Dying with Cancer: Perspectives of Bereaved Relatives/Friends

N. Ireland Cancer Registry

Cancer Focus Northern Ireland

HSC Public Health Agency

Queen's University Belfast

Dying with Cancer: Perspectives of Bereaved Relatives/Friends

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Contents

ABBREVIATIONS

DHSSPS	Department of Health and Social Services and Public Safety
DMB	Demography and Methodology Branch, NISRA
GP	General Practitioner
GRO	General Register Office, Northern Ireland
HCP	Healthcare Professional
HSC	Health and Social Care
ICD-10	International Classification of Diseases – Version 10
IQR	Interquartile Range
NI	Northern Ireland
NISRA	Northern Ireland Statistics and Research Agency
NICR	Northern Ireland Cancer Registry
ORECNI	Office for Research Ethics Committee, Northern Ireland
PPD	Preferred Place of Death
SPC	Specialist Palliative Care
SPSS	Statistical Packages for the Social Sciences
SD	Standard Deviation
vs	Versus
WHO	World Health Organisation

FOREWORD

Cancer Focus Northern Ireland is very pleased to be associated with and have facilitated this important research into the end of life experiences of people dying with cancer, based on the perceptions of their main family carer. This builds on our long association with the very valuable work of the Registry since its inception and we know that this research has been carried to the highest professional standards.

It is concerning to note that only half of the people who expressed a wish to die at home were able to have this final wish fulfilled. It is, however, encouraging that people had a very similar experience at end of life irrespective of their place of death, or their expressed preferences. Central to a positive experience is effective communication and co-ordination of services aimed at supporting patients and their families. The report also points to the level of informal care that is provided at end of life by family members and the financial burden that cancer places on families.

Cancer Focus Northern Ireland is committed to supporting people at every step of their journey with cancer. This report points to the need for end of life provision to be more in tune with individual needs. The findings should be used to inform decision-making and service provision to try to ensure that people dying with cancer and their families receive the best possible support when they need it most.

Roisin Foster
Chief Executive of Cancer Focus Northern Ireland, 2015

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This work would not have been possible without:

- The QUALYCARE study research team at the Cicely Saunders Institute of Palliative Care, King's College, London, who granted permission for the QUALYCARE protocol and research materials to be adopted and employed in Northern Ireland (NI) as part of the QUALYCARE–NI study.
- Cancer Focus NI who funded this work
- The Public Health Agency for NI which funds the work of the N. Ireland Cancer Registry (NICR)
- The members of the project Steering Group (listed in Appendix I)
- Northern Ireland Statistics and Research Agency (NISRA) Staff
- General Register Office (GRO)

I would especially like to thank the people who took the time to respond to this survey at a difficult time in their lives and without whom this research could not have been completed.

Anna Gavin .

Anna Gavin
Director, NICR
2015

1. INTRODUCTION

1 Introduction and Background

This report follows on from a previous N. Ireland Cancer Registry (NICR) report entitled 'Why cancer patients die in acute hospitals?: A retrospective study by note review' (1) which described characteristics of cancer patients who died within an acute hospital setting in Northern Ireland (NI) and identified factors associated with a hospital death. This further work was undertaken to establish factors which enable cancer patients to die at home.

The Palliative and End of Life Care Strategy for NI published by the Department of Health, Social Services and Public Safety (DHSSPS) (2) highlights that one feature of good end of life care is enabling patients to die in their place of preference. For the majority of cancer patients this preferred place of death (PPD) is home. A recent systematic review of 210 studies investigating PPD of terminally ill cancer patients and changes in PPD over time concluded that 75% of the studies showed that over half of patients preferred to die at home (3).

Cancer patients nearing their end of life very often have many physical symptoms including pain and psychological distress (4-5). End of life care aims to alleviate suffering and distress experienced by the patient and their family as much as possible by focusing on their needs in a holistic way (4-5). A study carried out by Heyland et al. in 2006 (6) of 440 patients aged 55 years or more with advanced stage cancer and/or advanced medical disease and 160 relatives, showed that patients and their relatives considered trust in the doctor providing care, effective communication and continuity of care to be the most important aspects of excellent end of life care. A recent review identified symptom control, being mentally alert and able to be involved in decisions relating to care, having trust in care providers and a having a strong alliance between the patient and their physicians as important (7). The opportunity to optimise relationships with family and friends with the burden to family minimised and good bereavement support for family in place, religious prayer or meditation, death in preferred place of care, getting personal affairs in order and leaving a legacy were also regarded as important factors (7).

In NI in 2012, there were 9934 newly diagnosed cases of cancer and 4,047 cancer deaths. It has been predicted that the need for end of life care services will increase as the population ages, therefore issues surrounding end of life care for cancer patients including the appropriate use of interventions, availability of Specialist Palliative Care (SPC) and dying in a preferred place are an increasing priority in NI.

Patterns and Trends in home deaths

Although the majority of cancer patients would prefer to die at home, this is not always achieved. A study of cancer patient deaths (2002-2003) across six European countries showed variations in deaths at home with 12.8% of cancer patients in Norway dying at home, 22.1% in England, 22.7% in Wales, 27.9% in Belgium, 35.8% in Italy and 45.4% in the Netherlands (8). The latest figures for NI show that in 2012, over a third (37.6%) of cancer patients died at home, while 42.1% died in hospital, 10.8% in a hospice setting and 9.4% in nursing/residential or care home (9).

Although achievement of a home death was higher in NI than other UK regions, it is still lower than the Netherlands. Such variance indicates that home deaths among cancer patients may be influenced by cultural, social and healthcare factors that are country or region specific.

An increase in numbers of terminally ill patients dying in institutionalised settings was noted in London between 1974 and 2003 (10). However, recent trends have seen home deaths increasing from 18.3% to 20.3% between 2004 and 2010 in England and Wales (11). A study carried out by Gao et al. in 2013 (12) in England showed an increase in the proportion of cancer patients dying at home from 20.9% in 2003 to 26.5% in 2010. This represented an annual increase in home deaths of 0.87% per annum (pa) (95% CI 0.74-0.99% pa) with a decrease in hospital deaths of -1.2% pa (95% CI 1.4—0.99 pa) being observed over the same period of time. It has been suggested that this rise in home deaths may have been associated with the introduction of government policies such as the End of Life Care Strategy (published 2008) which focuses on home-based models of end of life care (11).

Factors influencing place of death

Understanding the factors that influence place of death is essential if we are to inform interventions to help patients achieve their PPD. A systematic review of 58 studies carried out by Gomes and Higginson in 2006 (13) suggested that factors relating to place of death for cancer patients can be separated into three main areas:

1. Factors relating to the illness.
2. Factors relating to the individual, such as socioeconomic status, marital status and age.
3. Environmental factors such as healthcare input and social support.

Increased likelihood of a home death was positively associated with long length of disease, decreased ability to carry out usual daily activities e.g. personal care, good social conditions, healthcare support and a preference to die at home. Factors associated with dying in hospital included the availability of inpatient beds, prior hospital admissions, living in areas with a greater hospital provision and being from an ethnic minority (13). However, the findings of a further systematic review carried out by Murray et al. in 2009 (14) showed inconclusive findings particularly in the areas of functional status, social class, geographical location, caregiver support, marital status and tumour type. Another systematic review and meta-analysis carried out by Howell et al. in 2010 (15) to specifically explore the associations between tumour type and place of death showed that patients with haematological cancer were twice as likely to die in hospital as patients with other types of cancer. It has also been suggested that discussions about PPD when planning end of life care may play a role in whether a patient achieves PPD, with findings showing that patients were more likely to achieve PPD when doctors were aware of the preferences of the patient and family (16).

Hospital Deaths

A case note review of all deaths occurring within a district general hospital in the South West of England showed that a third of patients could have received end of life care at home if excellent end of life care services were in place (17). The previous NI retrospective note review ‘Why cancer patients die in acute hospitals?’ identified factors associated with dying in hospital. The findings showed that most patients were admitted in crisis, 14% died within 48 hours of admission and one quarter were diagnosed on their last admission (1). This was consistent with the findings of previous studies which reported that longer length of disease was positively associated with home death (18-21). While 93% of deaths within the note review study carried out by Blaney and Gavin (1) were anticipated, PPD was only recorded for 41% patients, with 61% of these indicating a preference for home. This was also consistent with the findings of other studies and has in the past been explained by people changing their minds as the illness progresses (22).

Is a home death a better death?

The evidence relating to whether patients who die at home actually experience better care and a 'better death' than those who die in institutionalised settings is inconclusive and may be associated with the level of healthcare support available. The findings of a study carried out by Teno et al. in 2004 (23) showed that relatives of patients who died in a nursing home or in their own home with support from community nursing services were more likely to report unmet needs for pain management and emotional support when compared with patients who received home hospice services. However, a study by Wright et al. in 2010 (24) has provided some evidence to suggest that patients who die at home may have a better quality of life and psychological well-being when compared to patients who died in an Intensive Care Unit or other hospital units.

2. STUDY AIM AND OBJECTIVES

Aim - To establish key factors that influence place of death and specifically those which enable cancer patients to die at home.

The key objectives were:

Objective 1 - To undertake a brief literature review of place of death for cancer patients.

Objective 2 - To document current patterns in place of cancer deaths in NI.

Objective 3 - To investigate home, hospital, hospice and care home deaths in relation to where cancer patients spent most of their time in the last three months of their life.

Objective 4 – To evaluate the use and type of formal care received in the last three months of life at home, hospital, hospice and care homes and their relatives' satisfaction with the care provided by place of death.

Objective 5 – To assess the influence of socio-demographic, disease factors and healthcare input on achieving a home death.

Objective 6 – To explore patients' palliative outcomes (symptoms and quality of life in the week before death); attainment of their preferred place of death (PPD) and relatives' outcomes (grief intensity and attainment of their PPD for their relative) by place of death and for patients who achieved their PPD compared with those who did not using carer reports.

Objective 7 - To write a report and scientific papers for peer review.

3. STUDY METHODS

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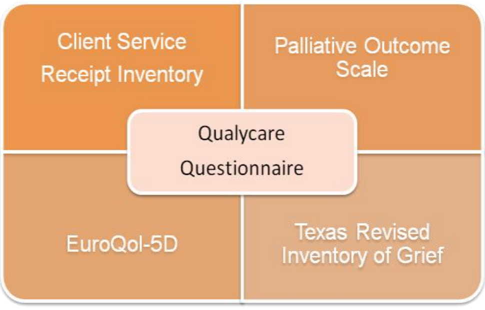
3.1 Study Design

A project steering group (Appendix I) was established to oversee and provide directional guidance on the study. Ethical approval was granted by the Office of Research Ethics Committee Northern Ireland (ORECNI) in April 2012 (Reference number 12/NI/0051). Information on deaths in NI was received from the General Register Office for NI and analysed. The study took the form of a postal questionnaire completed by relatives and carers (identified as informants on the patient's death certificate) on behalf of cancer patients who died during the study period of December 2011 to May 2012. Data were collected at one time point and only from respondents who completed the questionnaire. The study design was based on that of the QUALYCARE study (developed by Cicely Saunders Institute, King's College London) and used a questionnaire adapted from that developed by Ann Cartwright in the 1960s and which was successfully used in a number of research studies regarding end of life care (25-26).

