A nationwide survey of public attitudes and experiences regarding death and dying.

An Irish Hospice Foundation initiative supported by the Health Services National Partnership Forum.

Prepared by Weafer & Associates Research with TNS MRBI.

November 2004

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Chapter One

Introduction and Background

Introduction

This report presents the findings of research conducted on behalf of the Irish Hospice Foundation, with the support of the Health Services National Partnership Forum, by Weafer and Associates Research & Consultancy Ltd and TNS MRBI. The research has been undertaken as part of the work of the Care for People Dying in Hospitals Project, an Irish Hospice Foundation initiative, which is in partnership with the North-Eastern Health Board at Our Lady of Lourdes Hospital in Drogheda. The principal aim of the research was to explore and understand the attitudes of the Irish population towards death and dying and towards the care of people dying in Irish hospitals.

The research focused on the following issues:

- The degree to which Irish adults feel comfortable discussing death and dying generally, and speaking to recently bereaved people in particular.
- Where people would like to be cared for if they were dying.
- Whether they feel that this care would be available to them in their own locality if they needed it now.
- How they would feel if they were to die in their local hospital instead of a hospice or their own home.
- Attitudes towards the care of people dying in Irish hospitals.
- Overall rating of the care given to their family members in Irish hospitals.
- To what extent Irish adults have made arrangements for how they would like to be treated if they became terminally ill or died.
- What things Irish adults consider to be most important about the care available to them if they were dying or in the last stages of a terminal illness.
- The importance of the provision of care for the terminally ill in Ireland.

A copy of the questionnaire used in the survey is appended to this report.

Research Methodology

The questionnaire was designed with the active direction and assistance of the Project Board of the Care for People Dying in Hospitals Project[1]. For comparative purposes, some questions were taken directly from similar surveys conducted in the UK and these will be referenced in the text.

A sample of 1,000 adults, aged 15+ years was interviewed from various locations throughout the Republic of Ireland[2]. Respondents were selected for interview through random digit dialling (RDD). This method of respondent selection ensures that ex-directory households are as likely to be selected for interview as listed households. In order to ensure the sample reflects the profile of the national population 15+ years in the Republic of Ireland, quota controls were imposed for region, by age within sex and social class within sex. Where any discrepancies occurred in the sample, the data was weighted to ensure the final sample was representative of the Irish adult population.

The sample was first stratified by a total of 15 broad regions, encompassing five different community types (cities; towns 10,000+; towns 5,000 – 10,000; towns 1,500 – 5,000; and rural <1,500) within the four standard areas of Dublin, Rest of Leinster, Munster and Connaught/Ulster. This ensured a representative territorial spread of the sample. Within each cell of the resulting matrix (region by community type), the appropriate number of primary sampling units (District Electoral Divisions – DEDs) were chosen using probability sampling procedures i.e., probability to size of population.

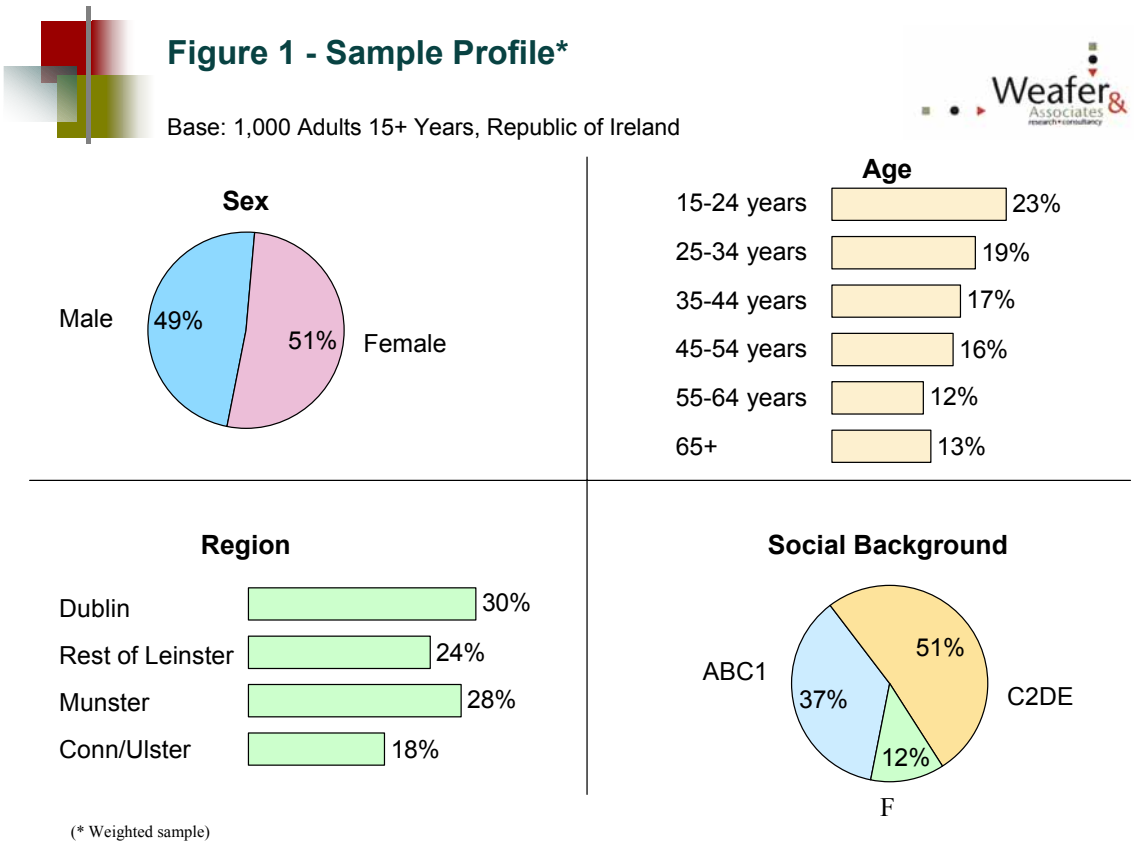
The second stage of the sampling procedure involved the systematic sampling of individuals within each of the pre-selected DEDs. At each DED, the interviewer adhered to a quota control matrix based upon the known profile of Irish adults in each region in terms of age, within sex, and socio-economic profile. The quotas for age and sex were derived from the most recent CSO data.

It is generally accepted that a quota sample of 1,000 respondents allows for a margin of error between 2% and 3% at the 95% confidence interval. So, for example, reported percentage frequencies of 10% or 90% have a +/- 2% range, while percentage frequencies of 50% to 70% have a range of +/-3%. Determining the statistical significance of any relationship is therefore only possible on a question-by-question basis.

An overview of the sample profile is presented in Figure 1 overleaf:

[1] The membership of the Project Board comprises: Eugene Murray CEO Irish Hospice Foundation; Orla Keegan, Education, Research & Development Manager, Irish Hospice Foundation; Dr. Doiminic Ó Brannagáin, Consultant in Palliative Medicine North-Eastern Health Board; and Mervyn Taylor, Project Manager, Care for People Dying in Hospitals Project

[2] References to Ulster include areas within the Republic of Ireland only - Counties Donegal, Cavan and Monaghan.



TNS mrbi conducted fieldwork for the research through their *PhoneBus* Omnibus survey. Interviewing was conducted using CATI (Computer Aided Telephone Interviewing) technology from 24th August – 2nd September 2004.

Finally, a note on the use of telephone survey methodology as an appropriate means of interviewing the general public on sensitive topics, such as death and sexual abuse. In the past, such topics were either avoided completely or conducted using face-to-face methods. However, in recent years, telephone survey methodology has been used in a number of important surveys. Two Irish studies by the Royal College of Surgeons, for instance, used this methodology quite effectively in their surveys of sexual abuse and violence in Ireland.[3]. Similarly, a study entitled, *'Priorities and Preferences for end of life care in England, Wales and Scotland'* by Professor Irene J. Higginson (2002) of the Department of Palliative Care and Policy, King's College London is based on a national telephone survey. Apart from the enhanced access this method brings to survey research, due to the high penetration of telephones in Ireland, it is also recommended for the anonymity it affords respondents in answering relatively sensitive questions.

