



Review of Processes
October 2024

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.

Contents

About the National Care Experience Programme	2
1. Background information.....	4
2. Purpose.....	4
3. Scope	5
4. Evaluation process.....	5
5. Overview of the responses received.....	5
5.1 Value and benefits	5
5.2 Communication and engagement.....	6
5.3 Methodology	7
5.4 Questionnaire.....	7
5.5 Reporting.....	8
5.6 Use of findings	8
6. Overview of recommendations	9
7. Next steps	9
Appendix I: Evaluation	10

1. Background information

The National End of Life Survey gives bereaved people the opportunity to report on the care their relative or friend received in the last months and days of life. The survey was developed by the National Care Experience Programme – a joint initiative between HIQA, the HSE and the Department of Health – and is supported by the Irish Hospice Foundation. The National Care Experience Programme creates surveys to collect feedback on people’s experiences of health and social care services and acts on this feedback to improve the quality of care in Ireland.

People who registered the death of a family member or friend between 1 September and 31 December 2022 were invited to participate in the first National End of Life Survey. The survey covered care provided at home, in a nursing home, an acute hospital and in a hospice. Sudden, maternal and child deaths were not included in the survey due to the differences in care pathways in these circumstances.

Why are process reviews conducted?

The National Care Experience Programme is committed to continuously improving care in Ireland and therefore conducts a review of processes after each survey cycle. During these reviews, key stakeholders identify which processes work well and which processes are in need of improvement, through a targeted consultation.

The National Care Experience Programme will utilise the findings from the review of processes to improve the planning and implementation of future survey cycles, by repeating processes that received positive feedback and developing areas that were identified as needing improvement. Stakeholder feedback from reviews of processes of other National Care Experience Programme surveys, such as the National Inpatient Experience Survey, have previously been used to inform survey promotion strategies, reporting of findings and potential stakeholder training for survey implementation.

2. Purpose

The purpose of this report is to give an overview of the feedback received in the review of processes regarding the planning, implementation, and outputs of the National End of Life Survey 2023. This document provides an overview of the evaluation process and recommendations for the administration of future survey cycles.

3. Scope

This document will review participants' feedback on:¹

- communication around the survey and survey findings
- survey design and methodology
- survey questionnaire
- reporting the findings
- uses of survey findings.

There were several challenges and concerns raised by participants in the consultation that are beyond the scope of this review, including resources, budgeting and the development of alternative survey methodologies.

4. Evaluation process

An invitation to participate in the evaluation was distributed by email to all stakeholders including the service providers involved in the survey. This included acute hospitals, hospices, nursing homes and those providing homecare.

A large representative proportion of service providers responded to the survey. The evaluation can be found in Appendix 1.

5. Overview of the responses received

5.1 Value and benefits

Participants in the consultation were appreciative of the insight provided by the National End of Life Survey into the lived experiences of bereaved people and their relatives or friends who received end-of-life care. The survey drew attention to how care is provided in a range of settings and identified where improvement was needed.

The feedback from the survey was identified as valuable to improving care. Participants noted the importance of giving bereaved people a voice in their loved ones' end-of-life care.

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.

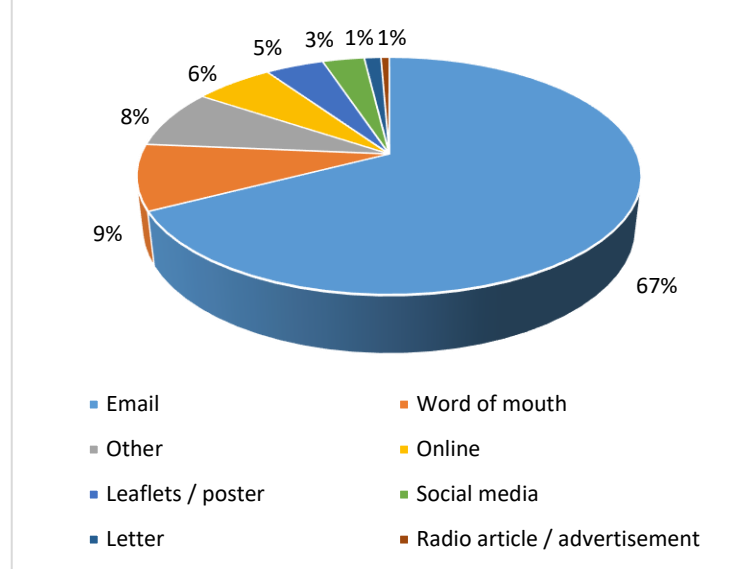
5.2 Communication and engagement

Bereaved people received a survey pack in the post between March and May 2023, which provided the option to complete the survey online at www.yourexperience.ie or by returning the survey questionnaire in the post.

A survey helpline and an email address were made available to answer survey-related questions throughout the survey cycle.

Participants in the consultation were asked how they were made aware of the survey, in their professional capacity, as healthcare providers. More than two thirds (67%) of participants reported that they heard about the National End of Life Survey through email, with other successful promotional methods including word of mouth, online, leaflets, posters, social media, letters and radio articles and advertisements.

