

Survey of Bereaved Relatives:

# VOICES MaJam

**Views of Informal Carers  
– Evaluation of Services (VOICES)**

**Mater Misericordiae University Hospital  
and St. James's Hospital (MaJam)**



## Members of the research team

<b>Mr Diarmuid Ó Coimín</b>	Principal Investigator Mater Misericordiae University Hospital Email: docoimin@mater.ie
<b>Ms Bettina Korn</b>	Principal Investigator St. James's Hospital Email: bkorn@stjames.ie
<b>Ms Geraldine Prizeman</b>	Trinity Centre for Practice and Healthcare Innovation, School of Nursing and Midwifery, Trinity College Dublin*
<b>Dr Sarah Donnelly</b>	School of Social Policy, Social Work and Social Justice, University College Dublin
<b>Dr Geralyn Hynes</b>	Trinity Centre for Practice and Healthcare Innovation, School of Nursing and Midwifery, Trinity College Dublin
<b>Ms Mairéad Curran</b>	Mater Misericordiae University Hospital, Dublin
<b>Ms Margaret Codd</b>	St. James's Hospital, Dublin**

\*Ms Geraldine Prizeman's position is part funded by the Royal City of Dublin Hospital Trust and the HSE Nursing and Midwifery Planning Development Unit.

\*\*At the time of publication, Ms Margaret Codd transferred employment to the Health Service Executive.

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# Contents

	Page
<b>Acknowledgements</b> .....	<b>5</b>
<b>Foreword</b> .....	<b>6</b>
<b>Executive summary</b> .....	<b>8</b>
Introduction and background .....	8
Methodology .....	8
Main findings.....	10
Recommendations.....	12
<b>Glossary of terms</b> .....	<b>17</b>
<b>Background</b> .....	<b>19</b>
<b>1. METHODOLOGY</b> .....	<b>23</b>
Introduction and background to the survey.....	24
Aims and objectives.....	24
Research design .....	25
Sample selection.....	25
Data collection .....	27
Data analysis.....	28
Study considerations .....	28
Ethical considerations.....	28
<b>People included in the survey</b> .....	<b>29</b>
Profile of respondents.....	29
Profile of the deceased person.....	30
<b>2. QUANTITATIVE RESULTS</b> .....	<b>33</b>
<b>Quality of care</b> .....	<b>34</b>
Quality of care during the last admission .....	34
Quality of care rating by staff group .....	35
<b>Meeting care needs</b> .....	<b>36</b>
Level of personal care in the last two days of life .....	37
Relief of pain in the last two days of life .....	38
Pain and symptom management during last admission.....	39
Emotional support.....	40
Spiritual support.....	41
<b>Dignity and respect</b> .....	<b>42</b>
Dignity and respect during the last admission .....	42
<b>Coordination of care</b> .....	<b>43</b>

<b>Patient preferences and shared decision-making</b> .....	<b>44</b>
<b>Communication</b> .....	<b>46</b>
Awareness about likelihood of dying .....	46
Quality of communication with the dying person .....	46
Contacting relatives in time before death .....	47
<b>Preferences and choice at end of life</b> .....	<b>49</b>
Articulating preferences regarding place of death .....	49
Staff awareness of preferred place of death .....	50
Deceased person’s choice about place of death.....	51
Hospital as the place of death .....	52
<b>Hospital environment</b> .....	<b>52</b>
Care in a single room at time of death .....	53
Reasons for the lack of availability of a single room.....	54
Privacy in the last two days of life.....	54
<b>Support for relatives</b> .....	<b>55</b>
Availability of a family room .....	55
Unrestricted visiting .....	57
Accommodating relatives overnight .....	58
Support for family members at the time of relative’s death .....	58
Bereavement support .....	60
Bereavement support – contact with hospital staff .....	61
Bereavement support – bereavement evenings and remembrance services ...	63
<b>Quantitative summary results</b> .....	<b>65</b>
<b>3. QUALITATIVE FINDINGS</b> .....	<b>69</b>
<b>Meeting care needs</b> .....	<b>72</b>
Personal care .....	72
Staff skills and availability .....	73
Pain and symptom management.....	74
Nutrition .....	74
Emotional and psychological support.....	75
Spiritual support .....	75
Access to specialist palliative care .....	76
<b>Dignity and respect</b> .....	<b>77</b>
Kindness and compassion.....	78
<b>Communication</b> .....	<b>79</b>
Good communication .....	79
Poor communication .....	80
Patient preferences and shared decision-making .....	80
Coordination of care .....	81
<b>Hospital environment</b> .....	<b>82</b>
Care in a single room .....	82
Hospital facilities .....	83
Route of admission .....	83
Atmosphere in the ward and single room .....	84

<b>Support for relatives .....</b>	<b>85</b>
During the stay in hospital .....	85
Access to a family room and overnight accommodation .....	86
Unrestricted visiting, affordable parking and ease of access .....	87
Support at the time of death .....	88
Bereavement support.....	89
Support from the social worker.....	90
Benefit from taking part in the survey .....	91
<b>Qualitative summary findings .....</b>	<b>92</b>
<b>4. RECOMMENDATIONS.....</b>	<b>95</b>
<b>Meeting patient care needs .....</b>	<b>96</b>
Personal care .....	96
Pain and symptom management .....	97
Emotional and spiritual support.....	97
<b>Patient preferences and shared decision making at end of life .....</b>	<b>98</b>
<b>Communication.....</b>	<b>98</b>
<b>Care environment at end of life .....</b>	<b>99</b>
Care in a single room .....	99
Improving the hospital environment.....	99
<b>Support for relatives .....</b>	<b>100</b>
<b>Education.....</b>	<b>101</b>
<b>Surveying bereaved relatives .....</b>	<b>102</b>
<b>5. CONCLUDING COMMENTS .....</b>	<b>104</b>
<b>6. APPENDICES .....</b>	<b>107</b>
Appendix 1: The Mater Misericordiae University Hospital and St. James's Hospital Hospice Friendly Hospitals Programmes.....	108
Appendix 2: <i>VOICES MaJam</i> survey questions in context of relevant national standards .....	121
Appendix 3: <i>VOICES MaJam</i> – designing, planning and conducting the survey .....	127
<b>7. REFERENCES .....</b>	<b>131</b>

## List of figures

Figure 1	Ratings of overall quality of care on last admission
Figure 2	Ratings of overall quality of care by staff group
Figure 3	Overall level of practical care provided by hospital staff in the last two days of life
Figure 4	Level of pain relief provided by hospital staff
Figure 5	Pain relief and management of other symptoms on last admission
Figure 6	Support for emotional needs by health professionals during the last admission
Figure 7	Support for spiritual needs during the last admission
Figure 8	Dignity and respect by care provider during last admission
Figure 9	Coordination of care with GPs and community services
Figure 10	Patients' involvement in decision-making about their care
Figure 11	Were any decisions made about your relative's care that they would not have wanted?
Figure 12	Relatives' involvement in the decision-making about the patient's care
Figure 13	Patients' awareness about impending death
Figure 14	Communication of likelihood of dying given in a caring and sensitive way
Figure 15	Contact to allow presence of family near time of death
Figure 16	Relatives' indication of preferred place of care at time of death
Figure 17	Location of preferred place of care
Figure 18	Documentation of preferred place of care
Figure 19	Choice regarding preferred place of care
Figure 20	Did your relative die in the right place?
Figure 21	Care in a single room at time of death
Figure 22	Reason why death did not occur in a single room
Figure 23	Adequate privacy in last two days of life
Figure 24	Availability of a family room as helpful
Figure 25	Unrestricted visiting
Figure 26	Overnight stay during last admission
Figure 27	Help and support at the time of death
Figure 28	Did staff deal with you in a sensitive manner when your relative died?
Figure 29	Receipt of information leaflet from ward staff
Figure 30	Receipt of a sympathy card
Figure 31	Helpfulness of speaking to staff after the person died
Figure 32	Staff member spoken to after the person died
Figure 33	Invitation to bereavement evening
Figure 34	Invitation to remembrance service
Figure 35	Qualitative findings – key themes
Figure 36	Five core elements of the hospital's Hospice Friendly Hospitals Programme

## List of tables

Table 1	Profile of the respondents
Table 2	Profile of the deceased person
Table 3	End-of-life care training and education sessions

## List of flow charts

Flow chart 1	Sampling process employed
Flow chart 2	Data collection process employed

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## Foreword

The primary purpose of our work as acute hospitals is to provide the highest standard of care to the people who utilise our services. Some of the most vulnerable people we look after are those diagnosed with a life limiting illness, those nearing the end of their life, or those who may die in the care of our hospital staff.

Of those who die annually, 43% die in an acute hospital setting. We are keenly aware that for those who die, many would not wish for their life journey to end in this setting. As healthcare providers, we strive to provide the best person-centred end-of-life care to every one of our patients and their families. We only have one opportunity to get it right for each patient, so we must ensure that their experience is the best one possible.

While dying, death and bereavement are universal human experiences, when experienced in an acute hospital, they can present their own unique set of complexities. To address these complexities, end-of-life care must not only deliver a high standard of care, but it must be responsive and flexible enough to meet individual patients' needs.

We recognise that the key to improving care is through measuring and monitoring performance and eliciting feedback from our service users. This Survey of Bereaved Relatives: VOICES MaJam report, provides us with the opportunity to acknowledge the aspects of care we deliver very well, and identify the areas of care where we can improve. It outlines detailed information to guide us through a strategic end-of-life care quality improvement process and helps us to focus our efforts on quality improvement and on the enhancement of end-of-life care in our hospitals.

This survey is unique. Never before have two acute hospitals in Ireland engaged on such a large scale study with bereaved relatives. We thank all the bereaved relatives who contributed to the study. Each contribution has provided us with an invaluable insight into how care is delivered from the perspective of the service user. Their stories and experiences reflect what is important at end of life for patients and their families.

Through the Hospice Friendly Hospitals Programme, our hospitals have strived to enhance end-of-life care. We look forward to continuing this partnership.

Staff across all departments and disciplines are instrumental to delivering good end-of-life care. In this regard, we would like to thank all staff members in our respective hospitals. Their commitment to, and passion for, providing the best possible care to patients is unwavering.

This journey has been an enlightening one. As hospitals we have learned, and continue to learn, from our engagements with bereaved relatives. We encourage all healthcare organisations to read this report to gain a better understanding of the needs of patients at end of life and their families.

We warmly welcome the publication of this report and are firmly committed to building on the existing excellent service which is highlighted within it. We will also focus our efforts on implementing the report recommendations which will enhance end-of-life care for future patients and their families.



**Mr Gordon Dunne**  
Chief Executive Officer  
Mater Misericordiae  
University Hospital



**Mr Lorcan Birthistle**  
Chief Executive Officer  
St. James's Hospital



**Prof Tanya King**  
Director of Nursing  
Mater Misericordiae  
University Hospital



**Mr Paul Gallagher**  
Director of Nursing  
St. James's Hospital



# Executive summary

## Introduction and background

End-of-life care is an experience that touches the lives of everyone on a personal or professional level. Of all people that will die in Ireland this year, 43% will die in adult acute hospital settings<sup>1</sup>.

Acute hospitals are busy places with a predominant focus on diagnosis, treatment and cure. However, caring for people who are seriously ill is also an important responsibility. The Mater Misericordiae University Hospital and St. James's Hospital are striving to ensure that people who are diagnosed with a life-limiting illness or who die in our care, experience a place of sanctuary where they are cared for in comfort and dignity and their families are supported in their bereavement.

The Mater Misericordiae University Hospital and St. James's Hospital have targeted end-of-life care as an area for improving the quality of care for patients and their families. To enable this, both hospitals have actively sought to improve end-of-life care through their active participation in the Hospice Friendly Hospitals Programme, an initiative of the Irish Hospice Foundation.

Measuring the quality of care provided is recognised as being fundamental to quality assurance and provides information to further enhance patient and family care. This study sought to ascertain the quality of care provided to patients and their families during their last admission to hospital from the perspective of bereaved relatives.

## Methodology

### Aims and objectives

The key aims of the study were to:

- determine the quality of end-of-life care in both hospitals as perceived by bereaved relatives in order to inform quality improvement.
- determine the processes required to undertake a modified version of the VOICES survey of bereaved relatives called *VOICES MaJam* as a means of monitoring the quality of end-of-life care in Irish adult acute hospitals.

## Background and design

This is a quantitative descriptive post-bereavement study which gathered data retrospectively, using a postal survey, from relatives or friends of patients who died in two adult acute hospitals. An adapted version of the VOICES (Views of Informal Carers – Evaluation of Services) questionnaire<sup>2</sup> was utilised. This adapted version, titled *VOICES MaJam*, reflects concerns and priorities raised in the *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup> and the *National Audit of End-of-Life Care in Hospitals in Ireland*<sup>4</sup>.

## Sample selection

Persons recorded as the next of kin in the deceased person's healthcare record were recruited for the sample. Relatives of people who died in our care from August 1<sup>st</sup> 2014 to January 31<sup>st</sup> 2015 were included. The sample included relatives who were bereaved no earlier than three months and no later than nine months. All deaths, including sudden and unexpected deaths, as well as those that were anticipated and expected were included. The exclusion criteria for this study included the following; patients aged less than eighteen years of age; patients who were deceased on arrival to the emergency department; patients who did not die in the hospitals; and, next of kin with a missing or incomplete address. The combined sample size was 792 (*Hospital A*, n=385; *Hospital B*, n=407).

## Data collection

Data was collected in three waves between May and September 2015. Information on bereavement supports was included with the survey pack. Relatives were also provided with contact details of the principal investigator in each hospital to assist them in making contact if they had any queries or concerns about the study. A total of 356 valid questionnaires were returned (*Hospital A*; n=167; *Hospital B*; n=189), giving an overall response rate of 46%.

## Data analysis

Quantitative data were inputted into MS Excel and converted to the statistical package IBM SPSS statistics v. 22<sup>5</sup> for analysis. Qualitative data were coded and analysed using NVivo 10<sup>6</sup>.

## Main findings

### 1. Quality of care

- Almost nine out of 10 respondents (87%) rated the overall quality of end-of-life care as outstanding, excellent, or good: just over one out of 10 (12%) rated care as fair or poor.
- Eight out of 10 respondents (81%) felt that on balance, the hospital was the right place for the person to be cared for during the last days of life.

### 2. Meeting care needs

- Four out of five (79%) of those for whom relief of pain was applicable to the patient, reported this was relieved in the last two days of life. A small number of relatives suggested that the assessment and management of pain could be improved outside of core working hours.
- Almost three quarters (73%) of respondents reported that their relatives' personal care needs were met during the last two days of life. However, 8% indicated that the person's care needs were not adequately met and suggested that this may have been due to the lack of sufficient staff.
- Respondents reported that 56% of emotional needs and 61% of spiritual needs were met at an excellent or good level.

### 3. Dignity and respect

- Nine out of 10 (90%) respondents reported that the patient was treated with dignity and respect by hospital staff all or most of the time.
- Respondents rated nurses as always showing dignity and respect at 76%, followed by doctors at 73% and other staff at 69%. Relatives commented on where this could be enhanced.
- The high skill level and dedication of staff left a significant impression and were a source of great comfort and reassurance for the majority of relatives.

### 4. Communication

- Three quarters (75%) of respondents indicated they were involved in decision-making as much as they wanted to be. However, 18% of respondents indicated they would have liked more involvement.
- Many relatives highlighted good communication practices both by individual staff but also within and across multidisciplinary teams. However, relatives also indicated that communication could be improved, specifically relating to diagnosis, prognosis and plan of care. Information about what to expect prior to death and what happens after death, including information about post-mortem examination also need to be considered.

## Main findings

### 5. Hospital environment

- The hospital environment, including care in a single room, route of admission and access to facilities, such as a family room, were deemed very important by relatives.
- Relatives reported that the route of admission needs to be considered for terminally ill patients, specifically in relation to the process of gaining admission to hospital via the Emergency Department.
- Seven in 10 respondents (69%) reported that their relative died in a single room. For one quarter (26%) this was not the case. Relatives highlighted the need for privacy and viewed care in a single room as a key requirement in the provision of good care at end of life.
- Relatives indicated the need for accessible, dedicated family rooms with appropriate facilities as a necessity on hospital wards.

### 6. Support for relatives

- Eight in ten (81%) respondents visited their relative outside regular visiting hours. However, 17% responded that they were not informed about the option of visiting outside regular hours but would have liked to avail of this.
- The majority (95%) of respondents reported they were cared for sensitively after their relative died. However, 4% indicated this was not the case.
- One out of six respondents (17%) indicated that they spoke with a healthcare professional from the hospital about their bereavement and found it helpful, while 29% stated that they hadn't but would have liked to.
- Several relatives indicated that all staff should be informed about what happens after death and suggested that relatives have access to the mortuary to view their deceased family member outside of core working hours.

### 7. Surveying bereaved relatives

- *VOICES MaJam* survey of bereaved relatives proved to be a meaningful method of evaluating the care at end of life in an acute hospital from the perspectives of bereaved relatives. The high response rate, the unanticipated volume of qualitative data, including expressions of support for the survey, indicates that bereaved relatives value being asked about their care experiences.

## Recommendations

### 1. Meeting care needs

Whilst most respondents believed their relatives' personal care needs were met by hospital staff, some relatives indicated that personal care needs were not always met adequately.

- Care needs should be reviewed and addressed to ensure that patients at end of life can access sufficient help and support with personal care needs, toileting and assistance during mealtimes.
- Hospitals need to review how they manage the multiple and more complex care needs of dying patients. Consideration needs to be given to how those needs are addressed outside of core working hours.
- Provision of emotional and spiritual support to dying patients and their relatives are integral to good end-of-life care. Hospitals need to review how they can better enhance the provision of emotional and spiritual support for patients and families.

### 2. Patient preferences and shared decision-making at end of life

While most respondents believed that on balance the hospital was indeed the right place for the person to die, some commented on lost opportunities to plan, to have conversations with loved ones and to discuss the preferred place of care at the time of death.

- Healthcare staff need to proactively engage in earlier conversations with patients and families about advance care planning and end-of-life care preferences.

### 3. Communication

Many bereaved relatives reported that hospital staff communicated in a kind, compassionate and caring way, however, relatives also suggested areas for improvement.

- Hospitals must develop strategies to address the communication issues raised in this report, encompassing how to deliver sensitive news in a timely and considerate manner, including how information is conveyed about diagnosis, prognosis and plan of care. Information about what to expect prior to death and what happens after death, including information about post-mortem examination, needs to be considered.

## Recommendations

### 4. Hospital environment

Relatives strongly endorsed the importance of end-of-life care being provided in a single room and the importance of having family rooms on acute hospital wards. Relatives also suggested that hospitals need to consider the broader hospital environment and the route of admission for terminally ill patients to hospital.

- Hospitals should ensure timely provision of a single room for end-of-life care in line with patient preferences.
- The route of admission for terminally ill patients via the Emergency Department to acute hospitals in Ireland needs to be considered by hospitals and state agencies.
- Hospitals should have dedicated family rooms and other spaces on every acute hospital ward where confidential and sensitive conversations can take place in private.

### 5. Support for relatives

End-of-life care encompasses support for both the dying person and their family. Relatives gave clear indications of the supports that should be available to them immediately, prior to and after the patient's death.

- Relatives need to be given opportunities to meet with the doctor and other healthcare professionals in family meetings to discuss advance care planning and end-of-life care in line with the patient's preferences.
- Healthcare staff should make relatives aware of the option of extended visiting arrangements and of staying overnight for relatives of seriously ill and dying patients.
- Access to free or subsidised car parking should be available to relatives when a patient is nearing end of life.
- All bereaved relatives should receive practical information about what happens following the death of a family member in hospital, including bereavement support information.
- All patients and relatives should have timely access to a social worker in order to avail of practical, emotional and psychological support.
- Hospitals should review access to the mortuary over weekends and bank holidays for family viewing and release of remains.
- Hospitals need to ensure standardised post-bereavement supports. This entails sending sympathy cards, organising remembrance services or bereavement support evenings and providing support from a bereavement counsellor or social worker.

## Recommendations

### 6. Education

The findings speak strongly on the need to enhance staff skills and knowledge through education programmes.

- End-of-life care training needs to focus on the importance of providing a holistic, person-centred care approach to ensure the person's needs, wishes and preferences are met.
- Enhancing end-of-life care communication skills. Training in this area should be embedded as an integral part of the undergraduate and postgraduate curricula for all healthcare professionals.
- All hospital staff, including administrative and support staff, such as, porters, catering and health care assistants should receive appropriate end-of-life care training.

### 7. Surveying bereaved relatives

Our experience of conducting this study and the information provided by bereaved relatives further strengthens the case for the regular monitoring of the quality of end-of-life care through surveys such as *VOICES MaJam*.

- Seeking the views of bereaved relatives should be considered by all hospitals and healthcare settings to ascertain the quality of care at end of life and to support the development of quality end-of-life care.
- Surveying of bereaved relatives should be undertaken in a sensitive, structured and safe way. Supports should be put in place for all elements of the process to minimise the potential of causing distress.
- Surveying of bereaved relatives should be conducted at a national level to support benchmarking of end-of-life care quality improvement initiatives and collaboration between healthcare organisations.

To date this is the largest survey of bereaved relatives undertaken in two acute hospitals in Ireland. Findings from the study indicate that the quality of care at end of life in the Mater Misericordiae University Hospital and St. James's Hospital is high. However, bereaved relatives also indicated areas where elements of care could be improved. The fact that so many relatives rated the care highly allows the hospitals to build on this high standard of care in ensuring that improvements are made to enhance the care for all future patients and their families.

# SURVEY OF BEREAVED RELATIVES

## VOICES MaJam Results



**356**  
Relatives



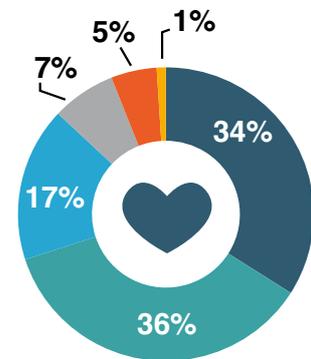
**2** Hospitals



**46%**  
Response Rate

### Quality of Care

■ Outstanding  
■ Excellent  
■ Good  
■ Fair  
■ Poor  
■ Don't know



## Care Needs



79% of relatives indicated **pain was relieved.**



73% of relatives indicated **personal care** was provided to a high standard.



56% of relatives indicated **emotional needs** were met to a high standard.



61% of relatives indicated **spiritual needs** were met to a high standard.



90% of relatives reported that the patient was treated with **dignity and respect** all or most of the time.



75% of relatives indicated they were involved in **decision making.** However, 18% of relatives would have liked more involvement.



81% visited their relative outside of **regular visiting times.** 17% were not informed about this option and would have liked to visit.



17% spoke with a healthcare professional about their **bereavement,** and found it helpful. 29% hadn't but would have liked to.



**Route of admission** via the Emergency Department to hospital for terminally ill patients needs to be considered.



69% of patients died in a **single room.** Relatives viewed care in a single room as key in the provision of good care at end of life.



**Family rooms** with appropriate facilities were deemed as a necessity on hospital wards.



**Surveying bereaved relatives** proved a meaningful method of evaluating care at end of life.

# SURVEY OF BEREAVED RELATIVES

## VOICES MaJam Recommendations

### Relatives Recommended



Improvements in communication to patients and their families relating to the progression of illness and dying.



Earlier conversations with patients and their families about advance care planning and end-of-life care preferences.



Timely help with meeting care needs.



Care in a single room in the days before a person dies.



Admission for terminally ill patients directly to wards bypassing the Emergency Department.



Family rooms on hospital wards to enhance communication and care experience.



Flexibility in visiting times, the availability of specialist palliative care to manage pain and other symptoms and access to the mortuary at weekends.



Standardised bereavement practices including the provision of information leaflets and access to bereavement support.

### This research recommends



Healthcare staff participation in education programmes to enhance their skills and knowledge on care at end of life.



Surveying bereaved relatives by all hospitals and healthcare settings to ascertain the quality of end-of-life care and support quality improvement.

# Glossary of terms

The following is a list of key terms and their definitions as we understand and use them in this report.

**Bereavement** takes account of a person's unique grief experience, through the anticipation of the death of someone significant and the subsequent adjustment to living following their death<sup>7,8</sup>.

**Bereavement support** is the provision of care including both formal and informal types of care provided by health and social care staff before, at the time of death and thereafter.

**End-of-life care/care at end of life** is the care provided for people who are 'approaching the end of life' when they are likely to die within the next 12 months such as people with incurable and life-limiting conditions and those who die unexpectedly. It also refers to care provided to relatives. It enables the supportive and palliative care needs of both the individual and relatives to be identified and addressed through the last phase of life and into bereavement. Care is focussed on personal care, management of pain and other symptoms, the provision of emotional and psychological care, spiritual and practical support<sup>9,10</sup>.

**Last days of life** refers to people who are very close to death, within hours or days of death.

**Life-limiting illness/condition** refers to a condition or illness which cannot be reversed by treatment and from which a person is expected to die.

**National Healthcare Charter** is a statement of commitment by the HSE on healthcare describing:

- what people can expect when using health services in Ireland, and
- what the providers of Irish health services can do to deliver more effective and safe services.

The Charter is based on eight principles: access, dignity and respect, safe and effective services, communication and information, participation, privacy, improving health and accountability<sup>11</sup>.

**Palliative care** is defined by the World Health Organisation as an approach "that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"<sup>12</sup>.

**Patient** describes a person who is admitted to hospital and is the recipient of the range of healthcare services offered by the hospital. The term ‘patient’ is used to enable the reader to differentiate between the person who received care and the person who completed the questionnaire.

We use the term patient in general, but occasionally use the term ‘service user’ or ‘dying person’ where appropriate.

**Person-centred care and support** places service users at the centre of all that the service provides. It does this by advocating for the needs of service users, protecting their rights, respecting their values, preferences and diversity, and actively involving them in the provision of care. Person-centred care and support promotes kindness, consideration and respect for service users’ dignity, privacy and autonomy<sup>13</sup>.

**Quality improvement interventions in palliative care** “are targeted improvements for service users with life-limiting conditions. These improvements are conducted within or linked to the healthcare system and have at least some elements of system change, or intended change in how the system will interact with the service user and family. Examples of targets include service user and family satisfaction with palliative care; service user and family perceptions of palliative care; symptom management and quality of care measures; grief and bereavement support; service access and healthcare utilisation”<sup>14(p28)</sup>.

**Relative** refers to both a family member or friend of the person who is being cared for or any significant other who the person determines or perceives to be part of the family unit. The term ‘relative’ is generally used; occasionally the term ‘respondent’ is used where appropriate.

**Specialist palliative care teams** are multi-professional teams who provide palliative care as their core speciality under the direction of a consultant physician in palliative medicine<sup>15</sup>.

**VOICES MaJam** is the title of this study.

**VOICES** is an acronym for: **V**iews of **I**nformal **C**arers – **E**valuation of **S**ervices

**MaJam** is an acronym for: **M**ater **M**isericordiae University Hospital and St. **J**ames’s Hospital

# Background

**Dying, death and bereavement is an experience that touches the lives of everyone on a personal or professional level.**

End-of-life care is a universal experience and 43% of all people that die annually in Ireland die in adult acute hospitals with 6% of people dying in hospices<sup>1</sup>.

Acute hospitals are busy places with a predominant focus on diagnosis, treatment and cure. However, caring for people who are seriously ill or dying is also an important responsibility. The Mater Misericordiae University Hospital and St. James's Hospital are striving to ensure that people who are diagnosed with a life-limiting illness or who die in our care, experience a place of sanctuary where they are cared for in comfort and dignity and their families are supported in their bereavement.