[3] McGee, H., Garavan, R., de Barra, M., Byrne, J, and Conroy, R. 2002 *Sexual Abuse and Violence in Ireland:* A National Study of Irish Experiences, Beliefs and Attitudes Concerning Sexual Violence (The SAVI Report). Dublin: Rape Crisis Centre.

Goode, H., McGee, H., and O'Boyle, C. 2003. *Time to Listen:* Confronting Child Sexual Abuse by Catholic Clergy in Ireland. Dublin: The Liffey Press.

Chapter Two

Research Findings

2.1 Deaths and Births in the Republic of Ireland

Since the turn of the century statistics collected by the Central Statistics Office indicate that approximately 30,000 people die each year in the Republic of Ireland. Overall, the CSO data indicates that the number of deaths in Ireland is decreasing while the number of births is increasing (Table 1).

Table 1 Births and Deaths in the Republic of Ireland, 1999-2003

	1999	**2000**	**2001**	**2002**	**2003**
Births	53,400	54,200	57,900	60,500	61,500
Deaths	31,700	31,100	29,800	29,300	28,800
Suicide	439	413	448	451	444
Infant deaths	293	322	337	306	311
Population	3,744,700	3,786,900	3,838,900	3,917,300	3,978,900

Source: CSO (www.cso.ie)

Hidden within these statistics are the real life stories of road traffic accidents, young male suicides, heart disease, cancer, homicide victims and old age[4]. Excluded also are the people who are terminally ill and awaiting death in the care of medical personnel and family members. This survey focuses on the perceived care given to people who die in Irish hospitals.

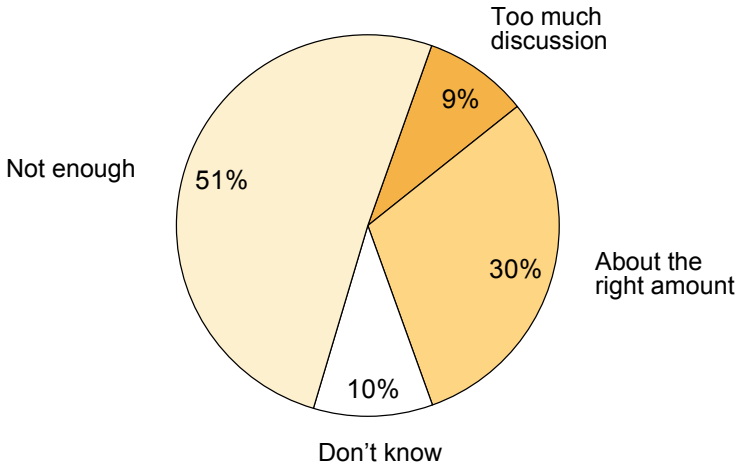
[4] During 2003, there were 444 suicides, 293 deaths from road traffic accidents, 5,600 deaths from ischaemic heart disease, 4,400 deaths due to respiratory diseases, 1,350 deaths due to injuries and poisonings, and 39 homicides (*Vital Statistics Four Quarter and Yearly Summary* 2003. CSO 2004).

2.2 Level of Discussion about Death and Dying in the Community

In spite of, or perhaps because of the inevitability of death, to speak of death continues to be a taboo subject in many societies, and it is often associated with rituals and superstitions. In this survey of Irish adults, respondents were asked if they think that as a community, Irish people discuss death and dying too much, about the right amount or not enough. The responses to this question (Figure 2) reveal that a majority of Irish adults feel that Irish society does not discuss death and dying enough, with just less than one third saying the discussion is 'about the right amount' and approximately one in ten respondents feeling there is 'too much discussion'. The comparable figures for a Scottish survey (Wallace 2003)[5] were 70% 'not enough', 28% 'about the right amount' and 2% 'too much discussion'.

Figure 2 – Level of discussion about death and dying in the community?

Base: All Respondents (n=1,000)



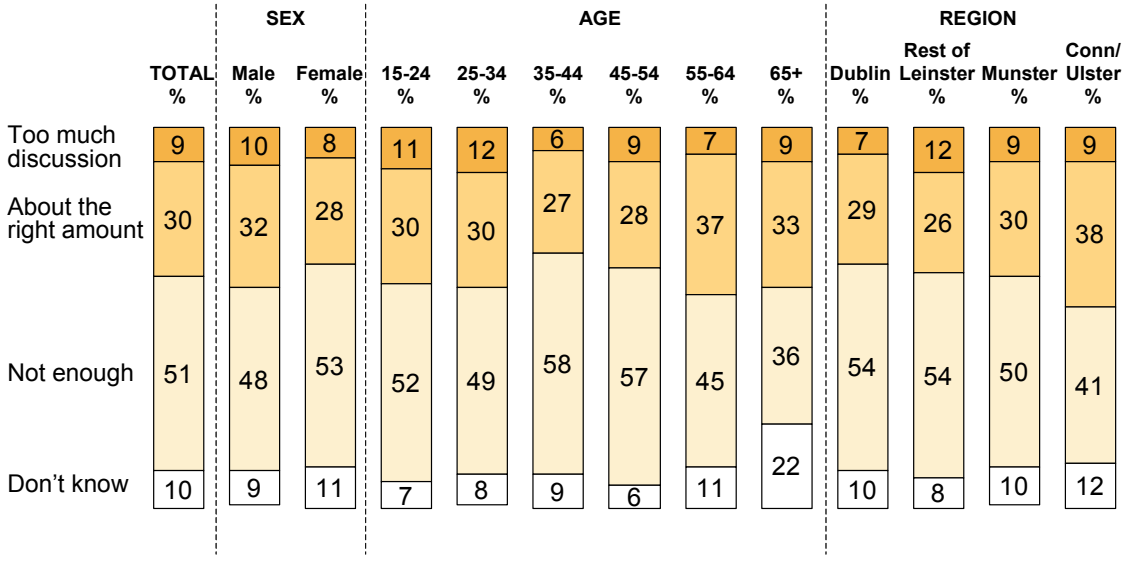
Q. Do you think that as a community, we discuss death and dying……?

[5] Wallace, J. 2003. '*Public Awareness of Palliative Care:* Report of the findings of the first national survey in Scotland into public knowledge and understanding of palliative care'. Scottish Partnership for Palliative Care, Edinburgh.

Age and region had an impact on whether people feel there is enough discussion of death and dying in Irish society, with older respondents, particularly those over 65 years of age and people living in Connaught/Ulster least likely to respond that there is not enough discussion of these issues. Conversely, respondents approaching or experiencing 'mid-life' (35-54 years) and females were most likely to say that there was not enough discussion of death and dying in Irish society (Figure 3).

Figure 3 – Level of discussion on death and dying within Irish Society by Sex, Age and Region

Base: All Respondents (n=1,000)



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

Overall, social class[6] had no significant impact on the responses to this question, with similar proportions of ABC1 and C2DE categories saying discussion of death and dying was too much, about the right amount and not enough. However, the opinions of the farming community differed from the rest of the population, with 20% of farmers feeling there is 'too much' discussion and only 32% saying there is

[6] Social class is typically measured in terms of eight different socio-economic groups. The defining characteristics of each group are as follows: **A** – professional/ very senior people in business/top level civil servants; **B** – middle management executives in large organisations, with appropriate qualifications. Principal officers in local government and civil servants. Top management or owners of small business concerns, educational and service establishments. **C1** – junior management; owners of small establishments; and all others in non-manual positions. **C2** – All skilled manual workers and those manual workers with responsibility for other people. **D** – All semi-skilled and unskilled manual workers. **E** – All those entirely dependent on the state long term through sickness, unemployment, old age or other reasons. **F1** – farmers with 50+ acres. **F2** – farmers with less than 50 acres and farm labourers. It is standard practice to combine these separate categories into three summary categories when analysing differences between different socio-economic groups as follows: ABC1, C2DE, and F.

'not enough' discussion. Unemployed[7] and retired respondents were also least likely to say that there was not enough discussion in this area. A summary of respondents' characteristics that felt there was not enough discussion is presented below (Table 2).