Figure 1: How participants heard about the survey



Recommendations

- Most participants in the consultation expressed general satisfaction in the communication around survey implementation and stated that the team implementing the survey in HIQA and the HSE were accessible and helpful.
- Several comments were made about the importance of comprehensively advertising the survey. Participants suggested to increase survey promotion and to communicate more clearly the value and importance of taking part in the survey to bereaved people.
- Email was noted to be the most effective way to share survey findings with healthcare providers and staff, followed by social media and webinars. Other suggestions included posters, flyers, media coverage, radio and TV advertisements, passing information through management, interacting with other professional bodies, and holding stakeholder meetings and public forums.

5.3 Methodology

The National End of Life Survey used a mixed-mode response approach where bereaved people had the option to complete the survey online or by returning a paper questionnaire in the post. However, the mode of contacting bereaved people was solely through the post.

Bereaved people who were eligible to participate in the survey received a survey pack in the post, approximately five to six months after the death of their relative or friend. The survey pack contained an invitation letter, an information leaflet, a paper questionnaire, a free-post envelope and information on bereavement support. The survey pack contained a unique survey code for each participant, which allowed them to take the survey online. Reminder letters were issued two weeks and four weeks after the initial invitation.

The majority of participants (84%) completed the survey by post, while the remaining 16% completed the survey online.

Recommendations

Participants in the consultation reported satisfaction with the survey methodology.

5.4 Questionnaire

The National End of Life Survey included a total of 110 questions, three of which were in free-text format. Questions discussed pain management, respect and dignity, emotional support, communication with healthcare staff and the provision of information.

Approximately 240 people were involved in the development of the questionnaire and selecting the most relevant questions for an Irish context. This included representatives of bereaved people, specialist palliative care, primary care, community care, nursing home care, acute hospital care, hospice care, academia and policy makers.

Recommendations

- Several participants stressed the value of qualitative data over quantitative and suggested increasing the number of free-text questions in the National End of Life Survey.

- Several participants felt the survey should be shorter to ensure that it is as accessible as possible.
- A number of participants that the survey was too broad and questions should be redesigned to be more specific.
- Several participants suggested the survey could capture the experiences of general and specialist palliative care in the community, and community care more generally.

5.5 Reporting

The survey findings were published on www.yourexperience.ie. A national report outlining the survey findings was published in April 2024. Nominated stakeholders from nursing homes, hospitals and hospices were granted access to a dashboard, which allowed them to see data for their service, as close as possible to the point of collection.

Question 7 of the consultation asked how the National End of Life Survey data can best be shared with stakeholders.

Recommendations

- Some participants found the dashboard difficult to navigate and suggested further training may be required to support dashboard users in extracting and interpreting survey response data.
- A number of participants suggested including infographics in the report for easier data interpretation.
- Survey findings should be benchmarked against similarly sized facilities.
- Survey participants in the National End of Life Survey could respond to three qualitative questions about the care their relatives and friends received across all services. Qualitative responses therefore often referred to a number of services. Respondents to the evaluation who had access to survey responses on the National End of Life Survey dashboard recommended that they receive qualitative response data for their service only.

5.6 Use of survey findings

The National Care Experience Programme offers training and guidance for healthcare staff on data extraction and submission for the conduct and promotion of the survey and for survey response interpretation.

Recommendations

- A number of participants requested clearer instructions on how to use the findings to improve the care offered by their facilities.
- A participant noted that the time in which to implement quality improvements was too short and put pressure on hospitals.

6. Overview of recommendations

- Communication surrounding survey development and implementation was effective and should continue similarly for future survey rounds.
- Further methods of promoting the survey could be explored, to maximise engagement, such as TV advertisements.
- The survey questionnaire should be shortened, questions should be specific and more focus should be given to qualitative data.
- Findings should be shared with facilities and should highlight what is relevant to those facilities.
- The dashboard should be made easier to navigate and interpret.

7. Next steps

The National Care Experience Programme Steering Group will review the recommendations outlined in this document and will use this information to inform and improve the future planning and delivery of the National End of Life Survey. The Review of Processes for the National End of Life Survey 2023 will be published on www.yourexperience.ie.

Appendix 1: Evaluation

The evaluation consisted of the following seven open-ended questions:

1. What area do you work in? (Please select more than one if appropriate)
 - Advocacy / support organisation
 - Hospice
 - Hospital
 - Nursing home
 - Home care
 - Public Health
 - Primary care
 - Community care
 - Social work
 - General Registry Office
 - National End of Life Survey – Advisory Group
 - Health Service Executive (HSE)
 - Department of Health
 - Health Information & Quality Authority (HIQA)
 - Academia
 - Professional body
 - Other (please specify)
2. What is your role? (For example, Public Health nurse, End-of-life Coordinator, PALS Officer, Chaplain)
3. How did you hear about the survey? (Please select more than one if appropriate)
 - Email
 - Letter
 - Social media
 - Online
 - Leaflets / poster
 - Word of mouth
 - Radio article / advertisement
 - Other
4. Where did you access information about the survey? (Please select more than one if appropriate)
 - Webinars
 - FAQs / information flyers provided on site
 - Website (yourexperience.ie)
 - Social media
 - Podcast
 - Dashboard
 - Report (available at yourexperience.ie)
 - Interactive results (available at yourexperience.ie)
 - Communications (For example, email or phone call)
 - Other
5. What was good about the survey? (Please comment on questionnaire, distribution, dashboard, reports, communication of findings and so on.)
6. What could be improved about the survey? (Please comment on questionnaire, distribution, dashboard, reports, communication of findings and so on.)
7. How can we best share the National End of Life Survey's findings with all stakeholders?