The questionnaire contained four validated outcome measurement tools: Client Service Receipt Inventory (CSRI), Palliative Outcome Scale (POS), EuroQoL-5D (EQ-5D 3L) and Texas Revised Inventory of Grief (TRIG) within six main sections, which are detailed below. The CSRI (27) collected information relating to health and social care (HSC) services use and informal care. The POS (28) was used to assess patient's physical and psychological symptoms, spiritual considerations, practical concerns, emotional concerns and psychosocial needs in the last week of life. The EQ-5D 3L (29) was used to establish patient's quality of life three months prior to death and last week of life and finally the TRIG (30) was used to ascertain respondent's grief through past behaviour (at time of patient's death) and current emotional feelings at the time of completing the questionnaire.



Sections 1 to 6 of the questionnaire were as follows:

- Section 1 - Care received by the patient in the last three months of life (CSRI)
- Section 2 - Patient's living circumstances and the respondent's views on the care received
- Section 3 - Care received by the patient in the last week of life (POS and EuroQol-5D)
- Section 4 - Circumstances of the patient's death and personal preferences
- Section 5 - Respondents and how they feel (TRIG)
- Section 6 - Patient and respondent demographics; experience of the questionnaire.

Questionnaire completion was anticipated to take between 60 and 90 minutes and participants were provided with a free phone number to aid completion or assist with questionnaire queries. A reminder was sent two weeks following the questionnaire to encourage increased response.

3.2 Inclusion and Exclusion Criteria

The GRO NI registration database within NISRA was used to identify bereaved relatives. Participants were eligible to take part in the study if they had registered the death of an individual whose primary cause of death was cancer and who had been registered as dying at home, hospital, nursing home or hospice. The Demography and Methodology (DMB) branch of NISRA conducted the identification process in complete confidence and independently of the research team in NICR. The DMB team identified all cases of death registered four to nine months prior to September 2012 and screened for further inclusion/exclusion criteria. The questionnaires were then mailed by the DMB team on behalf of the NICR research team.

Inclusion Criteria

- Deceased last resident in NI, as recorded on the death registration
- Date of registration of death to be within four to nine months before the invitation letters for participation dispatched
- A diagnosis of cancer (ICD-10 codes C00-D41 and D47; WHO 2010) which was recorded as the primary cause of death on the death certificate. ICD codes D41 and D47 (Benign brain tumours) were included as these can be fatal and also to be in keeping with the QUALYCARE study London
- Aged 18 or over at the time of death

Exclusion Criteria

- Death registered by a coroner
- Place of death other than a NHS hospital, deceased’s own home, residential/nursing home or a hospice
- Place of death unknown

3.3 Data Collection

All eligible informants were assigned an unique study identification (ID) number by the DMB team in NISRA. The NICR research team received a spreadsheet of ID numbers categorised by gender of the deceased and place of death which allowed communication between NICR and NISRA regarding questionnaire mailing, uptake of the study and response rates. Both the questionnaires and decline to participate response forms were assigned ID codes to facilitate additional mailings and separate questionnaires were prepared for male and female patients. Questionnaire packs were delivered to NISRA where personalised letters and address labels were prepared and mailed to death informants. The completed questionnaires were then returned by the respondent in the pre-paid envelope to the research team and all decline to participate response forms were returned to NIRSA. The research team monitored returns to enable a reminder to be sent to those who had not responded. The questionnaire data were then linked with data from the NICR on disease factors including tumour site, stage and grade of disease, and time from diagnosis to death. NIRSA provided the NICR research team with an anonymised and encrypted dataset containing the gender and age category of both the respondent and the patient as well as the cause of death, place of death and deprivation quintile for all patients who were eligible for the study. This allowed for comparisons of the population who participated/did not participate in the study.

3.4 Data Entry, Cleaning and Analysis

Questionnaire data were entered into SPSS (version 17; SPSS Inc, USA), checked and cleaned for errors including missing data. Descriptive statistics were used to present respondent and patient characteristics, preferred place of death (PPD) and actual place of death, care received in the last three months and last week of life using frequency tables with numbers and valid percentages**.**

Where applicable, data that are not normally distributed are presented as median and interquartile ranges (IQR) and where data are normally distributed, as means and standard deviations (SD). Item responses from the validated measures are presented along with total scores and compared by PPD and achievement of this. Relevant statistics were used for comparisons between groups (T-tests, ANOVA, Chi-Square).

3.5 Definitions of Place of Care and Place of Death

For the purposes of this report the following definitions for place of care and place of death were used:

- Home - includes a patient's own home as well as the home of a relative or friend.
- Care home - includes both Nursing and Residential homes and these were considered to be an institution in all cases because although 9.9% of patients included in the study were long-term residents in a care home, many still had a PPD of own home if all things were in place.
- Specialist Palliative Care (SPC) - refers to care provided by healthcare professionals (HCPs) (including Macmillan and Marie Curie teams) specifically trained to provide palliative care in a community or institutional setting.
- Other Nursing Care - includes care provided at home or in a care home by District or Community Nurses.

4. RESULTS

4.1 Background Cancer Mortality Statistics

Figure 1a. Cause of Death in Northern Ireland 2012 (n= 14,756)

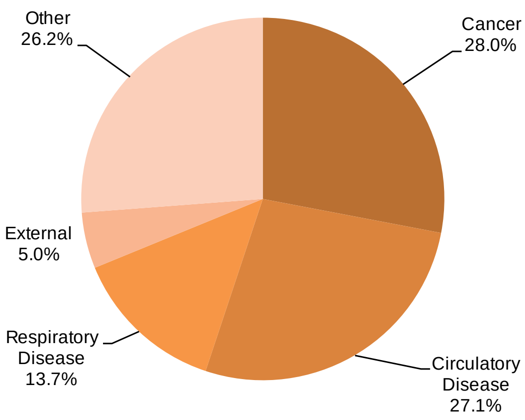
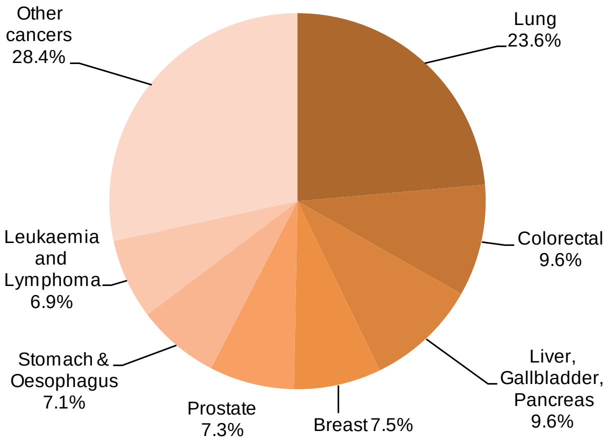


Figure 1b. Breakdown of Cancer Death in Northern Ireland 2012



Source: General Register Office, 2013

- Cancer is the leading cause of death in Northern Ireland and accounted for 28% of deaths in 2012 (Figure 1).

- The majority of cancer patients died in hospital but with a trend of increased death at home.

- The proportion of cancer patients dying in hospital fell from 46.7% in 2005 to 42.1% in 2012 while the proportion of cancer patients dying at home increased from 31.6% in 2005 to 37.6% in 2012 (see Figure 2 and Table 1, Appendix II). Further analysis of the trend over the eight year period (2008-2012) shows a 4.2% ($p<0.05$) increase in home deaths and 3.4% increase in care home deaths ($p<0.05$) which has coincided with a -0.58% decrease in hospital deaths ($p<0.05$) and -1.2% decrease in hospice deaths ($p<0.05$) over the same period of time.

- A higher proportion of males died both in hospital and at home when compared to females (43% vs 40% and 38% vs 37% respectively) and this trend was consistent through all years from 2005-2012. A higher proportion of females died in a care home (11 % vs 8% in 2012) and this was also observed consistently over the 2005-2008 period (see Appendix II, Table 2).

- In more recent times the majority of digestive organ (43%) and breast (38%) cancer patients died at home (see Appendix II, Table 3).

- Leukaemia / lymphoma patients were most likely to die in hospital (65%) (see Appendix II, Table 3).

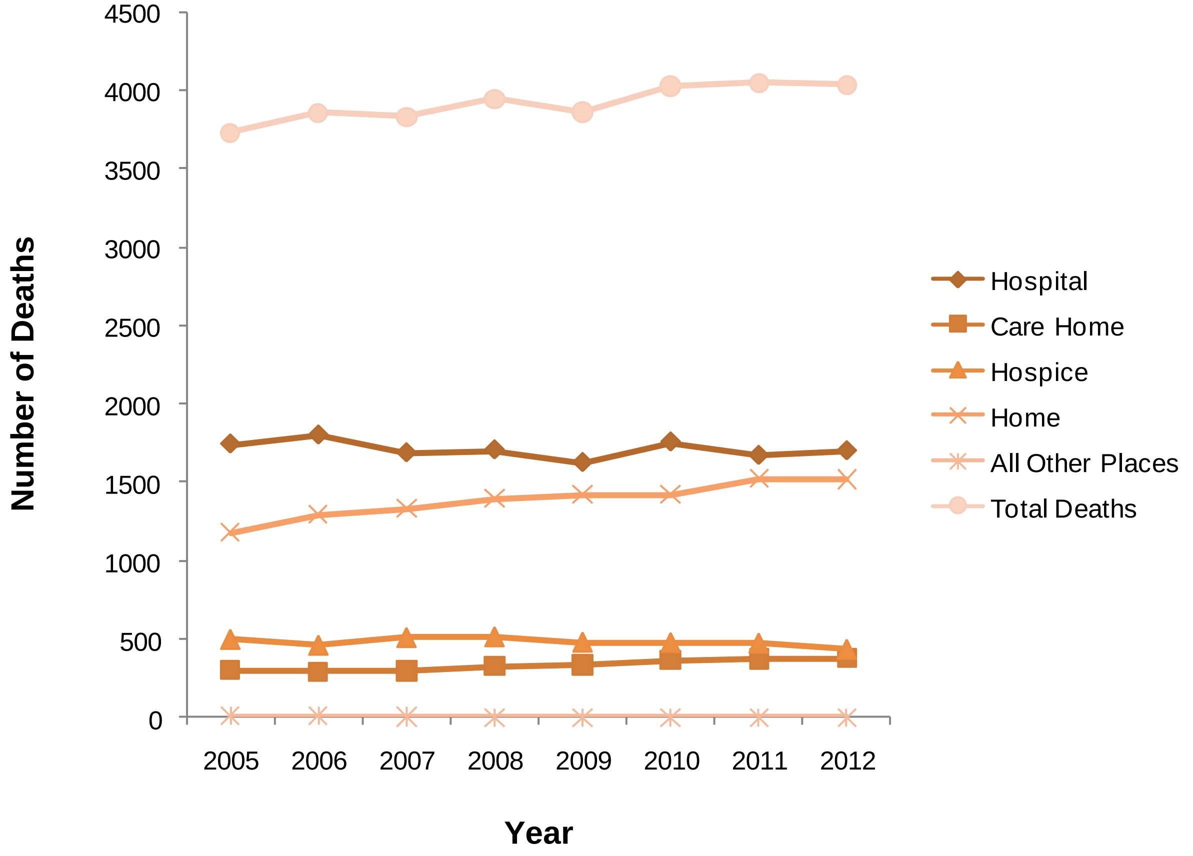
- Hospice death was more common in younger people with care home death more common in older people, especially women (see Appendix II, Table 4).

