



Developing and implementing Ireland's first National End of Life Survey

Improving care experiences together



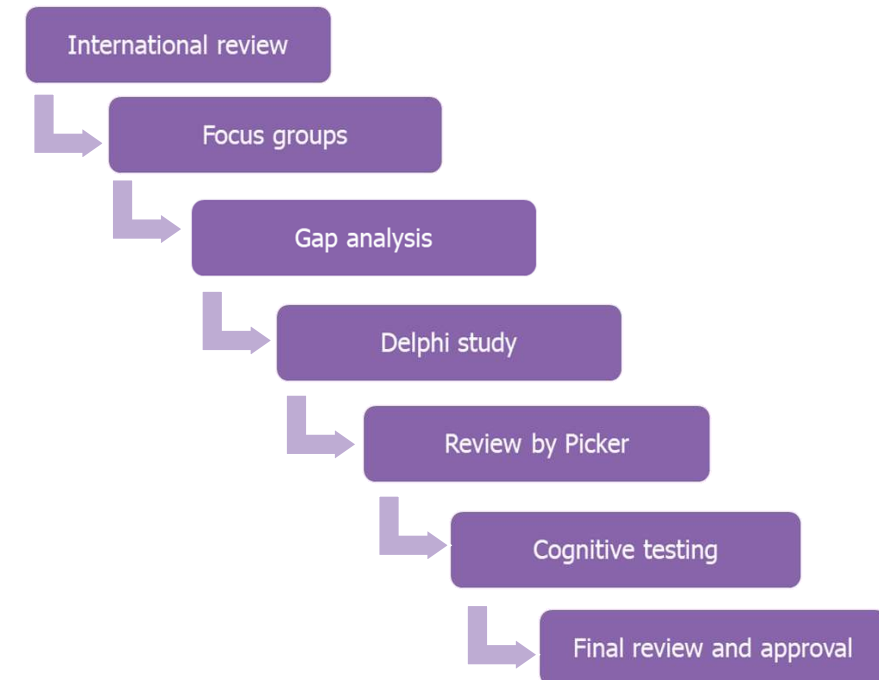
An Roinn Sláinte
Department of Health



About the survey

- **Aim:** identify areas of good experience and areas needing improvement, inform policy and the development of standards and guidance.
- **Scope:** care provided at home, in nursing homes, hospitals and hospices in last three months of life
- **Model and Methodology:** 110 item questionnaire (107 tick box and three open-ended), mixed modal postal/online.
- **Eligibility:** 9,500 people bereaved between September to December 2022; Contact details sourced from the General Register Office

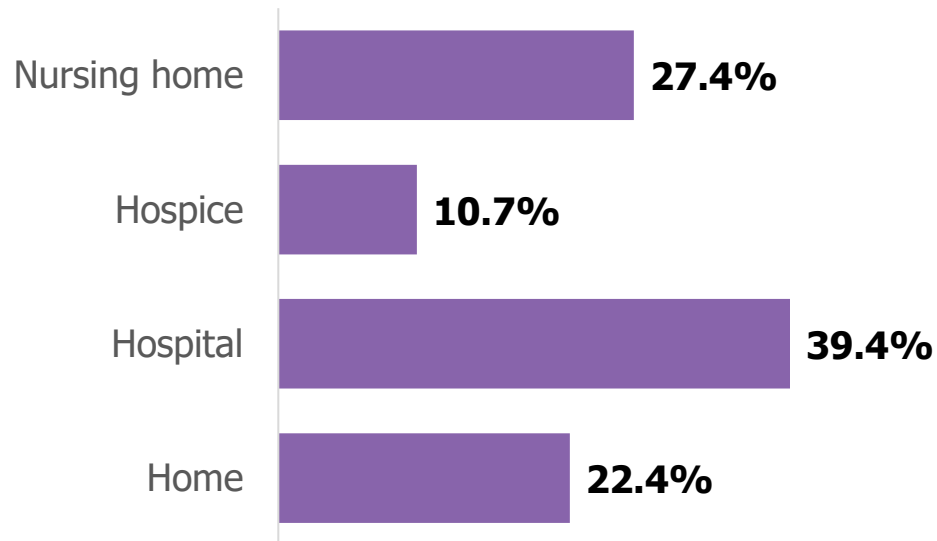
Survey development (O’Coimin et al, 2024)



