospice, Millbury Nursing Home	No redaction

Example	Recommended redaction
GP practice names The GP in the Cremore clinic	The GP in [GP practice]
Home care provider names Kare Plan, Castle Homecare etc.	No redaction
Location identifiers – person The consultant from Athy	[Location]
Location identifiers – service The nursing home in Kildare, home care in Sligo	No redaction
Procedures and operations Lumbar puncture, bypass, appendix operation, heart surgery, operation/surgery (generic)	No redaction
Specific therapies Intravenous anti-biotic drip, IV fluids etc.	No redaction
Conditions Diabetes, breast cancer, renal failure, colon cancer, heart attack, high blood pressure etc.	No redaction
Medication Medication names/classes (paracetamol, analgesic etc.), 650mg of Tramadol	No redaction
Illegible text	[...] and continue to the next legible part of the comment. Aim to get a balance between capturing the maximum amount of information possible and time spent on deciphering handwriting.
Any racist or derogatory remarks are typed as you see them	Redact in the normal way (that is, if nationality mentioned, redact etc.) but type in the precise remarks as you seem them.
Correct spelling mistakes	Correction should be of minor and obvious spelling mistakes, for example: their/there. This is to facilitate understanding and 'readability' of the qualitative data, it should in no way impact on meaning.
Other Wheelchairs and other medical devices	No redaction

Appendix 3

Data quality statement

1. Purpose

The National End of Life Survey is committed to ensuring that the processing and publishing of data adheres to the five dimensions of good quality data. The purpose of this statement is to provide transparency on the collection of National End of Life Survey data and provide data users with information about the quality of National End of Life Survey data. This will allow data users to make an informed decision about whether this data meets their needs.

2. Overview of data collection and remit

Data on experiences of end-of-life care are collected through eligible participants' responses to a survey. The survey asks bereaved relatives about the care provided to a family member or friend in the last months and days of their life, and includes structured tick-box questions as well as open-ended questions for comments. The findings of the survey are used to inform quality improvements care.

3. Data source

People who respond to the survey are the data source for the data that is collected on experiences of end-of-life care.

4. Overview of quality of data under each of the dimensions of data quality

This section provides an overview of how data quality is ensured under each of the five dimensions of quality.

Relevance

The relevance of National End of Life Survey data is ensured in the following ways.

- To ensure that data meets the needs of data users, the development of the survey tool involved a Delphi Study, focus groups and cognitive interviews with bereaved relatives, representatives from voluntary and advocacy organisations, health and social care service staff and other relevant stakeholders.
- The input of representatives from voluntary and advocacy organisations, health and social care professionals is sought in the implementation and planning of the survey through their representation on governance groups (steering group and advisory groups). This ensures that the needs of data-users are embedded into the design of surveys and the delivery of the survey results.
- A review of each survey is carried out, which involves a public consultation.

Data users provide feedback on all aspects of the survey, including the relevance of the survey data.

Accuracy and reliability

The accuracy and reliability of the data is ensured in the following ways:

- The coding or categorisation of survey responses is quality assured, through spot-check verification.
- The results of all data analyses are quality assured to ensure that they reflect the responses received from survey participants.

Timeliness and punctuality

Timeliness and punctuality is ensured in the following ways:

- Anonymised survey responses are uploaded to an online reporting platform once received by the data processor. Once five or more responses have been received, these are then disclosed to nominated staff, who have access to this platform and can view the data as close as possible to its point of collection.
- The findings of the survey are published at www.yourexperience.ie.

Coherence and comparability

The coherence and comparability of the data is ensured in the following ways:

- The National End of Life Survey uses one survey tool to measure experiences of end-of-life care.
- Anonymised survey responses are uploaded to a publically accessible, online reporting platform at www.yourexperience.ie.

Accessibility and clarity

The accessibility and clarity of the data is ensured in the following ways:

- The findings of the survey are presented in a traditional report format with graphs and textual explanations to appeal to different types of learners.
- Staff analysing the data and reporting the survey findings undergo data visualisation training to ensure that the findings of the survey are reported in an accessible and clear format.
- All outputs, such as the National End of Life Survey national report, are quality assured to ensure that they adhere to NALA (National Adult Literacy Agency) standards and are therefore reported in plain English.
- Survey findings are accessible through various platforms, such as an online reporting tool for nominated staff and a public facing reporting tool available at www.yourexperience.ie.
- A data access request policy and form are available for people who wish to

access and use the data for research purposes.

5. Limitations of the survey

Comparability

As this was the first National End of Life Survey, there are no previous findings to compare against. In addition, international comparisons are limited in scope, as where such surveys have been carried out, they have often used quite different methodological approaches.

Accessibility

The findings of surveys are made publically available at www.yourexperience.ie. Reports are published at a national level on a publically available, online reporting tool. Data, relevant to the needs of specific data users, is therefore accessible and easily obtainable.

Conclusion

The National Care Experience Programme is committed to high-quality data which is exemplified by meeting the five dimensions of data quality. The Programme Team will continually review these dimensions to provide assurance of the quality of the data for the National End of Life Survey.



Improving care experiences together