- Care home death was more likely with increased affluence. Hospice death was most common at the extremes of deprivation with highest levels in most deprived and most affluent quintile (see Appendix II, Table 5,).

- Home death was more common in the most deprived quintile than most affluent (see Appendix II, Table 5).

- Home death was more common in married patients with hospital deaths more common in single patients. Care home deaths were most likely among widowed and single persons reflecting their clientele (See Appendix II, Table 6).

Figure 2. All Cancer Patients Place of Death in NI 2005-2012



Note: Source= General Register Office Files
Note: Cancer Deaths (ICD 10 codes C00-C097; version 10, WHO 2010) that occurred and were registered in the same year between 2005-2012 have been included. It is important to note that a small number of deaths that occurred in 2012 and earlier years were not registered until 2013 and are therefore not included.
Note: Hospital = NHS hospitals. Care home= Nursing home, Residential home and care homes,
Home= Patients own home or home of relative/friend

4.2 Questionnaire responses

In total 467 completed questionnaires (representing 31.2% of the 1495 of the informants invited to participate) were analysed.

Table 1. Patient characteristics for responders vs non-responders and NI cancer deaths in 2012

Patient characteristics	Respondents (n=467)	Non-respondents (n=1028)	NI Cancer deaths 2012 (n=4047)[2]
Gender of deceased			
Male	251 (53.7%)	544 (52.9%)	2120 (52.4%)
Female	216 (46.3%)	484 (47.1%)	1927 (47.6%)
Age of deceased (years)			
Less than 18	excluded	excluded	12 (0.3%)
18-49	16 (3.4%)	49 (4.8%)	200 (4.9%)
50-59	46 (9.9%)	111 (10.8%)	396 (9.8%)
60-69	94 (20.1%)	421 (41.0%)	854 (21.1%)
70-79	154 (33.0%)	275 (26.8%)	1256 (31.0%)
80-89	127 (27.2%)	172 (16.7%)	1071 (26.5%)
90+	30 (6.4%)	0	258 (6.4%)
Place where patient died			
Hospital[1]	204 (43.7%)	451 (43.9%)	1704 (42.1%)
Home	178 (38.1%)	335 (32.6%)	1522 (37.6%)
Hospice	43 (9.2%)	130 (12.6%)	437 (10.8%)
Care home	42 (9.0%)	112 (10.9%)	380 (9.4%)
Other Places	0 (0.0%)	0 (0.0%)	4 (0.1%)
Cause of death – Cancer site			
Lung	110 (23.6%)	236 (23.0%)	930 (23.0%)
Colorectal	45 (9.6%)	104 (10.1%)	411 (10.1%)
Liver, Gallbladder, Pancreas	45 (9.6%)	90 (8.8%)	364 (8.9%)
Breast	35 (7.5%)	69 (6.7%)	288 (7.1%)
Prostate	34 (7.3%)	55 (5.4%)	262 (6.5%)
Stomach & oesophagus	33 (7.1%)	66 (6.4%)	276 (6.8%)
Leukaemia & lymphoma	32 (6.9%)	88 (8.6%)	248 (6.1%)
Other Cancers	133 (28.4%)	320 (31.1%)	1268 (31.3%)
Deprivation quintile			
1= Least deprived	87(18.8%)	161 (15.7%)	641 (15.9%)
2	80 (17.3%)	265 (25.8%)	799 (19.9%)
3	113 (24.4%)	373 (36.2%)	857 (21.3%)
4	103(22.2%)	144 (14.0%)	835 (20.8%)
5=Most deprived	80 (17.3%)	83 (8.1%)	890 (22.1%)
Not Recorded	4	2	25

[1] Deaths occurring within the Macmillan Unit at Antrim Area Hospital were registered as hospital deaths and not hospice deaths. [2] Data on place of death provided by the General Register Office.

4.2.1 Patient Characteristics

- No gender differences were observed between responders and non-responders and NI cancer deaths in 2012, with 46.3% (n=216) of patients female and 53.7% (n=251) male (see Table 1).

- The median age of patients at the time of diagnosis was 73 years (IQR 17; Range 23-96) and at the time of death was 75 years (IQR 18; Range 25-97).

- Lung cancer was the most common cause of death. There were no significant differences in cause of death between responders and non-responders and NI Cancer deaths in 2012 (see Appendix III, Tables A and D).

- Median time from diagnosis to death for patients was 9 months (IQR 25) and as expected from survival statistics was longest for those with a diagnosis of breast cancer (54 months; IQR 81) and least for patients with cancers of the respiratory and intrathoracic organs (5 months; IQR 13) (Appendix III, Table B).

- Almost half of patients (42.8%) died within six months of their cancer diagnosis,12.2% (n=57) of patients died within 1 month, 15.8% (n=74) within one to two months and 14.8% (n=69) within three to six months of diagnosis (further information relating to patient and disease characteristics is available in Appendix III). 88.4% of respondents and 83.8% of patients were aware (definitely/probably) of the likelihood of death due to their illness.

- Just over half of the patients (54.6%) were married or partnered.

- Before death, 47.1% of patients had lived with the respondent, whilst 25.3% of patients lived alone. For 94.0% of patients, travel time between their home and their nearest relative/friend was under 30 minutes.

- In the last three months of the patient's life, most (44.0%) were 'living comfortably" or "doing alright" (37.1%). However, 18.9% were having some degree of financial difficulty ('just about getting by'/'finding it quite difficult'/'finding it very difficult'). Patients with no financial difficulties were significantly older (median age: 75 years, IQR 16) than those with some degree of financial difficulty (median age: 69 years, IQR 22;$p<0.001$).

4.2.2 Respondent Characteristics

- The majority (89.4%) of respondents had helped to care for their deceased relative/friend. Respondents were predominantly female (60.4%) and the average age of respondents was 55 (±12, range 25-87) years. Over half (52.7%) of the questionnaires were completed by the patient's son or daughter and a quarter (25.1%) were completed by patient's spouse or partner (Appendix III, Table D).

- The median time from the patient's death until respondents completed and returned the questionnaire was 207 days (IQR 68; Range 135-276).

- Over a quarter (29.6%; n=135) of respondents were retired, 11.2% (n=51) were unemployed and 0.9% (n=4) were not working for other reasons. Of the respondents who were working (n=266), 68.4% reduced their hours or stopped working as a result of the patient's illness.

- In relation to the respondent's experience of completing the questionnaire, almost 60% did not find the questionnaire upsetting and 51.8% found it helpful. Significantly more women (70.5%) than men (53.6%) found the questionnaire upsetting to complete (p<0.001) (Appendix III, Table E).

4.3 Place of Care in the last three months of life

This section details the care received by patients (n=467) in the last three months of their life whilst at home, in hospital, hospice or in a care home (nursing or residential).

4.3.1 Time Spent at Home, in Hospital, Hospice and Care Home – last three months of life

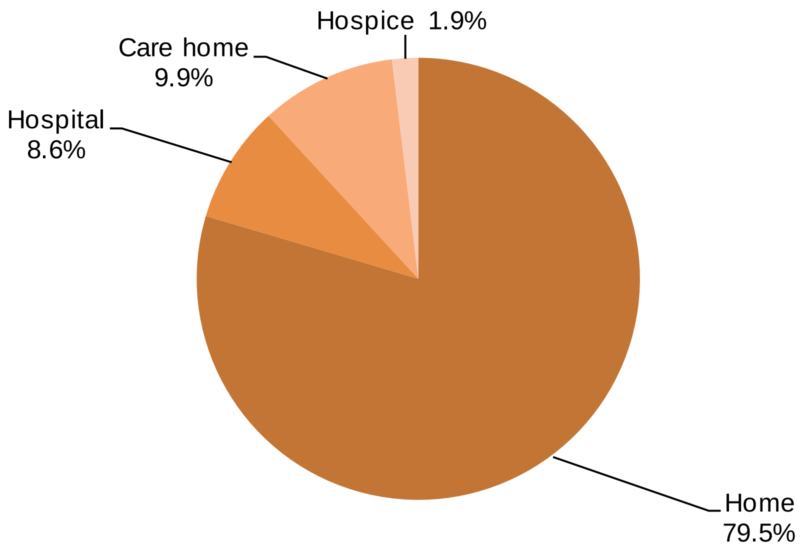
Table 2.Time Spent at home in Hospital, Hospice and Care Home

Time Spent at Home, in Hospital, Hospice and Care home	Frequency (n=467)	Percentage (%)	Time Spent Mean Days (SD)	Time Spent Range (Days)
Patient Spent time at home			n=401	
Yes	419	89.7	68.1 (24.8)	2-92
No	48	10.3		
Overnight Stay in an Intensive Care Unit				
Yes	54	11.6	10.2 (9.5)	1-44
No	413	88.4		
Overnight Stay in a Hospital unit or Ward				
Yes	367	78.6	21.7 (21.3)	1-92
No	100	21.4		
Overnight Stay in a Hospice				
Yes	77	16.6	16.9 (16.1)	1-80
No	388	83.4		
Not Recorded	2	---		
Overnight Stay in a Care home (Nursing/Residential*)*			n=58	
Yes	66	14.2	51.9 (31.6)	1-94
No	400	85.8		
Not Recorded	1	---		
Patient Visit an Accident and Emergency Department			n=230	
Yes	244	52.5	1.8 (1.3)	1-14
No	221	47.5		
Not Recorded	2	----		
Patient use Ambulance Services			n=465	
Yes	269	57.8	1.4 (0.5)	1-2
No	196	42.2		
Not Recorded	2	----		

- Over three quarters (78.6%) of patients had at least an overnight stay in hospital in the last three months of their life (Table 2) with the mean length of time spent in hospital being 14 days. 16.6% of patients had at least an overnight stay in a hospice and 14.2% in a care home.