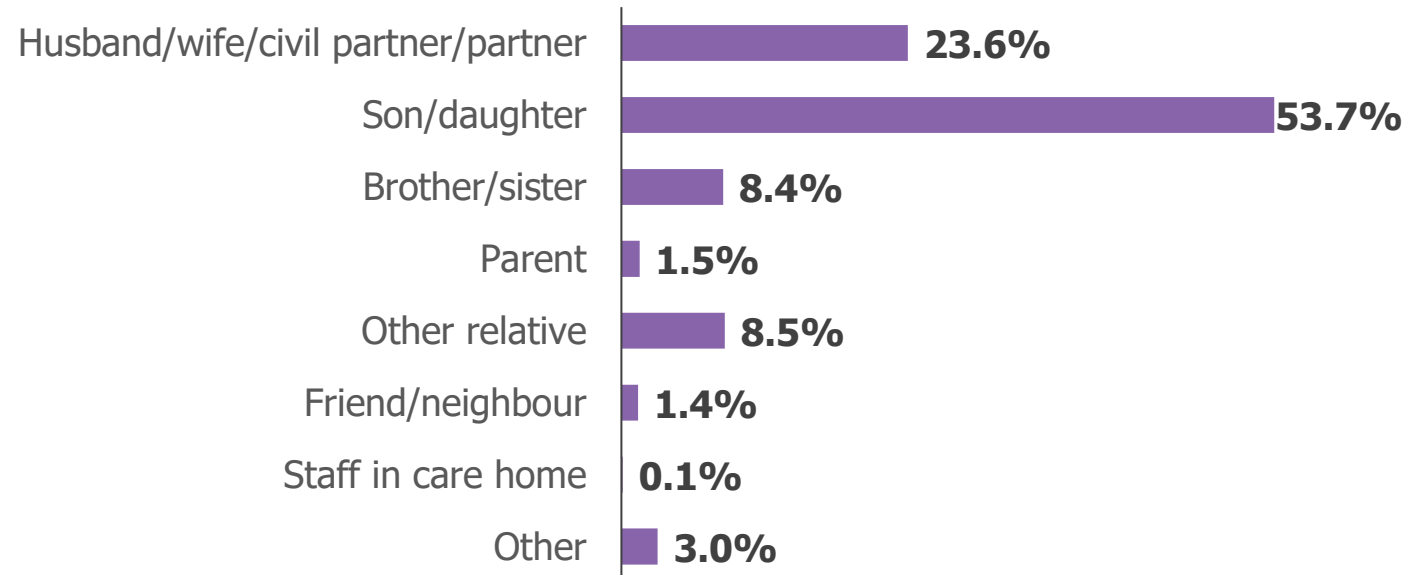
Who participated in the survey?

- 4,570 bereaved people responded (48% response rate)
 - Most were the children of people who had passed away
- Place of death very closely reflected official figures for the population as a whole

