



THE IRISH
HOSPICE
FOUNDATION

Irish Attitudes to Death, Dying and Bereavement

2004-2014



by Dr. John A. Weafer

**IRISH ATTITUDES TO DEATH, DYING AND
BEREAVEMENT 2004-2014**

By

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KEY FINDINGS

1. Introduction

This report presents the findings of a national survey of 891 Irish adults' attitudes towards dying, death and bereavement. The survey was commissioned by the *Irish Hospice Foundation* and managed by Dr John A. Weafer. The findings are based on an independent survey conducted by *Behaviour & Attitudes* during May 2014 with a nationally representative sample of adults aged 18 years and above living in the Republic of Ireland. More than half the respondents had lost someone close to them in the past two years or so. The main findings from the research are summarised overleaf under the following headings:

- Attitudes to death and dying.
- Preferred location of care in the final stages of life.
- Impressions of care for people who are dying or terminally ill in Ireland.
- The factors Irish people regard as most important when they are dying.
- Planning for end-of-life.

2. The Research Findings 2014

Attitudes to Death and Dying

Do you think that as a community, we discuss death and dying.....?	
Too much	6%
About the right amount	35%
Not enough	57%
Don't Know	1%
How comfortable are you personally with discussing death or dying?	
Completely comfortable	23%
Very comfortable	18%
Relatively comfortable	44%
Not at very comfortable	11%
Not at all comfortable	3%

Only a third of the Irish adult population believe that discussion around death and dying is sufficient in Irish society, with almost six in ten adults saying that the level of discourse is not enough. Little has changed in the attitudes of Irish people in the past decade. Only one third of respondents in both the 2004 and 2014 surveys (30% and 35%, respectively) believe that the level of conversation is 'about the right amount'.

A substantial number of Irish adults also said they would be comfortable discussing death and dying. These findings suggests that Irish adults are at least open to the possibility of discussing death and dying more than is the case with the current level of public discourse. The value of such discussion is supported by other research commissioned by the Irish Hospice Foundation, which found that Irish people are not familiar with end-of-life terminology or processes (McCarthy et al., 2010).

Preferred Location of Care in the Final Stages of Life

Where would you want to be cared for if you were dying?	
In a hospital	5%
In your own home	74%
In a hospice	15%
In a nursing or residential home	3%
Other	2%
Don't know	2%
Do you think this option would be available to you in your locality if you needed it now?	
I am fairly certain this care would be available to me.	46%
I am unsure if this care would be available to me.	38%
I do not think this care would be available to me.	15%
Don't Know	1%
If you were living with a terminal illness, in which location would you like to be cared for in the <u>final year</u> of your life?	
In a hospital	6%
In your own home	68%
In a hospice	20%
In a nursing or residential home	4%
Other	2%
Don't know	1%
If you were living with a terminal illness, in which location would you like to be cared for in the <u>final days</u> of your life?	
In a hospital	5%
In your own home	63%
In a hospice	27%
In a nursing or residential home	2%
Other	1%
Don't know	1%
Where do you think Irish people die most?	
In a hospital	45%
In their home	22%
In a hospice	12%
In a nursing or residential home	14%
Other	2%
Don't Know	5%

A large and increasing majority of Irish adults nominated their home as their preferred place of care if they were dying. This finding is consistent across many Irish and international surveys. However, less than half of Irish adults were certain that the type of care they desire would be available to them, with most people believing they will be cared for in a hospital or another institution outside the home. The proportion of people saying they would like to be cared for in a hospice increased and proportion preferring homecare decreased with respondents' age and when

they were asked to consider their preferred place of care if their death was imminent.

Impressions of Care for people who are Dying or Terminally Ill

Is it your impression that care for people who are dying or terminally ill in Ireland is	
Excellent, no real improvement possible	6%
Good but could be improved	50%
Fair, much room for improvement	31%
Poor, the care needs to be addressed urgently	11%
Don't Know	3%
Has anyone close to you died within the past two years or so?	
Yes	53%
No	47%
If yes, in what setting did they die?	
In an Irish hospital	38%
In your own home	26%
In a hospice	11%
In a nursing or residential home	12%
Other	12%
How would you rate the overall care given to this person?	
Excellent, no real improvement possible	45%
Good but could be improved	33%
Fair, much room for improvement	9%
Poor, the care needs to be addressed urgently	5%
Don't Know	7%

Very few people believe that care for people who are dying or terminally ill in Ireland is excellent. Conversely, only one in ten Irish adults believe that the care is so bad that it needs to be urgently addressed. The large majority of Irish people are somewhere in between, with half saying that the care is good but that there is room for improvement. However, despite their reservations around the care of people who are dying or terminally ill, their recent experience of loved ones dying tend to be much more positive. More than four in ten Irish adults believe that the care was excellent, with a similar proportion saying it was good, but could be improved. Only 5% were very disappointed with the experience and claimed that the care needs to be urgently addressed. The care given to people who died in a hospice was perceived most highly by their loved ones.

The Factors Irish People Regard as Most Important when they are Dying.

If you had a terminal illness, which of the following would be the most important to you regarding how you spend your final days?	
Being free from pain/ having your condition managed by medication.	70%
Surrounded by your loved ones	82%
Having privacy and dignity	46%
Being in familiar surroundings	42%
Being in a calm and peaceful atmosphere	42%
Surrounded by your personal things and/or your pets	23%
Trained carers nearby to help you and your family	34%
Feeling in control of your environment and what support you get.	21%
Professional medical support on standby for emergencies	41%
Access to professionals for last minute concerns about your family or legal affairs	25%
Having your religious, cultural or spiritual needs met	29%
Having other people around you going through the same thing, to talk to and provide support.	15%
Other	2%
Don't Know	2%

The top two factors identified by respondents if they had a terminal illness were to be surrounded by their loved ones, and to be free from pain. Both of these factors were also prioritised in the 2004 research. Other important factors prioritised by respondents in the current research included, having privacy and dignity, being in familiar surroundings, being in a calm and peaceful atmosphere, and to have professional medical support on standby for emergencies