- A total of 89.7% (n=419) of patients spent some time at home in the last three months of life with the average length of time spent there being 68 days (±24.8, range 2-92). Over three quarters of patients (79.5%; n=368) spent most of the last three months of life in their own home or the home of a relative/friend, 1.9% (n=9) in a hospice, 8.6% (n=46) in a hospital and 9.9% (n=40) in a care home (Figure 3).

Figure 3. Place Patients spent most of time in last three months of life



4.3.2 Types of formal care provided in the last three months of life

- The majority of patients (88.9%) who spent some time at home in the last three months received care from a GP whilst at home, 55.5% received Specialist Palliative Care (SPC) at home and 64.2% received care at home.

- All patients (n=66) who spent some time in a care home in the last three months received care from a GP, care home nurse and SPC and Other Nursing Care in a care home setting.

- All (n=367) patients who had at least an overnight stay in hospital received care from a hospital doctor and 97.5% from a nurse.

- All patients (n=77) who had at least an overnight stay in a hospice received care from a hospice doctor and nurse.

- For care received at home the majority of respondents felt that patients received as much help and support as was needed from GPs (69.9%), SPC (79.9%) and Other Nursing services (85.5%) respectively. The majority of respondents stated that patients either received care from GP (41.5%) or SPC (35.8%) at evenings/weekends or felt that it was not required (GP; 31.7% and SPC; 35.8%). However 6.4% and 5.5% of respondents stated that they did not receive care from GP and SPC respectively in evenings/weekend and there were times when they felt that the patient would have benefited from a home visit from the GP or SPC 'out of hours'.

- When the patient was at home, most respondents felt that the HCPs listened and discussed things fully with the patient/family. However 10.7% reported that this was not the case with their GP, and in particular more than a quarter (26.5%) felt that the GP was not knowledgeable about the patient's condition and how to care for the patient. Similarly, 23% and 25% of respondents for patients who had at least one overnight stay in hospital felt that the hospital doctors and hospital nurses were not knowledgeable about the patient's condition and how to care for the patient respectively (Table 3).

- The majority of respondents felt that HCPs had listened and discussed things fully, with overall satisfaction with communication lowest within the hospital setting and highest within the hospice setting (Table 3).

- Satisfaction with care provided by HCPs was high, especially in Hospice, less so in hospital or for GP whilst at home or in care home (see Figure 4).

Figure 4. Satisfaction with formal care provided by Healthcare professionals (HCPs) in different settings

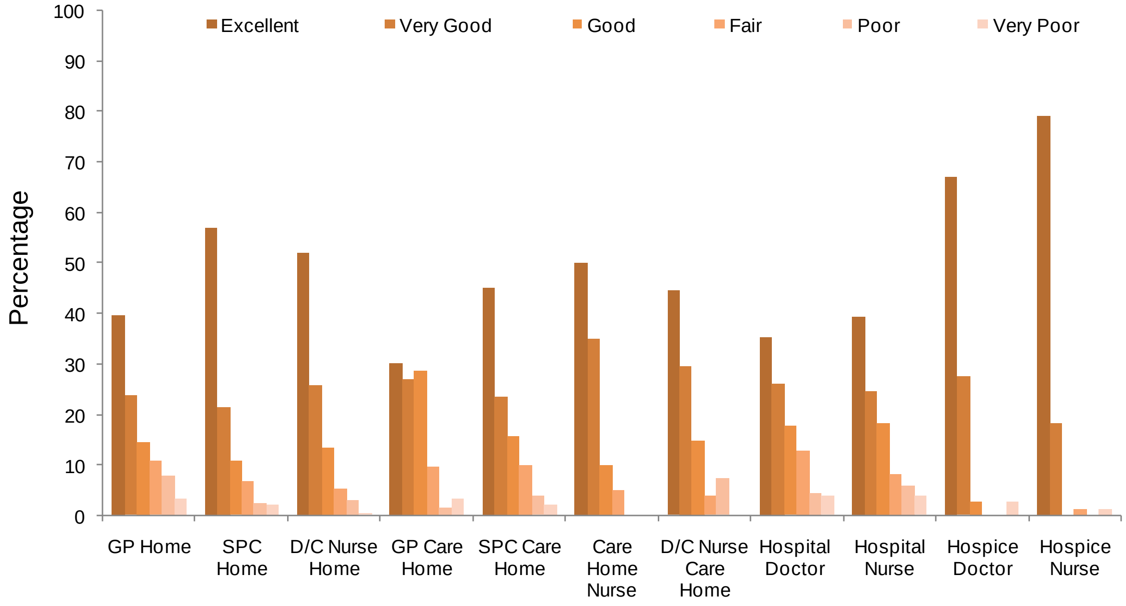


Table 3. Respondents' perspectives of care received from Healthcare Professionals (HCPs) across care settings.

		Listen and Discuss Things Fully with Patient/You/Family/Friends?		Knowledgeable About Patient and Their Care?	
Home	**GP**		(n=410)		(n=412)
	(n=419)	Yes, most of the time	302 (73.7%)		
		Sometimes	64 (15.6%)	Yes	303 (75.3%)
		No	44 (10.7%)	No	109 (26.5%)
	SPC		(n=257)		(n=257)
	(n=259)	Yes, most of the time	223 (86.7%)		
		Sometimes	22 (8.6%)	Yes	240 (93.4%)
		No	12 (4.7%)	No	17 (6.6%)
	Other Nursing care		(n=300)		n=300)
	(n=300)	Yes, most of the time	252 (84.0%)		
		Sometimes	32 (10.7%)	Yes	263 (87.7%)
		No	16 (5.3%)	No	37 (12.3%)
Care home	**GP**		(n=64)		(n=63)
	(n=66)	Yes, most of the time	47 (73.4%)		
		Sometimes	11 (17.2%	Yes	59 (93.7%)
		No	6 (9.4%)	No	4 (6.3%)
	Care home Nurse		(n=51)		(n=51)
	(n=66)	Yes, most of the time	39 (76.5%)		
		Sometimes	8 (15.7%)	Yes	42 (82.4%)
		No	4 (7.8%)	No	9 (17.6%)
	SPC		(n=27)		(n=28)
	(n=66)	Yes, most of the time	22 (81.5%)	Yes	25 (92.6%)
		Sometimes/No	5 (18.5%)	No	3 (7.4%)
	Other Nursing care		(n=20)		(n=21)
	(n=66)	Yes, most of the time	16 (80.0%)		
		Sometimes	4 (20.0%)	Yes	18 (90.0%)
		No	0	No	3 (10.0%)
Hospital	**Hospital Doctors**		(n=361)		(n=360)
	(n=367)	Yes, most of the time	235 (65.1%)		
		Sometimes	78 (21.6%)	Yes	279 (77.5%)
		No	48 (13.3%)	No	81 (22.5%)
	Hospital Nurses		(n=350)		(n=347)
	(n=367)	Yes, most of the time	234 (66.9%)		
		Sometimes	87 (24.9%)	Yes	259 (74.6%)
		No	29 (8.3%)	No	88 (25.4%)
Hospice	**Hospice Doctors**		(n=77)		(n=77)
	(n=77)	Yes, most of the time	66 (85.7%)		
		Sometimes	8 (10.4%)	Yes	74 (96.1%)
		No	3 (3.9%)	No	3 (3.9%)
	Hospice Nurses		(n=76)		(n=77)
	(n=77)	Yes, most of the time	67 (88.2%)	Yes	74 (97.4%)
		Sometimes/No	9 (11.8%)	No	3(2.6%)

Note: Cell counts less than three have been adjusted to a value of three to avoid disclosure of potentially identifiable patient or respondent data

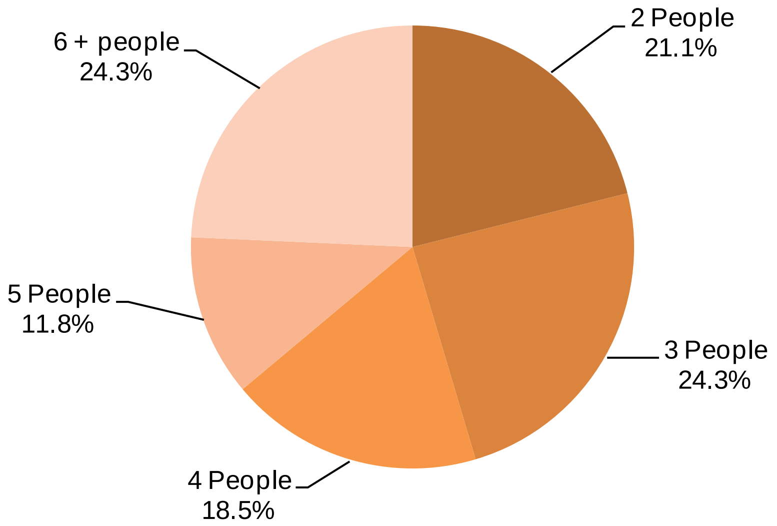
Table 3.continued Respondents' perspectives of care received from Healthcare Professionals (HCPs) across care settings

		Provide as much help and support as needed	
Home	**GP**		n=412
	(n=419)	Yes	288 (69.9%)
		Some, but not as much as needed	91 (22.1%)
		No	33 (8.0%)
	SPC		n=254
	(n=259)	Yes	203 (79.9%)
		Some, but not as much as needed	39 (15.4%)
		No	12 (4.7%)
	Other Nursing		n=297
	(n=300)	Yes	254 (85.2%)
		Some, but not as much as needed	31 (10.4%)
		No	12 (4.4%)
C are Home	**GP**		n=64
	(n=66)	Yes	53 (82.8%)
		Some, but not as much as needed	8 (12.5%)
		No	3 (4.7%)
	Care home Nurse		n=51
	(n=66)	Yes	42 (82.4%)
		Some, but not as much as needed/No	9 (17.6%)
	SPC		n=27
	(n=66)	Yes	24 (88.9%)
		Some, but not as much as needed/No	3 (11.1%)
	Other Nursing care		n=20
	(n=66)	Yes	17 (85.0%)
		Some, but not as much as needed/No	3 (15.0%)
Hospital	**Hospital Doctors**		n=360
	(n=367)	Yes	256 (71.1%)
		Some, but not as much as needed	79 (21.9%)
		No	25 (6.9%)
	Hospital Nurses		n=347
	(n=367)	Yes	239 (68.9%)
		Some, but not as much as needed	83 (23.9%)
		No	25 (7.2%)
Hospice	**Hospice Doctors**		n=76
	(n=77)	Yes	70 (92.1%)
		Some, but not as much as needed/No	6 (7.9%)
	Hospice Nurses		n=76
	(n=77)	Yes	73 (96.1%)
		Some, but not as much as needed/No	3 (3.9%)

Note: Cell counts less than three have been adjusted to a value of three to avoid disclosure of potentially identifiable patient or respondent data

4.3.3 Informal Care Provided by Family/Friends - Last three months of life

Figure 5. Number of Family/Friends involved in care in the last three months of life (n=346)



- High levels of care were provided for the patient by family/friends, with 89.4% of patients receiving informal care from family members in last three months of life and 91.5% (n=421) having on-call help from family or friends. Almost three quarters of patients (73.5%; n=339) received help with their personal care, 70.7% (n=326) with medical procedures (e.g. taking medication), 83.3% (n=383) attending appointments and 82.6% (n=381) with household tasks from friends and family (See Appendix III, Table F).