In recent years there have been a number of initiatives addressing end-of-life care in acute hospitals. This includes the Hospice Friendly Hospitals Programme, a national programme developed by the Irish Hospice Foundation<sup>16</sup>. This initiative seeks to ensure those patients who have a life-limiting illness or those who die suddenly and their families, have a seamless experience of care in hospital, provided by staff who are well-informed. Other developments include a national audit of end-of-life care<sup>17</sup>; and the development of quality standards for end-of-life care<sup>3</sup>. These developments led to a greater emphasis on end-of-life care in acute hospitals, with the setting up of committees focussed on improving end-of-life care and the appointment of end-of-life care coordinators in some hospitals. The Mater Misericordiae University Hospital's and St. James's Hospitals' multifaceted Hospice Friendly Hospitals Programme is outlined in Appendix 1. In addition, the National Clinical Programme for Palliative Care was established by the Health Service Executive (HSE) in 2010. The programme's aim is to ensure that patients with life-limiting conditions and their families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis. The programme has developed a range of resources to support healthcare staff in meeting the palliative care needs of patients and their families.

Efforts to set out principles to guide delivery of care to service users have led to the development and publication of standards by commissioning state agencies such as the HSE and the state regulatory body, Health Information and Quality Authority (HIQA). The *National Standards for Safer Better Healthcare*<sup>13</sup> and the *National Healthcare Charter*<sup>11</sup> outline a vision and commitment to promote high quality care for all users of health services. The *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup> set out a shared vision and benchmark the standard of end-of-life care within this setting in Ireland. The *National Standards for Safer Better Healthcare*<sup>13</sup> were published in 2012 by HIQA, the purpose of the standards are to assist healthcare services in continuous quality improvement.

The HSE subsequently published a number of workbooks associated with meeting HIQA Standards. The *Effective Care and Support Quality Assessment and Improvement Workbook*<sup>18</sup> considers palliative care as an essential element of care. This document provides the basis for staff to improve quality in healthcare and makes a number of recommendations on how this standard could be met through:

- seeking feedback from families, carers and staff as part of palliative care evaluation work.
- benchmarking care with that of other service providers to support the implementation of improved practice.

*The National Healthcare Charter*<sup>11</sup> states, “If quality and safety is at the heart of everything we do, we must understand it from the perspectives of our service users”. *The National Strategy for Service User Involvement in the Irish Health Service 2008-2013*<sup>52</sup> suggests that service users are given the opportunity to provide feedback, which can then be utilised to improve services.

Assessing and measuring the quality of care provided is a key component of all healthcare systems. However, this is challenging for healthcare providers and specifically for those providing care at end of life. End-of-life care research in this area needs to be considered sensitively. Surveying patients who are “likely to die” is extremely difficult given the challenges associated with predicting death, the significant ethical issues involved and the burden it would place on the dying person. Given the complexities and sensitivity of collecting data from dying patients, research has found the use of family members as proxies to be an adequate substitute. For this reason, studies have primarily focussed on ascertaining the views of family members to give “voice” to their experience of care and that of the person who died. Furthermore, surveying bereaved relatives is increasingly recommended to ascertain the quality of end-of-life care in healthcare settings<sup>19,20,21,23</sup>.

The Mater Misericordiae University Hospital and St. James’s Hospital through their active participation in the Hospice Friendly Hospitals Programme have developed strong collaborative links. This resulted in discussions about assessing the quality of end-of-life care in both hospitals and led to the decision to survey bereaved relatives for the purpose of quality improvement. Both hospitals engaged their respective academic partners; University College Dublin and Trinity College Dublin, to assist in undertaking this study.

## About this report

The findings from *VOICES MaJam* survey are based on the views of bereaved relatives and indicate how they rate the quality of care provided by hospital staff to their friend or relative and to themselves in bereavement. The study examines care during the last admission to hospital with some questions focusing specifically on care in the last two days of life, providing insights into experiences of care at this critical time in a person's life.

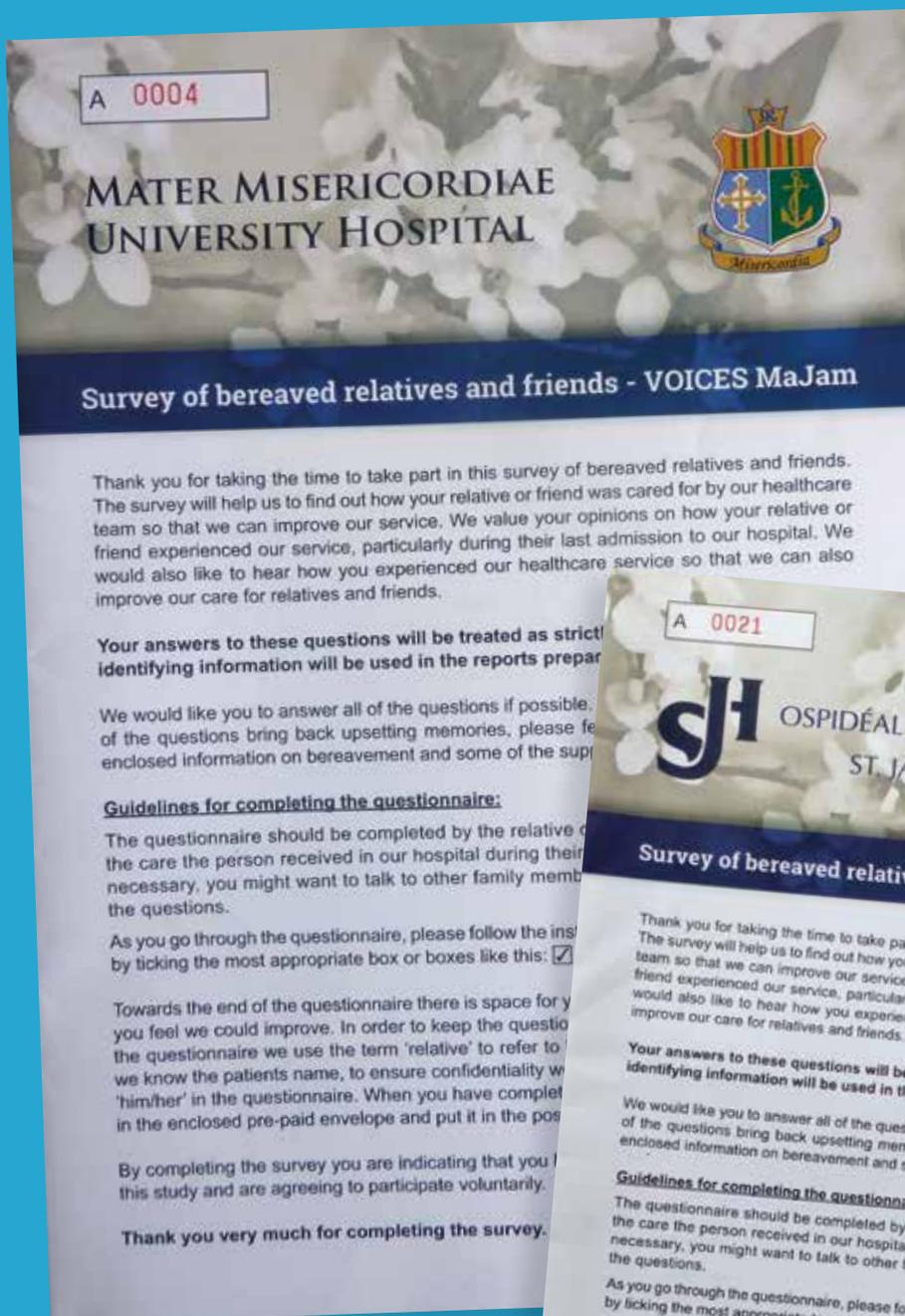
### Notes on presentation of the results

*VOICES MaJam* results are based on the opinions of bereaved relatives who responded to the invitation to take part in the survey. While 356 people responded, not all of the survey questions were relevant to all respondents. The percentages reported in the tables may therefore not always add up to 100 per cent. This is due to the following:

- some questions provided set answers that were not applicable to the respondent or there was a non-response not represented in the tables.
- not all survey questions are relevant to, or were answered by every respondent. In such instances, the findings are calculated from the total responses for those particular questions.
- Respondents could supply multiple responses to some questions and therefore totals may add to more than 100.
- Rounding of numbers.

Where relevant the number of respondents for a question is provided to aid interpretation. For example n=151, meaning the number of respondents was 151.

Throughout this report respondents' quotes are reproduced verbatim as written by the respondents and therefore may contain grammatical or typographical errors. However, the quotes are anonymised to protect the identity of respondents, deceased patients and their relatives, hospital staff and the individual hospitals.



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# 1. Methodology

# Methodology

## Introduction and background to the survey

The National Survey of Bereaved Relatives VOICES (Views of Informal Carers – Evaluation of Services) is an established method of collating information through a postal survey on the quality of care provided by the health service to a relative or friend in England<sup>24</sup>. VOICES was developed by researchers<sup>25</sup> to ascertain the experiences of end-of-life care in different settings such as in the person's home, in hospitals, in residential care homes and hospices. The VOICES survey is a validated post-bereavement survey and focusses on those aspects of care which are known to be indicative of the quality of care for patients nearing end of life and their families. VOICES was initially developed as a result of the publication of the *End of life Care Strategy in England*<sup>26</sup>. This strategy outlines the importance of measurement in end-of-life care provision and the need to monitor and evaluate progress as part of a commitment to promote high quality care for all adults at the end of life. For this reason, the Office of National Statistics in England conducts the VOICES survey on behalf of the National Health Service (NHS) in England on an annual basis.

A recent review conducted by the NHS in England concluded that continuing to survey bereaved relatives is an important method of assessing the quality of care at end of life in England<sup>19</sup>. The British Medical Association<sup>20</sup> has also endorsed the importance of collecting data from bereaved relatives through use of the VOICES survey “to identify trends and problems and to measure the improvements in end-of-life care”<sup>20(p42)</sup>. The Royal College of Physicians<sup>21</sup> published a set of quality indicators to assess the quality of care in acute hospital settings in England and also recommend surveying bereaved relatives. Therefore, surveying bereaved relatives is recognised internationally as a key quality indicator for end-of-life care.

There have been a number of studies in Ireland, which have surveyed bereaved relatives, the largest of which was conducted by the Irish Hospice Foundation in 2008/9<sup>4</sup>, reporting on the experiences of 461 bereaved relatives of patients who died in community and acute hospitals. At present, there is no standardised approach to surveying bereaved relatives in Ireland.

## Aims and objectives

The key aims of this study were to:

- determine the quality of end-of-life care in both hospitals as perceived by bereaved relatives in order to direct quality improvement.
- determine the processes required to undertake a modified version of the VOICES survey of bereaved relatives (*VOICES MaJam*) as a means of monitoring the quality of end-of-life care in Irish adult acute hospitals.

## Research design

VOICES is a postal survey about experiences of end-of-life care in the last days of life, focusing on quality of care and services received; domains for which patient and proxy agreement are good.

For the purpose of this study, we adapted VOICES<sup>27</sup> to the context of acute hospital care in Ireland to ascertain if the respective hospitals were meeting the principles of care outlined in the:

- *National Healthcare Charter*<sup>11</sup>
- *National Safer Better Healthcare Standards*<sup>13</sup>
- *Quality Standards in End-of-Life Care in Hospitals*<sup>3</sup>

The adapted questionnaire reflects the key elements of care outlined in each standard. An outline of the key aspects of each standard and the survey question relating to measuring this standard is presented in Appendix 2.

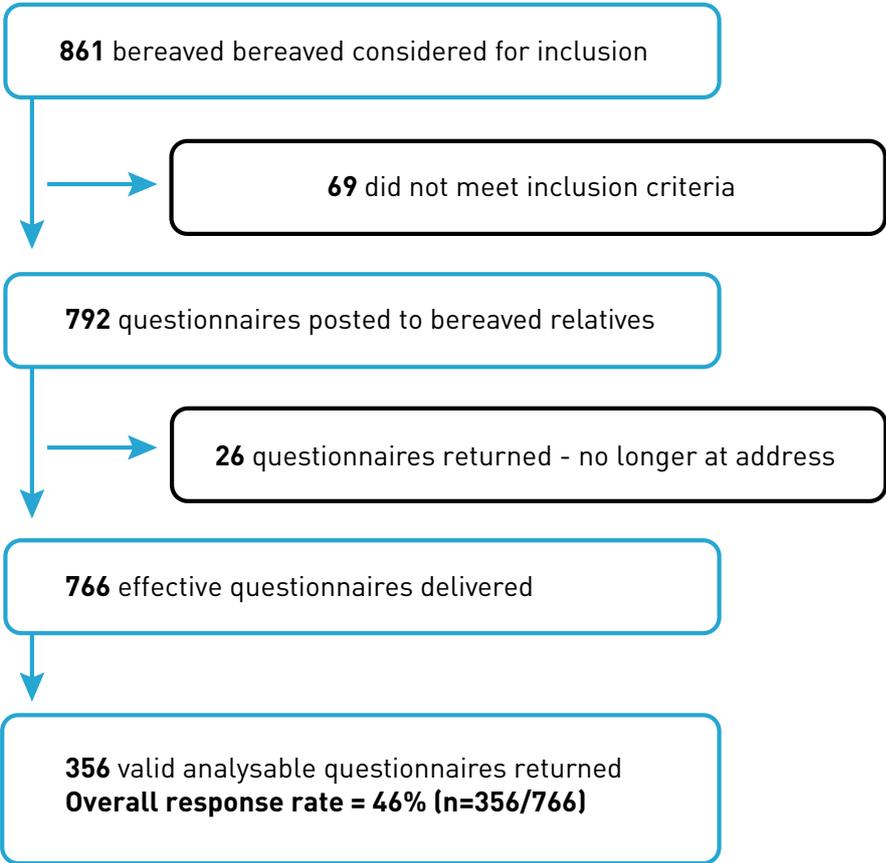
*VOICES MaJam* is the adapted questionnaire designed for the Irish context. *VOICES MaJam* has 29 core questions and an additional seven questions requesting personal demographic information. The questionnaire was designed to gather data on quality of care, dignity and respect, pain and symptom management, support provided to families, the care environment, communication and decision-making. In addition, three open-ended questions were designed to gather descriptive data about the care experience during the patient's last admission to hospital. Several new questions were developed in areas such as the provision of single rooms at end of life, the physical environment and bereavement support in line with the *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup> and the *National Audit of End-of-Life Care in Hospitals in Ireland*<sup>4</sup>. Content and face validity of the adapted questionnaire were conducted.

## Sample selection

Persons named as the next of kin in the deceased person's healthcare record were recruited for the sample. For the purposes of the study, we use the term 'relative' to refer to both family members and friends of the person who died. Relatives of people who died in our care from August 1<sup>st</sup> 2014 to January 31<sup>st</sup> 2015 were included. The sample included relatives who were bereaved no earlier than three months and no later than nine months.

All deaths, including sudden and unexpected deaths as well as those that were anticipated and expected were included. The exclusion criteria for this study included people who died and were aged less than eighteen years of age and those for whom there was no address or an incomplete address for the next of kin. Prior to the recruitment process, clarification was sought from various departments including the risk management and legal departments in the respective hospitals. Principal investigators took steps to ensure that the participants recruited to this research study were not simultaneously involved in other research projects. Relatives were not contacted if any of the exclusion criteria were met.

The combined sample size was 792 (*Hospital A*, n=385; *Hospital B*, n=407). The flow chart below outlines the sampling process employed.

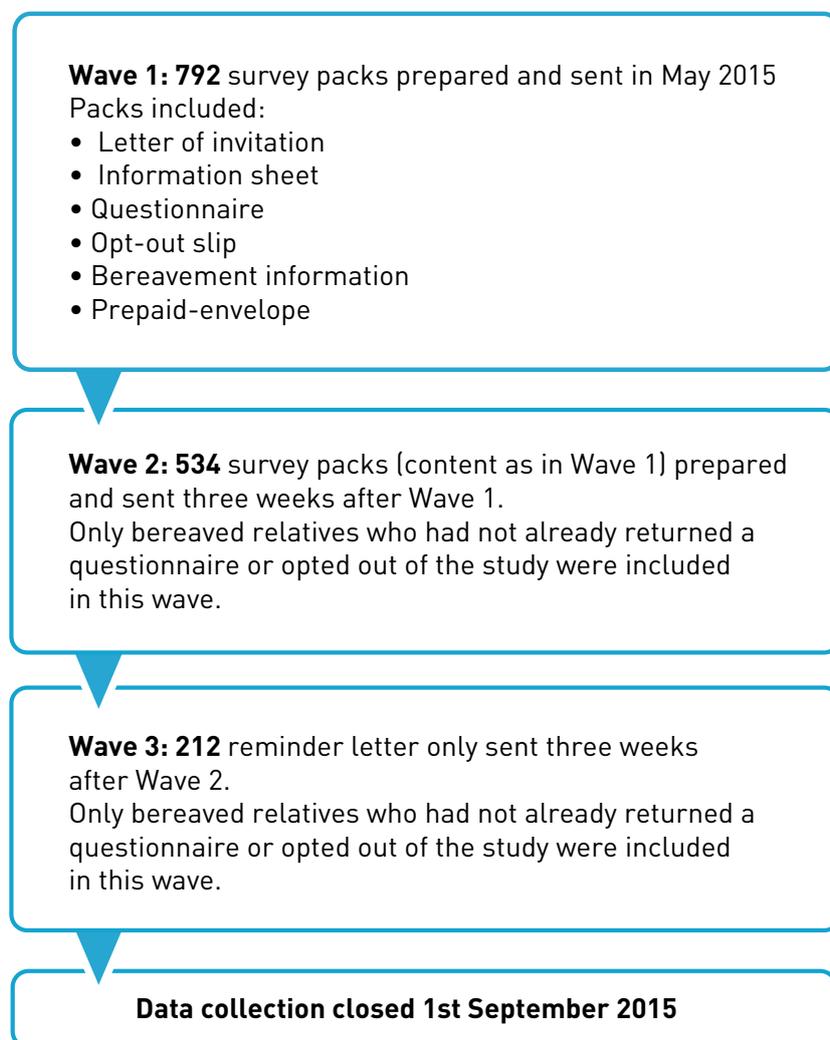


Flow chart 1: Sampling process employed

## Data collection

*VOICES MaJam* is a quantitative descriptive post-bereavement survey that gathered data retrospectively, using a postal survey, from relatives or friends of patients who died in two adult acute hospitals.

Survey packs were prepared and included a letter of invitation, an information sheet, a questionnaire, an opt-out slip, a bereavement information sheet and a prepaid envelope. Packs were posted to those next of kin listed in the sampling frame (n=792) in May 2015. In order to maximise responses, carefully timed reminder letters were sent. Experience from previous *VOICES* surveys suggests that two reminders are optimum and are associated with a considerable increase in response thereafter<sup>2,25</sup>. Flow chart 2 outlines the data collection process.



Flow chart 2: Data collection process employed

Information on bereavement supports was included with the survey pack. Relatives were also provided with contact details of the principal investigator in each hospital to allow them to make contact if they had any queries or concerns about the study. Forty bereaved relatives made contact with the research team about the survey, the majority wished to speak about or comment on their experience of care. Ninety-nine relatives formally opted out by returning the survey pack and/or completing the opt-out reply slip.

A total of 356 valid questionnaires were returned (*Hospital A*; n=167; *Hospital B*; n=189) giving an overall response rate of 46 per cent. This is relatively high for postal surveys of bereaved relatives' but comparable with the national VOICES survey in England<sup>24</sup> and the *National Audit of End-Life-Care in Hospitals*<sup>4</sup>.

## Data analysis

Quantitative data were inputted into MS Excel and converted to the statistical package IBM SPSS statistics v. 22<sup>5</sup> for analysis. Frequency and distribution tables were prepared for closed questions.

Qualitative data were managed and coded using NVivo 10<sup>6</sup>. A coding frame was developed based on the principles and standards of care outlined in the following: *National Healthcare Charter*<sup>11</sup>; *National Standards for Safer Better Healthcare*<sup>13</sup>; and *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup>. Inter-rater reliability tests were conducted indicating a kappa score of 0.62. Data were analysed thematically using a template analysis framework approach<sup>28</sup>. Five key themes emerged: meeting care needs, dignity and respect, communication, hospital environment and support for relatives.

## Study considerations

The data presented in this report represent the views of those relatives who volunteered to take part in the study and may not reflect the views of all relatives of those who died in the hospitals. There may be some degree of non-response bias in the sample, in that those who chose not to take part may differ on certain parameters, such as, gender or time lapse between the bereavement and receiving the questionnaire.

*VOICES MaJam* uses the bereaved relatives' perceptions of care at end of life as a proxy. While concerns have been raised about the use of proxy in representing the patient views, it has been accepted that bereaved relatives provide valuable information as they often spend a considerable amount of time with the patient<sup>29</sup>. In addition, bereavement is considered an "emotional and salient" event so relatives are able to recall events around that time<sup>30,31</sup>.

## Ethical considerations

The Research Ethics Committees in the respective hospitals granted approval for this research.

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# People included in the survey

## Profile of respondents

This section outlines the profile of respondents' characteristics.

As shown in Table 1 below the majority of respondents were female (74.2%: n=259). Over four in ten (43%: n=150) of all respondents being over the age of 60. Children of the deceased comprised the largest group (41%: n=144), followed by husband (incl. civil partner and partner) (22%: n=77) and wife (incl. civil partner and partner) accounted for (12.9%: n=45). One in ten (11%: n=38) were siblings of the deceased. A large majority of respondents (96.3%: n=338) were Irish.

Characteristics of the respondents	No.	Percentage
<b>Gender</b>	<b>349</b>	
Male	90	25.8%
Female	259	74.2%
<b>Age</b>	<b>350</b>	
18-29 years	3	0.9%
30-39 years	20	5.7%
40-49 years	66	18.9%
50-59 years	111	31.7%
60-69 years	58	16.6%
70-79 years	59	16.9%
80 + years	33	9.4%
<b>Relationship to the deceased</b>	<b>350</b>	
Husband/civil partner/partner	77	21.6%
Wife/civil partner/partner	45	12.9%
Son/daughter	144	41.1%
Brother/sister	38	10.9%
Son-in-law/daughter-in-law	2	0.6%
Parent	18	5.1%
Other relative	21	5.9%
Friend	3	0.9%
Other	2	0.6%

**Table1: Profile of the respondents**

## Profile of the deceased person

This section outlines the profile of deceased persons' characteristics as reported by the respondents.

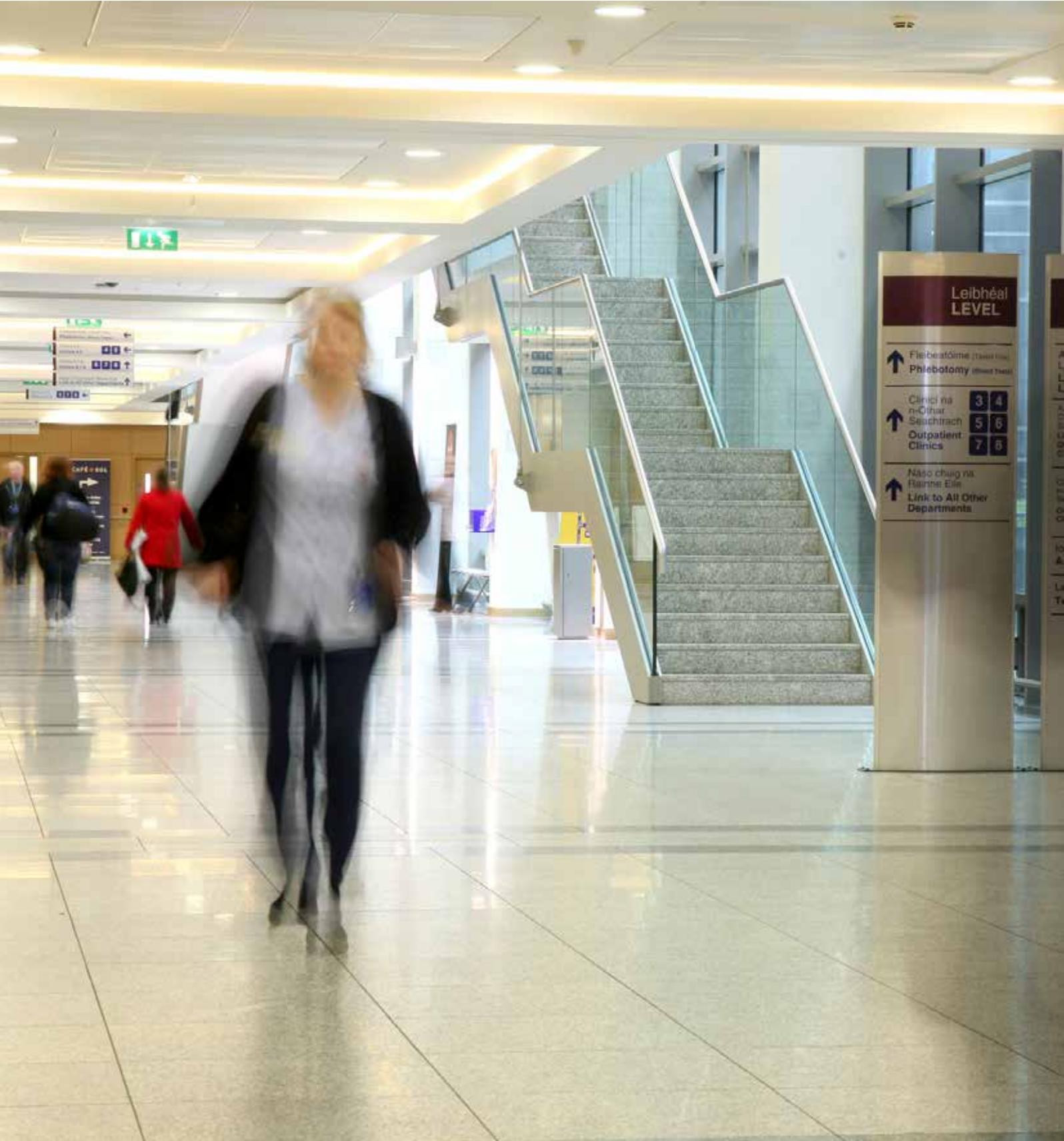
Table 2 below shows that six in ten (57%: n=199) people that died were male. At the time of their death 50% (n=178) were over the age of 80 and another large group (35%: n=126) being between the age of 60 and 80. The largest proportion (29%: n=99) spent between two days and two weeks in hospital on their last admission. All other patients' length of stay was almost evenly spread out between up to 48 hours, 2-4 weeks, 1-2 months and longer than two months.

Using a list of eight common illnesses, respondents were asked to indicate the illnesses they believed their relative was affected by towards the end of life. Many reported several morbidities. Heart failure (32.9%: n=117) was followed by cancer (27.5%: n=98), frailty (22.5%: n=80) and chronic obstructive pulmonary disease (20.8%: n=74). Dementia (12.9%: n=46) and end stage renal disease (13.5 %: n=48) were also reported. Over one fifth reported frailty (22.5%: n=80); acknowledging that the term 'frail elderly' could have been interpreted in various ways by respondents.