Planning for End-of-Life

Some people make arrangements for what they would like to happen in the case of an emergency or if they became terminally ill or die suddenly. Can you tell me if you have ever taken the following steps: seriously thought about, talked about, spoke about, and/or recorded?		
	Taken some Action	Taken no Action
Your views on organ donation.	77%	23%
Whether you would rather be buried or cremated.	75%	25%
Drawn up a will.	61%	39%
Told people where your important documents are.	51%	49%
In the event of an emergency do you have or carry a list of key people who should be contacted'	48%	52%
Your views on life prolonging treatment	43%	57%
What you would like at your funeral.	42%	58%
Religious/ cultural preferences or rituals you would like to be considered as part of your care	35%	65%
What your preferences are for care at the end of life.	35%	65%
Where you would like to be cared for if you were nearing death.	33%	67%
Written up an 'advance care directive' or appointed someone to consent to care and treatment on your behalf in the event that you are unable to do so yourself.	27%	73%
Appointing an attorney under an Enduring Power of Attorney	24%	76%

Most Irish people do not have arrangements in place for what they would like to happen if they became terminally ill or died. The most popular actions included making known their views about organ donation, burial or cremation, making a will, and carrying a list of key people in case of emergency. Conversely, Irish people are least likely to appoint an enduring power of attorney, write an advance care directive, or inform people where they would like to be cared for if nearing death. It may be that actions focussed on making things easier for others/ for those left behind are prioritised over actions focussing on actual personal dying and end of life, traditionally a more difficult concept to engage with.

CHAPTER ONE

INTRODUCTION

1.1 Introduction

This report presents the findings of a national survey on Irish adults' attitudes towards dying, death and bereavement. This survey is the second national study on Irish attitudes to death and dying commissioned by the *Irish Hospice Foundation* (IHF). The first national survey took place in 2004 (Weafer, 2004) and it captured, for the first time, the views of the Irish public on diverse issues related to death and dying, such as what constituted dying well, where they would like to be cared for when dying, and if there was enough conversation in Ireland about dying. The present survey replicates many of the same questions used in the 2004 survey, making it possible to monitor change in attitudes over time. Some new questions have also been included in the 2014 research to reflect various developments in the landscape relating to dying, death and bereavement in Ireland. Where relevant, the findings from the present survey are compared with comparable Irish and international research (Blackbox Research, 2014, Cox et al., 2013, Demos, 2013, Higginson, 2013, Lake Research Partners and The Coalition for Compassionate Care of California, 2012, McCarthy et al., 2010, NatCen, 2013, Amárach Research, 2011, Weafer et al., 2009, Wallace, 2003)

Each year approximately 30,000 people die in Ireland.¹ This figure is even more striking if one considers that approximately 400,000 people have already died in Ireland since the start of the century and that an additional two and a half million people will die in Ireland before this century is out.

¹ There were 30,018 deaths registered in the Republic of Ireland in 2013, compared with 38,000 in 1950. Life expectancy has increased significantly since the foundation of the state. In 1926, life expectancy for Irish males and females was 57 years. By 2010, male life expectancy had increased to 78 years and female life expectancy had increased to 83 years (www.cso.ie).

Many of these people can expect to avail of a range of general healthcare and palliative care² services during the final stage of their lives and accordingly, the general environment in which people die and the quality of the services they receive are very important. This viewpoint has underpinned the work of the *Irish Hospice Foundation* (IHF) since its foundation in 1986. In addition to advocating for quality end-of-life care services, the IHF also inform, educate and empower about key issues at end-of-life, and they seek to develop innovative responses to specific end-of-life care challenges in the areas of service equity, patient choice and the physical environment (<http://hospicefoundation.ie>)

During the past twenty years or so, the IHF has commissioned various research projects in order to ensure that their work and understanding of issues surrounding death and dying are informed by the public's experience of death and bereavement (Amárach Research, 2011, Irish Hospice Foundation, 2006, Irish Hospice Foundation, 2010, McCarthy et al., 2009, McCarthy et al., 2010, McKeown et al., 2010, Weafer et al., 2009, Weafer, 2004). The current survey has been commissioned to learn of the Irish public's current thinking on death and dying, when compared with an earlier survey conducted 10 years ago. It is hoped that the research will help the IHF to shape public policy and to raise public awareness of salient issues surrounding death and dying.

1.2 Methodology

Interviewing and Sampling

The research involved a telephone survey of a random sample of adults (18+ years) living in the Republic of Ireland. The interviews were carried out by *Behaviour & Attitudes* during the two-week period 6th – 20th May 2014 as part of their omnibus survey *Telebarometer*. The omnibus is a

² The World Health Organisation defines palliative care as an approach that improves the quality of life of patients and their families facing the problem 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 (www.who.int/cancer/palliative/definition/en/).

syndicated service that allows a number of clients to include questions on the same survey. It targets a total sample of 1,000 respondents 16 years of age and over with tight quota controls by sex (male, female), age (16-34, 35-54, 55+) and region (Dublin, Rest of Leinster, Munster, Connaught/Ulster).³ A nationally representative sample of 985 adults over the age of 18 years took part in the omnibus, thereby providing 'high-quality reliable data' not often found in surveys on this topic (Cox et al., 2013, p.44). An omnibus methodology was also used in the 2004 survey. However, while all respondents aged 15+ years in the 2004 survey were eligible to participate in the survey, it was decided for ethical considerations that only those 18 years of age and over would be eligible for the current survey.

The overall response rate for the omnibus was 75%, which is on par with other telephone surveys on sensitive topics. Two telephone surveys by the Royal College of Surgeons in Ireland on sexual abuse and violence in Ireland, for example, returned similar response rates (71% and 76%, respectively) (McGee et al., 2002, Goode et al., 2003). Nine in ten respondents (N=891) (90%) agreed to answer questions on the topic once they had been informed of the nature of the survey. Their willingness to participate in the survey was consistent across the key demographic sub-groups, such as gender, age, social class, region, and nationality. At the mid-point of the survey, respondents were told that some of the following questions dealt with their personal experience of death over the last two years or so and they were asked if they were happy to continue with the survey. The vast majority (98%) agreed to do so.