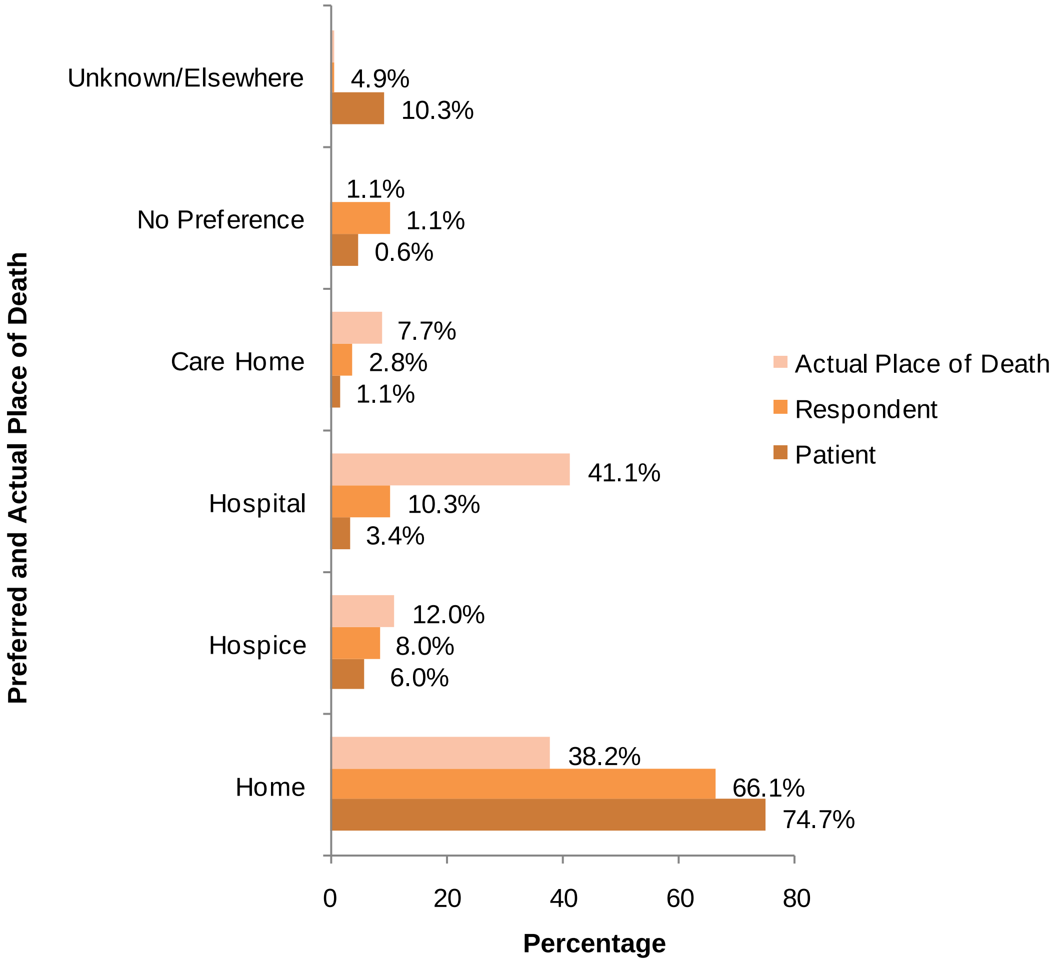
- 13% of patients received informal care from the respondent alone without the help of other family or friends. However, over half (54.6%) of patients who received informal care had 4 or more members of their family/friends helping care for them (see Figure 5).

- Of the respondents who were working (n=266), 68.4% reduced their hours or stopped working as a result of the patient's illness.

4.4 Place of Death

This section details the preferred place of death (PPD) of patients (n=467) and respondents in relation to actual place of death. The majority of patients 41.1% died in hospital, 12.0% in a hospice, 7.7% in a care home and 38.2% died at home. For the majority of patients (74.7%) and respondents (66.1%) PPD was home.

Figure 6. Patients' and Respondents' Preferred Place of Death at three months prior to death compared with Actual Place of Death

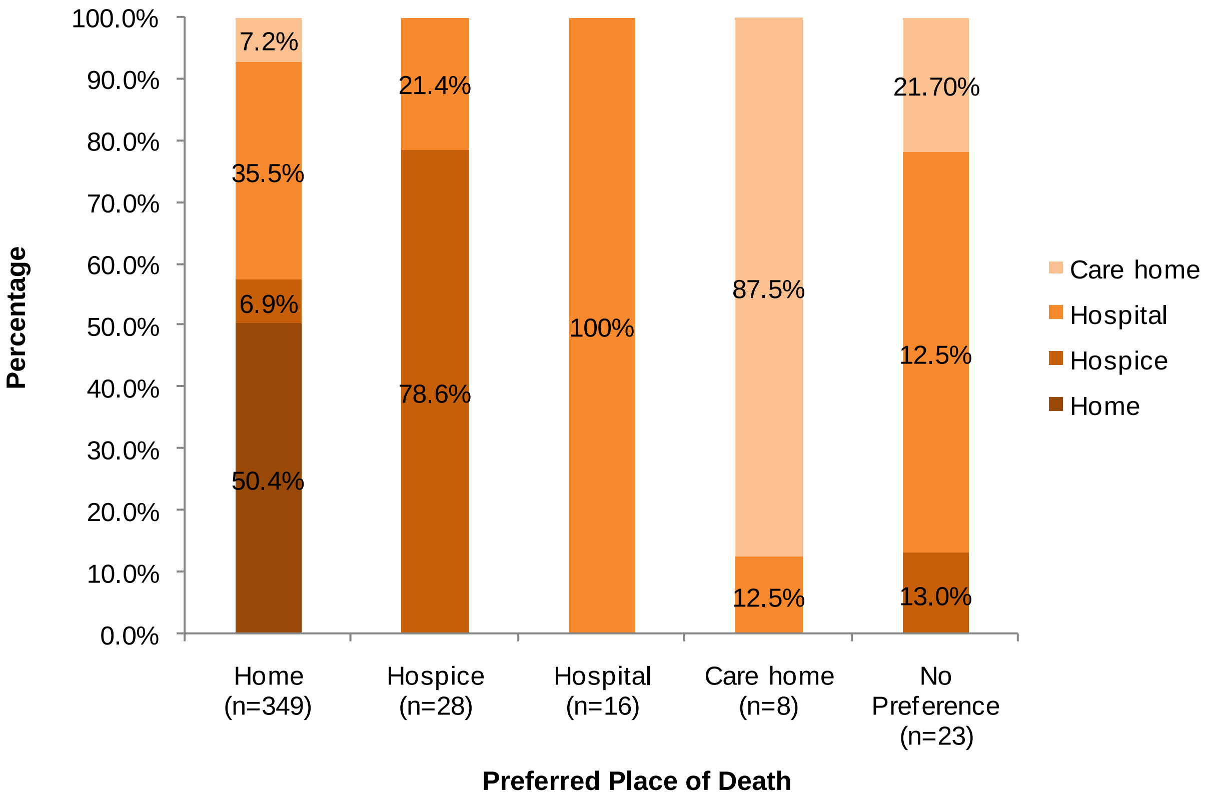


- Agreement between patient's PPD and that of the respondent was observed for hospice (8.0% vs 6.0%) and home (66.1% vs 74.7%). However respondents were three times more likely to have a PPD of hospital (10.3% vs 3.4%) than patients.

- Despite the majority of patients' and respondents' preference for a home death only 38.2% of patients died at home. In addition, while only 3.4% of patients' and 10.3% of respondents' PPD was hospital, a total of 41.1% died in a hospital.

- Of the patients and respondents whose PPD was known and those who had a preference, a total of 54.1% of patients and 59.3% of respondents achieved their PPD.

Figure 7. Patients' Preferred Place of Death by Actual Place of Death



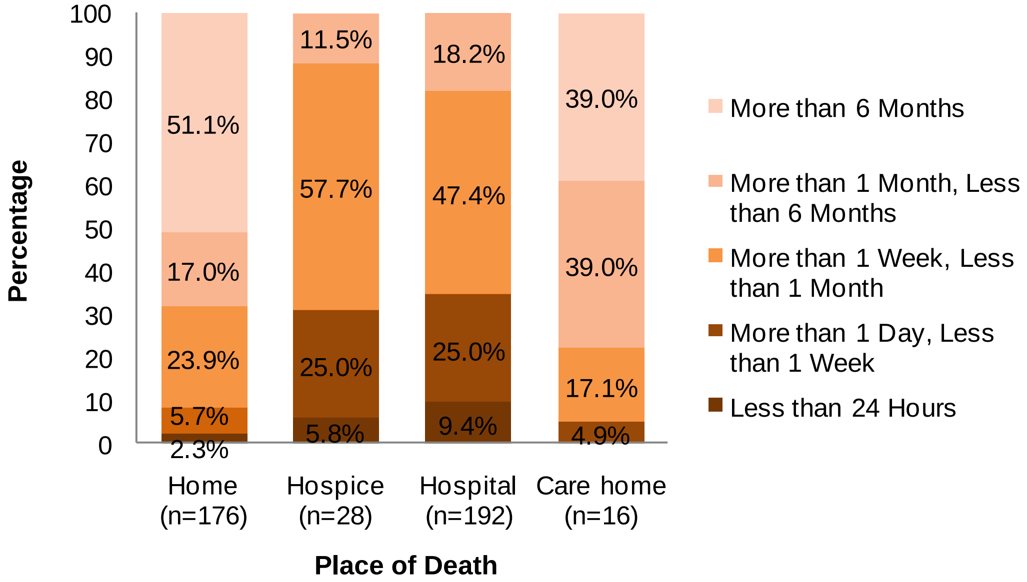
- Over half of patients (50.4%) whose PPD was home achieved this, whilst 35.5% died in hospital, 6.9% in a hospice and 7.2% in a care home.