Characteristics of the deceased person	No.	Percentage
<b>Gender</b>	<b>347</b>	
Male	199	57.3%
Female	148	42.7%
<b>Age</b>	<b>355</b>	
18-29 years	6	1.7%
30-39 years	11	3.1%
40-49 years	14	3.9%
50-59 years	20	5.6%
60-69 years	38	10.7%
70-79 years	88	24.8%
80 + years	178	50.1%
<b>Length of stay during last admission</b>	<b>342</b>	
Up to 48 hours	62	18.1%
2 days - 2 weeks	99	28.9%
2-4 weeks	59	17.3%
1-2 months	56	16.4%
Longer than 2 months	66	18.5%
<b>Illness during last days of life</b>	<b>356</b>	
Cancer	98	27.5%
Heart failure	117	32.9%
Chronic obstructive pulmonary disease	74	20.8%
End stage renal disease	48	13.5%
Dementia	46	12.9%
Frail elderly	80	22.5%
Motor-neuron disease	2	0.6%
Parkinson's disease	3	0.8%
Don't know	8	2.2%

**Table 2: Profile of the deceased person**





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## 2. Quantitative Results

The structure of the quantitative results sections of this report shares broad similarities with the actual questionnaire completed by the respondents. Each section is preceded by a short summary outlining national standards or policy documents to provide a context for the results.

Quantifiable data are presented in the form of figures. Text is also provided to expand on the interpretation of data in numbers and percentages. The results are then underpinned by respondents' quotes providing context to the numerical data.

The report presents results from combined data from both hospitals in most instances. However, in instances where notable differences between the two hospitals were observed, data are presented as *Hospital A* and *Hospital B*. Commentary is also provided in some sections to aid explanation.

## Quality of care

The key objective of all healthcare services is to provide a service that meets the needs of the person utilising that service and is of a standard that meets the person’s expectations. Healthcare institutions are continuously striving to improve the quality of the service they provide and ensure it meets the needs of those who utilise their services. There is a considerable body of evidence both nationally and internationally to suggest that there is a wide variation in the quality and standards of end-of-life care<sup>4,21,24,32,33,51</sup>. Bereaved relatives were asked a number of questions relating to the quality of care they and their relative received during the last hospital admission. One question looked specifically at how respondents rated the overall quality of care during the last admission and another at the quality of care delivered by different staff groups.

### Quality of care during the last admission

Ratings of the overall quality of care during the patient’s last admission were reported on by most respondents (98%: n= 349). Of these 87% (n=303) rated the care as outstanding, excellent, or good. One in 8 (12%: n=41) respondents rated care as fair or poor. One in 8 (12%: n=41) respondents rated care as fair or poor.

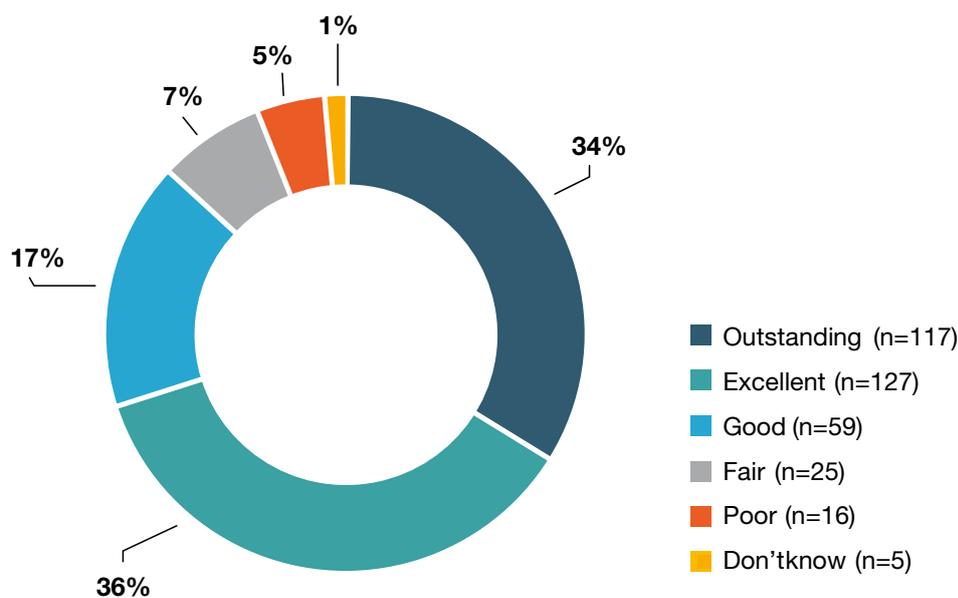


Figure 1: Ratings of overall quality of care on last admission

Many respondents provided insight into the quality of care by identifying what worked well for them, while others identified what was missing:

“The care attention and humanity offered to my much loved and irreplaceable aunt was all I could have wished ... she was treated with the upmost care, gentleness and respect which has meant so very, very much to myself and the rest of my family. Thank you so much. ... They were exceptional people, working under such pressure and definitely deserve special mention.”

“... Mam’s care overall was exceptional. (Name of hospital) cared for her since she was a teenager. On her last admission she was treated with the greatest respect as she always had been. It was a pity she died at the weekend as the standards change then. It was surreal to be at her bedside when she passed on, to hear laughter at the nurse’s desk. This was a little insensitive; however, I understand that their work day continued as normal. Finally I would say that we were blessed to have the care that mam was given in those last weeks. The (name of hospital) staff are exceptional people; the team ethic is so strong. The mission of the staff is shared and most importantly the medical team communicated so well with us. That was key for us even we had to realise she would not be coming home. Thank you.”

“I am a nurse myself and was in constant contact and conversation with the nursing staff...I felt they genuinely cared for my mother as a person... What will stay with me most of all is on the day she died, 2 of the nurses actually cried. I was deeply touched at their genuine affection for my mom we hugged and the 3 of us cried together, like a family. I will never forget that for the rest of my life.”

### Quality of care rating by staff group

In addition to the overall measure of quality of care, respondents were also asked to rate the quality of care provided within each setting by specific care providers such as doctors, nurses or other staff during the last admission. Quality of care by specific staff members was measured on a 5-point scale from exceptional to poor.

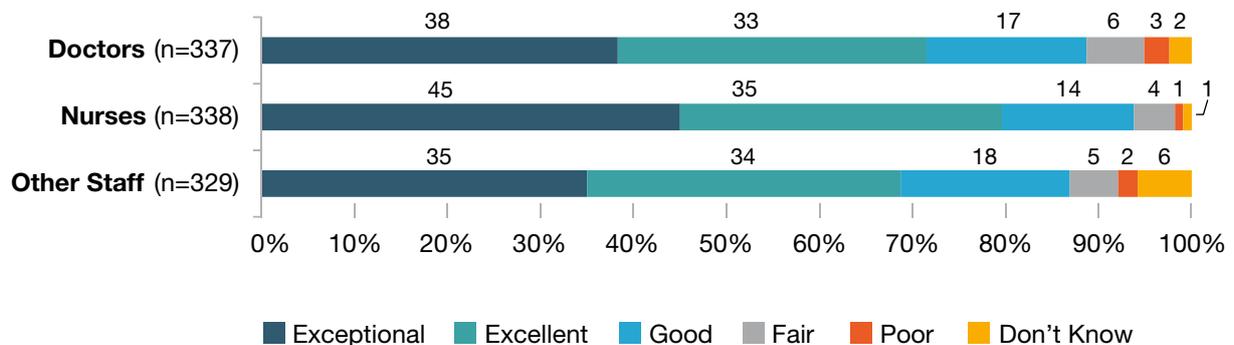


Figure 2: Ratings of overall quality of care by staff group

Figure 2 shows that the quality of care rated as exceptional or excellent was highest where care was provided by nurses (80%: n=317) and then by doctors (72%: n=299) followed by other staff (69%: n=226). As seen in overall quality of care, approximately one in 10 people rated care provided by hospital doctors (9%: n=30), as being fair or poor, with the care provided by nurses and other hospital staff being rated as 5% (n=18) and 7% (n=24) respectively in the same category.

Comments provided by respondents about the care provided by different staff groups:

“My mother received excellent care from all the staff in (name of hospital) and I would like to thank them all for their kindness and professionalism in my mother’s last few weeks ...This (name of ward) is such a lovely place I cannot thank the staff here enough from Doctors, nurses, carers, kitchen staff and porters in fact every single person involved in this wonderful place deserves a special thanks for all their hard work. They are extremely warm generous and caring people, and of course efficient and professional.”

“The care, respect and dedication of all of the healthcare staff during dad’s last admission meant we could go home after every visit happy in the knowledge that, although gravely ill, he was comfortable and very well cared for. This greatly enhanced our ability to accept dad’s passing with no regrets, anger or “unfinished business.”

The Health Service Executive (HSE) and the state regulatory body Health Information and Quality Authority (HIQA) through their publication of *The National Standards for Safer Better Healthcare*<sup>13</sup> and the *National Healthcare Charter*<sup>11</sup> outline a vision and commitment to promote high quality care for all those who utilise health services. It is widely recognised that there are different reporting measures on the quality of care at end of life and comparing data from other studies and different data sets has limitations. However, according to bereaved relatives in this study, the quality of end-of-life care in our hospitals is high by international standards. Eighty-seven percent of bereaved relatives rated the overall quality of care provided to the person during the last admission as outstanding, excellent or good. Comparing this to the quality of care in England’s most recent Office of National Statistics report<sup>24</sup> it was found that relatives rated care in hospitals at 69% for outstanding, excellent or good and 31% for fair or poor in hospitals in England. The equivalent for hospices in England was 79% and 21%<sup>24</sup>.

Whilst recognising that the quality of care is high, bereaved relatives have also outlined opportunities for the hospitals involved in this study to improve the quality of care provided at end of life. Narrative comments presented in the qualitative chapter provide detailed insights into the diversity of care experiences and examples of improvements that should be considered as part of acute hospital care provision.

## Meeting care needs

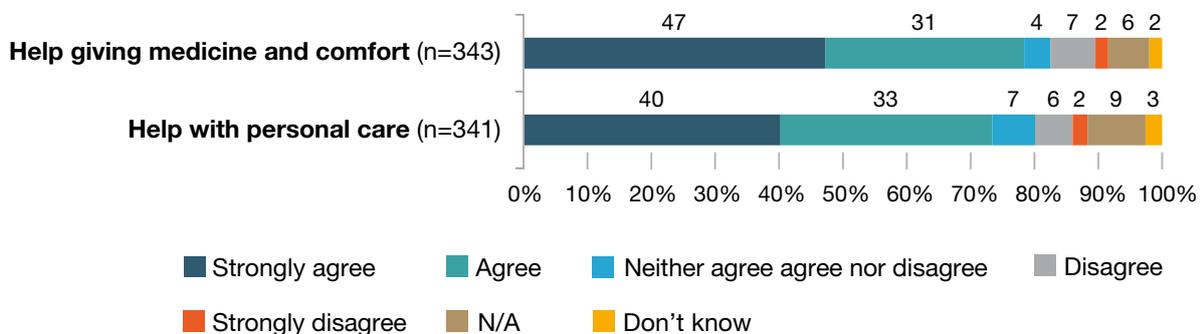
Palliative care has been defined by the World Health Organisation (WHO)<sup>12</sup> as: “An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”. In 2014, the HSE National Clinical Care Programme for Palliative Care developed the *Palliative Care Needs Assessment Guidance*<sup>53</sup> to help professionals assess and respond to the palliative care needs of patients with life-limiting conditions.

Quality care at end of life therefore follows a palliative care approach which addresses physical symptoms, psychological distress, social and emotional needs, spiritual or existential distress. One of the aims of this research was to establish the extent to which patients’ physical, emotional and spiritual care needs were supported by healthcare staff. Therefore, a number of

questions were asked to ascertain if care is provided in line with the WHO definition of palliative care and the HSE National Clinical Care Programme's for *Palliative Care Needs Assessment Guidance*<sup>53</sup>. Respondents were asked to rate the overall level of support given by staff in the areas of relief of pain, symptoms other than pain, spiritual support and emotional support.

### Level of personal care in the last two days of life

Respondents were asked questions centring on the overall level of care given by health professionals in the last two days of life. These questions related to the respondent's opinions on whether the person received sufficient help to meet personal care needs, received sufficient help with nursing care, such as giving medicine or help getting comfortable in bed, in the last two days of life.



**Figure 3: Overall level of practical care provided by hospital staff in the last two days of life**

Figure 3 shows that the majority of respondents (78%: n=269) indicated that there was adequate nursing care support for the patient to receive medicine or comfort. However, 9% (n=31) disagreed that this was the case. In 40% (n=137) and 33% (n=113) of cases, respondents strongly agreed or agreed respectively that patients had adequate support to meet personal care needs. This indicates that in at least three out of four cases (73%: n=250), the patient's physical comfort needs were met in the last two days of life. Despite this, nearly one in 10 respondents (8%: n=28) indicated that the patient's care needs were not met.

Respondents' comments on the provision of personal care include:

- “The care of my mother (92 years old) received in (name of ward) was outstanding, my mother was treated with love care and respect until the minute she died. The staff did their utmost at all times to ensure her comfort and well-being. They were so kind to her, doing small things such as putting curling tongs in her hair. This was on top of her usual personal hygiene and nursing care any concerns raised was immediately attended to, even a laxative for constipation or a visit from the doctor.”
- “It would also be difficult to find someone to come to dad if he needed toilet assistance, bottle etc., you could wait a while till someone came along...”
- “Bedding and clothing changed often.”

### Relief of pain in the last two days of life

The provision of appropriate methods of symptom management and pain relief is an important component of high-quality care at the end of life. Figure 4 presents results on how well pain was relieved during the last two days of life.

The majority, 96% (n=343) of respondents answered this question. Of those who did, one in five stated that their relative did not experience any pain (19%: n=64). Of the remaining 279 respondents, four out of five (79%: n=220) agreed that the person’s pain was relieved in the last two days of life.

Respondents reported relief of pain as being provided ‘completely, all of the time’ most frequently at 68% (n=189). More than one out of 10 (11%: n=30) responded that the patients pain was only ‘partially’ or not relieved at all in the last two days.

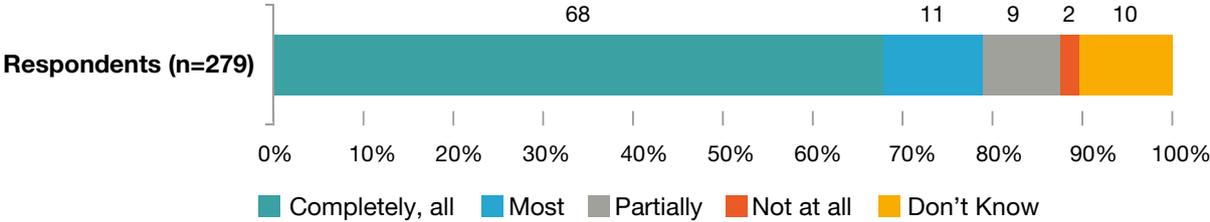


Figure 4: Level of pain relief provided by hospital staff

Several respondents commented on their relatives’ pain and pain relief:

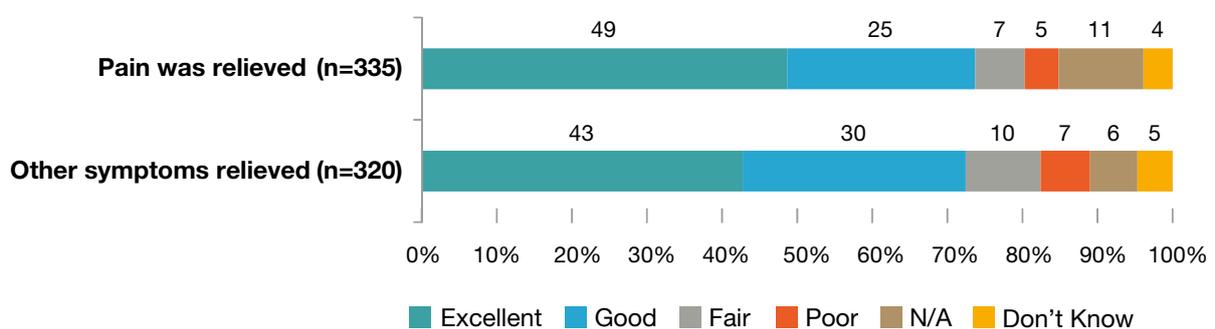
“Once he arrived in the (name of hospital) he was more hopeful about everything. Within a few hours his pain was under control.”

“On the Thursday before he died, dad was put in palliative care. There unfortunately was no bed in a hospice on either Thursday or Friday. Dad did move into a private room which was helpful. Unfortunately there was no palliative care personnel in the hospital on a sat/sun and I really felt dad was in quite a lot of pain on those days. Emergency & locum Doctors attended dad but they seemed to lack experience of palliative care & were not inclined to give pain medication. On the Monday, the palliative care team returned to the hospital and dad’s pain relief medication was corrected and he received adequate pain relief. Dad passed away on the Tuesday morning.”

### Pain and symptom management during last admission

Respondents were asked to rate the overall level of support given by staff in the areas of relief of pain and other symptoms during the last admission. These questions were asked as they provide an indicator of how well needs were met during their relative's last admission to hospital. The overall level of support is rated on a 4-point Likert scale from 'excellent' to 'poor'.

The majority of people (94%: n=335) responded to the question relating to pain during the last admission. Almost three quarters (74%: n=247) perceived that staff members response to the patients' pain was either 'good' or 'excellent'.



**Figure 5: Pain relief and management of other symptoms on last admission**

In relation to how the person's other symptoms were managed, a large number (73%: n=232) indicated that the symptoms were managed at the level of 'good' or 'excellent'. A further 7% (n=21) stated other symptoms were managed poorly.

The assessment and management of physical pain and symptoms other than pain is a major focus of end-of-life care. The dying person's physical problems must be anticipated and proactively addressed in order to provide comfort and maximise quality of life. This study found that pain and symptoms other than pain generally were managed well by hospital staff. As reported in the qualitative chapter, relatives commented on issues relating to poor symptom management and the need to have access to specialist palliative care expertise outside of the normal working hours (9am to 5pm, Monday to Friday) to support the management by the primary teams. Both findings are similar to those found in international reports on end-of-life care<sup>33</sup> and mirror the underfunding of specialist palliative care services in England<sup>34,35</sup> and Ireland<sup>36</sup>.

### Emotional support

It is widely recognised that the assessment and management of other aspects of the person’s well-being are vital for good end-of-life care. The *Palliative Care Competence Framework* states that all healthcare staff should consider “the needs of people with life-limiting conditions and their families (e.g. physical, psychological, social and spiritual) in a proactive and timely manner”<sup>37(p16)</sup>. The questionnaire included a question to assess the extent to which healthcare staff met the person’s emotional needs during the last admission.

Figure 6 outlines results from questions posed about emotional support provided to the person during the last admission. Nearly all relatives (92%: n=330) responded to this question. Over half, (56%: n=186) stated that overall level of emotional support was ‘excellent’ or ‘good’. One in ten people (n=33) indicated that emotional needs were poorly met.

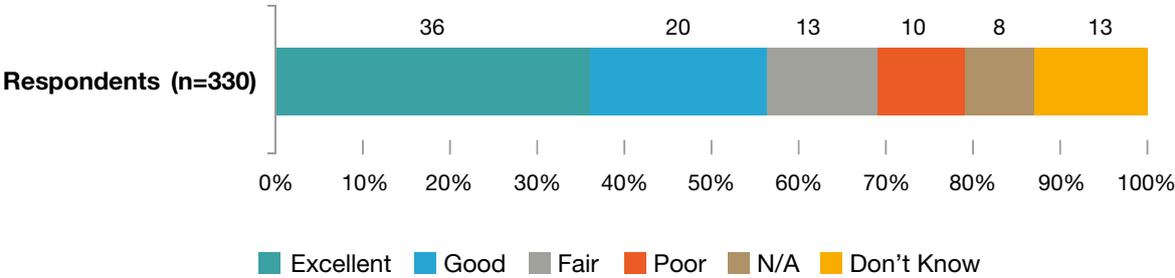


Figure 6: Support for emotional needs by health professionals during the last admission

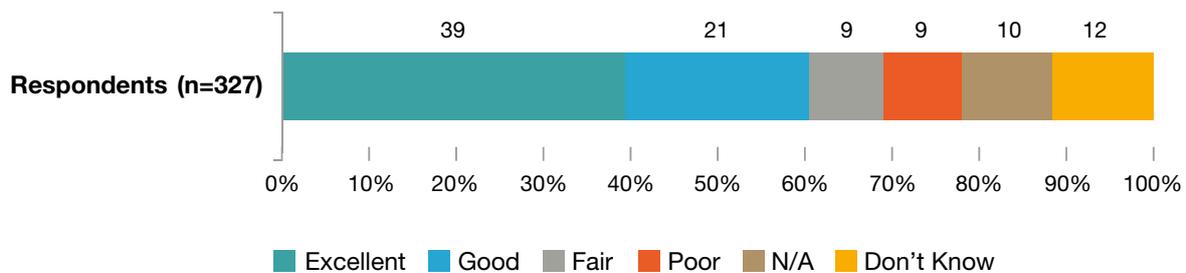
Some respondents commented on their relatives’ experience of emotional support, for example:

“...he was not offered to speak with anyone regarding his diagnosis.... His needs or wishes were not obviously discussed with him as he wasn’t offered any spiritual/counselling support following his diagnosis. This I know would have been important to him. I do not think he suffered physical pain in the last week of his life, but I do know he suffered emotionally which is every bit as bad and it shouldn’t be.”

“I felt that the care was good because they helped him physically and emotionally.”

## Spiritual support

In addition to emotional needs one survey question enquired about how healthcare staff met the patients' spiritual care needs during their last admission.



**Figure 7: Support for spiritual needs during the last admission**

A similar number of respondents reported on the questions relating to emotional and spiritual support as pain and symptoms other than pain (n=327) indicating respondents viewed these elements of care as equally important. Six in every 10 people (61%: n=198) indicated that spiritual support was provided at the level of 'excellent' or 'good'. One in every 11 respondents (8.9%: n=29) indicated that this was provided at a 'poor' level. Some respondents commented on the spiritual support they experienced:

“I would like to thank all of the doctors and nurses plus lay ministers for all their care and prayers.”

“The comfort and support and prayers by the priest.”

Provision of emotional and spiritual support to dying patients that responds to their needs and preferences is a key element of good end-of-life care. Living with a life-limiting illness and awareness of the imminence of one's own death may heighten concerns about issues related to quality of life, uncertainty about the future and death. This may give rise to emotional distress for some people who are dying and those important to that person.

In this study, according to relatives, healthcare staff met the emotional needs of dying patients at an 'excellent' or 'good' level at 56%. The spiritual needs according to relatives were met at an 'excellent' or 'good' level at 61%. Similarly, the *Let's Talk About Survey*<sup>38</sup> found a need for better emotional and psychological support with 51% of people in their study indicating their needs were least well met in this area.

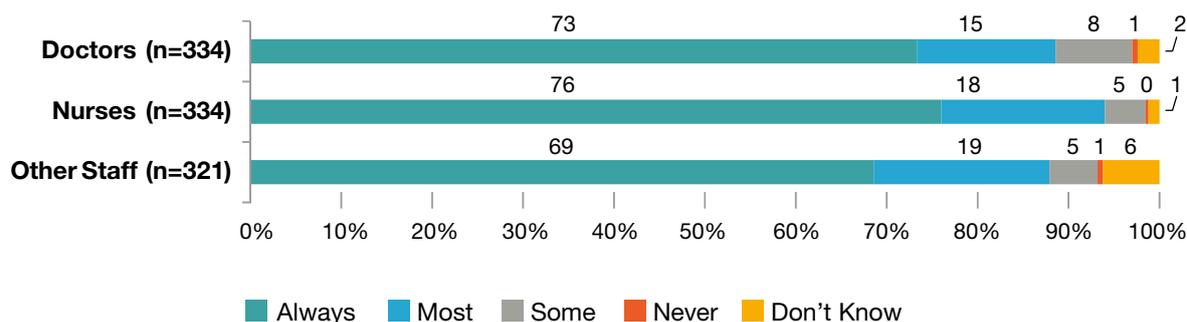
## Dignity and respect

Person-centred care is underpinned by dignity and respect. The *National Standards for Safer, Better Healthcare*<sup>13</sup> and *The National Healthcare Charter*<sup>11</sup> emphasise dignity and respect as an important element of person-centred care and support, wherein a patient’s dignity, privacy and autonomy are respected and promoted. Thus, dignity in care is expressed through the quality of care including attitudes, behaviour, compassion and dialogue<sup>39</sup>.

### Dignity and respect during the last admission

Respondents were asked if they thought healthcare staff treated the person with dignity and respect during the course of the last admission to hospital.

Nine out of 10 (90%: n=297) reported that the patient was treated with dignity and respect by hospital staff ‘always’ or ‘most of the time’. As shown in Figure 8, nurses rated highly with over three-quarters (76%: n=254) as ‘always’ showing dignity and respect to the patient followed by doctors at 73% (n=245) and other staff 69% (n=220).



**Figure 8: Dignity and respect by care provider during last admission**

In relation to dignity and respect, relatives reported the following:

“Upon his final admission to (name of hospital) his care was excellent- he was afforded dignity and respect and staff really cared for him. We were supported as a family throughout this difficult time by people who really knew our father.”

“She was often left in hospital gowns even though she had eight nightdresses in her locker.”

“As my husband was transferred from (name of referring hospital) with pneumonia, all that could be done was just to make him as comfortable as possible at that stage. I have to say all the staff, doctors etc. were excellent and attentive and did everything with dignity they were very supportive to the family during the night shifts.”

Ensuring people and their families are treated with dignity and respect is a key principle of statutory agencies such as the HSE, HIQA and healthcare providers. Findings from this study highlight that the majority of respondents reported their relative was treated with dignity and respect 'always' or 'most of the time' during the last admission although it is interesting to note that it was higher for nursing staff at 94% than doctors at 88%. In comparison, research in England<sup>24</sup> found that bereaved relatives reported the patient was treated with dignity and respect 'always' or 'most of the time' at 81% by nursing staff and 85% by doctors.

## Coordination of care

One question asked about coordination of care with community services outside the hospital including general practitioners (GPs). Of the 344 respondents (97%) who provided an answer to this question, 44% (n=152) said that the services definitely worked well together. One in every 10 people (10%: n=33) reported that the hospital services did not work well with GPs or community services.

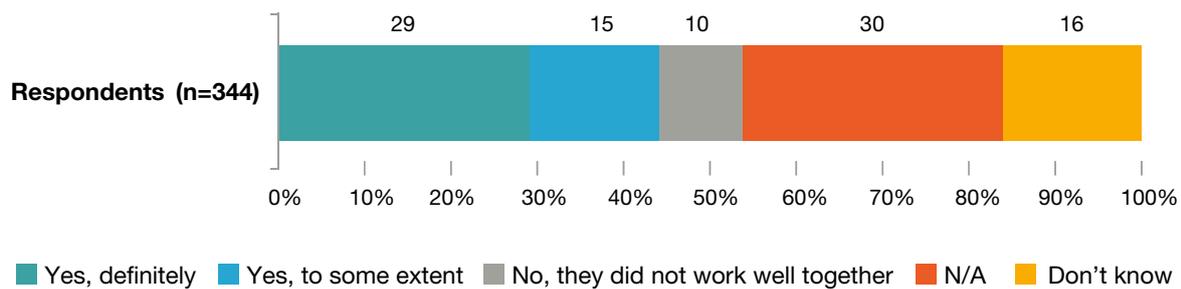


Figure 9: Coordination of care with GPs and community services

## Patient preferences and shared decision-making

The *National Healthcare Charter*<sup>11</sup> and *The National Safer and Better Health Care Standards*<sup>13</sup> outline the importance of involving patients and their families in the planning and delivery of good quality healthcare delivery. Similarly, the *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup> espouse this value as does the National Institute for Clinical Excellence (NICE) guideline *Care of Dying Adults in the Last Days of Life*<sup>9</sup>.