Place of death

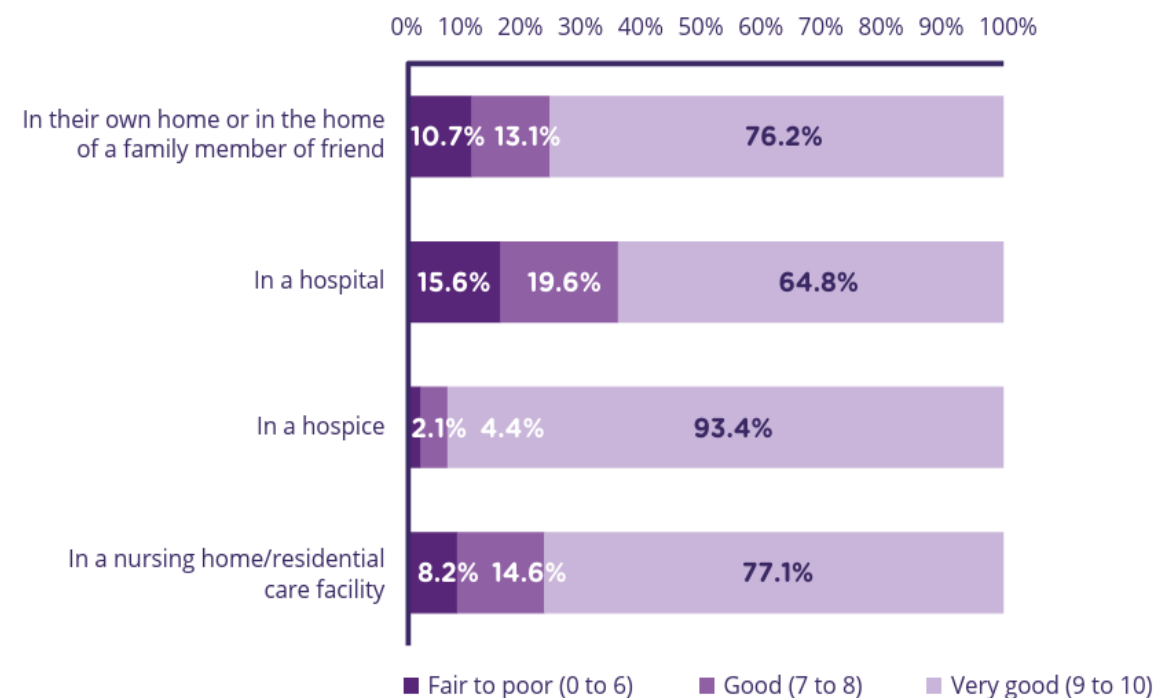


Relationship to the person who died

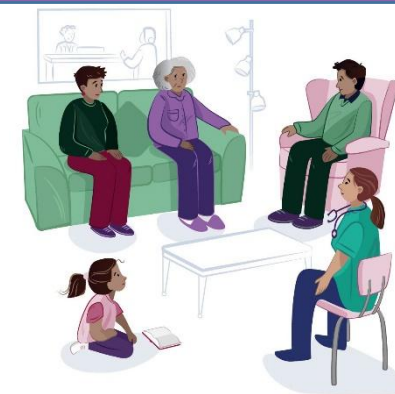


Care at the end of life

- 89% of participants rated the care that their relative or friend received as good or very good.
- Higher-scoring questions related to confidence and trust in staff, kindness and compassion, and respect and dignity.
- Lower-scoring questions related to the responsiveness and coordination of care, and support in talking to children about what was happening.
- Hospices received the most positive overall ratings, with hospitals the least positive



In their own words



- Open-ended questions asked what was good about the care received and what could be improved.
- Participants' positive comments related to
 - the respect and dignity with which their relative or friend was treated.
 - staff for the compassionate care they provided
 - the physical, spiritual and emotional support that was made available.
- Participants highlighted issues relating to
 - the continuity, availability and responsiveness of care
 - a desire for clearer and more consistent communication

"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"

"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."

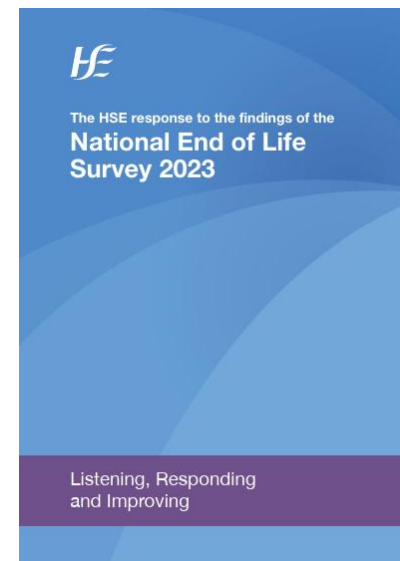
Care experience in different settings

- There was no one typical pathway of care.
- Most people received care in multiple settings in their last months and days.
- 1,699 participants (45.4%) answered that there 'definitely' was good coordination between the services and staff in the last three months.
- 3,007 participants (73.6%) answered that there was 'definitely' good coordination between the services and staff in the last two days.

Care setting in last three months	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%

Response to the survey

- Online dashboard created to allow providers access findings
- Sectoral response documents were created outlining key actions in response to survey findings
 - 'Hospice Friendly Hospitals Programme' – Increase from 6 to 21 end of life care coordinators working in hospitals
 - National guidelines published on care of deceased people and on post-mortems
 - €15m assigned by HSE to improve facilities for bereaved families
 - Rollout of Carú programme to nursing home staff
- Strong support from the Irish Hospice Foundation across all sectors
- Significant media and public interest in the findings of the survey



Response to the survey

- The physical environment had a large bearing on people's experiences, particularly in hospital.
 - 19% reported their loved one died in a multiple-occupancy room.
 - 51% of these said they died 'in the right place', compared with 81% whose loved one died in a non-shared room
- Design and Dignity guidelines to inform developments committed to by the HSE



Design & Dignity Guidelines

Transforming end-of-life care in
hospitals, one room at a time



Key lessons

- Strong network of people involved in end-of-life care throughout Ireland greatly facilitated survey's success
- Formal lessons-learned exercise carried out with stakeholders identified some key points
 - Appreciation of the insights provided into the lived experiences of people
 - Importance of giving a voice to people going through a difficult experience
 - Questionnaire was considered to be very long and onerous to complete
- Incredibly rich and valuable information yielded. Commitment made to repeat the survey
- Deeply humbling that people took the time to share such intimate stories, and we wish to express our gratitude for that.

Further information

To see the [questionnaire](#), [Frequently Asked Questions](#) or for any further information about the survey, please see:

- **Website:** www.yourexperience.ie
- **Email address:** info@yourexperience.ie

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Thank you

Questions?

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