- Over three quarters (78.6%) of patients who wanted to die in a hospice did so, whilst the remaining 21.4% died in a hospital.

- All of the patients who preferred to die in a hospital achieved this and the majority of patients whose PPD was a care home achieved this.

- All patients who died at home had expressed it as their PPD. The majority (65.3%) of those with no preference died in hospital, 21.7% in a care home and 13.0% in a hospice.

Figure 8. Time Spent in Place of Death Before Patient Died



- The majority of patients who died at home had been cared for there for more than six months. Only a small proportion of patients were at home for less than 24 hours (2.3%) or for more than one day but less than a week (5.7%) before death.

- Of those who died in a hospice or hospital, a small proportion (5.8% and 9.4%, respectively) had been there less than 24 hours prior to death, but most had been there for more than one week but less than one month (57.7% and 47.4% respectively).

- The majority of patients (78%) who died in a nursing/residential home had been there for more than one month.

4.5 Factors associated with achieving a home death: A comparison of patients who achieved and did not achieve preferred place of death at home.

This section of the report details patients whose PPD was home (n=351) and examines achievement of this by patient demographics, disease factors, HSC input, patient and respondent's social circumstances, respondents/family/friends input and information and communication.

A total of n=24 patients whose PPD was home spent no time at home in the last three months of their life. They spent most of the last three months of their life in a care home (n=13), hospital or a hospice (n=8) or hospital and a care home (n=3). These patients were included in analysis of patient demographics (Table 4) and disease factors (Table 5) in relation to achieving PPD at home but were removed from the analysis of HSC factors (Tables 6 and 7), patient's social circumstances and family/friend factors (Table 8) and Information and Communication (Table 9) as these related to care provided at home.

4.5.1 Patient Demographics

Table 4. Preferred Place of Death Home: Achieved/Did Not Achieve by Patient Demographics

Patient Demographics	Patient Achieved Death at Home Frequency (%)			
	Yes (n=175)	No (n=176)	Total (n=351)	P
Age Group				0.134
Less than 51	3 (1.7%)	5 (2.8%)	8 (2.3%)	
51-59	18 (10.3%)	14 (8.0%)	32 (9.1%)	
60-69	39 (22.3%)	31 (17.6%)	70 (19.9%)	
70-79	62 (35.4%)	56 (31.8%)	118 (33.6%)	
80-89	45 (25.7%)	54 (30.7%)	99 (28.2%)	
More than 89	8 (4.6%)	16 (9.1%)	24 (6.8%)	
Gender				0.028*
Female	87(49.7%)	68 (38.6%)	155 (44.2%)	
Male	88 (50.3%)	108 (61.4%)	196 (55.8%)	
Marital Status				0.059
Partnered	112(64.0%)	91 (51.7%)	203 (57.8%)	
Not Partnered	61(34.9%)	81 (46.0%)	142 (40.4%)	
Not recorded	2 (1.1%)	4 (2.3%)	6 (1.7%)	
Deprivation Quintile				0.562
1 Least Deprived	30(17.1%)	33 (18.8%)	63 (17.9%)	
2	30(17.1%)	29 (16.5%)	59 (16.8%)	
3	47(26.9%)	37 (21.0%)	84 (23.9%)	
4	41(23.4%)	40 (22.7%)	81 (23.1%)	
5 Most Deprived	26 (14.9%)	36(20.5%)	62 (17.7%)	
Not Recorded	1 (0.6%)	1 (0.6%)	2 (0.6%)	
Religion				0.028*
No Religion	7 (4.0%)	7(4.0%)	14 (4.0%)	
Roman Catholic	80 (45.7%)	54 (30.7%)	134 (38.2%)	
Presbyterian	38(21.7%)	57(32.4%)	95 (27.1%)	
Church of Ireland	34 (19.4%)	32 (18.2%)	66 (18.8%)	
Other Christian	13(7.4%)	21 (11.9%)	29 (9.7%)	
Not Recorded	3 (1.7%)	5 (2.8%)	8 (2.3%)	

*Note: * Significant at the p=≤0.05 level (Chi-Square analysis)*
Note: All patients whose PPD was home (n=351) were included in this analysis

- No significant associations between age (p=0.134) or deprivation (p=0.562) and achieving PPD at home were observed. However a trend approaching significance (p=0.059) between marital status and achieving PPD at home was observed with a higher proportion of patients achieving a home death being partnered (64.0% vs 51.7%) and a higher proportion of patients not achieving PPD at home not having a partner (46.0% vs 34.9%; see Table 4).

- A higher proportion of males (61.4%) did not achieve their preference to die at home when compared to females (38.6%%;p=0.028; see Table 4)

- A higher proportion of patients who achieved PPD at home were from a Catholic background (45.7%) and a higher proportion of patients who did not achieve PPD at home were from Presbyterian background (32.4%; P=0.028; see Table 4).

4.5.2 Disease Factors

Table 5. Preferred Place of Death at Home: Achieved/Did Not Achieve by Cancer type, and time from diagnosis to death

Disease	Patient Achieved Death at Home Frequency (%)			
	Yes (n=175)	No (n=176)	Total (n=351)	P
Cancer Diagnosis				
Breast	10 (5.7%)	15 (8.5%)	25 (7.1%)	0.310
Male Genital	14 (8.0%)	19 (10.8%)	33 (9.4%)	
Digestive Organs	54(30.9%)	41(23.3%)	95 (27.1%)	
Female Genital	7 (4.0%)	4 (2.3%)	11 (3.1%)	
Respiratory	44 (25.1%)	43 (24.4%)	87 (24.7%)	
Other	46 (26.2%)	54 (30.7%)	100 (28.4%)	
	Mean (SD) (n=173)	Mean (SD) (n=151)	Mean (SD)	P
Length of time from diagnosis to death (days)	693.0 (1002.5)	764.1 (1193.4)	726.2 (1094.5)	0.317
Length of time from diagnosis most similar to cause of death (days)	805.0 (1248.9)	807.7 (1219.2)	806.3 (1233.2)	0.947

*Note: * Significant at the p=≤0.05 level (Chi-Square analysis)*
Note: All patients whose PPD was home (n=351) were included in this analysis

- No statistically significant associations between overall cancer type, and length of time from diagnosis to death were observed in patients who achieved PPD at home and those who did not (Table 5).

4.5.3 Health and Social Care Factors

Table 6. Preferred Place of Death at Home: Achieved/Did not Achieve by care at home provided by Health and Social Care (HSC) Services Input and GP care at home

Health and Social Care (HSC) Services Input and GP care at home	Patient Achieved Death at Home Frequency (%)			
	Yes (n=175)	No (n=151)	Total (n=326)	P
Help from HSC Services				**≤0.001***
Yes	165 (94.3%)	85 (56.3%)	250 (76.7%)	
Help was not wanted/needed	7 (4.0%)	40 (26.5%)	47 (14.4%)	
No Help Offered/offered but not received	0 (0.0%)	21(13.9%)	21 (6.4%)	
Not Recorded	3 (1.7%)	5 (3.3%)	8 (2.5%)	
GP Home Visit				**≤0.001***
Yes	170 (97.1%)	111 (73.5%)	281 (86.2%)	
No	3 (1.7%)	39 (25.8%)	42 (12.9%)	
Not Recorded	2 (1.1%)	1 (0.7%)	3 (0.9%)	
GP did enough to relieve symptoms				**≤0.001***
Yes	145 (82.8%)	99 (65.6%)	244 (74.8%)	
Could Have Done More	27 (15.4%)	48 (31.8%)	75 (23.0%)	
Patient Did not Have any Symptoms	0 (0.0%)	4 (2.6%)	4 (1.2%)	
Not Recorded	3 (1.7%)	0 (0)	3 (0.9%)	
GP provided the help needed				**≤0.001***
Yes	138 (78.9%)	90 (59.6%)	228 (69.9%)	
Not as Much as Needed	25 (14.3%)	43 (28.5%)	68 (20.9%)	
No	9 (5.1%)	17 (11.3%)	26 (8.0%)	
Not Recorded	3 (1.7%)	1 (0.7%)	4 (1.2%)	
GP knowledgeable about patient and their care				**≤0.001***
Yes	143 (81.7%)	98 (64.9%)	241 (73.9%)	
No	29 (16.6%)	53 (35.1%)	82 (25.1%)	
Not Recorded	3 (1.7%)	0 (0.0%)	3 (1.0%)	
Number of GP visits at home				**0.014***
Less than 5	62 (35.4%)	75 (49.7%)	137 (42.0%)	
5-10	57(32.6%)	26 (17.2%)	83 (25.4%)	
More than 10	42 (24.0%)	6(4.0%)	48 (14.7%)	
Not applicable	14 (8.0%)	44 (29.1%)	58 (17.8%)	
Overall rating of GP care at home				**≤0.001***
Excellent	96 (54.9%)	40(26.5%)	136 (41.7%)	
Very good	36 (20.6%)	40 (26.5%)	76 (23.3%)	
Good	15 (8.6%)	26 (17.2%)	41 (12.6%)	
Fair	11 (6.3%)	21 (13.9%)	32 (9.8%)	
Poor	9 (5.1%)	18 (11.9%)	27 (8.3%)	
Very Poor	6 (3.4%)	4 (2.6%)	10 (3.1%)	
Not Recorded	2 (1.1%)	2 (1.3%)	4 (1.2%)	

*Note: * Significant at the p=≤0.05 level (Chi-Square analysis)*
Note: All patients whose PPD was home (n=351) were included in this analysis

- Over three quarters (77.0%) of patients (n=326) who had PPD of home had a key healthcare worker. The majority (59.5%) identified their key healthcare worker as GP alone (43.0%) or GP in combination with another HCP (16.5%). Significantly more patients who achieved PPD at home had a key healthcare worker in contrast to those who did not (87.1% vs. 64.4%, p<0.001) and almost all those who died at home had input from HSC services (94.3%). Conversely, higher percentages of patients who died in an institution did not want/need input from HSC services (26.5%) or were not offered services (13.9%).