Half of the respondents (50%: n=171) reported that they thought their relative was involved in decisions as much as they wanted to be. A much small number (7%: n=25) indicated that the recipient of care would like to have been more involved.

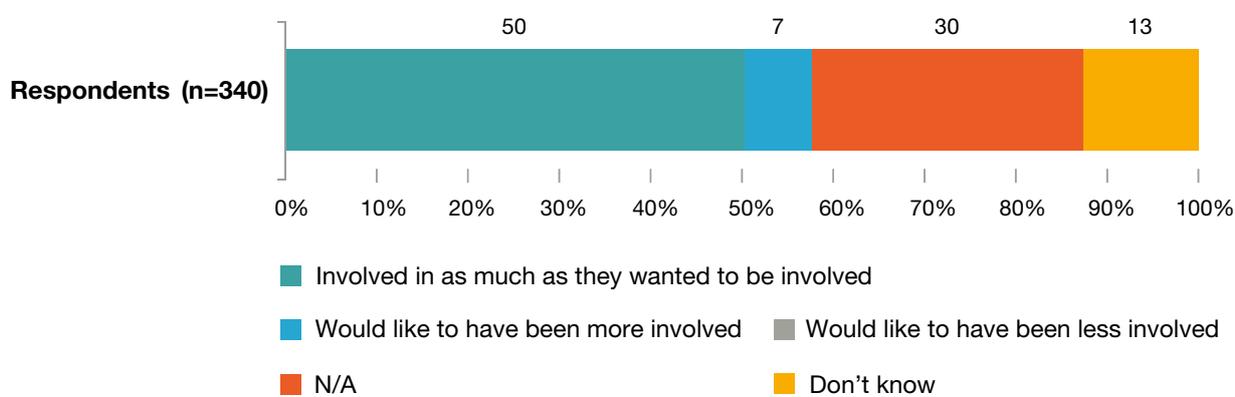


Figure 10: Patients' involvement in decision-making about their care

People have the right to be involved in discussions and make informed decisions about their care<sup>13</sup>. A question was asked if there were any decisions made about their relative's care that they feel the patient would not have wanted. Nearly two thirds (63%: n=214) of those who responded indicated that there were no such decisions. Just over one fifth (22%: n=74) indicated that they were not sure, while one in seven (15%: n=51) people reported there were decisions that the deceased person would not have necessarily wanted.

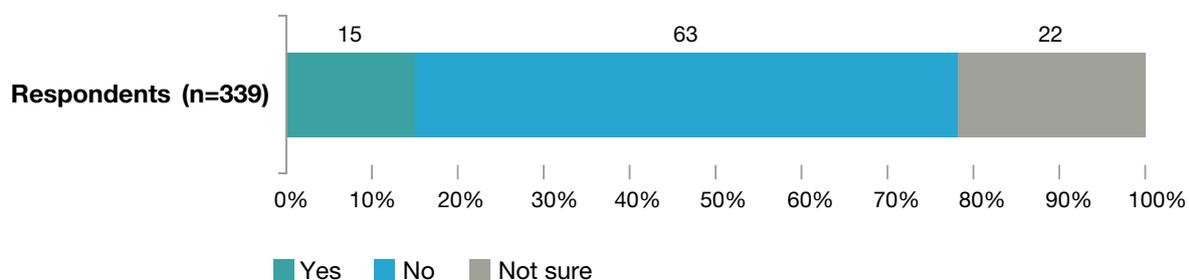


Figure 11: Were any decisions made about your relative's care that they would not have wanted?

The following quotes portray respondents' experiences regarding decision-making:

“The doctors took into account her wishes regarding cancer treatment and invasive testing.”

“No one knows a patient more than family if close. We have comparisons so we can tell when things are changing, we knew the end was close. Not once could we communicate properly with staff on this. They didn't seem to think this. Maybe this is the only way they can operate. ... The day mum died, I was meeting with my sister in the café to work out when to tell my brother to come back from (name of country). Trying to figure it all out. If the staff had communicated openly with us maybe we wouldn't have had to spend time doing this and would have spent the time with mum instead. Last time I saw mum, the physio was testing her walking, so I left her early. It would have been better if the physio accepted her saying No and left us to spend a little more time, just chatting and relaxing in the short time before she died.”

“On-going tests when my mother wasn't strong enough for them and when it was clear she was dying.”

Three quarters (75%: n=244) of respondents indicated they were involved in decision-making as much as they wanted to be while respecting the autonomy of the person receiving care. Nearly one fifth (18%: n=58) of respondents indicated they would have liked to have been more involved. None of the respondents indicated that they would like to have been less involved.

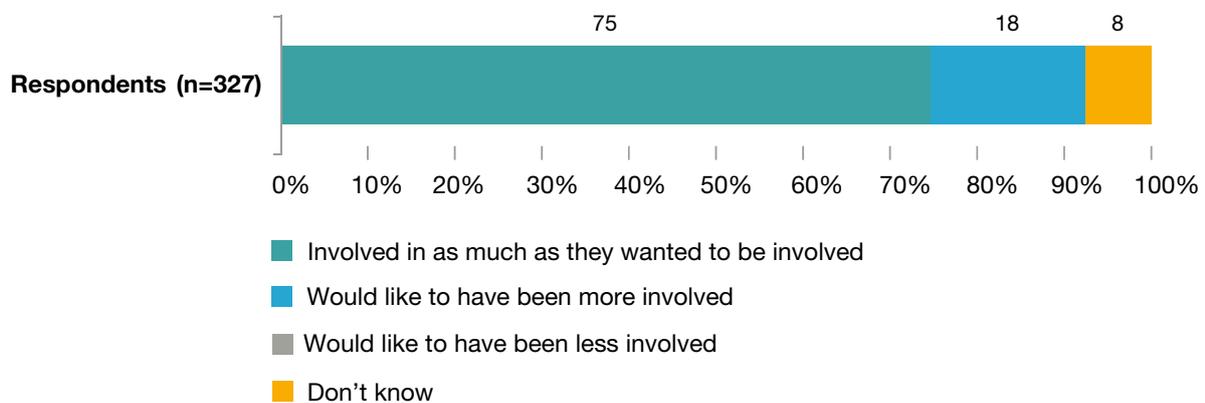


Figure 12: Relatives' involvement in the decision-making about the patient's care

## Communication

The *National Healthcare Charter*<sup>11</sup> stresses that service users can expect to be listened to and communicated with, openly and honestly. Furthermore, the *Quality Standards for End-of-Life Care in Hospitals* state that there should be “*timely, clear and sensitive communication with each person, as appropriate, in respect of a diagnosis that s/he may be approaching or at end of life*”<sup>13</sup> (p67). To ensure this, there needs to be effective communication across the healthcare teams and services involved in the care of a person who is approaching end of life.

To ascertain the quality of communication as experienced by the patient and relatives, respondents were asked three key questions relating to communication at end of life. These included whether their relative knew they were dying and if so, how was this communicated to them. Respondents were also asked to report on the timeliness of communication to allow their presence at the time of death.

### Awareness about likelihood of dying

Eighteen per cent (n=64) of respondents believed their relative was aware they were likely to die. Another 27% (n=94) saw it as probable. One fifth (20%: n=69) indicated their belief that their relative did not anticipate they were going to die, while 25% (n=86) definitely did not expect it. One in 10 (10%: n=35) were unsure.

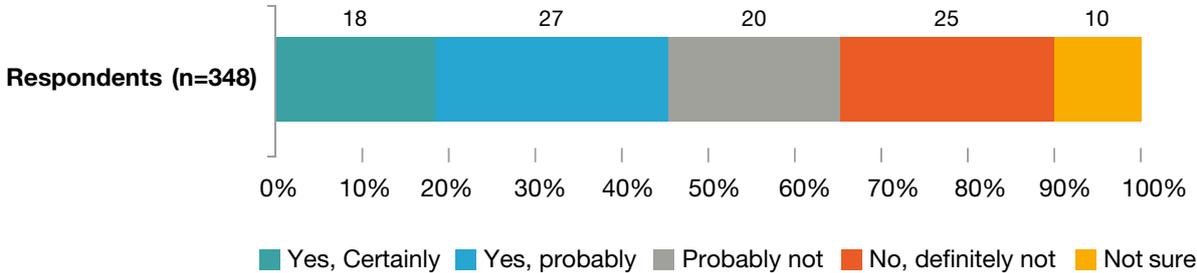
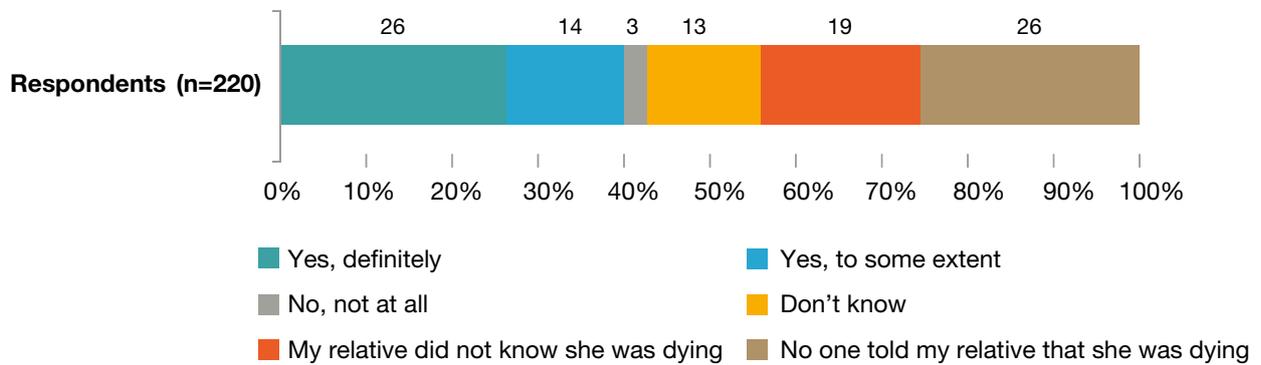


Figure 13: Patients’ awareness about impending death

### Quality of communication with the dying person

Sixty two per cent (n=220) of those surveyed, responded to the question relating to the sensitive communication of information to their relative. When asked about whether their relative was told in a sensitive way that he/she was likely to die, over a quarter (26%: n=58) answered ‘Yes, *definitely*’. A further 1 in 7 (14%: n=30) responded ‘Yes, *to some extent*’ while 26% (n=56) reported that no one told their relative that they were going to die.



**Figure 14: Communication of likelihood of dying given in a caring and sensitive way**

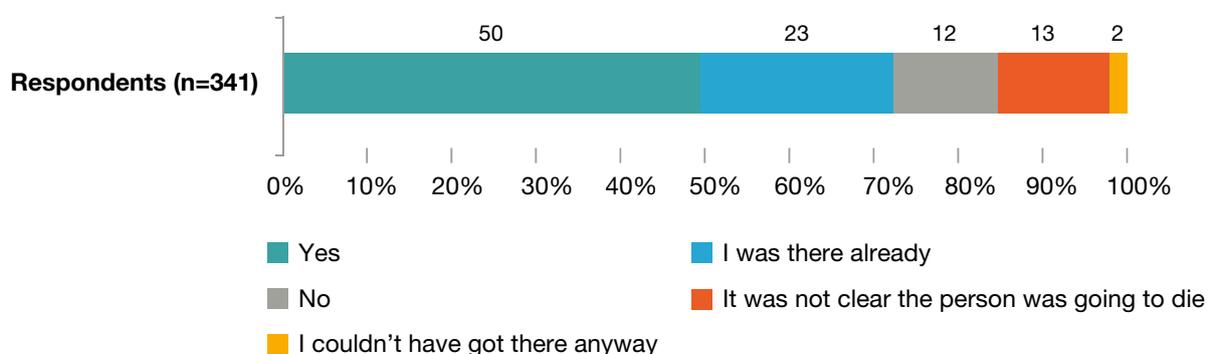
Respondents provided comments associated with communication. The following examples describe different experiences of how bad news was delivered:

“The Doctor’s and Nursing staff were very sensitive when telling us the difficult news that my mother was going to die. The staff in (name of the ward) in particular were amazing and as a family it was helpful to be with family the whole time. We were very lucky that my mother was given a room of her own...”

“Initial diagnosis of fatal condition was delivered in a direct almost brutal fashion by a nurse. This may not have been the intended mode of delivery but this is what happened.”

**Contacting relatives in time before death**

Half of all relatives (50%: n=169) said they were contacted soon enough to give them time to be with their relative before they died. Nearly a quarter (23%: n=78) said they were already at the bedside and a further 13% (n=45) stated it was not clear that their relative was going to die soon. One in 8 respondents (12%: n=42) felt that they were not contacted in time to be with their relative.



**Figure 15: Contact to allow presence of family near time of death**

Respondents provided comments about the importance of being present during a relative's death:

“On his final night I left him to go home, he suffered a bleed once I left. My Aunt arrived and was told to wait outside. She was not told that he was bleeding again. She thought staff were just doing rounds so she didn't contact me. By the time staff told her that there was a problem, I was already on the train to [name of west of Ireland county]. So I was not there when he died.”

“Myself and my family were given time to spend with him shortly before he died. He was pain free and so well cared for...”

The principles of person-centeredness as outlined in the *National Standards for Safer and Better Healthcare*<sup>13</sup> are underpinned by good communication. Good communication centres on respecting patients' dignity and privacy whilst ensuring their wishes and needs are heard and understood. This is of critical importance when the discussion with the patient and family is about dying. However, it is also recognised that there can be considerable uncertainty involved in identifying when someone is dying and at times changes can happen suddenly and unexpectedly. Open communication on these topics is crucial so that the person is fully enabled to participate in making informed decisions about care at end of life.

Healthcare professionals need to be skilled in effective, timely and sensitive communication in all aspects of end-of-life care. Lack of discussion about end-of-life care may lead to anxiety about dying with plans left incomplete and conversations not had. The Irish Hospice Foundations' *'Think Ahead'* programme<sup>54</sup> emphasises the importance of normalising discussions on all issues related to dying. The *'Think Ahead'* document encourages people to think, talk and make plans for the end of their life so that their wishes will be respected.

Communication has a significant impact on the patients' and their relatives' experience of care at the time of death and thereafter in their bereavement. Results from the *Let's Talk About Survey*<sup>38</sup> confirms the need for better and clearer communication, with 37% of study respondents reporting that they *'received too little information too late'*<sup>38(p20)</sup>. Bereaved relatives in the *VOICES MaJam* study related many situations where information about the diagnosis, prognosis and treatment options was communicated clearly and sensitively but equally, where communication was inadequate and insensitive. Respondents in this study identified several areas where different staff groups need to improve their communications skills both in the manner in which they communicated but also with regard to the timing of their communication.

## Preferences and choice at end of life

The *National Standards for Safer Better Healthcare*<sup>13</sup> clearly outline the expectations the public, patients and their families can place on acute hospital providers. One of these expectations is to deliver services using a person-centred approach where the service user is at the centre of all activities. *The National Healthcare Charter*<sup>11</sup>(parag.6) recommends for “patients to be fully involved in shared decision making about their health care and to take account of their preferences and values.”

Healthcare professionals therefore need to engage and actively involve people in shared decision-making about their care at end of life. Furthermore, the *National Safer Better Health Care Standards*<sup>13</sup> outlines the importance of eliciting people’s views about their care. This section of the report deals with questions respondents were asked about their deceased relatives preferences and choices such as preferred place of death, staff awareness of the dying person’s wishes and the perception of respondents on how much choice their dying relatives actually had about their place of death.

### Articulating preferences regarding place of death

A widely held quality marker for end-of-life care is that people should be able to die in their place of choice. However, only one in four (24%: n=81) of the survey respondents reported that their relative had expressed a preference of where they would like to die as presented in Figure 16.

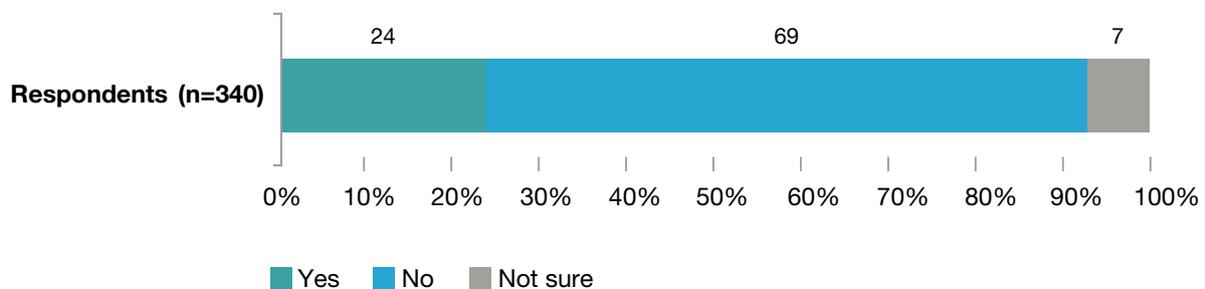


Figure 16: Relatives indication of preferred place of care at time of death

For those who expressed a preference (n=80), the majority preferred to die at home (80%: n=64) while 6% (n=5) had expressed a preference to die in hospital.

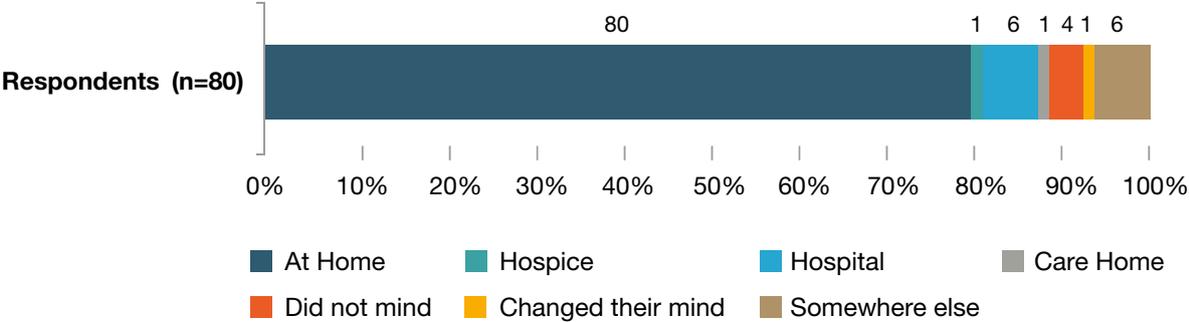


Figure 17: Location of preferred place of care

**Staff awareness of preferred place of death**

The *National Healthcare Charter*<sup>13</sup> advises that service providers put service users’ needs and preferences at the centre of all their activities. However, in order for service providers to be able to respond to patients’ needs, they first need to know what those needs are.

Respondents were asked if they knew if staff had recorded their relative’s preferred place for care at the end of life. Only 23% (n=80) of all survey respondents answered this question; of those who replied, 19% (n=15) were aware of the preferred place of death being documented, while 44% (n=35) were unaware and a further 38% (n=30) were unsure of it.

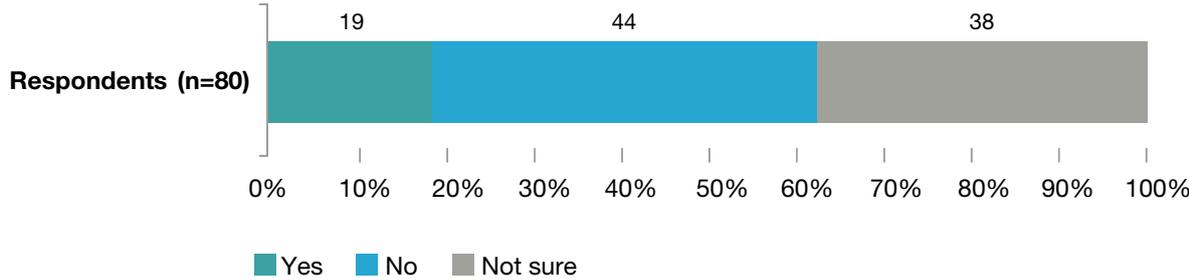


Figure 18: Documentation of preferred place of care

### Deceased person's choice about place of death

The survey asked bereaved relatives did they *'think their relative had enough choice about where they died?'* Only 22% (n=78) of all respondents answered this question with almost equal numbers responding 'Yes' (28%: n=22) and 'No' (30%: n=23). A further 31% (n=24) indicated that their relative died suddenly.

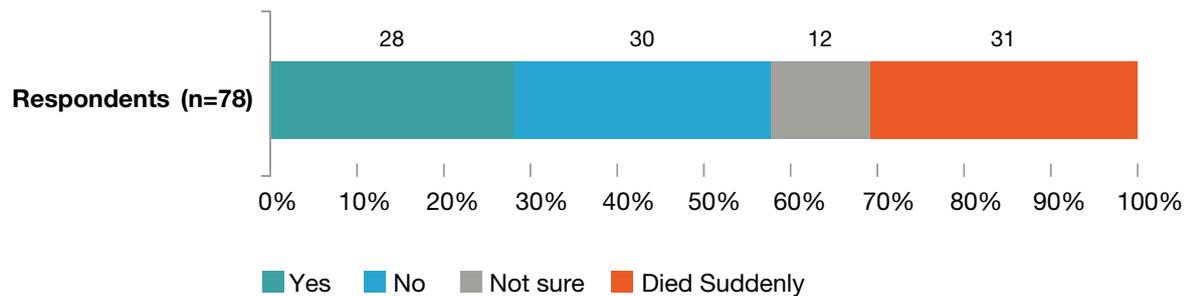


Figure 19: Choice regarding preferred place of care

Some relatives expressed frustration about wishes and choices in relation to preferred place of care at end of life:

“It now appears a pure lack of communication contributed to him not being transferred back to his local general hospital where he had a bed, thus (not) allowing him to die with dignity and support of those he loved.”

“I just want to say that my nana could have had a very peaceful death in her own bed in the nursing home that she loved, surrounded by her relatives. Instead, she died almost alone in a public ward, she couldn't hear or see very well, so she must have been very confused. She should have had a peaceful death. Her wishes should have been respected by the Doctor who sent her to hospital.”

### Hospital as the place of death

When asked the question ‘On balance do you think that your relative died in the right place?’ a substantial majority of respondents (81%: n=276) stated that they believed their relative died in the right place. However, one in eight (12%: n=41) indicated that they thought the hospital was not the right place.

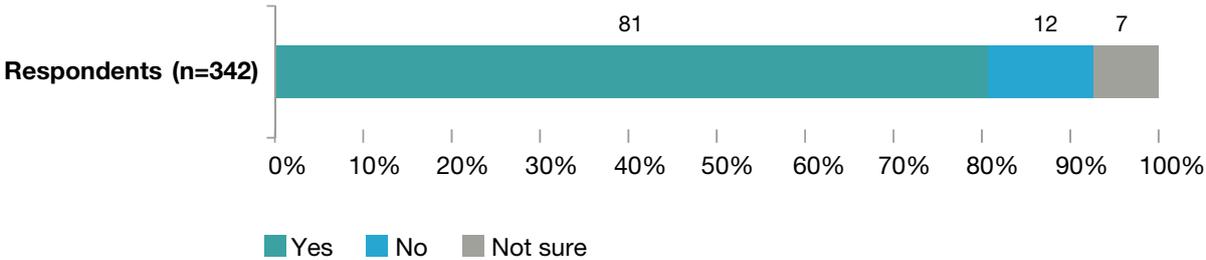


Figure 20: Did your relative die in the right place?

Two relatives commented that they believed their relatives died in the best and most appropriate place:

“I thought he might have been more comfortable in the hospice, a quieter place than an acute hospital. But he told me that he preferred to stay in (name of hospital) where he knew everyone. He got his wish and at the end, he died peacefully with one gentle last breath.”

“I think he was in the right place (name of hospital) than at home for care he received for example to control blood sugar levels, rest, visits from chaplain etc.”

### Hospital environment

The *National Audit of End-of-Life Care in Hospitals in Ireland*<sup>4</sup> confirmed the importance of care provision in single rooms at end of life. Research conducted on the conditions of the environment in Irish acute hospitals identified that there was a lack of facilities for private consultations and conversations in situations where confidentiality is paramount and that overall that there was a “lack of facilities for families and family rooms”<sup>40(pii)</sup>. The *VOICES MaJam* survey aimed to ascertain bereaved relatives views on care provision in single rooms, their understanding of reasons why a single room was not available and their experience of privacy provided at end of life.

### Care in a single room at time of death

The majority of people (98%: n=350) responded to the question about care in a single room with 7 in 10 people (69%: n=241) reporting that their relative died in a single room. Just over a quarter (26%: n=92) stated this was not the case and a further 5% of respondents answered that they were unsure. When examined the data differs between the two hospitals:

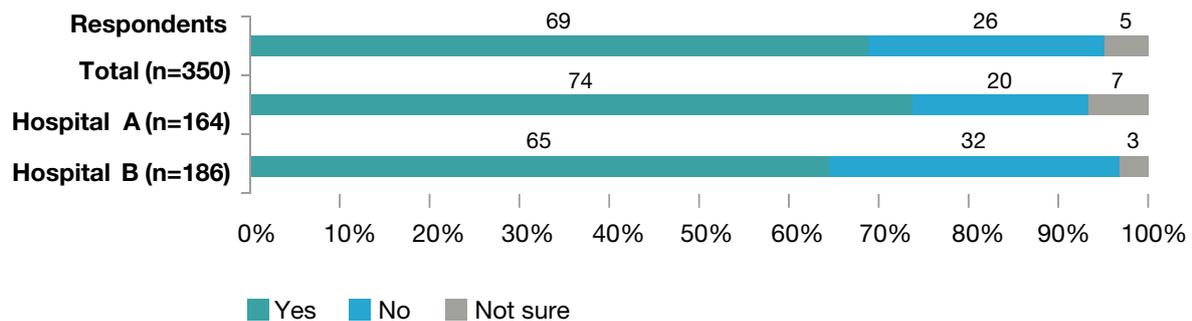


Figure 21: Care in a single room at time of death

Respondents commented on the significance of a single room at end of life in a hospital and the impact on their dying relative and the family when a single room was not available to them:

“Final days in a room on his own with open visiting for relatives. Great care and attention from nursing staff, doctor’s and consultants.”

“I cannot speak highly enough about the care the nursing staff gave to my relative. Unfortunately the lack of availability of a single room was an issue. I was with my relative when she died as I stayed all night she passed away early in the morning. My family (5 siblings) could not all stay and were not with my mum when she died. We were fortunate that she was sharing with a lovely lady who was VERY understanding of the constant visiting.”

“I appreciated that visitor numbers were allowed to be exceeded during his final hours, however, I feel that a private room should have been offered as it was felt that we couldn’t talk loudly and share experiences a lot of final speeches were whispered which I felt took away from the final goodbye.”

McKeown et al<sup>4</sup> reported that 45% of dying patients in *Hospital A* were cared for in single rooms compared with the national average of 44%. In 2011, the Hospital Board of *Hospital A* set a permanent quality indicator associated with ensuring more people are cared for in a single room at end of life<sup>48(p33-37)</sup>. *VOICES MaJam* study respondents from *Hospital A* indicated that 74% of people were cared for in a single room at time of death. This is a significant improvement compared to the findings of McKeown et al<sup>4</sup> indicating that considerable progress can be made with a coordinated approach to care provision in single rooms at end of life.