Table 2 Not Enough Discussion of Death and Dying in Irish Society.

	Number	%
Total	505	51
AGE		
15-17 years	35	51
18-24 years	84	52
25-34 years	92	49
34-44 years	100	58
45–55 years	92	57
55-64 years	53	45
65+ years	49	36
SEX		
Male	238	48
Female	267	53
REGION		%
Dublin	161	54
Rest of Leinster	128	54
Munster (incl. Cork)	140	50
Connaught/ Ulster	75	41
Cork[8]	61	50
Galway/Sligo/Donegal	46	44
SOCIAL CLASS		
ABC1	201	54
C2DE	266	53
F	38	32
STATUS		
Working	297	52
Student	77	54
Housewife	56	54
Retired	59	41
Unemployed	16	39
NUMBER IN HOUSEHOLD		
One	59	50
Two	101	49
Three	79	45
Four	115	51
Five	85	57
Six	44	52
Seven+	22	51

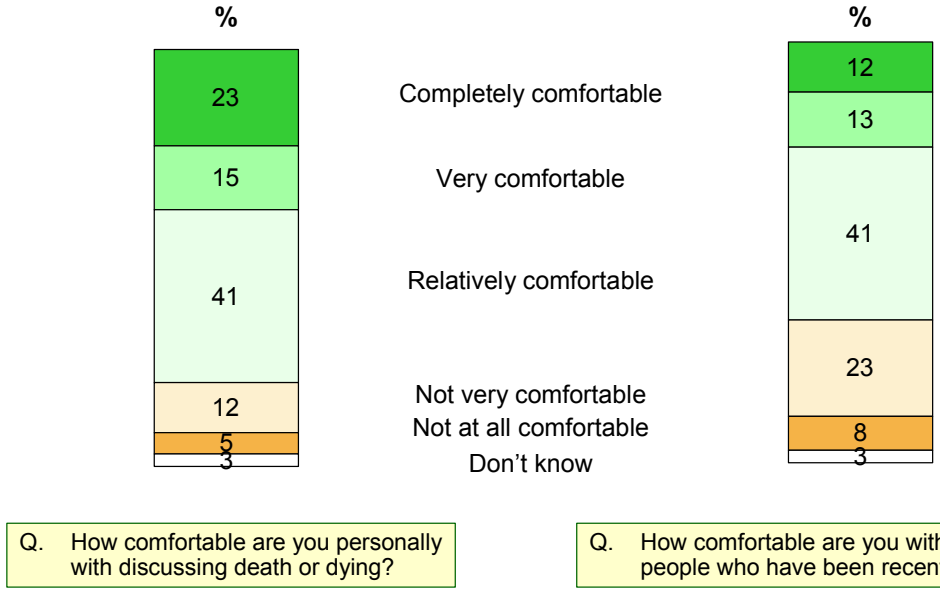
[7] Any reference to unemployed persons in this survey should be treated with caution as the total number of respondents in this category (n=42) is subject to large margins of error.
[8] Data for Cork and three Western counties (Galway, Sligo and Donegal) is sometimes presented separately. However, in all instances, the Cork data is also contained within Munster, while data relating to the three Western counties is contained in Connaught/Ulster.

2.3 Personal Feelings Towards Discussing Death and Talking to Recently Bereaved Persons

Opinions varied as to whether people were personally comfortable discussing death or dying in general or with talking to people who had been recently bereaved, with more respondents comfortable about the former than the latter. Almost four in ten respondents said they would be 'Completely or very comfortable' with discussing death or dying, compared with just one quarter of respondents who would be comfortable talking to people who have been recently bereaved (Figure 4).

Figure 4 - Personal Feelings Towards Discussing Death and Talking to Recently Bereaved

Base: All Respondents (n=1,000)

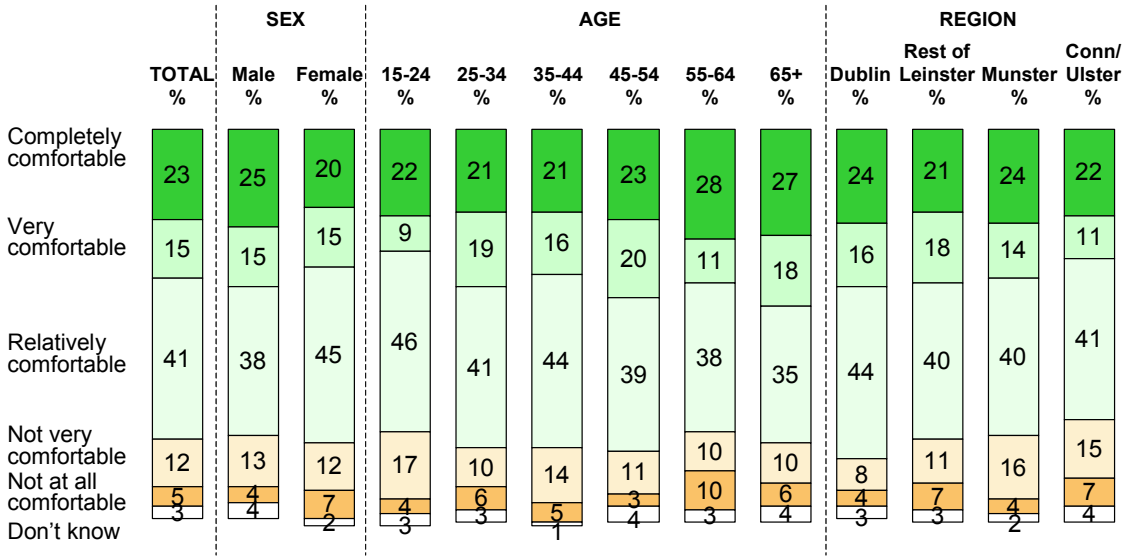


Most discomfort in discussing death and dying generally was expressed by respondents living outside Dublin and by the 15-24 year and 55-64 year groups (Figure 5). The youngest age groups, males and people living outside of Dublin are most likely to be uncomfortable talking to people who have been recently bereaved (Figure 6).

No significant difference emerged between the social groups, although farmers tended to be slightly more uncomfortable discussing death and dying, and with talking to recently bereaved persons than their urban counterparts. Allowing for the small sample size, unemployed persons were more comfortable than others in discussing death and dying. Finally, as will be noted later in this report, respondents who are most comfortable with discussing death and dying are also most likely to have made arrangements for their future if they become terminally ill or die.

Figure 5 - Personal Feeling Towards Discussing Death By Sex, Age and Region

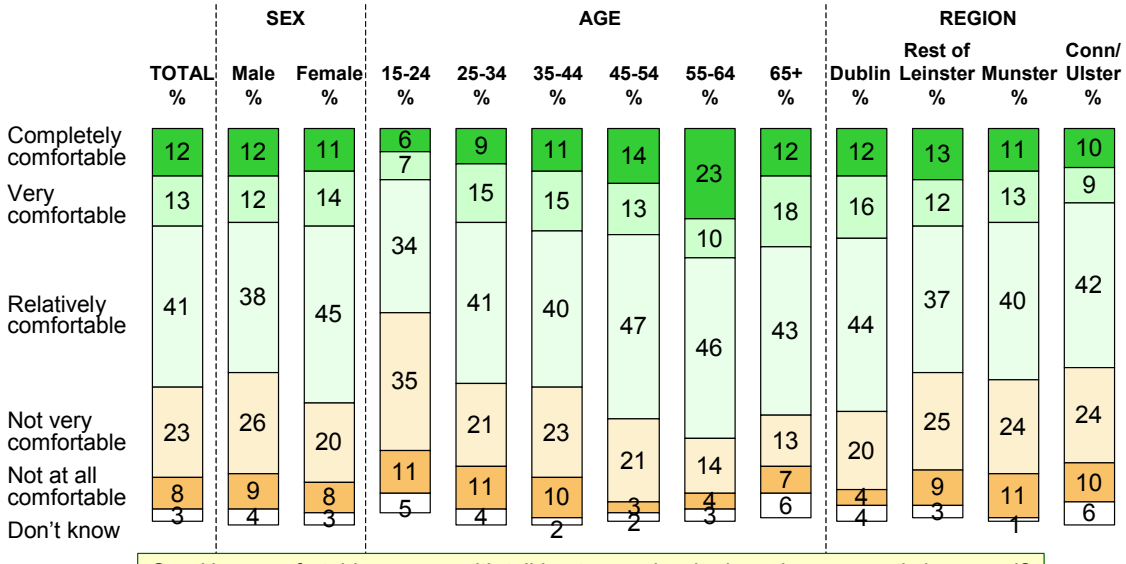
Base: All Respondents (n=1,000)