- Of those who achieved PPD at home, 97.1% were visited by their GP at home in the last three months of life compared with 73.5% of those who died in an institution (p<0.001).

- A higher proportion of respondents for patients who achieved PPD at home compared to those who did not achieve this felt that the GP did enough to relieve symptoms (82.8% vs 65.6%; p<0.001), provided as much help as was needed (78.9% vs 59.6%; p<0.001) and was knowledgeable about the patient and their care (81.7% vs 64.9%; p<0.001; see Table 6).

Table 7. Preferred Place of Death at Home: Achieved/Did not Achieve by care at home provided by Health and Social Care (HSC) Services Input: Nursing Care at home

Health and Social Care (HSC) Services Input: Nursing care at home	Patient Achieved Death at Home Frequency (%)			
	Yes n=175	No n=151	Total n=326	P
Patient Received SPC at Home				**≤0.001***
Yes	153 (87.4%)	63 (41.7%)	216 (66.3%)	
Visits not wanted	6 (3.4%)	11 (7.3%)	17 (5.2%)	
Visits not needed	5 (2.9%)	38 (25.2%)	43 (13.2%)	
Visits not offered/ Offered but not received	9 (5.1%)	37 (24.5%)	46 (14.1%)	
Not recorded	2 (1.1%)	2 (1.3%)	4 (1.2%)	
SPC Provide Help Needed				**0.864**
Yes	122 (69.7%)	48 (31.8%)	170 (52.1%)	
Not as Much as Needed	19 (10.9%)	9 (6.0%)	28 (8.6%)	
No	8 (45.7%)	4 (2.6%)	12 (3.7%)	
Not Applicable/Recorded	26 (14.9%)	90 (59.6%)	116 (35.6%)	
SPC Knowledgeable About Patient and Care				**0.740**
Yes	143 (81.7%)	58 (38.4%)	201 (61.7%)	
No	8 (4.6%)	4 (2.6%)	12 (3.7%)	
Not Applicable/Recorded	24 (13.7%)	89 (58.9%)	113 (34.7%)	
Overall rating of SPC				**0.402**
Excellent	90 (51.4%)	33 (21.9%)	123 (37.7%)	
Very good	36(20.6%)	12(8.0%)	48 (14.7%)	
Good/Fair	17(9.7%)	12 (8.0%)	29 (8.9%)	
Poor/Very Poor	7(4.0%)	4 (2.6%)	11 (3.4%)	
Not Applicable/recorded	25 (14.3%)	90 (59.6%)	115 (35.3%)	
Other Nursing Care Last 3 Months				**≤0.001***
Yes	162 (92.6%)	89 (58.9%)	251 (77.0%)	
Visits not wanted/needed	9 (5.1%)	38 (25.2%)	47 (14.4%)	
Visits not offered	0 (0)	17 (11.3%)	17 (5.2%)	
Offered but not received	0 (0)	4 (2.6%)	4 (1.2%)	
Not Recorded	4 (2.3%)	3 (2.0%)	7 (2.1%)	
Other Nursing Provide Help Needed				**0.004***
Yes	146 (83.4%)	68 (45.0%)	214 (65.6%)	
Not as Much as Needed	6 (3.4%)	13 (8.6%)	19 (5.8%)	
No	7 (4.0%)	6 (4.0%)	13 (4.0%)	
Not Applicable/Recorded	16 (9.1%)	64 (42.4%)	80 (24.5%)	
Other Nursing Knowledgeable about Patient	147 (84.0%)	71 (47.0%)	218 (66.9%)	**0.028***
Yes	13 (7.4%)	15 (9.9%)	28 (8.6%)	
No	15 (8.6%)	65 (43.0%)	80 (24.5%)	
Not Applicable/Recorded				
Overall rating of Other Nursing care				**0.864**
Excellent	98 (56.0%)	31(20.5%)	129 (39.6%)	
Very good	41 (23.4%)	23(15.2%)	64 (19.6%)	
Good	11 (6.3%)	17 (11.3%)	28 (8.6%)	
Fair	6 (3.4%)	7 (4.6%)	13 (4.0%)	
Poor/Very Poor	3 (1.7%)	5 (3.3%)	8 (2.5%)	
Not Applicable/Recorded	16 (9.1%)	68 (45.0%)	84 (25.7%)	

*Note: * Significant at the p=≤0.05 level (Chi-Square analysis)*
Note: SPC= Specialist Palliative Care
Note: Patients who did not spend any time at home in the last 3 months of life (n=24)were removed from analysis in this section

- 87.4% of patients who achieved PPD at home received SPC at home compared with 41.7% of those who did not achieve a home death (p<0.001).

- Relatives of those who did not achieve their preferred home death reported that SPC visits were not needed (25.2%) whilst 24.5% said they were not offered/offered but not received.

- Of those patients who achieved PPD at home 92.6% received Other Nursing Care at home compared to 58.9% of those who did not achieve a home death (p<0.001).

- Although a higher proportion of patients who died in an institutional setting felt that Other Nursing visits at home were not wanted or needed (25.2% vs 5.1%; p<0.001), a higher proportion also felt that Other Nursing visits were not offered (11.3% vs 0.0%; p<0.001) or offered but not received (2.6% vs 0.0%; p<0.001) when compared to those who achieved PPD at home.

- No significant differences in the overall rating of Other Nursing Care was observed between patients who achieved PPD at home and those who did not (p=0.864). However differences in specific aspects of Other Nursing Care received were observed with higher proportions of respondents for patients who achieved PPD at home feeling that Other Nursing Care provided the help needed (83.4% vs 45.0%; p=0.004) and were knowledgeable (84.0% vs 47.0%;p=0.028) when compared to those who did not achieve PPD at home.

- Significantly more respondents for those patients who died at home felt they got as much help as needed from all services compared to the patients who died elsewhere (75.0% vs 52.8%, p<0.001).

- Respondents for those who died at home tended to be ‘very confident’ of the patient’s care at home (67.4% vs 38.5%, p<0.001).

- Additionally, respondents for those who died at home rated the overall services provided to the patient at home significantly better, with 77.2% rating overall care at home as ‘excellent’ or ‘very good’ compared with 46.6% for patients who did not achieve PPD at home (p<0.001).

- The mean number of days spent at home in last three months was significantly higher in patients who achieved PPD at home (78.3 ±19.8 days) compared to those who did not (61.8 ± 24.9 days; P<0.001).

4.5.4 Patient’s Social Circumstances and Respondent/Family/Friends Factors

Table 8. Preferred Place of Death Home: Achieved/Did Not Achieve by Patient’s Social Circumstances and Respondent/Family/Friends Input

Patient’s Social Circumstances and Respondent/Family/Friends Input	Patient Achieved Death at Home Frequency (%)			p
	Yes (n=175)	No (n=151)	Total (n=326)	
Where Patient Lived Before Death				**0.009***
Alone	27 (15.4%)	43 (28.4%)	70 (21.5%)	
With Respondent	49 (28.0%)	44(29.1%)	93 (28.5%)	
With Respondent and Others	46 (26.2%)	35 (23.2%)	81 (24.8%)	
With Other People	51 (29.1%)	25 (16.6%)	76 (23.3%)	
Not Recorded	2 (1.1%)	4 (2.6%)	6 (1.8%)	
Where Patient Spent Most of Last 3 Months of Life				**≤0.001***
Own Home	167 (95.4%)	126 (83.3%)	293 (89.8%)	
Hospital/Hospice	7(4.0%)	18(11.9%)	25 (7.7%)	
Nursing Home/Residential Home	0 (0)	5 (3.3%)	5 (1.5%)	
Not Recorded	1 (0.6%)	2 (1.3%)	3 (0.9%)	
Length of Time at Place Where Died				**≤0.001***
less than24 Hours	4 (2.3%)	10 (6.6%)	14 (4.3%)	
More than 1 day, less than 1 Week	10 (5.7%)	43 (28.5%)	53 (16.3%)	
More than 1 Week, less than 1 Month	42 (24.0%)	73 (48.3%)	115 (35.3%)	
More than 1 Month, less than 6 Months	30(17.1%)	24(15.9%)	54 (16.6%)	
≥ 6 Months	88(50.3%)	0 (0)	88 (27.0%)	
Not Recorded	1 (0.6%)	1 (0.7%)	2 (0.6%)	
Respondent Help Take Care of Patient				**0.010***
Yes	171 (97.7%)	136 (90.0%)	307 (94.2%)	
No	4 (2.3%)	14 (9.3%)	18 (5.5%)	
Not Recorded	0 (0)	1 (0.7%)	1 (0.3%)	
Respondents Reduce Hours/Stop Work (only those working)	**(n=107)**	**(n=75)**	**(n=182)**	**0.010***
Yes	88 (82.2%)	48 (64.0%)	136 (74.7%)	
No	19 (17.8%)	27 (36.0%)	46 (25.3%)	
Other Family/Friends Help Take Care of Patient				**0.006***
Yes	158(90.3%)	112(0.74%)	270 (82.8%)	
No	17(9.7%)	35(23.2%)	52 (16.0%)	
Not Recorded	0 (0)	4 (2.6%)	4 (1.2%)	
People to Help Look After Patient	**(n=152)**	**(n=110)**	**(n=262)**	**≤0.001***
2	19 (12.5%)	34 (30.9%)	53 (20.2%)	
3	28 (18.4%)	30 (27.3%)	58 (22.1%)	
4	31 (20.4%)	17 (15.5%)	48 (18.3%)	
5	19 (12.5%)	13 (11.8%)	32 (12.2%)	
6+	55(36.2%)	16(14.5%)	71 (27.1%)	

Note: Significant at the p<0.05 level (Chi-Square analysis)
Note: Patients who did not spend any time at home in the last 3 months of life (n=24) were removed from the analysis in this section

- A significantly higher proportion of patients who achieved PPD at home lived with the respondent and/or others (83.3%) when compared to those who died elsewhere (68.9%;p=0.009). In addition patients who died at home (95.4%) were more likely to have spent most of the last three months there.

- Care from relatives/friends has been shown as a factor influencing whether patients achieved a home death, with significantly higher proportions (69.1%) of patients who died at home having 4 or more family members caring for them when compared to those who did not achieve PPD at home (41.8%;p<0.001).

- Respondents reduced their working hours/stopped working due to the patient's illness for a significantly higher proportion of patients who achieved PPD at home (82.2%) compared to those who died elsewhere (64.0%; p=0.010).

- A higher proportion of patients who achieved PPD at home had help with personal care (e.g. washing and dressing; 90.2%, P<0.001) and medical procedures (e.g. taking medicines; 90.2%, P<0.001) when compared to those who did not die at home (73.8% and 68.5% respectively).