### Reasons for the lack of availability of a single room

Respondents whose relative did not die in a single room (n=85) were asked what they understood to be the reason for this. One in five (21%: n=18) indicated that a single room was not available, another fifth (19%: n=16) responded that they did not expect their relative to die and 2% (n=2) did not want a single room. Almost one quarter (24%: n=20) did not know and 34% (n=29) indicated a variety of reasons, for example, dying in critical care areas such as Intensive Care Department or in the Emergency Department.

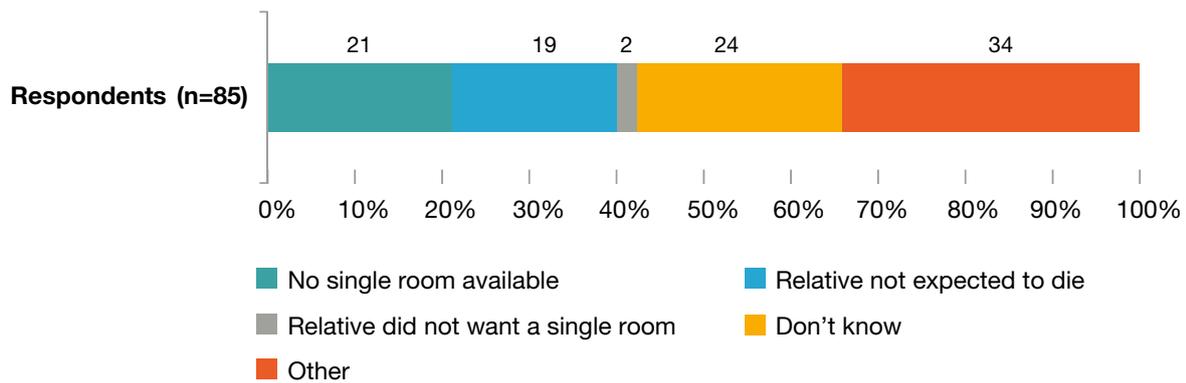


Figure 22: Reason why death did not occur in a single room

### Privacy in the last two days of life

The majority of those surveyed (96%: n=340) responded to the question relating to the privacy at the person's bed and the surrounding environment. Over two thirds (69%: n=235) agreed there was enough privacy, however, almost one sixth (17%: n=59) indicated that there was not enough privacy.

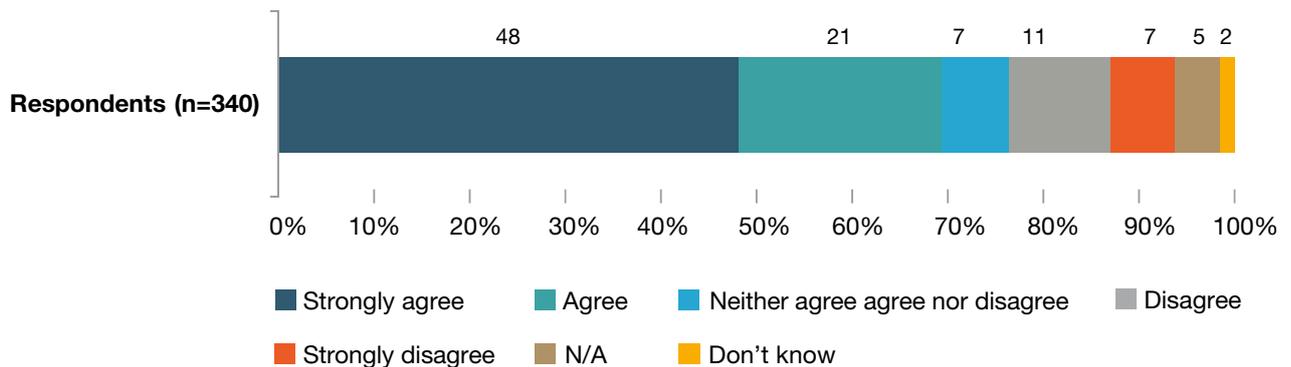


Figure 23: Adequate privacy in last two days of life

A respondent's comment relating to privacy and space:

“... the space was tiny. If you were to pull the curtains around the bed, any person sitting on the left hand side of the bed was automatically cut out. In addition, there was no comfort for anyone sitting on the left hand side of the bed, as the sinks were located there. This meant they had to constantly move in order to allow access to the nursing personnel.”

## Support for relatives

The *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup> highlight the importance of the practical supports hospital staff can provide to relatives. In response, the survey aimed to establish the availability of a family room, unrestricted visiting, as well as the level of support they received at the time of the person's death and in the form of bereavement support.

### Availability of a family room

The Irish Hospice Foundation and HSE developed two guidelines titled *The Design and Dignity Guidelines for Physical Environments of Hospitals*<sup>41</sup> and *Design & Dignity Style Book: Transforming End-of-Life Care in Hospitals One Room at a Time*<sup>42</sup>. Both stress the importance of having properly designed family rooms in all clinical areas. Furthermore, the *National Healthcare Charter*<sup>11</sup> stresses the importance of privacy, indicating that conversations between patients, relatives and staff take place in a private environment. Research has recommended that the environment within which patients and their families are cared for has a significant impact on their physical and psychological well-being<sup>43,44</sup>.

Figure 24 indicates that one in four people (24%: n=74) did not have access to a family room. More than seven in every 10 people (71%: n=219) who had access found this helpful. When the data were analysed separately, differences are apparent between the two hospitals.

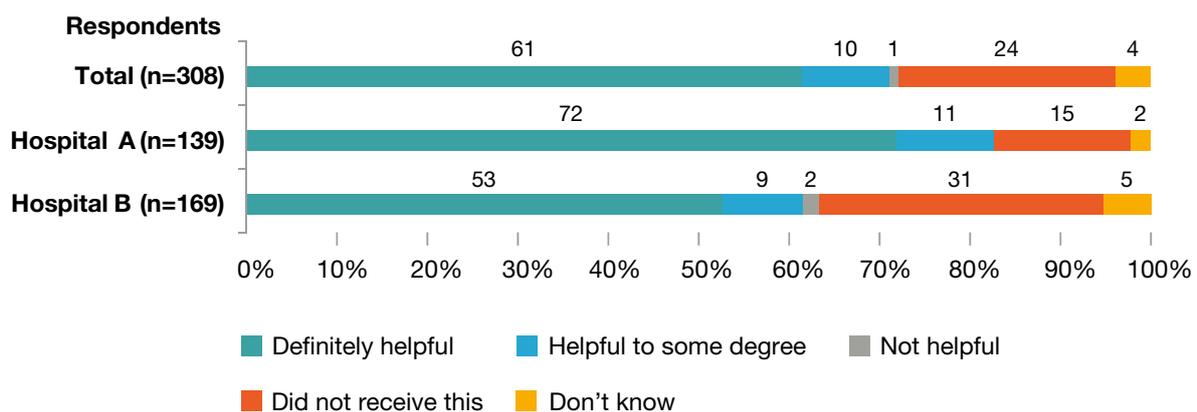


Figure 24: Availability of a family room as helpful

*Hospital A* has prioritised work on enhancing the environment for patients and their relatives by creating and refurbishing family rooms on their acute hospital wards. This work was inspired and initially supported by the Irish Hospice Foundation’s Design and Dignity Programme in conjunction with the HSE. Since 2012, ten family rooms have been developed in *Hospital A* through the work of the end-of-life care coordinator and hospital staff with a view to enhancing dignity, privacy and care experience for patients and their relatives. Importantly, the Hospital Board of Directors and Executive Management Committee support this work. Access to a family room is a quality indicator on the Board of Directors’ Quality Dashboard in *Hospital A*<sup>48(p33)</sup>. This appears to be reflected in the responses where 83% of relatives found having access to a family room helpful compared to 62% in *Hospital B*.

Examples of comments from respondents about the topic of family rooms include:

“We as a family never had a family room to talk to mam in private, everyone can hear your business in wards. Even on her last day when we were advised to come in. We had nowhere to make a cup of tea or sit in private we had to use a storage room, which just adds to your distress.”

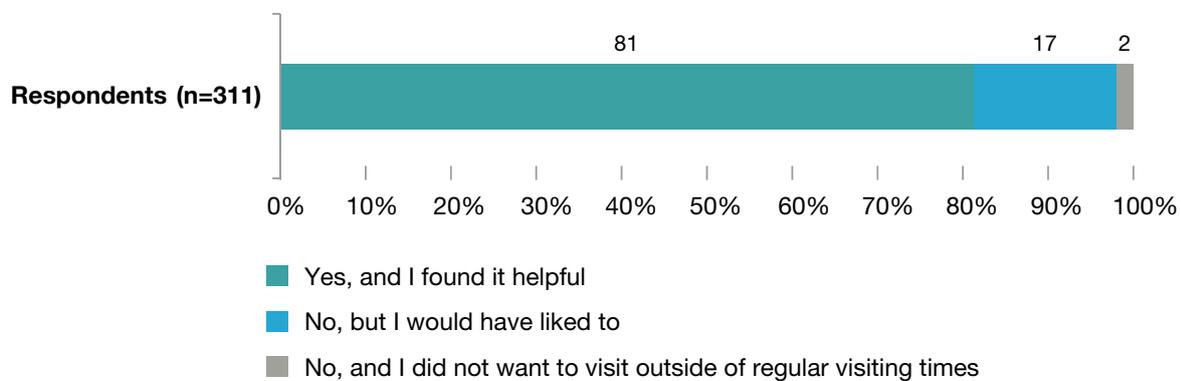
“The night before he died we left the hospital about 12am, as my mother is 82 and she was getting very tired and we live [outside Dublin]. We did not know there was a family room where she could have rested for a while. The next morning we left for the hospital but (name of person) died and we were nearly there. “



## Unrestricted visiting

The presence and involvement of family members and friends enhances patients' and relatives' experience of care. This is especially true when the patient is nearing the end of life when time is limited and each moment is precious. Unrestricted visiting allows family members and friends to be with the person at the most critical time in their lives. Open visiting for relatives increases satisfaction; at times it decreases the patients and families anxiety, promotes better communication between staff, patients and families and allows family members to become involved as active partners in the care of the dying.

Four in every five people (81%: n=252) visited the hospital outside of regular visiting hours. However, one in every six people (17%: n=52) indicated that they were not informed about the option of visiting outside regular hours and on reflection would have liked to avail of it.



**Figure 25: Unrestricted visiting**

Respondents wrote about their experiences in relation to visiting the hospital:

“...when she was moved to a single, private room, there was unrestricted visiting and overnight stays were allowed. This was very helpful as she died ... while we were still present.”

“We could only visit at visiting time, which was hard for mam and us as a family. I know it was a medical ward and that there are rules but she was so agitated and confused, if we could have been there with her it would have eased her agitation and ours.”

### Accommodating relatives overnight

Of the 346 (97%) who answered a question about overnight stay, almost half (49%: n=170) of all relatives stayed overnight and found it *'helpful'*. One in 10 respondents (11%: n=39) indicated that they were not informed about staying overnight but would have liked to. A further 10% (n=35) didn't stay but were informed and 22% (n=76) stated that this was not applicable.

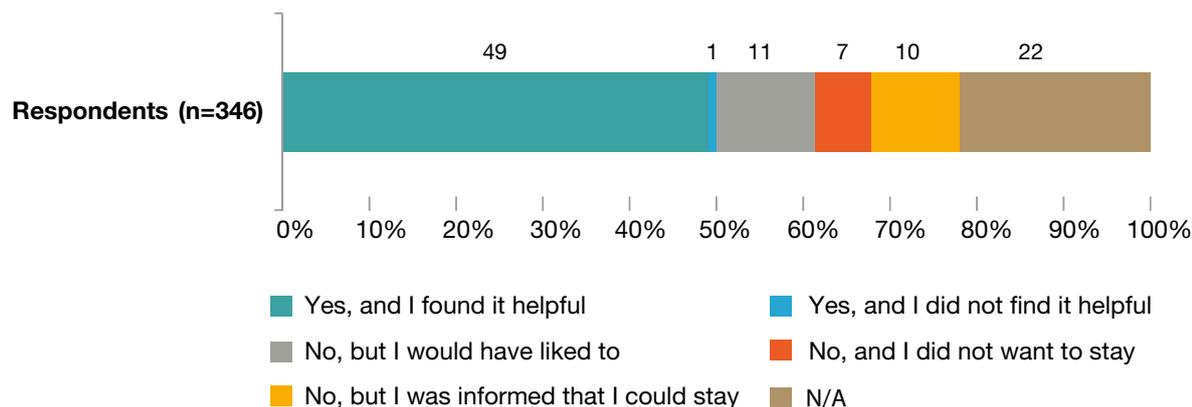


Figure 26: Overnight stay during last admission

### Support for family members at the time of relative's death

More than two thirds of respondents (69%: n=240) said that they had definitely been given enough support at the time of the death. A further quarter (24%: n=84) said that they had to some extent.

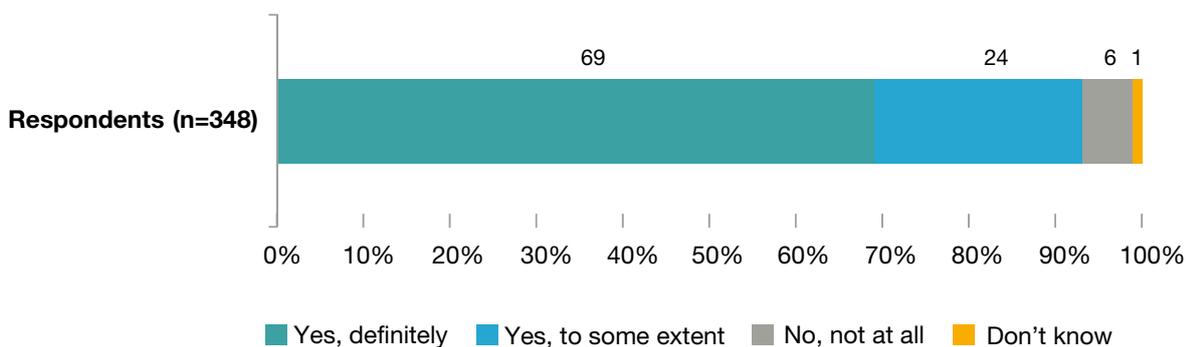


Figure 27: Help and support at the time of death

Relatives' comments relating to support at the time of death include:

“More practical support the day of his death no one seemed to know what happened following the death e.g. arrangements for our undertaker to remove the body from the morgue etc. considering we had such a journey, staff were not helpful.”

“They laid my father out lovely, gave us a lovely room with candle and flowers and gave us as much time and space as we needed but yet were there if we needed them or wanted to ask any questions.”

The majority (95%: n=331) of respondents indicated they were cared for sensitively after their relative died. A minority (4%: n=14) indicated they were not.

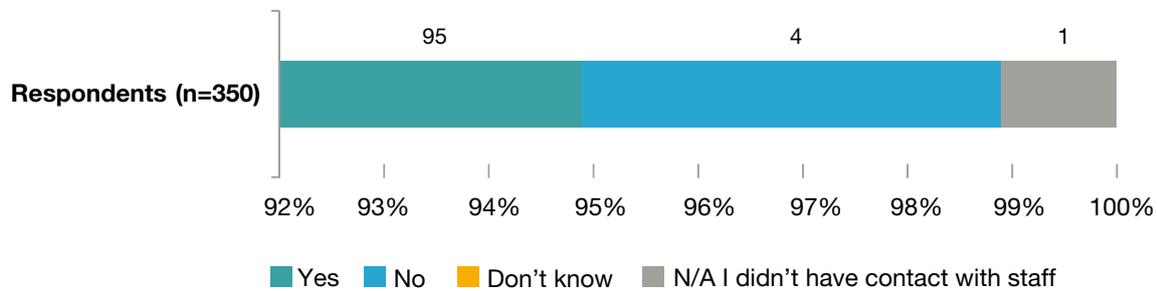


Figure 28: Did staff deal with you in a sensitive manner when your relative died?

One relative for example, commented on the support received at this time:

“Quick access to my mother’s body in a private room. Quick arrival of a priest. Staff checking on me regularly yet giving privacy to grieve. Tea, sandwiches for family when they all arrived. No rush to leave the room, all at my pace.”

## Bereavement support

Families and friends have varying needs after the death of someone close. It is important that they receive timely and appropriate practical information on what happens after the person dies, information on grief and loss and how to access bereavement support services. This includes verbal information as well the provision of leaflets.

Despite both hospitals having developed information leaflets outlining what happens after a patient dies, over half of the respondents (54%: n=172) indicated that they did not receive this leaflet. One in four (39% n=124) indicated that they found it to be ‘*definitely helpful*’ or ‘*helpful to some degree*’.

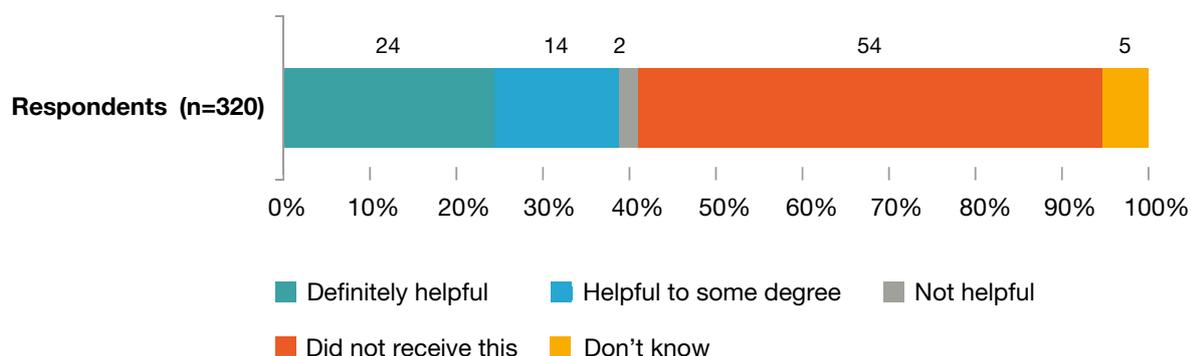


Figure 29: Receipt of information leaflet from ward staff

Both hospitals have systems in place to ensure relatives are sent a sympathy card or letter within one month of a patient’s death in line with the *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup>.

Figure 30 shows that two thirds (67%: n=222) of respondents found a letter or sympathy card as being ‘*helpful*’, the majority finding it ‘*definitely helpful*’ (54%: n=180). However, the structures behind this process differ between participating hospitals. This appears to be reflected in the responses where 34% (n=60) did not receive this in *Hospital B* versus 15% (n=24) in *Hospital A*.

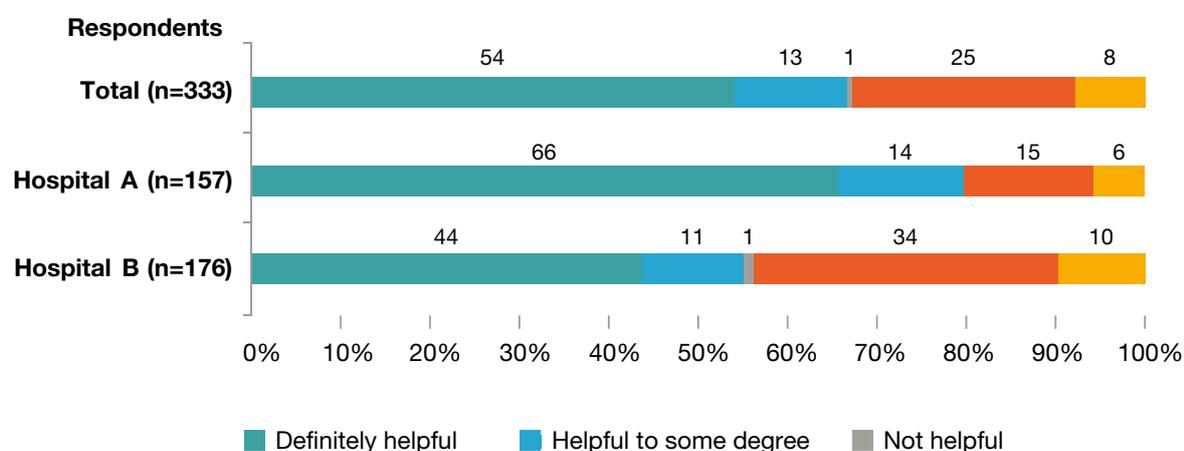


Figure 30: Receipt of a sympathy card

### Bereavement support - contact with hospital staff

Respondents were asked if they had spoken with anyone from the hospital about their feelings around their relative's illness and death. The majority of respondents (97%: n=346) answered this question. One in every 6 people (17%: n=57) had spoken with someone and found this helpful, 29% (n=99) did not but would have liked to and a further 54% (n=185) did not wish to speak with anyone about their feelings. One per cent of respondents reported having spoken with someone and reported finding this not helpful.

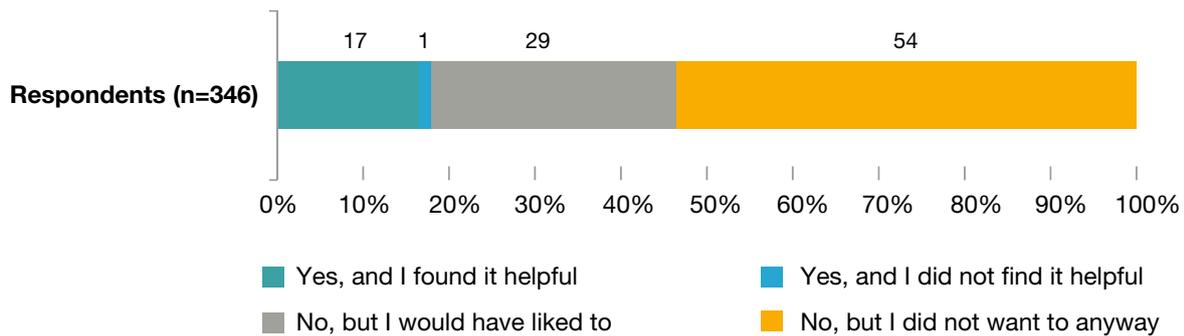


Figure 31: Helpfulness of speaking to staff after the person died

Of the aforementioned 346 respondents, eighty indicated which staff member they spoke with, which is detailed in Figure 32:

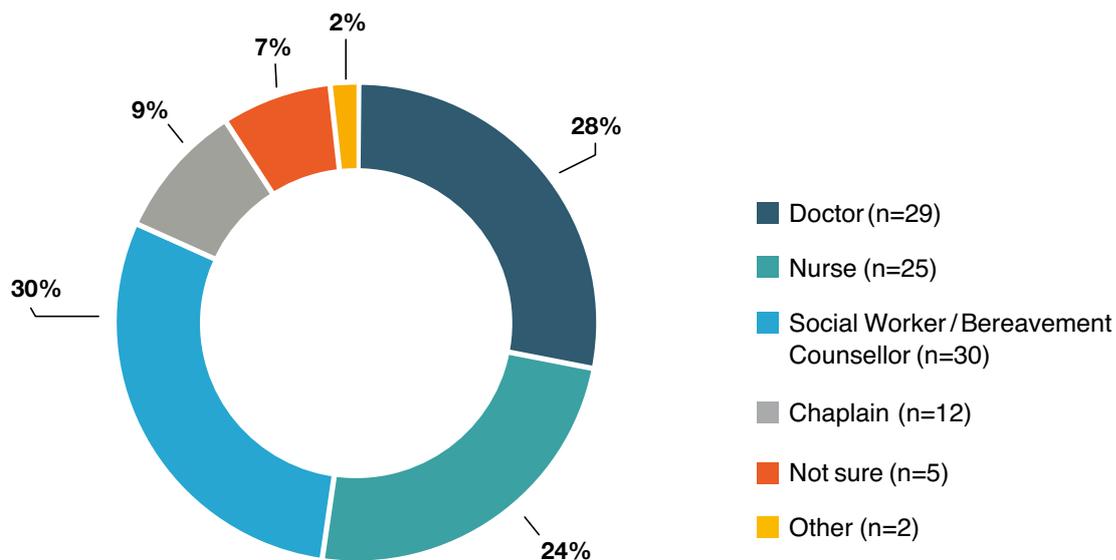


Figure 32: Staff member spoken to after the person died

Some relatives commented on the contact they had with hospital staff following their bereavement.

“Call from her doctor (doctor’s name), after her death much appreciated.”

“We deeply appreciate receiving a letter from the staff expressing their sympathy. Thank you.”

“We would have liked to receive a bereavement booklet and information on what services were available to us.”

“Communication re disposal/burial of relative organ poor, only after several phone calls re same was I advised that there could be interred with my son and that the cost would be borne by the coroner’s office. Also, that my undertaker would look after these arrangements through liaison with the coroner/pathology unit. The gathering of this information caused some weeks of stress, especially to the deceased’s mother.”

“Might be better if bereavement counsellor made direct contact by letter or phone call.”

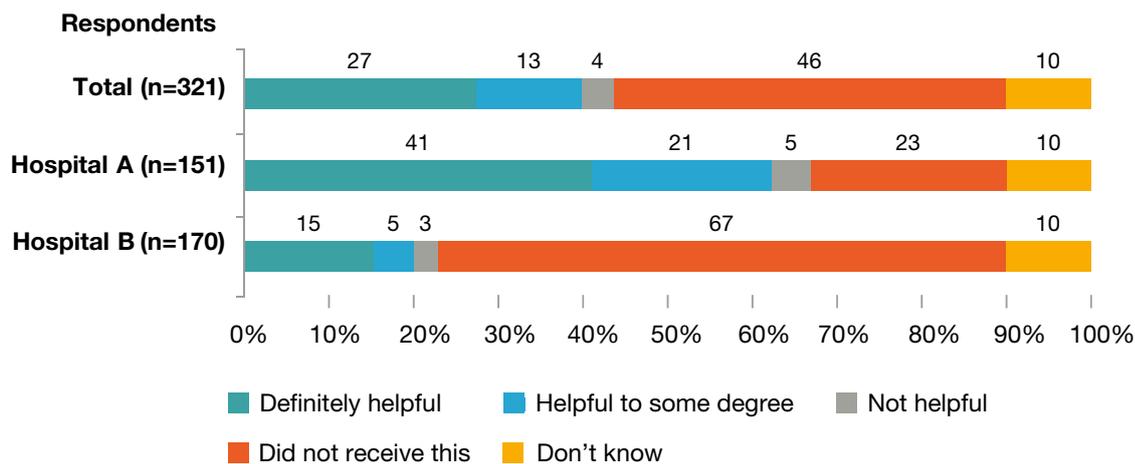


**Bereavement support – bereavement evenings and remembrance services**

Both hospitals offer multi-faith religious remembrance services as well as bereavement evenings and this is reflected in the data presented in Figure 33 and Figure 34. Bereavement evenings are secular in nature and focus on bereavement support. In *Hospital A* all bereaved relatives are invited to a bereavement support evening organised by the Social Work Department. Bereaved relatives from the Intensive Care Unit and Emergency Department are also invited to a separate remembrance service in *Hospital A*. In *Hospital B*, at the time of the survey only bereaved relatives of patients who were supported by the specialist palliative care team received an invitation to a bereavement evening.

The impact of these different practices is reflected in the survey responses with 67% (n=116) not receiving an invitation to a bereavement evening in *Hospital B*, compared with 23% in *Hospital A* (n=35).

In *Hospital A* 62% (n=94) attended a bereavement evening and found this either ‘definitely helpful’ or ‘helpful to some degree’.