The positive response rate and the quality of responses provided by the research participants reflects a number of factors including, the training provided to interviewers, the sensitive way in which Behaviour & Attitudes approached their work, the positioning of the research in an

³ The sample is subsequently re-weighted at analysis stage to ensure it is nationally representative by gender within age, social class (ABC1, C2, DE & F), country of birth, region and area (urban, rural).

omnibus survey, and the protocols that informed the research (see below). The interviewing was conducted in a specialist CATI (Computer Assisted Telephone Interviewing) Unit situated in the premises of Behaviour & Attitudes in Dublin. A dedicated CATI supervisor supervised the interviewers.

1.3 Ethical Considerations

Given the sensitive nature of the topic, a number of protocols were agreed in advance to protect the rights of respondents and the integrity of the research. First, the Social Research Ethics Sub-Committee of Maynooth University reviewed the survey proposal. Full approval was granted subject to some amendments to the introduction of the survey and further clarification on interviewer training, sampling, and data security. These issues were all resolved to the satisfaction of the ethics sub-committee. Second, every person that participated in the omnibus was informed of the sensitive nature of the IHF research in the introduction to the survey, and it was made clear to them that they had the right not to participate at all or to answer any individual questions. They were also told that they could withdraw from the survey at any point if they felt uncomfortable with the questions.

The following introduction was read out to everyone before seeking their permission to proceed with the survey:

This survey is being carried out on behalf of the Irish Hospice Foundation. The primary aim of the survey is to identify the concerns and views of the Irish public on dying, death and bereavement. Please note that some of the questions may be distressing for anyone who has been recently bereaved, or who has a potentially serious illness. They may also be distressing for anyone who has a family member or friend with a serious illness. For that reason, details of a professional counselling service (PCI Counselling) will be given to you at the end of the survey in case you wish to speak to anyone about the issues raised in the survey.

Please be assured that everything you say will be treated with the strictest confidence and that your responses will be anonymous. Your answers will be added together with those of hundreds of other people in the form of a statistical report, so individual responses will not be examined. You have the right not to answer any question or, if you wish, not to participate in the survey at all. You may also stop at any point during the survey if you feel uncomfortable. Please just let me know right away if this is the case and we can stop immediately.

Third, every respondent was given details of a counselling service, PCI Counselling, if they wished to discuss any issues raised in the survey. No one availed of this service in either the 2004 or 2014 surveys. Fourth, a protocol for talking to people who may be distressed was compiled by the Irish Hospice Foundation and given to interviewers during their training for this project.

CHAPTER TWO

THE RESEARCH FINDINGS

2.1 Introduction

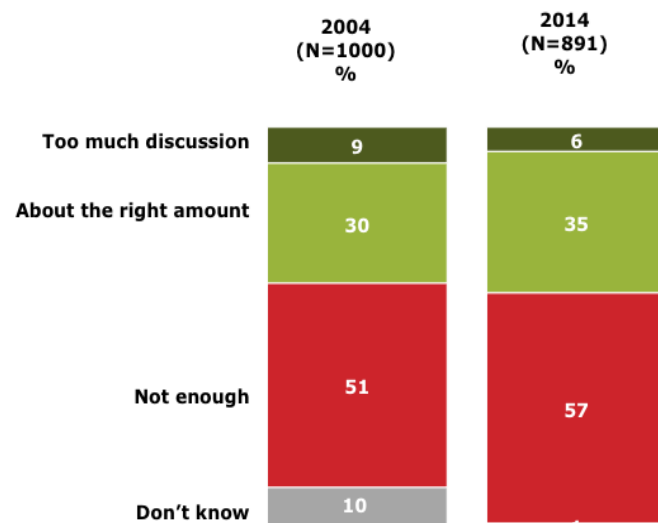
The main findings from the survey are summarised in this chapter, together with comparisons with the earlier 2004 national survey (Weafer, 2004). The data will also be compared with relevant Irish and international research (Amárach Research, 2011, Blackbox Research, 2014, Cox et al., 2013, Demos, 2013, Higginson, 2013, Lake Research Partners and The Coalition for Compassionate Care of California, 2012, McCarthy et al., 2010, NatCen, 2013, Palliative Care Australia, 2014, Weafer et al., 2009, Wallace, 2003). For the most part, it will be apparent that many of the attitudes expressed by Irish adults also reflect international trends.

2.2 Attitudes towards the amount of discussion on death and dying in Irish society

Almost six in ten Irish adults believe that the amount of discourse within Irish society about death and dying is ‘not enough’. The percentage of people holding this view has increased by six percentage points in the past ten years, from 51% to 57%. Conversely, approximately one third (35%) of respondents believe the amount of discussion is ‘about the right amount’ and only 6% believe there is ‘too much discussion’. Little has changed in the views of Irish adults during the past decade. Approximately one third of respondents in both surveys (30% and 35%, respectively) believe that the level of conversation is ‘about the right amount’ (Figure 1). The comparable figures for a Scottish survey were 70% ‘not enough’, 28% ‘about the right amount’ and 2% ‘too much discussion’ (Wallace, 2003, p.15).

The reasons for the perceived low level of public discourse on death and dying were not explored in this survey but it would appear that the majority of Irish adults are at least open to the possibility of more discussion on this traditionally taboo subject. This view is supported by research commissioned by the Irish Hospice Foundation in 2007, which found that most Irish people have ‘little or no understanding of end-of-life treatment and care terminology’(McCarthy et al., 2010, p.456). The authors of the report believe that the study ‘underlines the need for educators, health professionals and other stakeholders to raise awareness and deepen understanding of this neglected but inevitable stage of human life’ (McCarthy et al., 2010, p.458).

Figure 1: Attitude to the level of discourse on death and dying in Irish Society (2004-2014).



Q.1 Do you think that as a community, we discuss death and dying.....?

In the current survey, the groups that are most satisfied with the level of public discourse on death and dying included men, older respondents (55+ years), members of the farming community, rural dwellers, and residents in Connacht/Ulster (part of). Almost half (47%) of farmers, for example,

felt that the discussion on death and dying was ‘about the right amount’ compared with a national average of 35%. Conversely, the groups that are most critical of the level of discussion on death and dying in Ireland included, females, 25-34 year olds, residents of Dublin and Leinster, and those living in urban areas. Almost two thirds of women (63%), for example, believe there is ‘not enough’ discussion on death and dying, compared with 52% of men. Similar trends in those expressing dissatisfaction with the amount of discussion were reported in the 2004 survey, with most change across the decade in the more critical views of 25-34 year olds and older adults (Table 2.1).