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

Figure 6 - Personal Feeling Towards Talking to People Who Have Been Recently Bereaved

Base: All Respondents (n=1,000)



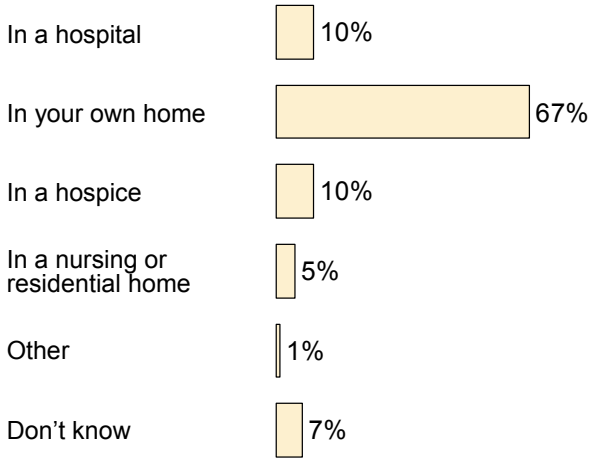
Q. How comfortable are you with talking to people who have been recently bereaved?

2.4 Preferred Place of Care if Dying

When respondents were asked where they would like to be cared for if they were dying, the majority replied 'in their own home'. One in ten respondents chose either a hospital or a hospice as their preferred place of caring in such a situation (Figure 7). In the survey conducted in Great Britain previously referred to (Higginson 2002), the majority of respondents also expressed a preference for home care (56%), followed by hospice care (24%).

Figure 7 - Preferred Place of Care if Dying

Base: All Respondents (n=1,000)



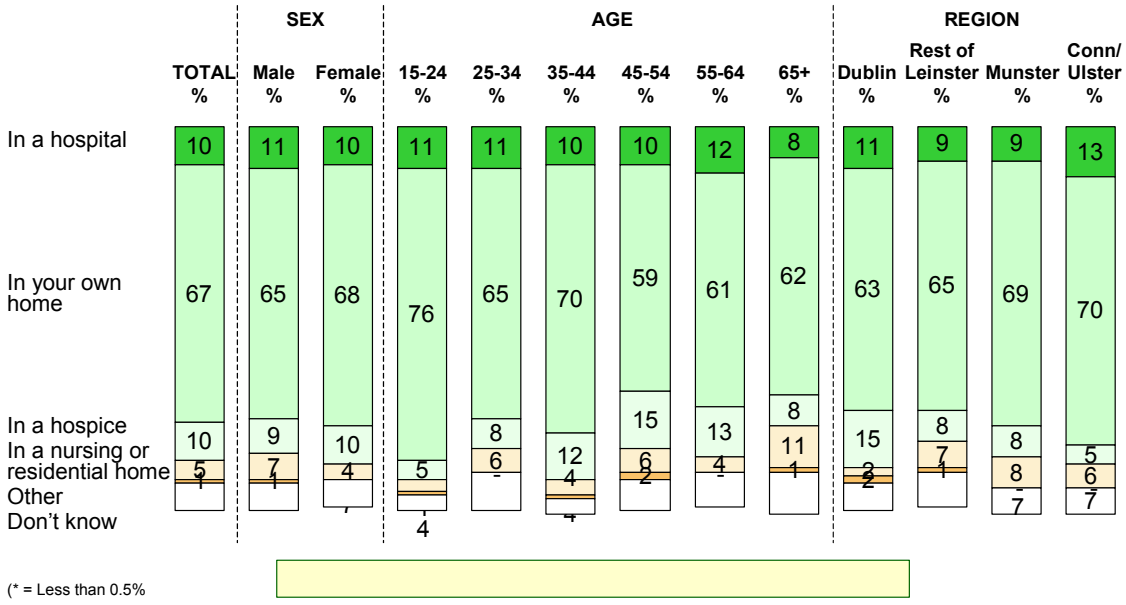
Q. Where would you want to be cared for if you were dying?

This pattern of stated preference differs significantly from the actual place of deaths in Irish society. In Ireland the Central Statistics Office code home deaths under 'domiciliary'. During 2003, 25% (7,245) of all deaths were domiciliary, while 57.5% (15,580) of deaths occurred in general, district, county or cottage hospitals. These figures exclude deaths in private nursing homes, hospices and community care.

In general, the youngest age group, females and those living outside of Dublin were most likely to choose 'own home' as their preferred place of caring. Conversely, a higher proportion of the middle age group (45-54 years) selected a hospice as their preferred place of caring than any other age group (Figure 8).

Figure 8 - Preferred Place of Care If Dying By Sex, Age and Region

Base: All Respondents (n=1,000)



Respondents from the ABC1 social class, particularly those in the AB group were most likely to select a hospice when compared with their counterparts in other social groupings. The middle-class (C1C2) opted more for hospital care, while the farming community expressed the highest preference for nursing/residential homes (Table 3).

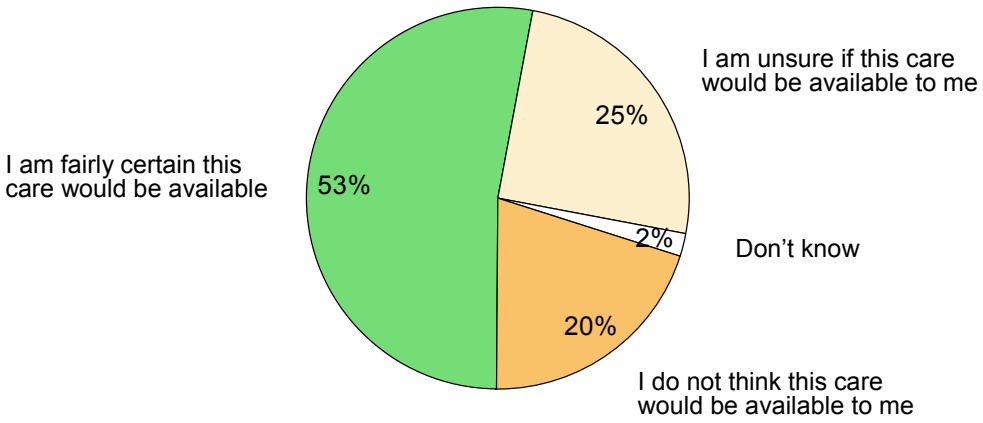
Table 3 Choice of Hospice by Social Class

Social Class	Number	Hospice	Home	Hospital	Nursing/ Residential
		%	%	%	%
AB	122	16	66	7	5
C1	253	13	65	10	5
C2	191	8	67	15	2
DE	315	9	69	8	5
F	120	2	63	13	16
Total	**1,000**	**10%**	**67%**	**10%**	**5%**

Respondents were then asked if they thought their preferred place of care would be available to them in their own locality if they needed it now and, as indicated in Figure 9 below, just less than half of all respondents expressing a choice felt 'fairly certain' that the care would be available. However, a substantial proportion said they were either unsure or more definite that the required care would not be available to them.

Figure 9 - Would Desired Place of Caring be Available in Your Locality?

Base: All Expressing A Choice (n=927)



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

Those most likely to feel that their choice of care would not be available to them included those aged 25-54 years and persons not living in Connaught/ Ulster. Part of the explanation for the regional difference is that an above average proportion of persons living in Connaught/ Ulster chose 'own home' as their preferred place of caring, while more of those aged 45-54 years chose 'a hospice'. Social class was not a significant differentiating factor in this instance.