**Figure 33: Invitation to bereavement evening**

With regard to remembrance services, 71% (n=120) of relatives in *Hospital B* did not receive an invitation compared to 38% (n=57) in *Hospital A*. Taking account of the differences between the two hospitals, 47% (n=70) found an invitation to a remembrance service as either ‘definitely helpful’ or ‘helpful to some degree’ in *Hospital A*.

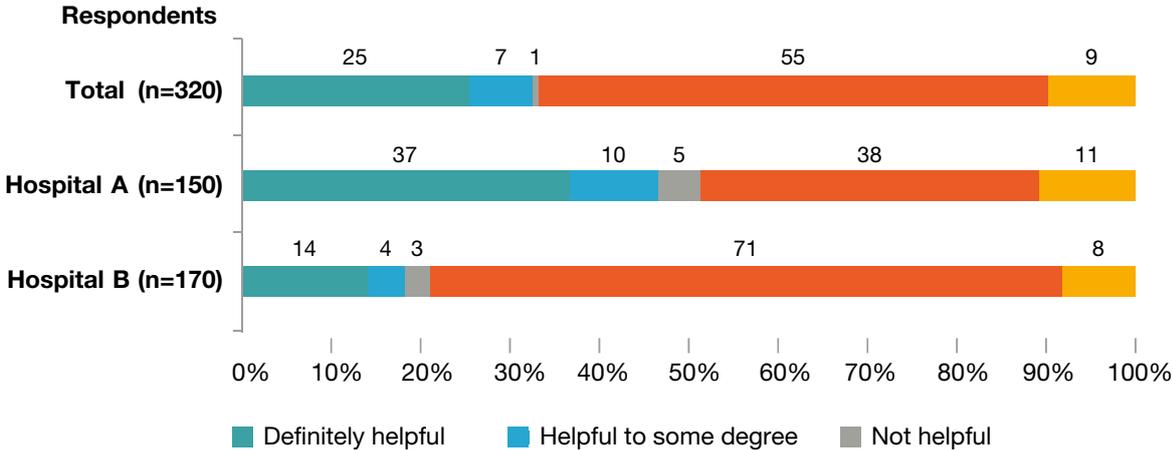


Figure 34: Invitation to remembrance service

Relatives commented on the significance of remembrance services or bereavement evenings:

- “I also got an invite to a bereavement evening about 6 weeks ago which I attended. It was wonderful and really helped me. They made me feel cared about and the upset that I was going through was normal.”
- “The information given to myself and family after my brother died was helpful. The bereavement service 6 months after my brother’s death was helpful to myself and my family.”
- “I think the bereavement services are a great thing for some people.”
- “The hospital has dealt well with bereavement services.”

## Quantitative summary results

1. Nine out of 10 respondents (87%) rated the **overall quality of end-of-life care** for their relative during the last admission to hospital as outstanding, excellent, or good: just over one out of 10 (12%) rated care as fair or poor.
2. Respondents rated as exceptional or excellent the **quality of care provided by nurses** (80%), **doctors** (72%) and **other staff** (69%).
3. Almost three quarters (73%) of respondents reported that their relatives' **personal care needs** were met during the last two days of life. However, 8% indicated that the person's care needs were not met.
4. Four in every five respondents (79%) agreed that the patient's **pain was relieved** in the last two days of life. One in 10 (11%) responded that the patient's pain was only partially or not relieved at all in the last two days.
5. More than half of respondents (56%) reported that the level of **emotional support** during the last admission was excellent or good. One in ten indicated that the patient's emotional needs were poorly met.
6. Six in 10 people (61%) indicated that the **spiritual support** provided was excellent or good. However, one in 11 (9%) reported poor spiritual support.
7. Nine out of 10 people (90%) reported that the patient was treated with **dignity and respect** by hospital staff all the time or most of the time. Respondents rated nurses as always showing dignity and respect at 76%, followed by doctors at 73% and other staff at 69%.
8. Almost half of respondents (45%) reported that **hospital services worked well together with GPs and other services outside the hospital**. One in 10 respondents reported that this was not the case.
9. Half (50%) of respondents reported that their relative was **involved as much as they wanted to be**, in decisions about their care in their last three months of life. One in 15 (7%) indicated their relative could have been more involved.
10. Almost two thirds (63%) of respondents indicated that no **decisions were made about the care** of their deceased relative that they would not have wanted. A further 22% of respondents indicated that they were not sure about this and one in seven (15%) reported there were decisions made that the deceased person would not have wanted.
11. Three quarters (75%) of respondents indicated they were **involved in decision-making** as much as they wanted to be. However, 18% of respondents indicated they would have liked more involvement. No respondent indicated the wish to have been less involved.

12. Almost two in ten (18%) respondents believed their **relative was aware they were likely to die**. Another 27% saw it as probable, while 20% indicated their belief that their relative did not anticipate they were going to die. Furthermore, 25% definitely did not expect it and 10% were unsure about this.
13. When asked about whether their relative was **told in a sensitive way that he/she was likely to die**, over a quarter (26%) answered ‘yes, *definitely*’. A further 14% responded ‘yes, *to some extent*’ while 26% reported that no-one told their relative that they were going to die.
14. Half of all respondents (50%) said they were **contacted soon enough to give them time to be with their relative** before they died. Nearly a quarter (23%) were already at the bedside and a further 13% stated it was not clear that their relative was going to die soon. One in 8 respondents (12%) reported that they were not contacted in time to be with their relative.
15. Almost one quarter (24%) of respondents indicated that they knew about the **deceased person’s preferred place of death**. For those who expressed a preference, the majority preferred to die at home (80%) while 6% had expressed a preference to die in hospital.
16. Only one quarter of respondents (23%) answered a question relating to **healthcare staff’s awareness of the patients preferred place of death**. Of those, 19% were aware of the preferred place of death being documented, while 44% were not aware of this and a further 38% were unsure.
17. Only 22% of all respondents answered the question ‘*did they think their relative had enough choice about where they died?*’ Almost equal numbers responded ‘yes’ (28%) and ‘no’ (30%) to the question. A further 31% indicated that their relative died suddenly.
18. Eight out of 10 respondents (81%) felt that on balance, the hospital was the **right place for the person to be cared for during the last days of life**.
19. Seven in 10 respondents (69%) reported that their relative **died in a single room**. For one quarter (26%) this was not the case. This is an area where there are differences between the two hospitals.
20. One in five (21%) indicated that a **single room was not available**, 19% responded that they did not expect their relative to die and only 2% reported that their relative did not want to die in a single room.
21. Over two thirds (69%) of respondents reported **enough privacy in the last two days of life**. However, 18% indicated a lack of privacy.
22. One in 4 people (24%) did not have **access to a family room**. 71% of those who had access to a family room found this helpful.
23. Eight in ten (81%) respondents **visited** their relative **outside regular visiting hours**. However, 17% responded that they were not informed about the option of visiting outside regular hours but on reflection would have liked to avail of this.

24. Almost half (49%) of all **relatives stayed overnight** and found it helpful. 11% of respondents said they would have liked to stay but were not informed about this option.
25. Nearly seven in ten (69%) respondents reported that they had definitely been given **enough support at the time of the death**. A further 24% reported this to be true to some extent.
26. The majority (95%) of respondents reported they were **cared for sensitively** after their relative died. However, 4% indicated this was not the case for them.
27. Just over half (54%) of respondents indicated that they did not receive an **information leaflet about what happens after the death of a relative**. 39% indicated that they found the leaflet to be definitely helpful or helpful to some degree.
28. One out of six respondents (17%) indicated that they **spoke with a healthcare professional** from the hospital **about their bereavement** and found it helpful, while 29% stated that they hadn't but would have liked to.



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## 3. Qualitative findings

## Qualitative findings

Bereaved relatives were given the opportunity to tell, in their own words, how they experienced the care of their relative during the last admission to hospital. The qualitative component of the survey tool consisted of three open-ended questions as follows:

1. *What, if anything, do you feel was good about the care?*
2. *What, if anything, do you feel was bad about the care?*
3. *Please use the space below if there is anything more you would like to add about the care provided by the hospital to your relative/friend during their last admission.*

Of the 356 relatives who completed the survey, three quarters (75%: n=268) availed of the opportunity to respond to at least one of the three open-ended questions.

Three quarters (75%: n=268) commented on some aspect that was good about the care. Forty-seven percent (n=166) responded to the second question *What, if anything, do you feel was bad about the care?* However, 58 (16%) of those who answered this question indicated clearly that they experienced nothing bad about the care their relative received.

Finally, 163 (46%) relatives provided additional comments on the care provided by the staff during their relative's last admission to hospital.



Qualitative data were analysed thematically using a template analysis framework approach<sup>28</sup>. Five key themes emerged as detailed in Figure 35. These include, meeting care needs, dignity and respect, communication, hospital environment and support for relatives. Findings from each of these themes are reported in this chapter and are underpinned by respondents' quotes. Due to the volume of comments, only a selection of quotes for each theme is presented in this report. The comments provided by a single respondent may be relevant to several themes and are reported where appropriate.



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**Figure 35: Qualitative findings – key themes**



## Meeting care needs

A large amount of data was coded under this theme, resulting in the emergence of seven subthemes:

- Personal care
- Staff skills and availability
- Pain and symptom management
- Nutrition
- Emotional and psychological support
- Spiritual support
- Access to specialist palliative care

### Personal care

Some relatives believed that the patient's personal care needs had been well met with a high standard of care and attention provided, as the examples below illustrate:

- “*The (name of ward) care was outstanding when he was transferred there following a procedure to insert a tracheotomy tube to aid breathing.*”
- “*I have no complaints about the staff who all did their best to give my mother the best care possible in her last few weeks. The nurses and care staff always treated her well and not in a patronising manner.*”

However, some relatives felt that care could be improved and this is reported in the next subtheme.

### Staff skills and availability

Many relatives remarked specifically on the high skill level of staff members and particular mention was given to staff from different disciplines and their skills, compassion and dedication were highlighted. The quotes below are a small sample of such comments:

“As I’ve said throughout this survey I am amazed by the dedication, empathy and patience of doctors, nurses and ancillary staff...My family could not fault our experience at all.”

“From my long stay with my relative, which was for 5 months it was very obvious there was a shortage of nursing staff, even so the nurses gave all they had and more. They were loving and kind to all the patients, even the difficult ones. They work very long hard hours. I would like to say thank you to all involved in my relative’s care.”

“The care in A&E was outstanding. The doctors and nurses on the day shift kept an eye on my mother and made her last days comfortable.”

It is clear from the quotes above that the high skill level and dedication of staff left a significant impression on relatives. Comments also illustrate that all staff, with whom patients and families come into contact have an influencing role on the quality of a patient’s end of life journey and care.

The positive impact of therapeutic relationships between staff and patients was also highlighted by relatives, for example:

“The week spent in (name of ward) was the only time we felt he was being well cared for as we had the opportunity to build relationships with the staff there and they built a relationship with my dad.”

It appears that the strong relationships, which often developed between staff and patients, were a source of great comfort and reassurance for many relatives.

Other relatives had a less positive experience of staff skills and many reported dissatisfaction and concerns about standards of care. A strong recurring theme, within relatives’ responses relating to care provision, was the evident lack of sufficient staff and staff working under difficult working conditions.

“We felt the nurses were very overworked and just didn’t have the time to give my father the attention he needed and he was reluctant to ask/bother them.”

“I felt the nurses were also supportive, despite the fact that they are under such pressure due to staff shortages.”

“Because my mother was in a room by herself because of infection. She was left by herself for long periods of time because of staff shortages.”

While many relatives praised the high skill level of staff and their ability to meet care needs, some relatives indicated that care could be improved. Relatives cited staff shortages repeatedly as impacting on the provision of patient care.

### **Pain and symptom management**

Findings show that many respondents indicated that the patient's pain was well managed. This is displayed in the following comments:

“*They managed her pain as well as they could and her palliative care nurse was extremely kind and always explained things to my mother.*”

“*She was made comfortable with pain relief as she was in terrible pain and this obviously gave us some comfort at a terrible time.*”

There were, however, negative comments relating to the management of physical symptoms. These focussed on times when pain did not seem to be managed well or when a patient's care needs did not appear to be fully met. One relative commented about care after surgery stating that “*the skin got broken*”, and expressed dissatisfaction that this was not communicated to them until witnessed. Another relative reported nursing staff's slow response to managing symptoms “*it took ages before they responded.*” Relatives also commented that at times what they perceived as unnecessary and burdensome interventions continued when the person was dying.

Findings suggest that while pain is managed well for the majority of patients, for others, it does not appear to be the case.

### **Nutrition**

Several relatives commented on different aspects of patient nutrition. While some relatives reported satisfaction with the quality of food:

“*The food looked tasty and nutritious.*”

Other relatives expressed dissatisfaction and noted the poor choice or quality of food provided:

“*There was also a very limited range of food available for “soft diets”. It wasn't easy to bring in your own food, nowhere to re-heat anything.*”

Relatives also highlighted that patients were at times not given the help and support they required during mealtimes:

“*...patients should be treated with more care, especially at meal times when some of them are unable to eat unaided.*”

One relative did comment on the “*willingness of the canteen staff to go the extra distance to help find something mam could eat.*” Relatives also commented on the importance of monitoring patients nutritional intake.

The majority of comments in this subtheme related to the need for greater support and assistance with the provision of meals and nutritional care for patients.

## Emotional and psychological support

Positive comments relating to the management of emotional and psychological care needs at end-of-life were expressed by several relatives. One relative said that the staff were *"...exceptional in understanding mums fear of death and being alone and permitted visiting outside of hours especially in her final days."*

Another stated that *"... all their team went beyond the call of duty to ensure our mother and all our family were comfortable emotionally and physically."*

One relative noted the importance of the emotional support provided by hospital staff and the positive impact this had on the family:

“*Nurses, carers, staff and doctors were truly excellent with our father. Their genuine concern and tenderness was above the call of duty ... the carers maybe just held his hand and consoled him and told him things would be OK. This meant so much to my family...we will be forever in the nurses and staff debt...*”

Another relative commented on the support staff provided:

“*(Name of person) was very frightened and insecure, they recognised this and treated him with respect and understanding. They came to know me by name and as I was still working fulltime and would wait for me to arrive from work to give me a daily report and sometimes a hug for which I will be eternally grateful.*”

However, several of the comments relatives made about the management of the emotional needs were negative in tone and referred to ways in which hospital staff failed to address patient care and relatives' concerns. Other comments reflected the psychological distress caused by staff communications and the care environment.

“*The fair deal scheme discussions put undue pressure on the situation. Just a few weeks before death there was still talk of taking him home or putting him in a home adding to the stress of the situation when we knew at that time that he was probably going to go to a hospice and die.*”

From some relatives' perspective, the provision of appropriate emotional and psychological support was not always achieved resulting in some patients and their relatives experiencing upset.

## Spiritual support

Several relatives commented on the spiritual aspects of care in the hospitals. Those that highlighted a positive experience, referred to the important role played by the chaplain or pastoral care worker in the spiritual care of patients at the end of life and the recognition of patients' needs in this respect. One relative stated *"... [the] chaplain was excellent after my relative's death prayerful and consoling."* Another stated, *"...spiritual care was very good which was very important to my husband and myself."*

A small number of relatives noted their negative experiences of spiritual care during the patient's last admission. The emphasis here was on the lack of consideration of the patient's wishes and beliefs regarding spiritual and religious matters. The importance of spiritual care for some patients was not always acknowledged.

“*Maybe there could be a little more spiritual needs for patients across all cultures and a proper room or oratory available to all.*”

Findings suggest that spiritual care is considered an important aspect of end-of-life care that is not always fully considered and responded to appropriately by hospital staff.

### **Access to specialist palliative care**

Many relatives commented on palliative care provided to their relatives. Some relatives had an extremely positive experience of the specialist palliative care team's involvement and valued the expertise and unique skills which this team could offer:

“*... Towards the end, the last 5 days, the palliative care team, dealt with us (family) in a totally professional and gentle manner. This was our first time dealing with a relative with a terminal illness in a public hospital and we were very impressed with the staff and level of care provided.*”

*“The palliative care team were particularly helpful in every way, explaining her options in detail, arranging a private room straight away, and unrestricted visiting.”*

*“When the palliative care team in the hospital joined forces with it all, it was even better. They get her back into PJs, she was less a patient, more a cared for as a human being who was very ill.”*

However, some relatives expressed surprise and dissatisfaction that there was no access to specialist palliative care at the weekends.

“*I found it strange that the “hospice team” did not work weekends!!! This makes no sense at all. My mother died on a Sunday and we could have done with their support instead we had a weekend staff who were awkward dealing with the situation.*”

*“It is not adequate to provide palliative care on a 5 day a week basis. It is a very specialised knowledge and it cannot be expected that mainstream doctors are adequately trained for the situation. In my view it is imperative that palliative care be available 24/7.”*

Relatives therefore strongly believed that specialist palliative care services in hospitals should be accessible outside core working hours and that there should be no restriction to this service at the weekend.



## Dignity and respect

Findings under this theme are reported under two themes, dignity and respect and kindness and compassion.

With regard to dignity and respect, many positive comments were recorded. Relatives referred to the impact that dignity and respect shown to patients had on their overall hospital experience. The examples below highlight this:

“*The most impressive aspect was the degree to which the team made us feel that our Mother’s wellbeing was important, that our feelings were respected and there was a real sense of staff caring and not viewing the situation as “one of many cases” – which of course it was.*”

“*The care, respect and dedication of all of the healthcare staff during dad’s last admission meant we could go home after every visit happy in the knowledge that, although gravely ill, he was comfortable and very well cared for.*”

However, in contrast the following comment illustrates where a relative believed dignity and respect was lacking:

“*We argued that she as a person deserved her dignity and privacy around herself in the last hours of her life. We also felt that it was not fair to either her large family or the other ward patients that my mother’s final hours be lived out on a hospital ward.*”

It seems that while there are many occasions where staff treated their dying relative and their family with dignity and respect, there were also occasions where relatives felt that this was lacking in the care provided.

### Kindness and compassion

There were many positive comments about occasions where kindness and compassion was displayed to patients and their relatives. These comments focussed mainly on the attitude of staff and their professionalism and the ways in which they engaged with patients, their families and friends. This can be seen in the selection of comments below:

“The team that sat and prepared us for [the] death did so with care, empathy, that went far beyond their daily job.”

“He was called by his name, his name was used when carrying out any procedure, even though some of the time he was unaware. The staff ... were kindness itself. We can never underestimate the power of kindness.”





## Communication

This theme centred on good and poor communication. It explored relatives' experience of communication with the patient and family and within the multidisciplinary team. While this section reports on findings specific to communication, the issue of communication also threads through most of the other themes in this report. This indicates that communication significantly impacts on all aspects of end-of-life care.

### Good communication

Many relatives highlighted good communication practices both by individual staff members but also within and across multidisciplinary teams to patients and their family members.

“The care and attention shown to my brother was excellent. At all stages of his illness we were kept informed and that was important to me, my wife and family.”

“His consultant and her team were very, very good to us. They took time to explain things to us which was a comfort before and after his death, we felt that we knew what was happening and that he was getting the best possible care. This helped us after his death, as we didn't feel guilty, that enough wasn't done for him. We felt so strongly about this that we requested donations to the hospital foundation instead of flowers.”

“There was always someone on duty to explain to us what was happening at all stages of his illness and eventually his death. This is a great comfort when you know your loved one is about to die. And it helps ease the pain of knowing they are going to pass away.”

“If our family had any questions or concerns – we found the nurses to be very helpful, informative and approachable.”

Many relatives had contact with staff who communicated in a timely, sensitive and compassionate manner both to patients and their family members; this was a great source of comfort to relatives.

### Poor communication

Poor communication was frequently mentioned by relatives in their feedback, including lack of sensitive and compassionate communication by hospital staff.

“Consultant was not very compassionate his attitude was very blunt.”

*“The Dr taking care of my mother’s needs, came into the room where she was lying still alive, and spoke over her bed telling me that there was no more they could do for her and they made her comfortable. My mother was still awake and listening to all this. I think maybe he should have called me outside to tell me this.”*

*“Regarding the care my dad received. I feel it was excellent but relaying of information to relatives was poor at times.”*

Others would have liked to receive additional information around Garda Síochána identification at time of death, information about post-mortems examinations and autopsy results. One relative explained that without the thoughtfulness of one consultant, who came to the hospital on his day off to authorise the release of the deceased patient, their relative would have otherwise remained in the hospital mortuary all weekend.

Lack of communication or information being conveyed in what was deemed an inappropriate manner was also reported:

“...staff never appeared to have any time, a small number of staff took time to talk to my Dad, no conversation appeared to have been about his diagnosis/illness. I appreciate there are a lot of constraints on staff but surely it’s important to get the basics right.”

*“He was told his diagnosis and no family were present to support him.”*

Relative’s comments indicated that communication of information in a supportive, timely and regular manner could be improved.

### Patient preferences and shared decision-making

Several relatives made comments relating to patient preferences and their experiences of shared decision-making during the patients’ last admission to hospital. A number of positive comments were made and referred to hospital staff taking the wishes of the patient into consideration when determining treatment.

“I knew she was quite ill, the doctors took the time to meet with us and explain the current situation, the options, prognosis and also that they had spoken to my aunt for her wishes.”

Negative comments focussed on failing to keep relatives informed and not seeking their input to ensure patients’ preferences could be adhered to where possible.

### Coordination of care

Many relatives commented positively on the coordination of care within and across multidisciplinary teams:

“*The various teams of people who were involved in his care were a credit to themselves, their families and the hospital.*”

However, some relatives commented on a lack of coordination of care and communication within and between teams.

“*The only thing I found difficult was what I saw as a lack of communication between teams and on several occasions the morning team came and informed my husband what was to be done and then evening team sometimes came and told him the opposite.*”

A further issue which was evident in the negative comments relating to coordination of care was the matter of transfer of patients between wards. Relatives stated that communication between wards, staff and relatives was at times less than ideal.

“*I think the transitioning from ICU to regular wards could do with a little finesse in relation to communication with families.*”



## Hospital environment

Findings under this theme are reported under four subthemes:

- Care in a single room
- Hospital facilities
- Route of admission
- Atmosphere in the ward and single room

### Care in a single room

Privacy was viewed as a key factor influencing a patient's end of life experience. The importance of having access to a single room is highlighted in the comments below. Relatives indicated that privacy was very important to them, making for a better overall hospital experience.

“As mam deteriorated she was transferred to a private room with an ensuite. Here we were offered as much access to mam and could stay overnight if we wished.”

“They allowed us stay with our mother, there was no single room available but the staff went over and beyond to get us a single room for the last two days of her life.”

Other relatives indicated that as they were in a shared ward, they had to be mindful of other patients and this lack of privacy was distressing for them:

“It would have been less distressing for all if he had his own room earlier. We were trying to keep him calm and other people on the ward were not that sick. I could never complain about this care as it was 100% excellent.”

Other relatives who were unable to access a single or family room explained how this significantly impacted on their relatives' quality of life in a negative way during their final days. One relative commented on the noise in the ward made by staff and other visitors on the day of their family member's death:

“*During the day, when mam was in effect dying I found it hard to hear other peoples visitors laughing and Hoovers, cleaners shouting....We were really hoping that we could have a private room. Two hours before mam died, we moved into a two-bedded room. It was better than being in the six- bedded ward but still far from ideal. Not only for us, but for the poor woman who mam had to share with. I was grateful that mam died at midnight and the lady was asleep and the place was quiet and mam had a most beautiful death.*”

It is evident that without access to a single room, patients and family members were unable to spend treasured time together or to say their final goodbyes in a private, relaxed and comfortable way.

### **Hospital facilities**

One relative stated that the *“facilities were good, clean and modern”* and another noted that *“the facilities are world class... and kept in excellent condition by the staff in terms of hygiene etc.”*

However, other comments were negative in tone and focussed on the suitability of the hospital facilities, hospital hygiene and experiences in the Emergency Department. Two examples of a relatives' experience are set out below:

“*The hospital should have a warm, airy environment for all their patients; some of the wards are a disgrace. The first thing you meet in some wards are large bags of dirty laundry waiting to be collected, which does not help the air quality.*”

*“Knowing that our mum may not make it and waiting in that HORRIBLE waiting room outside of ICU added to our trauma it was cold and uncomfortable, while we waited for more information on our relative, it was totally impersonal. It was nothing to do with staff, care or anything else, we knew mum was being looked after to the best of their ability.”*

### **Route of admission**

Relatives reported that accessing beds for terminally ill patients was often problematic, particularly as the only process for admission to hospital, even for patients who were well known to the hospital, was via the Emergency Department. Relatives reported that this experience was often extremely stressful and that the Emergency Department was not a suitable environment for terminally ill or older patients to await admission. The comment below describes one relative's concerns:

“*As he (name of person) was diagnosed as a terminally ill patient, he should have been seen straight away by a doctor from the team that looked after him. I think the hospital should really consider their procedures surrounding admittance of terminally ill patients.*”

One relative questioned the appropriateness of an elderly, sick person being transferred to the acute hospital setting from a long stay facility:

“My uncle was in (name of hospital) and had to be transferred back to (name of hospital) when he deteriorated he had to go through A&E which I felt was completely inappropriate for someone so ill, who had been referred by the consultant... It should have been possible to organise a ward to ward transfer.”

### **Atmosphere in the ward and single room**

Many comments highlighting the positive experiences of relatives were recorded under this sub-theme. These mainly referred to the general atmosphere in the ward or room.

Relatives commented on the atmosphere in the wards or rooms of the hospital as being ‘ideal’. Other comments express relatives’ views on this:

“The staff made the atmosphere in my relative’s private room very serene! They came in when necessary and carried out their duties in a very unobtrusive way.”

“It was a nicer atmosphere and the aesthetics of the unit was better. In the [other hospital] my mother had a view of a brick wall for weeks on end. In [this hospital] she could see grass and trees.”

Other relatives did not share the same experiences; they acknowledged that the environment is an issue in hospitals and highlighted the impact of the atmosphere on their hospital experience.

“I realise that the hospital is understaffed and lacking in facilities, space is also an issue, e.g. for someone in my mother’s position lying in a ward in an acute hospital... I am not in any way criticising the nursing/medical staff who did their utmost with what they had to make the position bearable.”



## Support for relatives

Data relating to various kinds of supports are reported under seven subthemes:

- During the stay in hospital
- Access to a family room and overnight accommodation
- Unrestricted visiting and affordable parking and ease of access
- Support at the time of death
- Bereavement support
- Support from the social worker
- Benefits from taking part in the survey

### During the stay in hospital

Comments made by relatives highlight the support received from hospital staff. Relatives appreciated the “*courteous and sympathetic attention*” that was given and being allowed to spend precious time with their sick relative.

“ *It meant so much to be able to hold his hand and reassure him; staff were always on hand to help me cope when things got bad and I was feeling overwhelmed.*”

*“We were offered tea and coffee – and even food on a regular basis – which was so greatly appreciated. As we never had to leave my relatives’ bed side and for that we are eternally grateful.”*

Other relatives reported situations where staff displayed great sensitivity and thoughtfulness:

“ *The doctors and nursing staff were very sensitive when telling us the difficult news that my mother was going to die. The staff in [name of ward] particular were amazing and as a family it was helpful to be with mum the whole time. We were very lucky that my mother was given a room of her own...*”

One relative stressed that the hospital care was “*excellent*” but felt that “*some more consideration for family feelings and queries would help...*”

Another respondent stated “*I did not know who to approach re: telling my husband he was dying, I knew years ago the ward sister was the guide for this. I did seek advice from a lady ... and her most unhelpful answer ‘just ask him if he has anything he wants to say to you’...*”

### **Access to a family room and overnight accommodation**

The large number of comments about family rooms reflects the importance relatives placed on this resource. Relatives identified them as a crucial resource, greatly enhancing their care experience.