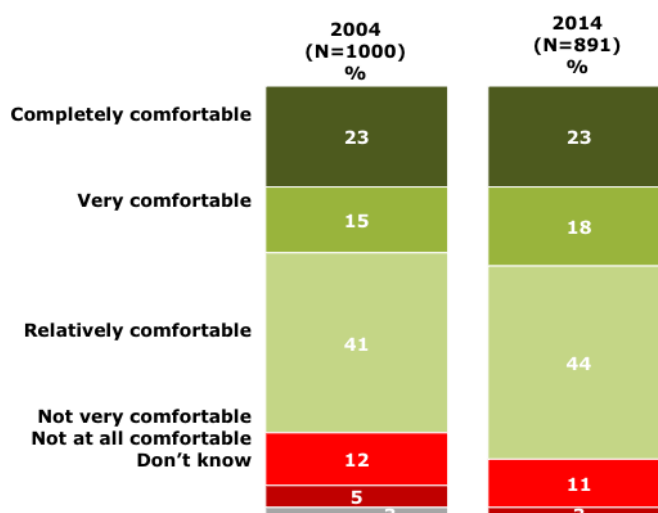
Table 2.1 ‘Not Enough’ Discussion on Death and Dying in Irish Society, 2004-2014

	2004 (N=1000) %	2014 (N=891) %
TOTAL	51	57
GENDER		
Male	48	52
Female	53	63
AGE		
18-24 years	52	56
25-34 years	49	64
35-54 years	58	58
45-54 years	57	60
55-64 years	45	52
65+ years	36	51
SOCIAL CLASS		
ABC1	54	59
C2DE	53	59
Farmer	32	43
REGION		
Dublin	54	62
Leinster (Rest of)	54	60
Munster	50	52
Connacht/Ulster (part of)	41	54

2.3 Personal feelings towards discussing death and dying

Four in ten respondents (41%) said they were personally ‘completely’ or ‘very’ comfortable discussing death and dying, while a slightly larger proportion (44%) of respondents said they were ‘relatively’ comfortable. These findings are very close to the results reported in the 2004 research (Figure 2). Thus, the vast majority (85%) of Irish adults in 2014 believe that they would be comfortable discussing death and dying. This finding is largely consistent with other research commissioned by the Irish Hospice Foundation in 2011, where three quarters of Irish adults said they would be at least relatively comfortable discussing death and dying (Amárach Research, 2011). Conversely, approximately one in six respondents in both the 2004 and 2014 surveys said they would not be comfortable engaging in such a discussion.

Figure 2: Personal feelings towards discussing death and dying (2004-2014)



Q.2 How comfortable are you personally with discussing death or dying?

Men and people aged 45-54 years of age said they would personally be most comfortable discussing death and dying. Conversely, members of the farming community, residents of Connacht/Ulster (part of), women, and

younger respondents (less than 35 years of age) said they would feel less than comfortable with such a discussion. Similar demographic trends were noted in the 2004 survey (Table 2.2).

Table 2.2 Percentage Saying They Would be Completely or Very Comfortable Discussing Death and Dying, 2004-2014

	2004 (N=1000) %	2014 (N=891) %
TOTAL	38	41
GENDER		
Male	40	44
Female	35	39
AGE		
18-24 years	31	35
25-34 years	40	34
35-54 years	37	44
45-54 years	43	49
55-64 years	39	39
65+ years	45	45
REGION		
Dublin	40	43
Leinster (Rest of)	39	43
Munster	38	42
Connacht/Ulster (part of)	33	33

Note: The 2004 survey was based on all adults 15+ years.

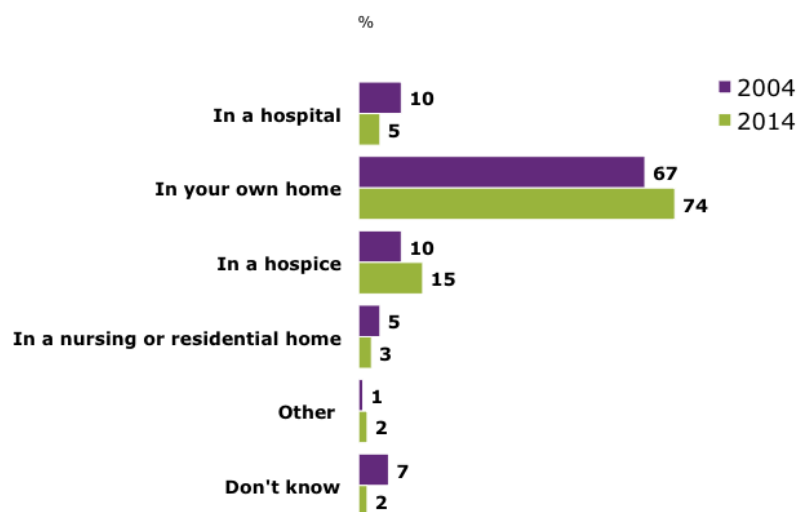
Allowing for some differences in question wording, the findings from the Irish research are comparable to a number of international studies. The British Social Attitudes survey, for example, reported that most people in the UK (70%) said they feel comfortable talking about death. However, in spite of their stated relative comfort in discussing death, a number of surveys suggest that people are less than comfortable in discussing the specifics of death. The authors of the British study found that the relatively high levels of comfort in talking about death ‘had not translated into specific conversations about their own deaths’ (NatCen, 2013, p.9). A survey of Singapore residents found that while 36% of respondents said they were comfortable with talking about their own death, only 20% said

they would be comfortable talking to someone who is terminally ill, (Blackbox Research, 2014). Irish research also suggests that people are not particularly comfortable discussing death or making provisions of their death. Ireland, McCarthy et al, for example, observed that their study ‘paints a picture of a general public that is not very comfortable with or informed about the processes of dying and death’ (McCarthy et al., 2010, p.458). The findings from the current research also indicate that the stated comfort in discussing death is not always translated into practical planning for end-of-life (see section 2.9) and where planning occurs it is more likely to focus on benefits for *other* rather than self – for example organ donation, legacy/wills and identifying locations of important documents.