Respondents opting for home care were least likely to feel that this care would be available to them if they needed it now, while those selecting a nursing/ residential home were most confident of the availability of the care. In spite of the fact that most people die in hospitals, one fifth of respondents do not think that hospital care would be available to them if they needed it now (Figure 10).

Figure 10 - If Desired Place of Caring Would be Available by Place of Care Chosen

Base: All Who Would Like To Be Cared For In …….

	Total	**Prefer A Hospital** (n=101)	**Prefer Own Home** (n=664)	**Prefer A Hospice** (n=106)	**Prefer Nursing/ Residential Home** (n=51)
I am fairly certain this care would be available to me	53%	62%	50%	56%	73%
I am unsure if this care would be available to me	25%	18%	27%	27%	21%
I do not think this care would be available to me	20%	20%	22%	15%	6%
Don't know	2%	1%	2%	1%	-

Q. Do you think …. would be available to you in your locality if you needed it now?

With the exception of home care where the sample is sufficiently large for sub-group analysis, the relatively small number of people opting for other forms of care means that the sub-group analysis should be treated with extreme caution. Thus, the only thing we can say with any degree of confidence is that the groups most confident of the availability of home care are: female, young adults, working class, living outside Dublin, and living in households with four or more persons (Table 4).

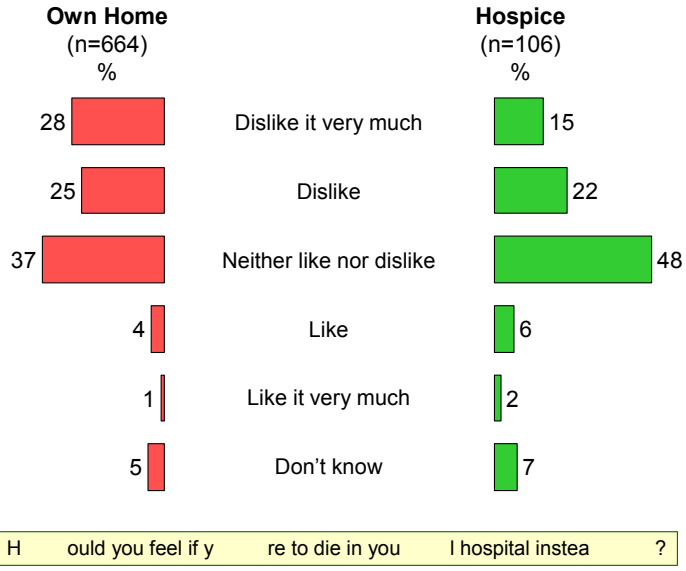
Table 4 If Fairly Certain Care Would be Available in Locality

	Hospital* **(N=103)**	**Home** **(N=665)**	**Hospice*** **(N=97)**	**Nursing/ Residential Home*** **(N=55)**
Sex	%	%	%	%
Male	72	47	54	80
Female	53	53	59	62
Age				
15-24 years	56	60	83	86
25-34 years	57	47	41	84
35-44 years	68	38	59	70
45-54 years	51	52	63	67
55-64 years	70	52	32	72
65+	87	47	63	69
Social Class				
ABC1	65	46	55	64
C2DE	56	52	57	61
F	77	52	75	93
Region				
Dublin	58	43	58	52
Rest of Leinster	46	52	23	75
Munster	70	48	80	79
Conn./ Ulster	76	59	67	69
Cork	87	55	79	86
Galway/Sligo/Donegal	91	51	67	77
Status				
Working	77	46	55	88
Student	31	60	87	44
Housewife	43	48	59	62
Retired	77	52	58	55
Unemployed	48	63	11	0
Number of People in Household				
One	68	41	53	70
Two	60	48	79	32
Three	51	44	46	79
Four +	67	54	56	79

Respondents expressing a preference for home care or hospice care were asked how they would feel if they were to die in their local hospital instead of their own homes or a hospice. Many of these respondents would not like the prospect, although a substantial number of respondents were not concerned (Figure 11).

Figure 11 - If You Were to Die in Your Local Hospital instead of Home

Base: All Those Who Would Like To Be Cared For In Their Own Home (n=664) Or In A Hospice (n=106) If They Were Dying



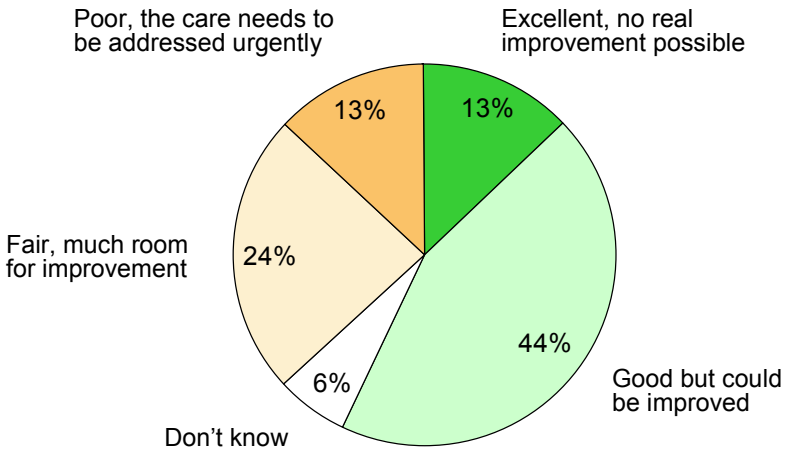
Females and younger respondents were generally most critical of the prospect of not receiving their preferred form of care.

2.5 Impressions of Hospital Care for people who are Dying or Terminally Ill in Irish Hospitals

With the exception of just over one in ten respondents (13%) who felt that care for people dying or terminally ill in Irish hospitals is 'excellent', everyone else said that some improvement is needed, with a substantial proportion (37%) feeling that considerable or urgent improvement is needed (Figure 12).

Figure 12 - Impressions of Hospital Care for People Who Are Dying or Terminally ill in Irish Hospitals

Base: All Respondents (n=1,000)



Q. Given that a majority of people do die in hospitals, is it your impression that care for people who are dying or terminally ill in Irish hospitals is ……?

Those most likely to have positive impressions of hospital care included: female, older, working class, living in Cork, farmers, housewives, unemployed and retired respondents (Figure 13 and Table 5).

Figure 13 - Impressions of Hospital Care for People Who Are Dying Or Terminally ill by Sex, Age ar Region

Base: All Respondents (n=1,000)

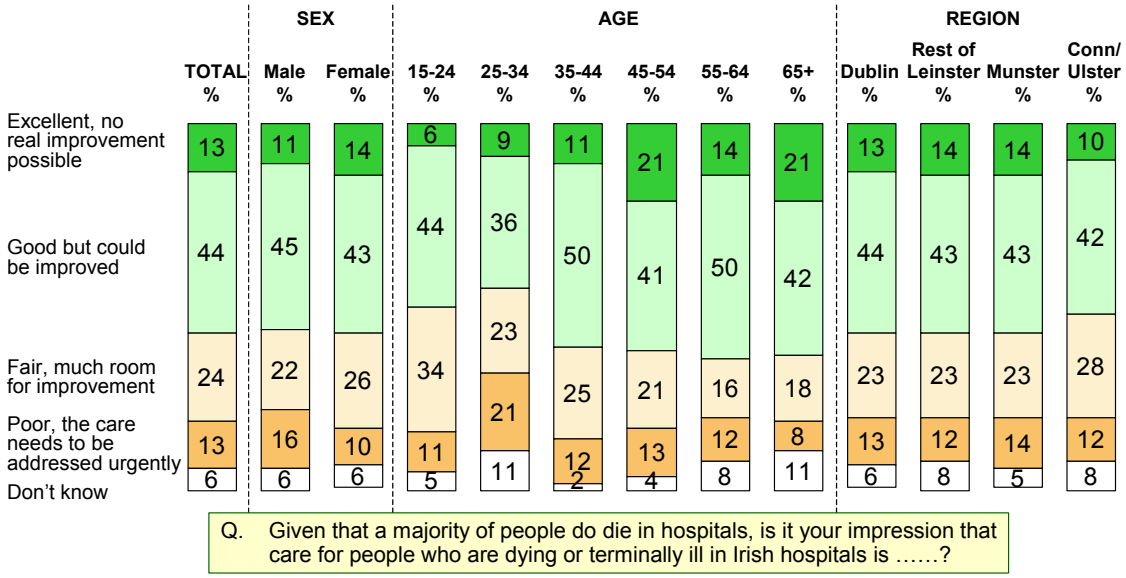


Table 5 Impressions of Hospital Care for People who are dying or Terminally Ill.