Having access to a family room was ‘*useful*’ or ‘*vital*’ allowing privacy and unrestricted visiting for which families were grateful.

“*The family room was very useful. We were able to visit dad outside visiting hours which we really appreciate now as we didn’t realise that this would be his last month.*”

“*His care in [name of ward] was exceptional, and the staff there were nothing less than professional, attentive and compassionate. The family room was an invaluable resource.*”

“*I am type 1 diabetic and anything I need food etc. was brought to me. I really feel very strongly about having the family room.*”

“*We were hugely grateful for the use of the family room and for the chance to be with my husband as a family in his final days. As a large family, our presence in the ward was tolerated in a very compassionate manner for the most part by the nursing staff. For this we are extremely grateful.*”

The following comments acknowledge the importance of having access to a family room but highlight the need for adequate facilities in the room.

“*The family room was vital to us. There could perhaps be a little more practical help e.g. food storage/tea/coffee making facilities in family room, but again in an ideal world.*”

“*Family room is a benefit but in this case the room was full of old furniture and not very comfortable and two families waiting at a time which limited privacy.*”

“*Family room could have been brighter and fresher. Furniture was smelly and uncomfortable.*”

“*If the family room had a bed settee that would be great for an overnight stay when a patient is dying.*”

The importance of having access to family rooms and the impact on families when the rooms are not available is reflected in the following comments:

“The family room was a great asset but on one ward it was not always available as staff used it for case conferences.”

“There was no room available for us, we sat outside on the wooden chairs by the lift outside CCU we watched the crash teams go down the corridor only for the nurse to redirect them to mam’s room we also watched as the chaplain went in and then left.”

The challenge of finding a private space in which to have difficult or potentially distressing conversations with the medical team was noted by several respondents:

“The consultations about the condition of the patient was very informative. We did not like the fact that the consultations were held in the corridors, was not the best or most comfortable place but the doctors could only use what space was available.”

“Little privacy, doctor found it hard to find a room where they could talk to me about my brothers condition. A lot of noise around the area with other things going on when my brother was dying.”

For the relatives in this study, having access to a family room positively impacted on their end-of-life care experience in an acute hospital. However, relatives indicated the need for dedicated, accessible family rooms with appropriate facilities on hospital wards.

### **Unrestricted visiting, affordable parking and ease of access**

The issue of unrestricted visiting was raised by relatives and their comments emphasise the stress felt by family members who were “not given the opportunity to visit outside of visiting hours.” In some cases, out of hours visiting was allowed but relatives were not made aware of this:

“I would have liked to have visited outside of regular visiting times.”

“I don’t like to criticise hospital staff they do a great job, but as I said earlier I didn’t know I could visit outside visiting hours... If I was made aware of how ill he was I’d have stayed.”

For several relatives, problems with car parking caused additional stress at what was a very difficult time for them. They suggested that the cost of parking in hospitals was too high and that while in certain circumstances, assistance was available, they were not made aware of this. This is highlighted in the comments below:

“The cost of parking was outrageous. Given that we were there for 11 weeks, it would be nice if family members could get some help with this cost.”

“I was visiting the hospital every day for 8 months, and using the car park. Very expensive as you can imagine. I was told there was a form I could get from the nurse manager that would limit the cost to a certain amount per day. It would have been a good saving for me ... I asked numerous times for the form but never got it. I gave up in the end!”

One relative also noted that when she was called to the hospital late at night, the “... entrance appeared closed; there was no security staff present... I then had to go to A&E and find someone to show me how to get to the ward, I lost about 15 mins in time and I will never know for sure if it would have meant I would have been with my relative when she passed.”

### Support at the time of death

Comments made by respondents about their experiences after the death of their relative were mixed. Relatives described the support they experienced in the following ways:

“I felt that even though in the last 24 hours we were all aware that my husband was brain dead, but there was no drop in standard of care that he received for that I am extremely grateful. Also the time we were given when the machines were turned off and disconnected was needed by all his family this was so sudden.”

“Everyone at the Hospital was very nice, they contacted for me anyone I had to call “family” to tell them what had happened. They contacted a priest who set up a table with candles etc. so when he arrived he could guide me ... They were very sympathetic. They brought the body out with a curtain around so I could be with him and grieve which was what I needed at the time...”

Other relatives had a less positive experience, one relative commented about how they were informed about the person dying:

“The lady that rang me told me that he had ‘expired’. I had to ask her a few times what she meant. I know she did not mean it to upset but it’s not a good word to use when it’s a loved one. It’s not a big thing but my mum was next of kin and if she got the call she would have found it hard.”

Others commented on the upset caused by not being able to view their relative's body in the hospital mortuary for two days over the weekend. Another commented:

“My mother died on New Year's Day, day staff were unaware of procedures regarding the mortuary on a bank holiday. This was really distressing and no help was offered just told to phone mortuary the next day.”

Another relative reported that they would have liked to have “been assisted with the paperwork after his passing. The issue with the signing of his death certificate was very distressing and just added to our anguish.”

It appears that some relatives did not believe that things always happened in a timely manner and that they did not always receive the information and support they required.

### **Bereavement support**

Several relatives reported that they received a letter offering “bereavement counselling”. Others were appreciative of the sympathy displayed by the hospital whether in person, by a letter or card or remembrance service:

“The information given to myself and my family after my brother died was helpful. The bereavement service six months after my brother's death was helpful to myself and my family.”

“...they couldn't do enough, explained everything all levels of staff called in to sympathise and chat and to help in any way they could.”

“Receiving a hand written sympathy card from the sister in charge of his care was very special. It was personal and comforting.”

“A big thank you to all the staff in (name of hospital) and for such a lovely remembrance service.”

Other relatives commented on having accessed bereavement counselling offered:

“Had six sessions with the Bereavement Counsellor received from the Hospital.”

“The hospital has dealt well with bereavement services. The loss was so great I was unable to avail of it.”

One relative described what she thought was “exceptional” bereavement support that she received:

“I have to say that the aftercare that I received when I arrived at the hospital was exceptional, especially from the nursing staff. I was contacted the next day by a bereavement counsellor who was more than helpful and continues to support me six months later. Outstanding work by all in an extremely difficult situation.”

Several relatives highlighted bereavement support that they would have liked to receive from the hospital. These included, timely bereavement information, follow up contact from the bereavement counsellor in the hospital (for example, three months' post-bereavement), the provision of a memorial service, provision of links to people who have experienced a similar bereavement and information regarding supports and entitlements available to the bereaved.

“I did not get the help I needed at the proper time – no social worker...I live alone, no relatives. Had to do all myself with the help of a friend.”

“I received an invitation to bereavement support evening, but at the time was unable to take up the invitation. I would now like to go to such an evening.”

“...I did not receive any advice or help with my situation after the death...no advice while he was in hospital ...as to what my entitlements might be...no bridge between being a carer after such a long time and what I would do with myself following the death.”

This relative was left with unanswered questions:

“On the one hand we were told that his heart had given up, however his death cert makes no reference to heart failure or such like ... the communication channels which we encountered were disjointed, leaving some of us with some information whilst others got none. It would have been beneficial to have had a family meeting with dad's care team to have things explained to us all, therefore leaving us with no doubts or misunderstandings of the situation.”

### Support from the social worker

A subtheme to emerge was that of the role of social work in providing support to family members.

Many relatives acknowledged the help and support which the medical social worker was able to offer and the useful role of family meetings in providing information and facilitating decision-making:

“Also I'd like to thank the social worker who liaised with us regarding home care etc. but unfortunately my mother's condition deteriorated pretty quickly once diagnosed.”

“Everything was explained to us at a few family meetings.”

Other relatives expressed their frustration at being unable to access social work support or the difficulties they experienced in trying to get an appointment to see the social worker in a timely manner.

“I don't feel I was prepared for when she came home for the last time (approx. 5 weeks before her death) I had to research myself on how I might get some support and about things like walking frame/commode myself. I just felt that a call from a social worker might have pointed me in the right direction ...”

Relatives appeared to have mostly positive experiences when they could access support from a social worker. Some relatives however, were unhappy that they were not able to access help from a social worker, in a timely manner when they felt they really needed it.

### **Benefits from taking part in the survey**

An unexpected finding was that relatives spoke about the cathartic process of completing the questionnaire. It gave relatives a 'voice' to describe their experiences; provided an opportunity for reflection and many gained support from taking part in this process.

Some relatives reported appreciation for the opportunity to express their gratitude to the hospital for their *"dedication and professionalism"*, while others used the survey to *"express their feelings"* about aspects of end-of-life care provided to them and their relatives:

“*I would like to express my gratitude to the staff in the hospital for the care they gave my mother. It wasn't perfect but it's not easy in these situations.*”

*"Thank you all so much, sorry I took so long to fill these in, it was hard to actually sit down and make myself do it. Many thanks to everyone at (name of hospital)...I have made a point of telling everyone I know about our experience and we continue to sing the praises for your great work. We need more places like this in our country."*

*"I think this survey is a great idea..."*

*"... I am glad to have this opportunity to fill out this questionnaire, so that I can express my feelings."*

It appears that some relatives welcomed the questionnaire as an opportunity to report on their experiences and that of their relative who had died. It was viewed as an opportunity for their voices to be heard on their end of life hospital experience:

“*I understand that this survey has little to do with the prescribed treatment of our mother and how it affected her. It is however the only platform we have had so far to state our feelings on this matter.*”

*"... I'm glad this survey booklet came out to me as it's a chance to express the positive feedback about her time in hospital while dealing with a terminal illness...It's also a good chance to raise any issues that caused upset or annoyance to the patient or the family during her stay or after her death. It's been therapeutic to complete this survey, knowing that it's been taken into account at some level and may contribute to improving services in the future. It confirms the positive areas at work every day that make such a difference to both patients and families."*

## Qualitative summary findings

1. The high **skill level and dedication** of staff left a significant impression on relatives. It was evident that all staff, who patients and families encounter, have an influencing role in a patient's end of life journey and care. Often strong **relationships developed between staff and patients** and were a source of great comfort and reassurance for many relatives. Other relatives reported some concerns about aspects of care and some associated this with a lack of sufficient staff.
2. Many relatives indicated that the patient's **pain was well managed** and the patient was well cared for, however, care needs did not always seem to be fully met. Relatives indicated that the **management of psychological and emotional** needs in line with patient preferences at end of life could be improved. In addition, **spiritual care** was seen as an important aspect of end-of-life care that is perhaps not always fully considered and responded to by hospital staff.
3. Relatives expressed their satisfaction with support received from **specialist palliative care**. However, relatives also believe that specialist palliative care services in hospitals should be accessible outside core working hours and that there should be no restrictions to this service at the weekend.
4. Most relatives were treated with **dignity and respect** and experienced **kindness and compassion**. However, some families reported negative experiences.
5. Many relatives highlighted good **communication practices** both by individual staff but also within and across multidisciplinary team to patients and their family members. However, many were dissatisfied with the type and level of communication received. It would appear that **timely, sensitively communicated information**, which was conveyed in a supportive manner, did not occur for all patients and their family members.
6. Relatives indicated the need to provide them with verbal and written **information on 'what to expect when someone is dying'** and how they can support the dying person with personal care, emotions and spirituality. For some relatives this also included the need for **guidance on 'how to talk to their relative about dying'**.
7. **Coordination of care** was identified by a number of relatives as requiring improvement with specific reference to communication within and between multidisciplinary teams.
8. Relatives strongly endorse **care provision in a single room**. It is evident that without access to a single room, patients and family members were unable to spend treasured time together or to say their final goodbyes in a private, relaxed and comfortable environment.

9. Several relatives referred to the need for greater care and support being available at **mealtimes** and the need to monitor nutritional intake.
10. **Hospital facilities**, including the atmosphere in the ward and single room, were deemed important by relatives.
11. Relatives reported that the **route of admission** needs to be considered for terminally ill patients particularly as the only process for gaining admission to hospital, even for patients who were well known to the hospital, was via the Emergency Department.
12. The importance of having access to a **family room** on the ward to allow conversations take place with the healthcare team in private was commented on by many relatives. Relatives commented on the need for accessible, dedicated family rooms with appropriate facilities on hospital wards.
13. Access to **unrestricted visiting times** impacted hugely on the patients' and relatives' care experience. Relatives identified the importance of being able to visit outside of regular visiting hours, the need for staff to inform them of this option and facilitate access.
14. In many cases, hospital staff provided **quality care and support to the families** during the last admission, at the time of death and during their bereavement. However, there was evidence that some relatives did not experience adequate levels of support.
15. Several relatives indicated that all staff need to be knowledgeable about **what happens after death** and offered suggestions as to the information they required at this time.
16. Many relatives were appreciative of the **sympathy displayed** and **bereavement support** provided by the hospital staff whether in person, by a letter or card or remembrance service. Having said this, however, there was evidence of a lack of **appropriate bereavement support**. Several relatives highlighted post-bereavement support that they would have liked to receive from the hospital including timely access to a social worker for practical, emotional and psychological support.
17. In addition to nurses and doctors, several relatives highlighted the **important role** which **ancillary or non-clinical staff** such as healthcare assistants, porters and catering staff had in end-of-life care for patients in hospital.
18. Relatives reported **completing the questionnaire** as a cathartic experience; an opportunity to express their views about end-of-life care and others used it to express their gratitude to the hospital and staff.





# 4. Recommendations

# Recommendations

This study was conducted to establish the quality of end-of-life care provided in two acute hospital settings. The results indicate that the quality of care at end of life in the Mater Misericordiae University Hospital and St. James’s Hospital is high, with eighty seven per cent of respondents rating the overall quality of end-of-life care received by their relative on the last admission to hospital as outstanding, excellent, or good. This reflects well on the quality of care in both hospitals and compares favourably with research conducted on the quality of end-of-life care in acute hospitals internationally<sup>21,24</sup>. However, bereaved relatives also indicated elements of care which could be improved. The fact that so many relatives rated the care highly allows both hospitals to build on this high standard of care whilst ensuring that improvements are made to the elements of care where weaknesses were identified.

Findings from both hospitals are broadly similar and where there were differences, these reflected a hospital’s particular emphasis and focus on improvement, for example, the allocation of single rooms for dying patients.

The findings provide clear pointers to areas for improvement and a continued focus on end-of-life care service development. The recommendations are applicable to a wider audience, other than the hospitals in this study, including healthcare settings involved in the provision of end-of-life care and statutory and voluntary agencies. The recommendations based on the results of this research are outlined below.

## Meeting patient care needs

### 1. Personal care

Whilst most respondents (73%) believed their relatives’ personal care needs were met by hospital staff, some relatives indicated that personal care needs were not always met adequately and suggested that this may have been due to the lack of staff or to over stretched staff. Several relatives referred to the need for greater care and support being available at mealtimes. These findings reflect challenges of staffing across acute hospitals that are well documented in the public arena<sup>45,46</sup>.

#### **Recommendations:**

- Care needs should be reviewed and addressed to ensure that patients at end of life can access sufficient help and support with personal care needs, toileting and assistance during mealtimes.
- Hospitals need to prioritise initiatives to improve choice, timing and support for nutrition at end of life.

## 2. Pain and symptom management

Assessment and management of physical pain and symptoms other than pain is a major focus of end-of-life care. Four out of five (79%) relatives reported that the person's pain was relieved in the last two days of life. Relatives commented on how well pain and other symptoms were managed. However, relatives also suggested the need to have access to specialist palliative care outside core working hours, that is, after 5pm and at weekends. Some relatives referred to what they perceived as unnecessary and burdensome interventions being continued, which they believed did not improve the dying person's care or comfort.

### Recommendations:

- Hospitals need to review how they manage the multiple and more complex care needs of dying patients. Consideration needs to be given to how those needs are specifically addressed out of core working hours.
- The route of admission for terminally ill patients via the Emergency Department to acute hospitals in Ireland needs to be reconsidered.
- The availability of on-site specialist palliative care staff outside core working hours needs to be considered.

## 3. Emotional support and spiritual support

Provision of emotional support and spiritual support to dying patients and their relatives in accordance with their wishes and beliefs are integral to good end-of-life care. Respondents deemed this aspect of care important and reported that healthcare staff met patients' emotional needs (56%) and spiritual needs (61%) at an excellent or good level.

### Recommendations:

- All hospital staff involved in direct care require the skills to improve the provision of emotional and spiritual care to patients at end of life for instance through the adoption of the *Palliative Care Needs Assessment Guidance*<sup>53</sup>.
- Hospitals need to review how they can better enhance the provision of emotional support and spiritual support for patients and families.

## Patient preferences and shared decision making at end of life

Most respondents (81%) whose relative died in hospital believed that on balance this was indeed the right place for their relative to die. However, some commented on lost opportunities to plan, have conversations with loved ones and discuss their preferred place of care at time of death.

### Recommendations:

- Healthcare staff need to proactively engage in earlier conversations with patients and families about advance care planning and end-of-life care preferences.
- Hospitals need to ensure, as a matter of policy, that all members of the multidisciplinary healthcare team know and record the patients' preferences, and incorporate them into decision-making.
- Healthcare staff need to normalise conversations on dying and death and facilitate individualised advance care planning in an effort to meet patient preferences. For instance the use of the Irish Hospice Foundations '*Think Ahead*' form<sup>54</sup> or other such initiatives could assist advance care planning conversations.

## Communication

Many bereaved relatives reported that hospital staff communicated in a kind, compassionate and caring way to them and their deceased relative. However, relatives also suggested room for improvement. This is despite several national and local initiatives to promote better, clearer and more sensitively delivered information in relation to dying, death and bereavement.

### Recommendations:

- Hospitals must develop strategies to address the communication issues raised in this report, encompassing how to deliver sensitive news in a timely, sensitive manner including how information is conveyed about diagnosis, prognosis and plan of care.
- Healthcare staff need to consider how they can improve the provision of verbal and written information about what to expect when a person is dying.
- Hospitals need to review existing communication training programmes to address the findings in this report.
- Hospitals should consider mandatory training initiatives specifically relating to communicating sensitive news.
- Hospitals need to improve communication with families about what happens after death, including information about post-mortem examinations.

## Care environment at end of life

### 1. Care in a single room

Seven in 10 respondents (69%) reported that their relative died in a single room. For one quarter (26%) this was not the case. Relatives strongly endorsed the importance of end-of-life care being provided in a single room. For relatives, this offered privacy and permitted extended visiting while for patients, it allowed for the supportive presence of family members.

#### Recommendations:

- Hospitals should ensure timely provision of a single room for end-of-life care in line with patient preferences.
- Hospitals need to prioritise patients who come through the Emergency Department and are actively dying, to access a single room.

### 2. Improving the hospital environment

The importance of having family rooms on acute hospital wards and the need to consider the broader hospital environment was highlighted. Respondents commented on experiences of being told bad news in open corridors, which lacked privacy and where they were exposed emotionally to other relatives and hospital staff.

#### Recommendations:

- Hospitals should ensure the provision of family rooms to support end-of-life care.
- Family rooms should provide access to free tea/coffee facilities and provide comfort for those staying overnight e.g. sleepover sofa or reclining chairs.
- Family rooms should be supplemented by the creation of well-designed informal gathering spaces in the wider hospital environment.
- Hospitals should have dedicated spaces on every ward where confidential and sensitive conversations can take place in private.

## Support for relatives

End-of-life care encompasses supporting both the dying person and family members. Relatives gave clear indications of the supports that should be available to them immediately, prior to and after the patient's death.

### Recommendations:

- Relatives need to be given opportunities to meet with the doctor and other healthcare professionals in family meetings to discuss advance care planning and end-of-life care in line with the patient's preferences.
- Doctors and members of the healthcare team need to initiate conversations about the possibility of the person dying and what to expect.
- Healthcare staff need to consider the support needs of relatives, specifically the provision of information to relatives on how they can support the person who is dying. This includes how they can support the person with personal care, and with emotional and spiritual matters, including how to talk to the person about dying if that is the person's wish and preference.
- Hospitals should have a policy of extended visiting for relatives of seriously ill and dying patients.
- Healthcare staff should make relatives aware of the option of extended visiting and staying overnight.
- Relatives should have access to free or subsidised car parking when their relative is nearing the end of their life.
- All bereaved relatives should receive practical information about what happens following the death of a family member in hospital, including bereavement support information.
- All patients and relatives should have timely access to a social worker in order to avail of practical, emotional and psychological support.
- Hospitals should review access to the mortuary over weekends and bank holidays for family viewing and release of remains.
- Hospitals need to ensure standardised post-bereavement supports. This entails sending sympathy cards, organising remembrance services or bereavement support evenings and providing support from a bereavement counsellor or social worker.
- Hospitals need to offer relatives the option of attending a bereavement evening at a different time if the relative is not ready to attend or in a position to avail of this support when initially offered.

## Education

End-of-life care training and education is extremely important to ensure that healthcare staff have the knowledge and skills to appropriately respond to and support seriously ill patients and their families. The findings speak strongly about the need to enhance staff skills and knowledge through education programmes.

### Recommendations:

- End-of-life care training needs to focus on the importance of providing a holistic, person-centred care approach to ensure the person's needs, wishes and preferences are met. This could be enhanced through the use of the model of care outlined in the *Palliative Care Needs Assessment Guidance*<sup>53</sup> and the *Palliative Care Competence Framework*<sup>37</sup>.
- End-of-life care communication skills training needs to be an integral part of continuous professional and educational development of all staff.
- End-of-life care communication skills training needs to be an integral part in the undergraduate and postgraduate curricula for all healthcare professionals.
- Ensure that all hospital staff, including administrative and support staff such as porters, catering and healthcare assistants receive appropriate end-of-life care training e.g. *Final Journeys*<sup>55</sup>.

## Surveying bereaved relatives

This study represents the largest survey of bereaved relatives conducted in two Irish acute hospitals. *VOICES MaJam* survey of bereaved relatives proved to be a meaningful method of evaluating the care at end of life in an acute hospital from the perspectives of bereaved relatives. The high response rate of 46%, the unanticipated volume of qualitative data and receipt of several positive comments about being surveyed indicate that bereaved relatives value being asked about their care experiences.

### Recommendations:

- Seeking the views of bereaved relatives should be considered by all hospitals and healthcare settings to ascertain the quality of care at end of life and to support the development of quality end-of-life care.
- Surveying bereaved relatives should be undertaken in a sensitive and structured manner. Supports should be put in place for all elements of the process to minimise the potential of causing distress.
- The *VOICES MaJam* survey used a quantitative approach including open-ended questions to survey bereaved relatives. This provided relatives with the opportunity to comment on their experiences of care. The results provide significant insights and context to the care experience, thus providing direction for quality improvements. This approach is therefore recommended if further research is being conducted with bereaved relatives.
- Surveying of bereaved relatives should be conducted at a national level to support benchmarking of end-of-life care quality improvement initiatives and collaboration between healthcare organisations.
- Structures and expertise are in place within Irish healthcare governance agencies and voluntary agencies to undertake such a nationwide survey. The National Patient Experience Survey undertaken by Health Information Quality Authority in conjunction with the Health Service Executive and acute hospitals is a good example of how a national survey of bereaved relatives could be undertaken in Ireland<sup>47</sup>.

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## 5. Concluding comments

## Concluding comments

The Mater Misericordiae University Hospital and St. James's Hospital are committed to providing quality care to patients and their relatives and have invested heavily in continuous quality improvements. While both acute hospitals focus on the diagnosis, treatment and cure of illness and the care and management of serious or chronic illness, their ethos has always placed end-of-life care as a priority. Over the past six years, the Mater Misericordiae University Hospital and St. James's Hospital have placed an increasing emphasis on improving the care at end of life through their participation in the Hospice Friendly Hospitals Programme.

Conducting the *VOICES MaJam* survey of bereaved relatives further reflects both hospitals' commitment to improve end-of-life care by seeking to ascertain the quality of care provided to patients during their last admission to hospital and to their families. To date, this is the largest survey of bereaved relatives undertaken in Ireland in two acute hospitals. The results of the study indicate the quality of care at end of life in the Mater Misericordiae University Hospital and St. James's Hospital is high. Almost nine out of ten respondents (87%) rated the overall quality of end-of-life care for their relative on the last admission to hospital as outstanding, excellent, or good. While the quality of care is rated highly by bereaved relatives, they also indicated that improvements could be made in areas such as communication, individualised care and the hospital environment.

Surveying bereaved relatives provides an insight into the experience of people whose 'voice' may not otherwise be heard. Service user engagement is a key principle for both organisations. The postal survey response rate was high and compares with response rates from bereaved relative surveys conducted elsewhere. Clearly, this speaks to public interest in commenting on end-of-life care experiences. Moreover, respondents took advantage of the opportunity to answer open-ended questions that invited comments on care and in doing so provided extremely valuable information. It is evident that people are willing to engage in research of this kind and when invited, take time and effort to write additional comments.

Asking bereaved relatives about their care experience is not routinely carried out in Irish healthcare settings. Doing so has provided a powerful snapshot in time into what works well and what could be improved to enhance care at end of life. This study highlighted numerous examples of the effective management of the seriously ill or dying person's care where staff worked to ensure patients and their families received the highest quality of care. Furthermore, it showed that a systems-wide approach needs to be undertaken to enhance the experience of care for all dying persons and their relatives. This study has contributed to our understanding and knowledge of what is important to people at end of life, what good end-of-life care looks like and where care can be improved; thus enabling our hospitals to direct quality improvement.

Findings from both hospitals are broadly similar, which leads us to conclude that the results provide learning opportunities for other hospitals', hospices and residential care homes. The recommendations are potentially applicable to other healthcare settings. However, it is clear that there is much to be gained from each healthcare setting surveying bereaved relatives on their care experience. It is recommended that surveying bereaved relatives should be conducted at a national level to support benchmarking of end-of-life care and drive quality improvement.

The Mater Misericordiae University Hospital and St. James's Hospital are committed to build on the high standard of care provided by our staff and to making the necessary improvements to enhance the care for all future patients and their families.





# 6. Appendices

# Appendix 1

## The Mater Misericordiae University Hospital and St. James's Hospital Hospice Friendly Hospitals Programmes

### Background

The Hospice Friendly Hospitals (HFH) Programme was initiated by the Irish Hospice Foundation in partnership with the Health Service Executive (HSE) in view of the fact that seventy five per cent of the population currently die in healthcare institutions such as acute hospitals and residential care facilities<sup>1</sup>. The HFH programme was established in 2007 and seeks to ensure that end of life, palliative and bereavement care is central to the everyday business of hospitals<sup>56</sup>.

### Aims of the Hospice Friendly Hospitals Programme

- To develop the capacity of acute and residential care settings to meet the *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup>.
- To improve the culture in hospitals and residential care settings in relation to all aspects of dying, death and bereavement.

The Hospice Friendly Hospitals Programme seeks to ensure that patients who have a life-limiting illness or those who die suddenly and their families have a seamless experience of care in hospital, provided by well-coordinated and well-informed staff. The Mater Misericordiae University Hospital and St. James's Hospital have participated in this initiative from the outset, building on existing good practice in the respective hospitals.