2.4 The location people would like to be cared for if dying.

Almost three quarters (74%) of respondents would like to be cared for in their own home if they knew they were dying. This figure has increased by seven percentage points since the 2004 survey. More people would also like to be cared for in a hospice than was the case in 2004, while less people would like to receive care in a hospital if their death was imminent (Figure 3). The preference for home-care is also a trend found in a number of international surveys. Research conducted in California reported that 70% of respondents would prefer to die at home (Lake Research Partners and The Coalition for Compassionate Care of California, 2012). A similar findings was reported in a study of people living in Singapore, which found that 70% of respondents would want to be cared for at home if they dying, and even more (77%) said they would like to die at home (Blackbox Research, 2014). Two UK studies found that 63% (Demos, 2013) and 67% (NatCen, 2013) of people want to die at home. Given that most people die in hospitals in many countries, including Ireland (see section 2.9), it is clear that many people are unsuccessful in dying where they wish.

Figure 3: Preferred location of care if dying (2004-2014)

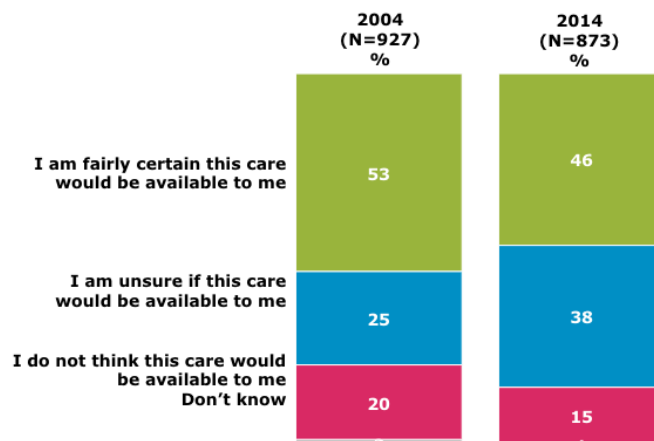


Q.3 Where would you want to be cared for if you were dying?

The groups most likely to choose home as their preferred location for end-of-life in the current survey were men, young adults (18-35 years of age), and residents of Leinster (excl Dublin) and Munster. Conversely, while all categories of respondents indicated they would prefer to be cared for at home, those most likely to select a hospice included, women, residents of Dublin and Connacht/Ulster (part of), and those older than 35 years of age.

Once they indicated their preferred location for care when dying, respondents were asked if they thought their preferred place of care would be available to them in their own locality if they need it now. Less than half (46%) of respondents felt certain that their preferred care would be available to them, a drop of seven percentage points since 2004. Furthermore, there is more uncertainty about whether their preferred type of care would be available to them (Figure 4).

Figure 4: Do they believe that their desired place of care be available in their locality (2004-2014)?



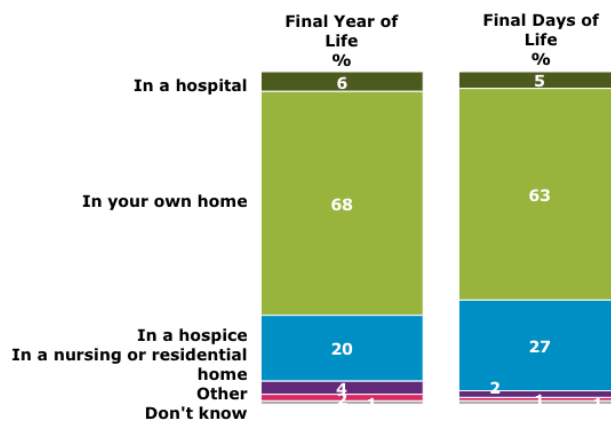
Q.4 Do you think (place of care selected) would be available to you in your locality if you needed it now?

When asked to select a place of care if their death was imminent, the majority of respondents still chose their homes (63%), a drop of 9% in the preference when the question was more general.

While the majority of people continued to opt for care in their home if death was imminent, an increasing number of people said they would prefer to be cared for in a hospice in the final stages of their lives (Figure 5).

Figure 5: Preferred Location for care if death imminent (2014)?

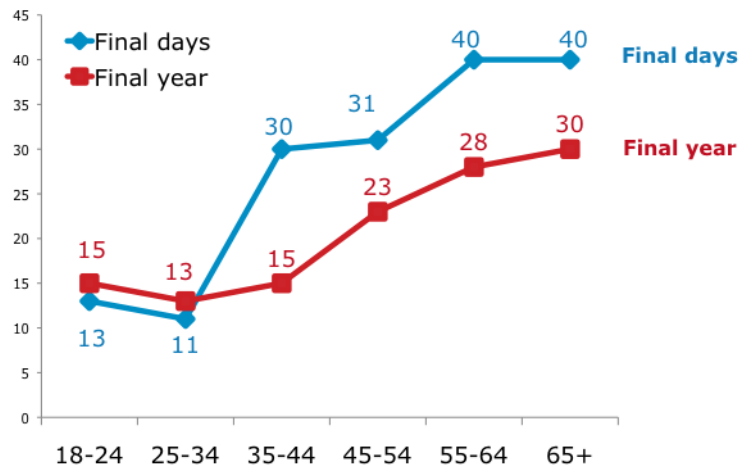
(Base: All Adults 18+, N=873)



Q.5 If you were living with a terminal illness, in which location would you like to be cared for (a) in the final year of your life and (b) in the final days of your life?

Figure 6: Preference for hospice care by age (2014).

Base: All Adults 18+, N=873



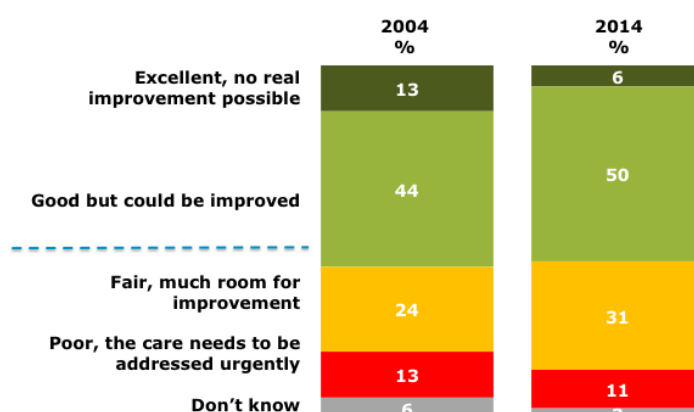
Q.5 If you were living with a terminal illness, in which location would you like to be cared for (a) in the final year of your life and (b) in the final days of your life?