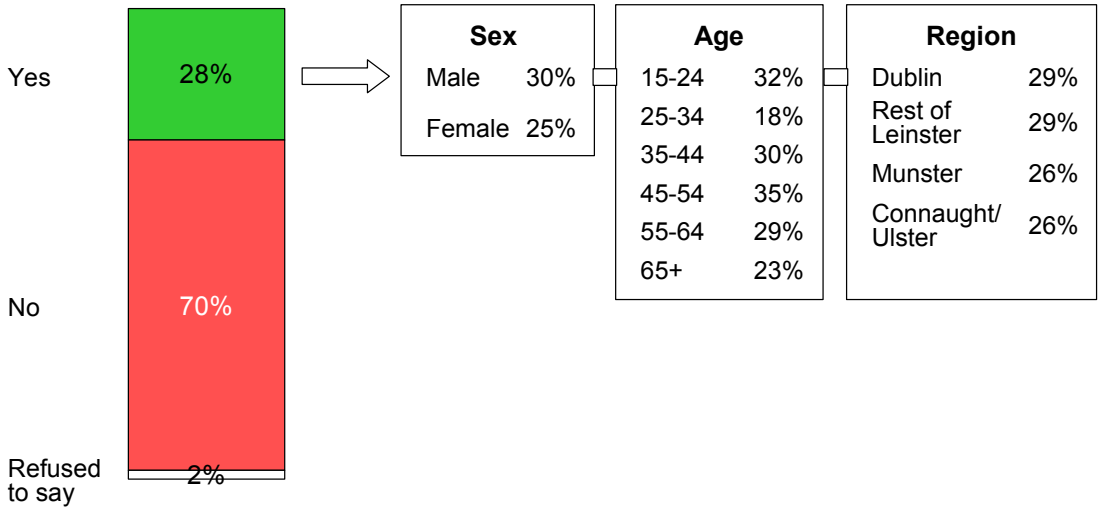
	Excellent	Good	Fair	Poor	Don't Know
Social Class	**%**	**%**	**%**	**%**	**%**
ABC1	9	45	26	13	6
C2DE	14	41	23	15	8
F	18	50	22	7	3
Region					
Dublin	13	44	23	13	6
Rest of Leinster	14	43	23	12	8
Munster (incl. Cork)	14	43	23	14	5
Conn./ Ulster	10	42	28	12	8
Cork	20	41	17	14	7
Galway/Sligo/Donegal	9	47	26	11	7
Status					
Working	11	44	24	15	7
Student	6	49	32	10	4
Housewife	19	40	26	12	3
Retired	19	42	17	9	12
Unemployed	22	29	26	11	11
Number of People in Household					
One	17	37	19	17	10
Two	14	42	21	11	12
Three	11	39	26	17	7
Four +	11	47	25	11	6

2.6 Care of people close to them who died in an Irish Hospital

Almost one in three respondents (28%) said that someone close to them had died in an Irish hospital within the past two years or so. This distribution was consistent across the country and, with the exception of 25-34 year olds, within the different age groups (Figure 14).

Figure 14 - If Anyone Close to Them Has Died In An Irish Hospital

Base: All Respondents (n=1,000)

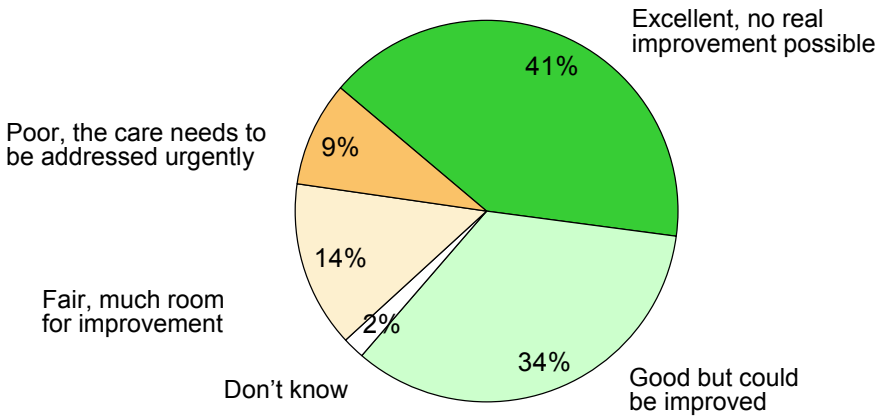


Q. Has anyoneclose to you died in an Irish hospital within the last two years?

The impressions of this group who said someone close to them had died in an Irish hospital in the past two years or so was much more positive than the population as a whole as reported earlier in Figure 12. More than four in ten respondents felt that the care provided was 'excellent, with no real improvement possible' and most of the remainder had relatively positive views of the care (Figure 15).

Figure 15 - Rating of Care Given to Person Who Died In Hospital

Base: All Respondents Who Said Someone Close To Them Had Died Ir. An Irish Hospital In The Past Two Years Or So (n=287)



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

As was the case with the overall rating of hospital care noted earlier, those most likely to positively rate current hospital care for their family members included: female, older, working class, living in Cork, housewives, unemployed and retired respondents. In addition, respondents whose family members died in a single room rather than an open ward were more likely to say that the care provided was 'excellent' (Table 6).

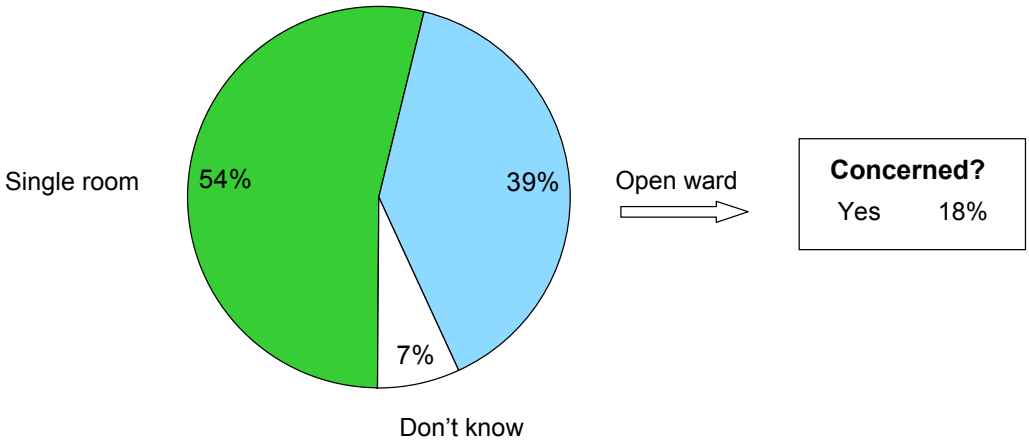
Table 6 Impressions of Hospital Care by Single Room or Open Ward

	Total (N=278)	**Open Ward** (N=108)	**Single Room** (N=150)	**Don't Know** (N=20)
	%	%	%	%
Excellent	41	34	48	24
Good	34	32	36	34
Fair	14	19	10	13
Poor	9	15	5	14
Don't Know	2	-	2	14

The majority of people who died did so in a single room, with just less than four in ten (39%) dying in an open ward. Working class respondents and people from Cork had the highest incidence of people dying in open wards, at 43% and 54% respectively. Just less than one fifth of respondents (18%) whose family members had died in an open ward expressed concern about the situation (Figure 16).

Figure 16 - Where Person Died – Open Ward Or Single Room?