### Governance structure

Both hospitals have established governance structures to oversee developments of the Hospice Friendly Hospitals Programme whose aim is to implement the *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup>:

- The appointment of an **Executive Lead in End-of-Life Care** who is a member of the Hospital Executive and is responsible for and reports to the CEO and Board of the Hospital on all aspects of end-of-life care.
- The appointment of an **End-of-Life Care Coordinator** who is tasked with leading, supporting and coordinating all activities associated with implementing the *Quality Standards for End-of-Life Care*<sup>3</sup> and quality improvements identified by patients, their families and hospital staff. Both hospitals recognised that improving end-of-life care requires a whole-systems approach within acute hospitals and in 2012 invested in a dedicated end-of-life care coordinator position.

- **End-of-Life Care Committees** with representatives from clinical, administrative and support services from across the hospital are in place in both hospitals. This committee reviews all aspects of end-of-life care and supports quality improvement initiatives aimed at implementing the *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup>.
- Measurable **Quality Improvement Plans** (QIPs) drive the work of end-of-life care committees and coordinators in both hospitals.

See for example, *Enhancing Care at End of Life*<sup>57</sup> for an overview of how the Hospice Friendly Hospitals Programme is sustained and enhanced in one acute hospital setting.

### How are we improving end-of-life care in our hospitals?

The Hospice Friendly Hospitals Programme is a multidimensional programme and is focussed on enhancing all aspects of end-of-life care in our hospitals. The following model was developed to best describe the key elements of the Hospice Friendly Hospitals Programme in both hospitals:



Figure 36: Five core elements of the hospitals' Hospice Friendly Hospitals Programme



## Audit and Research

A key role of the executive lead in end-of-life care, the end-of-life care committee and coordinator is to undertake audit and research to support on-going quality improvement. Examples of audit and research undertaken include:

1. A quality indicator associated with ensuring more people are cared for in a single room at end of life was developed by the end-of-life care coordinator in one of the hospitals. For examples of the Mater Misericordiae University Hospital's planning and development work of ensuring more patients are cared for in single rooms at end of life see : *Enhancing Care at End of Life: Dying in a Single Room*<sup>58</sup> and *Improving End-of-Life Care through use of single rooms*<sup>59</sup>. Importantly, this work was embedded within the Hospital Board's overall focus on quality improvement<sup>48</sup>.
2. Both hospitals participated in the *National Audit of End-of-Life Care in Hospitals in Ireland*<sup>4</sup> and the National End-of-Life Care Audit and Review System developed by the Irish Hospice Foundation and the National Clinical Programme for Palliative Care<sup>49,60</sup>. See also: *Dying Matters in the Mater: Surveying bereaved relatives*<sup>61(p19)</sup>.

The hospitals participation in this study and the feedback obtained from relatives reinforced the view in the respective hospitals of the importance of eliciting feedback for quality improvement through a survey of bereaved relatives.

3. This *VOICES MaJam* study was developed as a result of both hospitals' need to evaluate the experience of care in their respective hospital settings.
4. Both hospitals have developed and continuously measure relevant Quality Indicators to track changes in end-of-life care service delivery.



## Education and Training

Through participation in the Hospice Friendly Hospitals Programme our hospitals offer two core staff education courses designed by the Irish Hospice Foundation, to improve communication and care around end of life:

**FINAL JOURNEYS<sup>55</sup>** is a one-day workshop, which aims to improve end-of-life care through raising awareness and empowering staff to become more competent, confident and comfortable when dealing with patients and families.

**DEALING WITH BAD NEWS** is a four-hour workshop, which aims to help healthcare professionals to deliver bad news well, and to provide support and care to those who have received bad news (patients and their families).

In addition, hospitals have developed training and education sessions relating to end-of-life care responsive to staff and service needs. These are delivered by the end-of-life care coordinators and other hospital staff. Each of the topics aims to enhance healthcare staff knowledge, confidence and competence in the following areas:

Advance care planning / Advance healthcare directives	Care of the dying	Challenging conversations at end of life
Dementia palliative care	Discussing ceilings of care including do not attempt cardiopulmonary resuscitation orders	Care of the deceased
Palliative care needs assessment	Psychosocial care at end of life	Spiritual care
Communicating with bereaved relatives about post-mortem examination	Bereavement	Staff support and self-care
Witnessed resuscitation	Sustaining hope	End-of-life care review meetings
Nutrition at end of life	Intercultural care	Clinical/illness specific aspects of end-of-life care
Palliative care competency framework	Supporting families	Bereavement support for staff

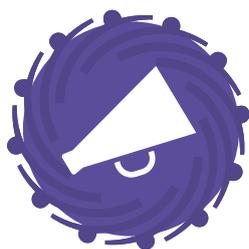
**Table 3: End-of-life care training and education sessions**

Education sessions on the above topics are provided to hospital staff in a variety of settings and formats such as:

- Journal clubs
- Ward-based education sessions
- Induction for new staff
- Educational programmes for instance:
  - FETAC level 5
  - Dementia Care programme
  - Introduction to Palliative Care programme
  - Medical & Surgical programme
- Clinical skills fairs
- End-of-life care information stands
- Bespoke sessions in response to a particular service requirement e.g. workshops for non-clinical staff e.g. household, catering, porters and technical staff

The coordinators routinely contribute to formal education programmes such as undergraduate and postgraduate nursing, medical and health and social care professional programmes.

Both hospital coordinators are involved in highlighting the importance of advance care planning. Advance care planning education for patients and relatives takes place in one hospital in the form of regular education sessions during a rehabilitation programme and within a residential care setting affiliated with the acute hospital.



## Advocacy

A key role of the executive lead in end-of-life care, the end-of-life care committee and coordinator is to advocate for improvements to be made that will enhance care in hospitals.

Advocacy focusses on various issues including but not limited to the following:

- Free or reduced car parking costs for relatives of patients who are seriously ill or dying.
- Flexibility in visiting hours for relatives of patients who are seriously ill or dying and ensuring staff inform relatives of such flexibility. Information on flexible visiting hours is available on the Mater Misericordiae University Hospital's website<sup>62</sup>.
- Change of practice in hospitals so that hospital bills are not sent earlier than 6 weeks after the person's death.
- Support for the implementation of the *HSE Standards and Recommended Practices for Post Mortem Examination Services*<sup>50</sup>. The standards are utilised by the HSE to evaluate post-mortem examination services in health care facilities. The standards recommended that all relevant staff receive training in relation to effective communication regarding post-mortem examination services. Improvements have included the development of practical resources and publication of leaflets such as '*Coroner's Post Mortem Examination a brief guide*' Mater Misericordiae University Hospital<sup>63</sup>.
- Staff support initiatives to improve the care of hospital staff to help them sustain their work in the provision of good end-of-life care. See for example:
  - *Taking care of yourself when working with people who are facing and dealing with significant losses*<sup>64</sup>.
  - *End-of-Life Care and Supporting Staff; a literature review*<sup>65</sup>.
- Identifying and responding to bereavement support needs of staff. Both hospitals are focussed on building on existing good practice and enhancing knowledge and awareness about bereavement support for staff. The members of the end-of-life care committee in one hospital developed a *Bereavement Policy: A Guide for Staff* in 2012<sup>66</sup>. Its aim is to enhance all employees' understanding of issues related to bereavement and loss, the effects that it may have on individuals and colleagues, and to inform staff how to support colleagues who have experienced bereavement. The policy also informs staff of the support and guidance available to them. A similar structure and policy is being developed in the other hospital. Other initiatives, in both hospitals, include the organisation of lunchtime talks on topics such as bereavement, normal grief reactions, supporting a family member, friend or colleague when someone close has died.

- Support for the implementation of the *HSE National Consent Policy*<sup>67</sup>, specifically part 4 which relates to cardiopulmonary resuscitation (CPR) and do not attempt resuscitation (DNAR) orders. Advocacy has focussed on ensuring hospital policy conforms with the national policy on these issues. It has also focussed on supporting the development of an information leaflet explaining DNAR with a view to assisting patients and their relatives in understanding this subject.
- Advocating for staff to promote advance care planning with their patients taking account of their individual needs. This includes the promotion of the Irish Hospice Foundation's 'Think Ahead' campaign<sup>54</sup>. The 'Think Ahead' form allows people to record their wishes about care in the event of serious illness or death. Advance care planning and 'Think Ahead' assists in the process of normalising conversations on dying, death and bereavement in an effort to ensure that when a person's end of life approaches, his /her wishes will be respected.
- Seeking every opportunity to engage with staff and partner organisations to develop projects to improve end-of-life care.

## Fundraising

The end-of-life care committees and coordinators in the respective hospitals have sought the support of staff in their fundraising efforts to enhance the environment to provide comfort, dignity and better facilities for patients and their families. Fundraising associated with end-of-life care in the hospitals has two key objectives:

- to heighten awareness of staff about the important role the hospital has in providing end-of-life care and the need to improve the hospital environment.
- to generate funds to create family rooms, end-of-life care patient and family suites and improve the broader hospital environment.

Various fundraising initiatives take place within each hospital and include coffee mornings, cake sales and raffles. Further examples are:

- The Mater Hospital's *Remember in November* campaign. The end-of-life care coordinator with the support of the chair of the end-of-life care committee and members, and the Mater Foundation developed the *Remember in November Ribbon* campaign. The ribbon is worn during the month of November to remember family members, friends, colleagues who have died. The money raised from the sale of ribbons goes towards refurbishing family rooms.
- St. James's Hospital *website donation stream*. St. James's Hospital Foundation developed a direct website donation stream for donors wishing to support end-of-life care initiatives.

Both Hospital Foundations are directly involved in activities and initiatives to support improvements to end-of-life care in both hospitals.



## Improving the Hospital Environment

The end-of-life care committees and coordinators in both hospitals have focussed their efforts on heightening staff awareness on the quality of environment in which care is provided at end of life. Both hospitals are working to improve end-of-life care by enhancing the hospital environment. This work stream is inspired by the *Design and Dignity Programme* of the Irish Hospice Foundation<sup>41,42</sup> and HSE.

### Family rooms

Many families spend long days and many hours with relatives who are seriously ill or dying in our hospitals. Dedicated family rooms are warm and welcoming spaces that offer comfortable seating, free tea/coffee making facilities and a sleepover sofa to allow a family member stay overnight. Undoubtedly, family rooms enhance the care for both the dying patient and family members. In the absence of family rooms, relatives of patients who are dying often sit in open plan waiting areas or meet hospital staff on corridors and are given 'bad news' in public spaces. Family rooms therefore provide patients and their families with a quiet, private space to meet with hospital staff in a comfortable room away from the busy ward.

Since 2012, ten family rooms to enhance dignity, privacy and the care experience for patients and their relatives have been developed in one of the hospitals through the work of the end-of-life care coordinator, committee and hospital staff<sup>68,69,70,71</sup>. This hospital continues to focus efforts on the provision of family rooms and have set a quality indicator of having a family room on every acute hospital ward<sup>48(p33)</sup>.



Photographs of family rooms before and after refurbishment



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Photographs of family rooms before and after refurbishment



Photographs of a family suite with kitchenette and interlinking door to patient's room

### Family suites / comfort care suites

One of the hospitals has focussed efforts to improve end-of-life care by creating dedicated end-of-life care patient and family suites. Each suite consists of two rooms - one room for the patient and another serving as a family area. The family suite has an interlinking door with direct access to the patient's room. The patient's rooms are refurbished with beautiful artwork and warm soothing colours which soften the space making it feel less clinical. The family suite area provides access to comforts such as a sleepover sofa allowing a family stay overnight, kitchenette and toilet facilities. The family suites provide much needed privacy and comfort to patients and their relatives through the most challenging and difficult time in their lives.

### Hospital environment

Both hospitals are focussed on improving the broader hospital environment which includes but is not limited to public areas of the Intensive Care Unit (ICU), Hospital Mortuary and Emergency Department as shown in photographs below:



Photographs of ICU waiting room before and after refurbishment



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**Photographs of mortuary family facilities before and after refurbishment**



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**Photographs of Emergency Department bereavement suite before and after refurbishment**



## Practical Resources and Support for Relatives

### Practical end-of-life care resources

The Mater Misericordiae University Hospital and St. James's Hospital utilise practical resources to enhance end-of-life care, which are available to all hospitals participating in the Hospice Friendly Hospitals Programme throughout Ireland. The utilisation of these resources has been recognised as enhancing the experience of care. Below is a selection of key end-of-life care resources used in both hospitals:



#### End-of-life care spiral symbol

The end-of-life care spiral symbol is displayed on wards and units when a person is very close to death or has died. It is a signal to all staff, other patients, families and visitors that an intensely personal and profound event is happening. The symbol is displayed to heighten awareness and promote an environment of dignity and respect at this time.



#### Ward locker

This multi-denominational wooden locker is placed at the patient's bedside. It contains articles to support spiritual and cultural care before and after a person's death.



#### Family handover bag

A sensitive and dignified way of returning a deceased person's belongings to the family.



#### Hand prints

Staff in the ICU of one hospital offers the taking of a handprint and a lock of hair from dying patients. This practice, long established in the area of organ donation creates space and opportunity for important conversations and a personal memento for families.

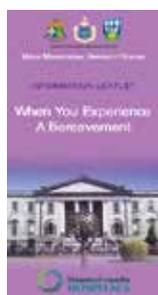


### Bed and trolley drape

The drape is a sensitive means of conveying respect and dignity to the person who has died. It may be utilised when family members are present to view the person who died and also on the mortuary trolley while transporting the body of a deceased person through the hospital or when laying out the deceased in the mortuary.

## Bereavement Support

Relatives are provided with information on practical matters and on bereavement supports available in both hospitals. This includes:



### Information leaflets

Both hospitals have developed a range of leaflets and resources which provide advice on different aspects of care after death and what happens next. The information leaflets *When You Experience A Bereavement*<sup>72</sup> and *When someone close dies what happens next?*<sup>73</sup> provide practical advice to relatives when a family member has died.



### Sympathy cards

Sympathy cards are sent by hospital staff within 5-30 days after the patient's death. The structure around the sending of the cards varies between hospitals and wards.



### Bereavement information

In one hospital a bereavement pack is sent to the bereaved relatives by the CEO. This includes a letter of sympathy and information on bereavement support services as well as the HSE booklet *Bereavement when someone close dies*<sup>74</sup>. In the other hospital this information is provided by staff on the wards and by the Death Notification Office.

## Support for relatives - bereavement evening and remembrance services

Each hospital provides a variety of supports for bereaved relatives, led by individual departments such as remembrances services led by Critical Care Units, Emergency Departments, Social Work and Specialist Palliative Care teams. The Social Work Department in one hospital also facilitates a bereavement support evening biannually for all bereaved relatives which heightens awareness and understanding of normal and expected responses to the death of a relative.

## Appendix 2

### VOICES MaJam survey questions in context of relevant national standards

This appendix outlines how VOICES MaJam survey questions reflect relevant healthcare standards. Questions are reproduced as they appeared on the questionnaire. This allows for survey results to be understood in the context of *The National Standards for Safer Better Healthcare*<sup>13</sup> and *The National Healthcare Charter*<sup>11</sup> and *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup>.

National Standard	VOICES MaJam Survey Question
<p><b>National Healthcare Charter</b> describes what a patient can expect: 'To be treated with dignity, respect and kindness.'</p>	<p>Q2: How much of the time do you feel your relative was treated with respect and dignity by the hospital doctors, nurses and other staff?</p> <p>Q5: Overall, do you feel that the care your relative received from the doctors and nurses and other staff in the hospital on the last admission was: Exceptional, Excellent, Good, Fair, Poor, Don't Know.</p>
<p><b>National Healthcare Charter</b> describes what a patient can expect:</p> <p>'Safe and effective healthcare delivered with competence, skill and care in a safe environment, delivered by trusted professionals.'</p> <p>And:</p> <p>'To ensure that they have adequate personal space and privacy when using health services.'</p>	<p>Q6: Please look at the following statements and tick the answer box that corresponds most with your opinion about the help your relative received in the last two days of life.</p> <p>A) There was enough help available to meet his/her personal care needs (such as toileting needs).</p> <p>B) There was enough help with nursing care, such as giving medicine and helping him/her find a comfortable position in bed.</p> <p>C) The bed area and surrounding environment had adequate privacy.</p>

**National Healthcare Charter** describes what a patient can expect:

‘To be fully involved in shared decision making about their healthcare, to take account of their preferences and values.’

**Quality Standards for End-of-Life Care in Hospitals**

state: ‘There is timely, clear and sensitive communication with each patient and his/her family as appropriate on matters relating to end-of-life care’ (1.3)

And:

‘There are effective mechanisms in place to identify patients who may be approaching or at the end of life.’ (1.7)

**Quality Standards for End-of-Life Care in Hospitals**

state: ‘The patient is actively involved in discussions and decisions regarding admission, discharge home, or transfer to another setting for end-of-life care.’ (3.1, 3.5)

Q8: Did your relative know he/she was likely to die?

Q9: In your opinion, did the person who told your relative that he/she was likely to die, break the news in a sensitive and caring way?

Q13: Did your relative ever say where he/she would like to die?

Q14: Where did your relative say that he/she would wish to die?

Q16: Do you think your relative had enough choice about where he/she died?

Q17: On balance, do you think that your relative died in the right place?

Q22: Looking back over the last three months of your relative’s life, was he/she involved in decisions about his/her care as much as they would have wanted?

Q23: Looking back over the last three months of your relative’s life, were you involved in decisions about his/her care as much as you would have wanted?

Q24: Were any decisions made about your relative’s care that he/she would not have wanted?

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**Quality Standards for End-of-Life Care in Hospitals**

state: 'There is timely and clear communication with the General Practitioner and or/ other service providers regard the patients admission and discharge.' (3.5)

Q4: Did the hospital staff work well together with your relative's GP and other services outside of the hospital?

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**Quality Standards for End-of-Life Care in Hospitals**

state: 'The patient's experience and description of pain and symptoms, including verbal, non-verbal and behavioural expressions of discomfort and pain, are identified, regularly assessed and responded to promptly. There is on-going dialogue with the patient regarding his/her experience of pain, distress and other symptoms and the level of comfort obtained from different interventions.'(3.4)

Q3: During the last two days of your relative's life, how well was his/her pain relieved?

Q7: During your relative's last admission, how would you rate the overall level of support given by those caring for him/her, in the following areas? A) Relief of pain B) Relief of symptoms other than pain C) Spiritual support D) Emotional support E) Support to stay where he/she wanted to be.

Q25: Overall and taking all services into account, how would you rate your relative's care on his/her last admission?

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**Quality Standards for End-of-Life Care in Hospitals**

state: 'The dying patient is cared for in a private and dignified space and as far as possible in a single room unless otherwise requested.' (1.5, 3.6)

Q11: Did your relative die in a single room?

Q12: If your relative did not die in a single room, why not?

**National Healthcare Charter** describes what a patient can expect: ‘To be fully involved in shared decision making about their healthcare, to take account of their preferences and values.’

**Quality Standards for End-of-Life Care in Hospitals Standards**

state: ‘The patient’s family are advised as a matter of urgency when death may be imminent and are facilitated to be present with the patient, where this is not contrary to the patient’s wish.’ (3.6)

‘When a death is believed to be imminent, the patient’s family is informed and facilitated as far as possible and in accordance with the patient’s wishes to spend as much time as they wish with the patient, including overnight stays if feasible.’ (4.5)

Q10: Were you contacted soon enough to give you time to be with your relative before he/she died?

Q18: Were you informed that you could visit outside of regular visiting hours/at any time during the patients stay on their last admission to the hospital?

Q19: Did you stay in the hospital overnight at any time during the patient’s stay in their last admission to the hospital?

Q 20: Were you or the patient’s family given enough help and support by the healthcare team at the actual time of their death?

Q21: After your relative died, did the staff deal with you and other family members in a sensitive manner?

**Quality Standards for End-of-Life Care in Hospitals**

state: 'Families are offered timely appropriate bereavement supports including information regarding awareness and understanding of normal and expected grief reactions.' (1.13, 4.6)

'A letter sympathy card is sent to the patients families within two weeks of the person's death.'(4.6)

'The hospital facilitates access to rooms and spaces where discussions between patients, staff and family members take place in a quiet, comfortable environment where privacy is ensured.' (1.5)

'The hospital facilitates family members with overnight rest and refreshment facilities.' (1.5)

Q26: Since your relative died, have you talked to anyone from the hospital about your feelings around your relative's illness and death?

Q27: If 'Yes', to whom did you speak?  
Responses: Doctor, Nurse, Social Worker, Chaplain, Bereavement Counsellor, Other

Q28: This question is about whether you have found support you may have received from the hospital helpful. For example, if you found it 'definitely helpful' to receive a Bereavement Booklet, you should put a tick in the 'definitely helpful' box next to that statement.

Hospitals offer a variety of supports, so, if you did not receive any of the types of support listed here, please tick 'did not receive this.'

Responses:

- A) Availability of a family room on the ward
- B) Leaflet from ward staff giving information about what to do after the death
- C) Bereavement booklet(s) (e.g. HSE or Citizens Information booklet)
- D) Sympathy card/letter from the staff
- E) Invitation to a bereavement evening organised by the hospital
- F) Invitation to a remembrance service organised by the hospital

Q29: If there is any other help or support you would have liked to receive from the hospital since your relative's death, please feel free to comment below:

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**National Healthcare Charter** states that a patient can expect hospitals ‘To welcome their feedback about their experience and if needed to investigate their complaint and address their concerns.’

And:

**Quality Standards for End-of-Life Care in Hospitals** state: ‘End-of-Life Care in the hospital is continuously evaluated.’ (1.6)

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Three open-ended questions were also asked : We would like to give you the opportunity to tell us in your own words about the care your relative received in our hospital. To do this, you may like to answer the three following questions:

Q1: What, if anything do you feel was good about the care?

Q2: What, if anything do you feel was bad about the care?

Q3: Please use the space below if there is anything more you would like to add about the care provided by the hospital to your relative/friend during their last admission:

# Appendix 3

## **VOICES MaJam – designing, planning and conducting the survey**

### **The VOICES survey**

The VOICES (Views of Informal Carers – Evaluation of Services) survey uses the post-bereavement method to gather information from bereaved relatives and friends in England<sup>24</sup>.

VOICES is a postal questionnaire about experiences of end-of-life care in the last days of life, focusing on quality of care and services received.

### **Aims of the VOICES MaJam Survey**

The overall aim of the study was to evaluate, from the perspective of bereaved relatives, the quality of end-of-life care provided in two acute hospital settings, in order to support a process of continuous improvement in the care of persons, including their families, at this time.

### **Ethical approval**

Ethical approval was granted from the Research Ethics Committees in the respective hospitals.

### **Development of the VOICES MaJam questionnaire**

The VOICES MaJam questionnaire was developed using an adapted version of the VOICES questionnaire developed by Catherine Hunt and Julia Addington-Hall<sup>2,25</sup>. Several new questions were developed in areas such as the provision of single rooms at end of life, the physical environment and bereavement support in line with the *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup> and the *National Audit of End-of-Life Care in Hospitals in Ireland*<sup>4</sup>.

- VOICES MaJam is a 36-item questionnaire, including questions requesting personal demographic information. In addition, there are three open-ended questions designed to gather descriptive data about the care experience during the patient's last admission to hospital.
- Content and face validity of the adapted questionnaire were conducted.

## Identifying the sample

### Sample selection

- Hospital records were used to identify the persons recorded as the next of kin in the deceased person's healthcare record.
- Next of kin of people who died between three months to nine months before the fieldwork commenced were selected.

### Inclusion criteria

- All deaths in the participating hospitals, including sudden and unexpected deaths as well as those that were anticipated and expected were included.

### Exclusion criteria

- Patients aged less than eighteen years of age
- Next of kin with a missing or incomplete address

Prior to the recruitment process clarification was also sought from various departments including Risk Management Departments and Legal Departments in the respective hospitals. Principal investigators took steps to ensure that the participants recruited to this research study were not simultaneously involved in other research projects.

## Sample size

- The sample size was based on the number of deaths occurring in both hospitals during the three to nine months before data collection. The final sample size was determined after the inclusion and exclusion criteria were checked and verified.

## Survey management

### Providing written information about the survey for respondents

- A formal letter of invitation was prepared and included in the survey pack.
- An information sheet explaining why the survey was being carried out and how the findings would be used was prepared and included in each survey pack.

### Giving respondents the option to opt out

- Due to the sensitive nature of the questionnaire and because relatives were not forewarned about the survey it was necessary to provide the option to opt out of the survey. Each survey pack contained an opt-out reply slip. Once the opt-out slips were returned, a record was made to ensure the relative was not contacted again.

### Preparing the survey pack

- The final questionnaire was sent to a printer for typesetting, design and final printing.
- Personalised 'Freepost' (prepaid) envelopes were funded, prepared and printed.
- All other survey pack documentation was printed, including:
  - Letter of invitation
  - Information sheet
  - Bereavement information sheet
  - Opt-out slip

### Sending the survey pack

- The VOICES survey 'toolkit'<sup>25</sup> suggests that two reminders are optimum with the most appropriate timing of these reminders being three weeks after the initial mail-out, and then again three weeks later. This format was adhered to:
  - Wave 1: A survey pack was posted to bereaved relatives listed in the sampling frame. The pack included a letter of invitation, an information sheet, a questionnaire, an opt-out slip, a bereavement information sheet and a Freepost envelope.
  - Wave 2: (Approximately three weeks after Wave 1): A survey pack was sent to bereaved relatives who had not already returned a completed questionnaire or had not opted-out of the study.
  - Wave 3: (Approximately three weeks after Wave 2): A reminder letter only was sent to bereaved relatives who had not already returned a completed questionnaire or had not opted-out of the study.

### Monitoring returns and communication

- During each wave all returned questionnaires and opt-out slips were logged.
- Records were kept of all telephone conversations with relatives who contacted the principle investigators regarding any aspect of the survey.

## Mechanisms for dealing with distress

### Responding to emotional distress

- Information on bereavement supports was included with the survey pack. Relatives were also provided with contact details of the principal investigator in each hospital to allow them to make contact if they had any queries or concerns about the study.
- The Social Work Department in each hospital was notified about the survey in the event that bereavement support or counselling was required for participants.

### Responding to concerns

- The principal investigator was the point of contact in each hospital. Any concerns raised by relatives were brought to the attention of the relevant hospital personnel.

## Quantitative data entry and analysis

### Data entry

- Each hospital entered data in an MS Excel spreadsheet using a prepared template.
- The number of replies to open-ended questions was recorded in the spreadsheet.
- The Excel spreadsheets from each hospital were combined to create a single SPSS file for data analysis.

### Data cleaning

- Data were cleaned to identify any incorrect records or other inconsistencies

### Data analysis

- Data were analysed using SPSS IBM SPSS statistics v. 22. Frequency and distribution tables were prepared for closed questions.

## Qualitative data entry and analysis

### Data entry

- Each hospital entered the verbatim text of the open-ended questions in an MS Excel spreadsheet or MS Word document.

### Data cleaning

- Spelling checks to identify data entry errors were conducted. All identifying information such as patient name, healthcare staff name, ward name and hospital name were removed.

### Data analysis

- Data were managed and coded using NVivo v10<sup>6</sup>. A coding frame was developed based on the principles and standards of care outlined in the *National Healthcare Charter*<sup>11</sup>, *National Standards for Safer Better Healthcare*<sup>13</sup> and *Quality Standards for End-of-Life Care in Hospitals*<sup>3</sup>. Inter-rater reliability tests were conducted. Data were analysed thematically using a template analysis framework approach<sup>28</sup>.

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**Mater Misericordiae University Hospital**  
Eccles Street  
Dublin 7  
[www.mater.ie](http://www.mater.ie)



**St James's Hospital**  
James's Street  
Dublin 8  
[www.stjames.ie](http://www.stjames.ie)