Their preference for a hospice increased with age, a trend also noted in a UK study (Demos, 2013). Their preference for care during end-of-life was also influenced by their experience of care given to loved ones. For example, while 27% of respondents would like to be cared for in a hospice in the final days of life, this figure increased to 52% for people whose loved one had died in a hospice.

2.5 Impressions of care for people who are dying or terminally ill in Ireland

Most people believe that the care for people who are dying or terminally ill in Ireland could be improved, with more than four in ten respondents believing that there is ‘much room’ for improvement or that care needs to be addressed urgently. Overall, their perceptions of the quality of end-of-life care are largely consistent during the past decade.

Figure 7: Perceptions of (hospital) care for people who are dying or terminally ill in Ireland (2004-2014)



Perceptions of the care have declined over the decade.

Q.6 Is it your impression that care for people who are dying or terminally ill in Ireland is

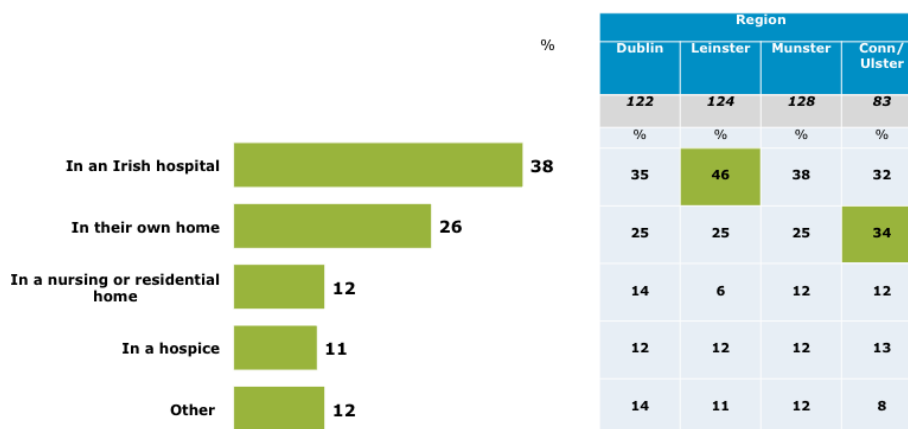
The groups most critical of the care provided to dying or terminally ill people included, women, working class, and residents in Connaught/Ulster (part of).

2.6 Locations where their loved ones died

Just over half (53%) of respondents indicated that someone close to them had died within the past two years or so and many of these people had died in a hospital.⁴ These figures indicate that there is a significant discrepancy between Irish adults' desired and actual place of death (Figure 3). While 74% of respondents would like to be cared for in their own homes if they were dying, only one quarter (26%) of their loved ones had died at home. A similar trend is also found in other countries. Four in ten (42%) people who die in California died in a hospital, compared with three in ten (32%) people who died at home. Interestingly, the number of Californians who died at home has grown 146% since 1989, while deaths in hospitals have declined (Lake Research Partners and The Coalition for Compassionate Care of California, 2012).

Figure 8: In what locations do people die (2014)?

Base: All experience of a close bereavement, N=457



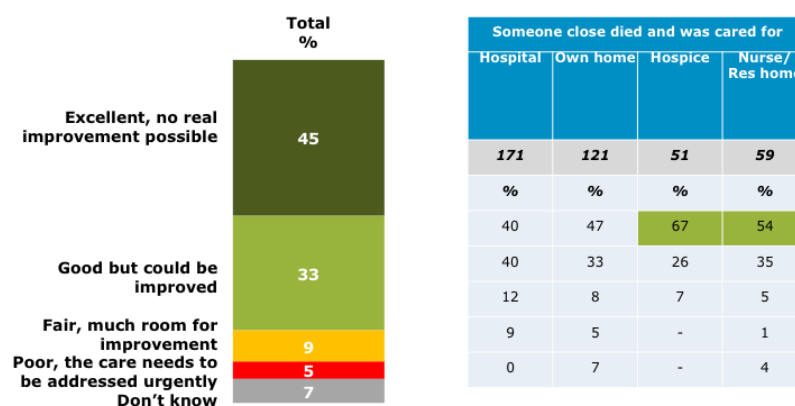
Q.8 In what setting did they die?

⁴ The respondents' data is largely consistent with the national profile of deaths. Almost half (48%) of deaths in Ireland take place in acute hospitals, 20% occur in long-stay care facilities such as nursing homes, 4% take place in a hospice and 28% take place at home/other location <http://hospicefoundation.ie/what-we-do/hospice-friendly-hospitals/>.

2.7 Respondents' experience of end-of-life care

In spite of their somewhat critical view of end-of-life care (Figure 7), their personal experience of end-of-life care is much more positive. Thus, while only 6% of respondents believe that care for people who are dying or terminally ill in Ireland is 'excellent, no real improvement possible', this figure increased to 45% when they rated the care given to their loved ones. This was especially the case for people who had been cared for in a hospice. Almost seven in ten (67%) people whose loved one had died in a hospice said the care they received was 'excellent', compared with a national average of 45% and 40% of respondents whose loved one had died in a hospital (Figure 9).

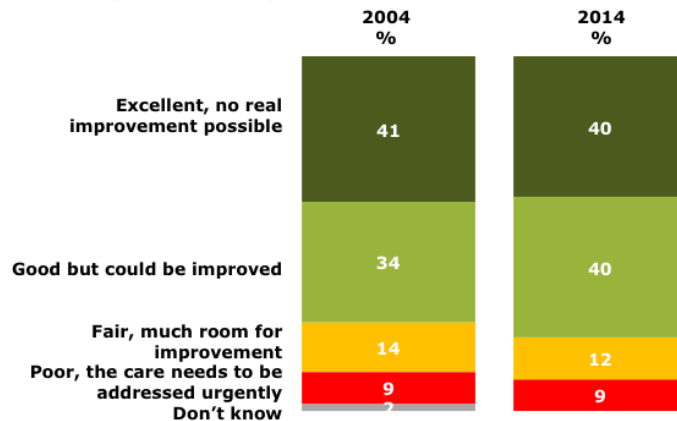
Figure 9: Perceptions of care given to loved ones (2014).
Base: All experience of a close bereavement, N=457



Q.9 How would you rate the overall care given to this person. Was the overall care?