Base: All Respondents Who Said Someone Close To Them Had Died In An Irish Hospital In The Past Two Years Or So (n=287)

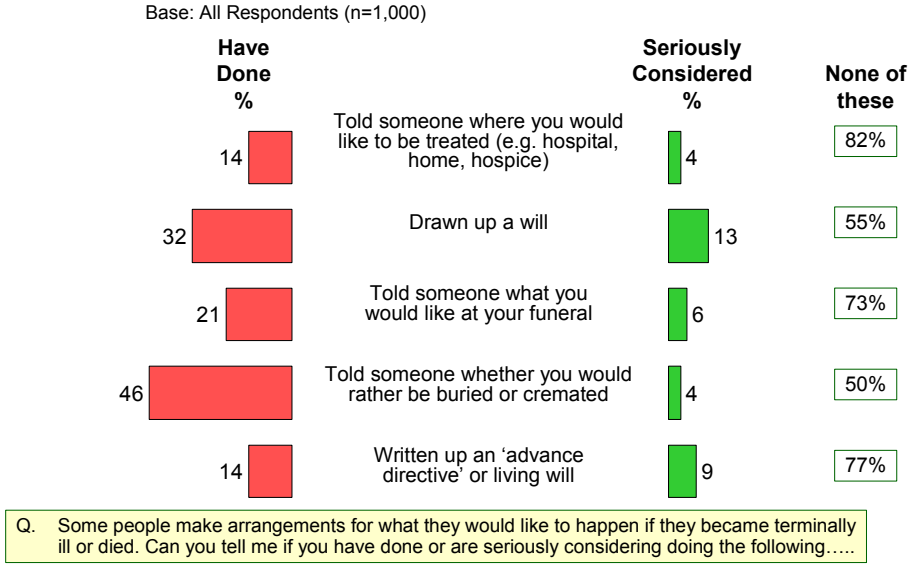


Q. Did this person die in an open ward among other patients or in a single room?
Q. Did the fact he/she died in an open ward concern you or your relations in any way?

2.7 Arrangements in Place in Case of Terminal Illness or Death

The majority of respondents do not have any arrangements in place for what they would like to happen if they became terminally ill or died. However, as the following chart illustrates, a substantial number have either 'told someone whether they would rather be buried or cremated' or 'drawn up a will' (Figure 17). Just over one in ten respondents (14%) said they had written up an advance directive or 'living will'[9].

Figure 17 - Arrangements in Place If Terminally ill or Dead



[9] Interviewers gave the following explanation of a living will. 'A living will allows an individual to make decisions about their health care in advance in case they are ever incapacitated and unable to do so'.

Different groups of respondents tend to have made diverse or no arrangements for a terminal illness or death, with the following groups most likely to have arrangements in place: females, older, ABC1, residents of Dublin and Cork, retired, and those comfortable with discussing death and dying. However, some interesting variations also occurred in the overall pattern (Table 6). Males, for instance, are most likely to have drawn up a general will or a living will; farmers are most likely to have made arrangements for a living will; and people living alone are consistently above average for each of the listed arrangements. This latter trend reflects the higher incidence of elderly people living alone in Ireland.

Table 6 If Arrangements are in Place for Terminal Illness or death

	Where Like to be Treated	Drawn up a will	Funeral	Buried or Cremated	Living Will
	%	%	%	%	%
Sex					
Male	12	34	17	39	17
Female	17	30	25	53	12
Age					
15-24 years	6	4	18	34	3
25-34 years	8	21	22	42	9
35-44 years	23	26	23	48	11
45-54 years	19	45	23	53	23
55-64 years	15	55	16	47	24
65+	21	67	23	59	27
Social Class					
ABC1	18	36	22	50	16
C2DE	13	27	22	43	11
F	10	39	14	46	26
Region					
Dublin	16	35	22	50	14
Rest of Leinster	12	30	22	42	11
Munster	19	36	23	47	19
Conn./ Ulster	7	24	15	43	13
Status					
Working	15	33	21	45	16
Student	4	2	16	28	2
Housewife	19	26	26	57	11
Retired	19	66	25	61	27
Unemployed	17	14	12	36	6
Number of People in Household					
One	25	54	29	61	22
Two	16	43	21	51	18
Three	9	26	21	43	15
Four +	13	24	19	41	11

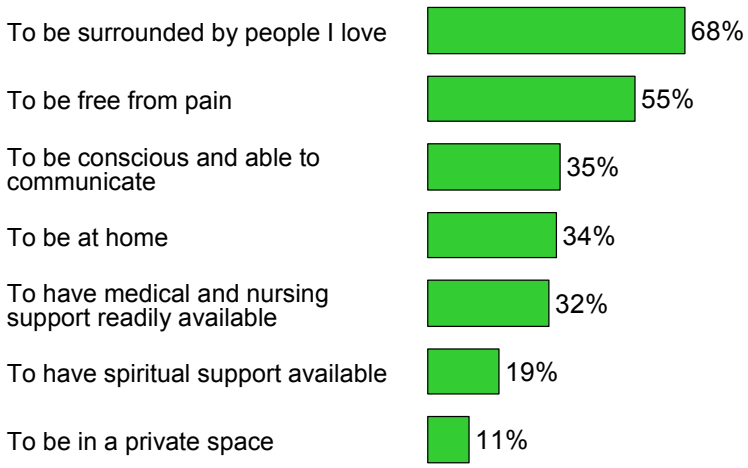
Respondents who previously had stated they were comfortable discussing death and dying were also most likely to have put arrangements in place for their own death or terminal illness.

2.8 Most Important Things About Care Available If Dying or Terminally Ill

When given a choice of selecting up to three things they would consider most important about the care available to them if they were dying or in the last stages of a terminal illness, the majority of respondents chose 'to be surrounded by people I love', followed by 'to be free from pain' (Figure 18). Additional sub-group analysis is presented in Table 7 (overleaf).

Figure 18 - Most Important Things About Care Available to You If Dying Or Terminally ill?

Base: All Respondents (n=1,000)



(*Total exceeds 100% - Respondents selected up to 3 important things)

Q. What three things would you consider to be mo important about the care vailable to yo you were dy e last stages of a term illness?

Table 7 What Three Things are Considered Most Important about the Care Available if Dying or Terminally Ill

	Total (N=1,000)	**Male** (N=493)	**Female** (N=507)
	%	%	%
Free from pain	55	54	56
Conscious and able to communicate	35	37	33
Surrounded by people I love	68	63	72
At home	34	33	34
Have medical support	32	28	36
Spiritual support	19	19	19
In a private space	11	11	10

Table 7 (Continued) What Three Things are Considered Most Important about the Care Available if Dying or Terminally ill

	Total	AGE						REGION			
		15-24 (N=228)	25-34 (N=187)	35-44 (N=172)	45-54 (N=162)	55-64 (N=117)	65+ (N=134)	Dublin (N=298)	Rest of Leinster (N=239)	Munster (N=280)	Conn./ Ulster (N=183)
	%	%	%	%	%	%	%	%	%	%	%
Free from pain	55	56	60	59	58	57	35	58	60	49	54
Conscious and able to communicate	35	43	37	35	31	30	28	39	31	34	35
Surrounded by people I love	68	78	68	74	62	63	54	75	63	68	62
At home	34	35	34	41	30	28	32	33	35	34	34
Have medical support	32	27	26	39	41	30	30	37	24	34	31
Spiritual support	19	16	11	9	23	30	35	16	20	21	20
In a private space	11	11	10	12	12	10	8	8	7	12	16

Table 7 (Continued) What Three Things are Considered Most Important about the Care Available if Dying or Terminally ill