The views of people who had someone close to them die in an Irish hospital have not changed much during the past decade. Four in ten of this group rated the care provided in the hospital as excellent (Figure 10).

Figure 10: Perceptions of care given to loved one who died in an Irish hospital (2004-2014). (Base: All Respondents Who Said Someone Close To Them Had Died In An Irish Hospital In The Past Two Years Or So (N=287/171))



Q.9 How would you rate the overall care given to this person. Was the overall care?

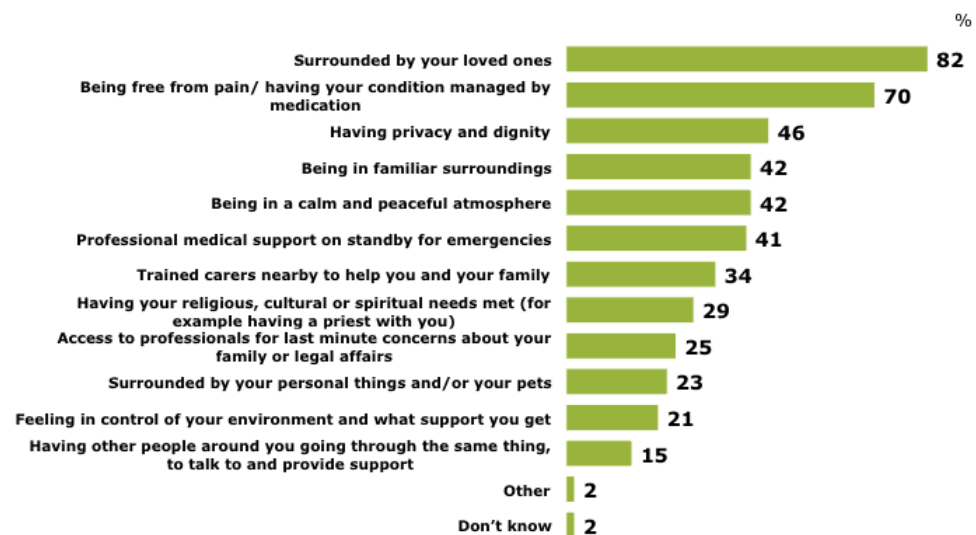


2.8 What people want at the end of their lives.

The top two factors identified by respondents if they had a terminal illness were to be surrounded by their loved ones, and to be free from pain. Both of these factors were also prioritised in the 2004 research (Weafer, 2004). Other important factors prioritised by respondents in the current research included, having privacy and dignity, being in familiar surroundings, being in a calm and peaceful atmosphere, and to have professional medical support on standby for emergencies (Figure 11).

Figure 11: Most important factors if person had a terminal illness, 2014

Base: All adults, N=891



Q. 10 If you had a terminal illness, which of the following would be the most important to you regarding how you spend your final days? (Please pick your top 5 priorities).

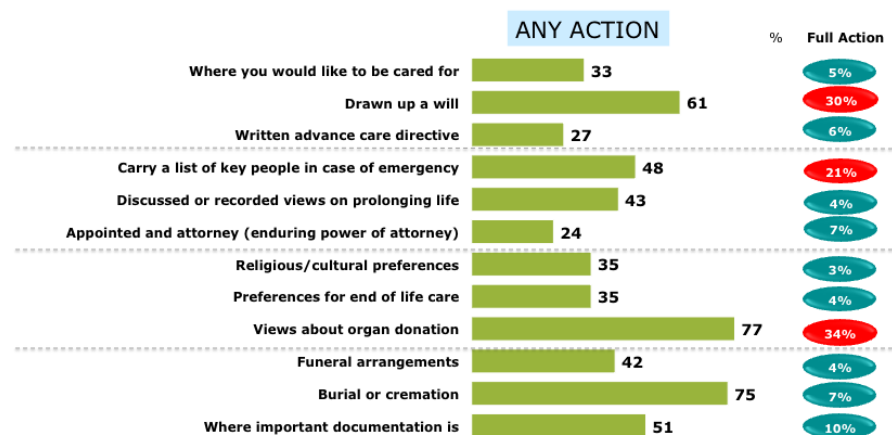
Similar factors were also prioritised in a number of international surveys. The four key factors identified in a UK study commissioned by Sue Ryder (Demos, 2013) were, being free from pain and discomfort (78%), being surrounded by loved ones (71%), having privacy and dignity (53%), and being familiar surroundings and being in a calm and peaceful atmosphere (45%). The higher financial costs of medical care in the US is reflected in the factors a study of Californians identified as most important at end-of-

life (Lake Research Partners and The Coalition for Compassionate Care of California, 2012). The most important factors prioritised by Californians included making sure their family is not burdened by their care (67% ‘extremely important’), being comfortable and without pain (66%), being at peace spiritually (61%), making sure family is not burdened by tough decisions about their care (60%), and having loved ones around them (60%). Research conducted in Singapore also prioritised financial issues (Blackbox Research, 2014). The top three end-of-life priorities identified by respondents in this study were to ensure their death is not a financial burden to loved ones (87% very or quite important), to have control over pain relief (81%), and to be surrounded by loved ones (78%)

2.9 Planning for end-of-life

Most Irish people do not have arrangements in place for what they would like to happen if they became terminally ill or died. The most popular actions included making known their views about organ donation, burial or cremation, making a will, and carrying a list of key people in case of emergency. Conversely, Irish people are least likely to appoint an enduring power of attorney,⁵ write an advance care directive, or inform people where they would like to be cared for if nearing death (Figure 12).

Figure 12: Activities Undertaken to deal with end-of-life situations Base: All experience of a close bereavement, N= 457



Q.11 Have you discussed or recorded the following

⁵ On the understanding that many Irish people are not familiar with end-of-life care terminology (McCarthy et al. 2010), the following explanations of ‘enduring power of attorney’ and ‘an advance care directive’ were read out to respondents during the interview. An **Enduring Power of Attorney** is a document in which one person may authorise another (or more than one other person) to make certain-decisions on their behalf in the event that they become mentally incapable of doing so. An **Advance Healthcare Directive** is a written statement made by an adult, in which they set out their will and preferences about treatment decisions that may arise in the future when they no longer have the capacity to make those decisions for themselves

A more comprehensive overview of the actions taken by respondents are presented in rank order in Table 2.3.

Table 2.3 Actions Taken to Plan for End-of-Life

	Seriously Considered	Talked About	Told Someone	Recorded Your Views	None
	%	%	%	%	
Your views on organ donation.	55	37	34	34	23
Whether you would rather be buried or cremated.	53	44	38	7	25
Drawn up a will.	39	33	28	30	39
Told people where your important documents are.	25	34	29	10	49
In the event of an emergency do you have or carry a list of key people who should be contacted'	25	22	18	21	52
Your views on life prolonging treatment	26	24	18	4	57
What you would like at your funeral.	25	26	21	4	58
Religious/ cultural preferences or rituals you would like to be considered as part of your care	21	19	17	3	65
What your preferences are for care at the end of life.	20	18	14	4	65
Where you would like to be cared for if you were nearing death.	16	20	17	5	67
Written up an 'advance care directive' or appointed someone to consent to care and treatment on your behalf in the event that you are unable to do so yourself.	15	13	12	6	73
Appointing an attorney under an Enduring Power of Attorney	13	13	11	7	76

Allowing for the different format of the wording used in both surveys, a comparison of the 2004 and 2014 surveys suggests that more Irish people are increasingly seriously considering or actively planning for end-of-life.

Table 2.4 Told someone or have put arrangements in place if terminally ill or dead

	2004*	2014**
Told someone where you would like to be treated	18%	33%
Drawn up a will	45%	61%
Told someone what you would like at a funeral	27%	42%
Told someone whether you would rather be buried or cremated	50%	75%
Written up an advance directive or living will	23%	27%

*Seriously considered or have done.

** Seriously considered, talked about, told someone, or recorded.

Previous research commissioned by the Irish Hospice Foundation found that the majority (60%) of Irish adults believe it is important to discuss their preferences for end-of-life (Amárach Research, 2011). Other research indicates that Irish people are willing to record their end-of-life preferences if requested (O'Shea et al., 2014). However, in spite of these findings and an increase in certain aspects of end-of-life planning during the past decade noted above, many Irish people are reluctant to engage with the practicalities of death, such as writing a living will or appointing an enduring power of attorney. This reluctance to plan for end-of-life has also been noted in various international research studies, such as the British Social Attitudes survey, which reported that only 5% of UK respondents had a living will or advance care plan (NatCen, 2013). Research commissioned by Palliative Care Australia also found that whereas 82% of Australians said it was important or very important to have plans in place should anything unfortunate happen to them, considerably less Australians had a plan in place (Palliative Care Australia,

2014). Conversely, the Australian study noted that older people were more likely to have written a plan. This age difference was also noted in the current Irish survey (Table 2.5). With the exception of expressing their views on organ donation, older respondents are consistently more likely to have seriously considered or followed through on an end-of-life action than their younger counterparts.

Table 2.5 No Action Taken by Age

	18-24	25-34	35-44	45-54	55-64	65+
	%	%	%	%	%	%
Your views on organ donation.	23	17	16	21	31	34
Whether you would rather be buried or cremated.	28	28	27	24	22	18
Drawn up a will.	84	62	34	24	19	9
Told people where your important documents are.	78	66	51	40	34	25
In the event of an emergency do you have or carry a list of key people who should be contacted'	62	53	46	56	52	48
Your views on life prolonging treatment	68	61	55	55	56	47
What you would like at your funeral.	58	59	63	55	57	52
Religious/ cultural preferences or rituals you would like to be considered as part of your care	77	71	69	65	63	46
What your preferences are for care at the end of life.	75	70	63	61	68	57
Where you would like to be cared for if you were nearing death.	80	75	61	64	63	58
Written up an 'advance care directive' or appointed someone to consent to care and treatment on your behalf in the event that you are unable to do so yourself.	87	78	76	69	70	58
Appointing an attorney under an Enduring Power of Attorney	87	83	75	73	77	59

2.10 Perceptions and Actual Causes of Death

Finally, respondents were asked to identify the three main causes of death in Ireland.⁶ Almost half of the total sample first mentioned cancer as a cause of death, followed by three in ten respondents who first mentioned heart failure as a cause (Table 2.6).

Table 2.6 Perceived Causes of Death in Ireland

Cause of Death	First Mentioned	Second Mentioned	Third Mentioned	Average*
	%	%	%	%
Cancer	48	32	11	31
Heart Failure/ heart attack	30	33	18	27
Stroke	4	10	19	11
Suicide	9	16	22	16
Accident	4	5	16	8
Dementia/ Alzheimer's	2	3	9	5
Other	2	-	4	2
Don't Know	2	-	-	-

* The vast majority of respondents gave three replies to this question. Accordingly, the average was generally calculated by dividing the total responses by 3. Where respondents gave two or one replies, their average was calculated by dividing their responses by two or one, respectively.

When the three replies were averaged out, cancer and heart failure emerged as the most likely perceived causes of death, corresponding closely to the actual causes of death recorded by the CSO in 2013. There were 30,018 deaths registered in the Republic of Ireland in 2013 (Central Statistics Office, 2014). Of these deaths, approximately three in ten deaths (32%) were due to circulatory diseases, such as heart failure, and a similar

⁶ Respondents were not asked to prioritise their answers. A list of possible causes was read out to them and they were asked to select three causes from the list.

proportion (29%) were caused by cancer. Conversely, many Irish adults exaggerated the impact of suicide. The CSO data indicates that less than 2% of deaths in 2013 were due to suicide (n=475), compared with 16% of survey respondents who considered it as a main cause of death in Ireland.

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