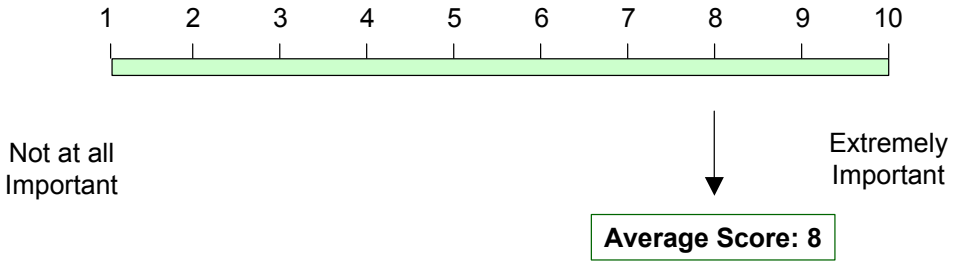
	Total	SOCIAL CLASS			STATUS					PEOPLE IN HOUSEHOLD			
		ABC1 (N=375)	C2DE (N=506)	F (N=120)	Working (N=567)	Student (N=143)	Housewife (N=104)	Retired (N=143)	Unemployed (N=42)	One (N=116)	Two (N=206)	Three (N=176)	Four+ (N=503)
	%												
Free from pain	55	60	51	56	59	57	52	37	68	46	47	55	61
Conscious and able to communicate	35	35	36	30	37	37	26	27	53	32	30	37	36
Surrounded by people I love	68	68	70	59	68	76	77	53	63	62	58	74	71
At home	34	29	37	34	33	38	38	33	21	32	32	36	41
Have medical support	32	34	31	29	30	31	47	32	27	33	31	28	33
Spiritual support	19	21	18	17	16	16	21	34	15	23	13	14	17
In a private space	11	14	8	10	12	12	8	7	6	10	11	11	11

2.9 Overall Importance of Care for Terminally Ill in Ireland

The majority of respondents described the provision of care for the terminally ill in Ireland as very or extremely important.

Figure 19 - Overall Importance of Care For Terminally ill in Ireland

Base: All Respondents (n=1,000)



Q.

ca 10.

Although consistently high scores were given by each of the sub-groups to this question, some rated the provision of care for the terminally ill higher than others. A comparison of the mean scores for each of the major sub-groups is presented overleaf (Table 8).

Table 8 The Importance of the Provision of Care for the Terminally Ill in Ireland (Mean Scores)

	Mean Score
TOTAL	**7.87**
AGE	
15-24 years	7.95
25-34 years	7.54
34-44 years	7.85
45–55 years	7.76
55-64 years	7.75
65+ years	8.44
SEX	
Male	7.63
Female	8.10
REGION	
Dublin	7.99
Rest of Leinster	7.61
Munster (incl. Cork)	7.89
Connaught/ Ulster	7.95
Cork	7.94
SOCIAL CLASS	
AB	8.25
C1	7.85
C2	7.78
DE	7.88
F	7.60
STATUS	
Working	7.64
Student	8.02
Housewife	8.08
Retired	8.28
Unemployed	8.60
NUMBER IN HOUSEHOLD	
One	8.01
Two	8.03
Three	7.90
Four	7.51
Five	8.12
Six	7.81
Seven+	7.68

Appendices

Useful Websites

Irish Hospice Foundation	www.hospice-foundation.ie
Care for People Dying in Hospitals Project	www.newgrange-process-net
Health Services National Partnership Forum	www.hsnpf.ie
North Eastern Palliative Care Services	www.nehbpalliativecare.com

Hospital Care Research

I.D. No. (1-4)

Ass. No. _____ **Qst. No.** _____ **TNS mrbi/110288/04**

Now I would like to ask you a number if questions on your views of how people are cared for in Irish hospitals when they are dying.

Q.1 Do you think that as a community, we discuss death and dying……?
READ OUT. FLIP. SINGLE CODE

Too much	1
About the right amount	2
Not enough	3
Don't know (DNRO)	4

Q.2 How comfortable are you personally with discussing death or dying? **READ OUT. FLIP. SINGLE CODE**

Completely comfortable	1
Very comfortable	2
Relatively comfortable	3
Not very comfortable	4
Not at all comfortable	5
Don't know (DNRO)	6

Q.3 How comfortable are you with talking to people who have been recently bereaved?
READ OUT. FLIP. SINGLE CODE

Completely comfortable	1
Very comfortable	2
Relatively comfortable	3
Not very comfortable	4
Not at all comfortable	5
Don't know (DNRO)	6

Q.4 Where would you want to be cared for if you were dying?
READ OUT. ROTATE. SINGLE CODE

IF NECESSARY ADD: A HOSPICE IS A PLACE THAT CARES FOR PEOPLE WITH LIFE THREATENING ILLNESS

In a hospital	1
In your own home	2
In a hospice	3
In a nursing or residential home	4
Other (specify)	5
Don't know (DNRO)	6

Q.5 Do you think …. (option chosen at Q.4) would be available to you in your locality if you needed it now? **READ OUT. FLIP. SINGLE CODE**

I am fairly certain this care would be available to me	1
I am unsure if this care would be available to me	2
I do not think this care would be available to me	3
Don't know (DNRO)	4

ASK ALL WHO HAVE NOT CHOSEN HOSPITAL AS A PLACE TO BE CARED FOR IN (NOT CODE 1 AT Q.4): OTHERS GO TO Q.7

Q.6 How would you feel if you were to die in your local hospital instead of … (option chosen at Q.4)? **READ OUT. FLIP. SINGLE CODE**

Dislike it very much	1
Dislike	2
Neither like nor dislike	3
Like	4
Like it very much	5
Don't know (DNRO)	6

ASK ALL

Q.7 Given that a majority of people do die in hospitals, is it your impression that care for people who are dying or terminally ill in Irish hospitals is ……? **READ OUT. FLIP. SINGLE CODE**

Excellent, no real improvement possible	1
Good but could be improved	2
Fair, much room for improvement	3
Poor, the care needs to be addressed urgently	4
Don't know (DNRO)	5

Q.8 Has anyone close to you died in an Irish hospital within the past two years or so?

INTERVIEWER: The person who died could have been a family member or friend and must have spent at least one day in hospital before dying

Yes	1	**CONTINUE**
No	2	**GO TO Q.12**
Don't know/refused (DNRO)	3	

Q.9 How would you rate the overall care given to this person. Was the overall care ….? **READ OUT. FLIP. SINGLE CODE**

Interviewer: If more than one bereavement has occurred in the past two years, please ask in relation to the most recent bereavement.

Excellent, no real improvement possible	1
Good but could be improved	2
Fair, much room for improvement	3
Poor, the care needs to be addressed urgently	4
Don't know (DNRO)	5

Q.10 Did this person die in an open ward among other patients or in a single room?

INTERVIEWER: It doesn't matter if the ward was private or public

Open ward	1	**CONTINUE**
Single room	2	**GO TO Q.12**
Don't know (DNRO)	3	

Q.11 Did the fact he/she died in an open ward concern you or your relations in any way?

Yes	1
No	2
Don't know (DNRO)	3

ASK ALL

Q.12 Some people make arrangements for what they would like to happen if they became terminally ill or died. Can you tell me if you have done or are seriously considering doing the following…..

INTERVIEWER: A living will allows an individual to make decisions about their health care in advance in case they are ever incapacitated and unable to do so.

	Have Done	Am seriously considering	DK/ Refused
Told someone where you would like to be treated (e.g. hospital, home, hospice)	1	2	3
Drawn up a will	1	2	3
Told someone what you would like at your funeral	1	2	3
Told someone whether you would rather be buried or cremated	1	2	3
Written up an 'advance directive' or living will'	1	2	3

Q.13 What three things would you consider to be most important about the care available to you if you were dying or in the last stages of a terminal illness? **READ OUT. ROTATE. MAXIMUM OF THREE RESPONSES.**

To be free from pain	1
To be conscious and able to communicate	2
To be surrounded by people I love	3
To be at home	4
To have medical and nursing support readily available	5
To have spiritual support available	6
To be in a private space	7
Other (specify)	8
Don't know (DNRO)	9

Q.14 Using a 10 point scale where 1 means it is not important at all and 10 means it is extremely important, how would you describe the importance of the provision of care for the terminally ill in Ireland? You can choose any number between 1 and 10.

Not at all important	1
.....	2
.....	3
.....	4
.....	5
.....	6
.....	7
.....	8
.....	9
Extremely important	10
Don't know (DNRO)	11