- Over half (55.6%) of patients who achieved PPD at home had help with personal care for more than 20 hours/week compared with 37.8% of patients who died elsewhere (p=0.010).

- A higher proportion of patients who achieved PPD at home had help with household tasks for more than 10 hours per week (74.7% vs 63.1%; p=0.004) and on call support for more than 20 hours per week (82.9% vs 62.9%; p=0.004) compared with those who died elsewhere.

- There were no differences between patients who achieved PPD at home and those who did not in terms of the distance from where patients lived to their nearest relative or friend (p> 0.05).

4.5.5 Information and Communication

Table 9. Preferred Place of Death (PPD) Home: Achieved/Did Not Achieve by Information and Communication

Information and Communication	Patient Achieved Death at Home Frequency (%)			
	Yes (n=175)	No (n=151)	Total (n=326)	P
Information Provided (last week)				**0.020***
Full Information Given	132 (75.4%)	90 (59.6%)	222 (68.1%)	
Would Have Liked More/ Yes, but Hard to Understand	21(12.0%)	37(24.5%)	58 (17.8%)	
Very Little Given	9 (5.1%)	14 (9.3%)	23 (7.1%)	
None Given	11 (6.3%)	8 (5.3%)	19 (5.8%)	
Not Recorded	2 (1.1%)	2 (1.3%)	4 (1.2%)	
Patient Aware of Likelihood of Death				**0.030***
Definitely Knew	111 (63.4%)	72 (47.7%)	183 (56.1%)	
Probably Knew	45 (25.7%)	51 (33.7%)	96 (29.4%)	
Probably Not	4 (2.3%)	9 (7.4%)	13 (4.0%)	
Definitely Not	4 (2.3%)	8 (5.3%)	12 (3.7%	
Not Recorded	11 (6.3%)	11 (7.3%)	22 (6.7%)	
HCP Discuss Likelihood of Death with Respondent/Family/Friends				**0.030***
Yes	149 (85.1%)	114 (75.5%)	263 (80.7%)	
No	17 (9.7%)	28 (18.5%)	45 (13.8%)	
Not Recorded	9 (5.1%)	9 (6.0%)	18 (5.5%)	
Patient Discuss PPD with Respondent/Family/Friends				**≤0.001***
Yes	145 (82.8%)	83 (55.0%)	228 (69.9%)	
No	27 (15.4%)	63 (41.7%)	90 (27.6%)	
Not Recorded	3 (1.7%)	5 (3.3%)	8 (2.5%)	
Patient Discuss PPD with HCP				**≤0.001***
Yes	107 (61.1%)	40 (26.5%)	147 (45.1%)	
No	38 (21.7%)	66 (43.7%)	104 (31.9%)	
Not Recorded	30 (17.1%)	45 (29.8%)	75 (23.0%)	
Respondent and Patient Agreed on Patient's PPD	n=175	n=152	n=327	**≤0.001***
Yes	167 (95.4%)	98 (6.5%)	265 (81.3%)	
No	6 (3.4%)	37 (24.5%)	43 (13.2%)	
Not Recorded	2 (1.1%)	17 (11.3%)	19 (5.8%)	

*Note: * Significant at the p=≤0.05 level (Chi-Square analysis)*
Note: Patients who did not spend any time at home in the last 3 months of life (n=24) were removed from the analysis in this section. Note: PPD=Preferred Place of Death, HCP=Healthcare Professional

- Overall, the majority of respondents were aware of the likelihood of the patient's death (85.1%) and the patient discussed their PPD with the respondent, family and friends in 82.8% of cases. No significant differences existed between groups on the respondent's awareness of the likelihood of the patient's death (p=>0.05).

- A higher proportion of respondents for patients who achieved PPD at home (75.4%) felt they had received full information in the last week of life when compared to those who died elsewhere (59.6%; p=0.02).

- A higher proportion of patients who achieved PPD at home discussed their PPD with the respondent and their family/friends (82.8%vs 55.5%; p=0.03) and/or a HCP (61.1% vs 26.5%; p=0.03) when compared to those who did not achieve PPD at home.

4.6 Do patients who died at home have better outcomes than those who died elsewhere? : A comparison of preferred place of death (PPD) by actual place of death.

This section of the report details patients for whom preference for place of death was known (n=420) and examines differences in Palliative Outcomes in their last week of life, Quality of Life and respondent's grief for those patients who achieved PPD at home (n=175), PPD in institution (n=43), those who did not achieve PPD at home (n=173), those who did not achieve death in preferred institution (n=7) and those patients who did not have a PPD (n=22).

(A total of 44 patients for whom PPD was not known were removed from this analysis. A further 29 patients who did not achieve death in a preferred institution (n=7) or did not have a PPD (n=22) were also excluded to avoid potential identification of individuals. No significant changes in findings were observed following the exclusion of these patients).

4.6.1 Palliative Outcome in last week of Life (Palliative Outcomes scale)

The Palliative Outcome Scale (POS) (28) was used to assess the patient's physical and psychological symptoms, spiritual and practical considerations, emotional concerns and psychosocial needs in the last week. The POS is scored out of a total of 40 with a higher score representing poorer palliative outcomes for the patient.

The full POS was completed for 333 patients and the mean score was 14.2 ± 6.1 (Range 1-35). No significant difference in POS scores were observed between patients who achieved PPD at home or institution and those who did not (p=0.149). [For patients who achieved PPD at home (n=150) or institution (n=37) the mean POS scores were 13.5 ± 6.5 (range 1-30) and 13.2 ± 6.5 (range 3-26) respectively. The mean POS score for patients who did not achieve PPD at home (n=145) was 15.1± 7.2 (range 8-32)].

Each individual item was investigated between patients who achieved PPD at home or institution and those who did not achieve PPD at home (Table 10). A higher proportion of respondents for patients who achieved PPD at home (79.3%) or in an institution (78.4%) felt that they had received full information in the last week of the patient's life when compared to those who did not achieve PPD at home (61.6%) or institution (14.3%; p=0.028). There was no difference found in the individual items of the POS i.e. management of pain or other symptoms, confusion and being unconscious in last week of life, patient feeling good about themselves, depression in patient, friends feeling anxious or worried and whether practical matters were up to date in the last week of life.

Table 10. Palliative Outcomes in last week of life for patients who achieved preferred place of death (PPD) vs those who did not achieve PPD and those who did not have PPD

Last week of Patients Life: Symptoms and Feelings	Achieved PPD		Did not achieve PPD	P
	Frequency (%)			
	PPD at Home (n=150)	PPD Institution (n=37)	PPD at Home (n=146)	
Confusion			n=143	
No, not at all	66 (44.0%)	12 (32.4%)	54 (37.0%)	0.411
Occasionally	43 (28.7%)	4 (10.8%)	39 (26.7%)	
Sometimes	26 (17.3%)	8 (21.6%)	28 (19.2%)	
Most of the time/Always	15 (10.0%)	13 (35.1%)	22 (15.1%)	
Unconscious/Coma			n=143	
No, not at all	78 (52.0%)	18 (48.6%)	71 (48.6%)	0.792
Occasionally	39 (26.0%)	7 (18.9%)	35 (24.0%)	
Sometimes	24 (16.0%)	6 (16.2%)	24 (16.4%)	
Most of the time/Always	9 (6.0%)	6 (16.2%)	13 (8.9%)	
Pain (despite medication)				
Pain was completely controlled	40 (26.7%)	12 (32.4%)	28 (19.2%)	0.778
Slightly	28 (18.7%)	7 (18.9%)	26 (17.8%)	
Moderately	41 (27.3%)	10 (27.0%)	48 (32.8%)	
Severely	31 (20.7%)	5 (13.5%)	32 (21.9%)	
Overwhelmingly	10 (6.7%)	3 (8.1%)	12 (8.2%)	
Other symptoms (despite medication)				
Other symptoms completely controlled	42 (28.0%)	10 (27.0%)	38 (26.0%)	0.786
Slightly	39 (26.0%)	9 (24.3%)	31 (21.2%)	
Moderately	35 (23.3%)	10 (27.0%)	39 (26.7%)	
Severely	26 (17.3%)	8 (21.6%)	33 (22.6%)	
Overwhelmingly	8 (5.3%)	0 (0.0%)	5 (3.4%)	
Patient Anxious/Worried				
No, not at all	46 (30.7%)	13 (35.1%)	41 (28.1%)	0.763
Occasionally	58 (38.7%)	11 (29.7%)	47 (32.2%)	
Sometimes	26 (17.3%)	5 (13.5%)	32 (21.9%)	
Most of the time/completely preoccupied by anxiety and worry	20 (13.4%)	8 (21.6%)	26 (17.8%)	
Family Anxious/worried				
No, not at all	5 (3.3%)	2 (5.4%)	9 (6.2%)	0.700
Occasionally	23 (15.3%)	5(13.5%)	18 (12.3%)	
Sometimes	8 (5.3%)	3(8.1%)	6 (4.1%)	
Most of the time	39 (26.0%)	16 (43.2%)	45 (30.8%)	
Always	75 (50.0%)	11 (29.7%)	68 (46.6%)	
Information				
Full information	119 (79.3%)	29 (78.4%)	90 (61.6%)	0.038*
Incomplete information	31 (11.3%)	8 (21.6%)	56 (38.4%)	

Note: Cell counts less than 3 have been adjusted to a value of three to avoid disclosure of potentially identifiable patient or respondent data

*Note: * Significant at the p=≤0.05 level (Chi-Square analysis)*

Table 10 continued. Palliative Outcomes in last week of life for patients who achieved preferred place of death (PPD) vs those who did not achieve PPD and those who did not have PPD

Last week of Patients Life: Symptoms and Feelings	Achieved PPD		Did not achieve PPD	P
	Frequency (%)			
	PPD at Home (n=150)	PPD Institution (n=37)	PPD at Home (n=146)	
Share Feelings				
Yes, as much as the patient wanted	60 (40.0%)	10 (27.0%)	47 (32.2%)	0.201
Most of the time	43 (28.7%)	3 (8.1%)	18 (12.4%)	
Sometimes	23 (15.3%)	11 (29.7%)	27 (18.5%)	
Occasionally	12 (8.0%)	7 (18.9%)	25 (17.1%)	
No, not at all	31 (20.7%)	6 (16.2%)	29 (19.8%)	
Depressed				
No, not at all	64 (42.7%)	16 (43.2%)	56 (38.4%)	0.962
Occasionally	38 (25.3%)	11 (29.7%)	41 (28.1%)	
Sometimes	26 (17.3%)	5(13.5%)	24 (16.4%)	
Most of the time/ Yes, definitely	22 (14.7%)	5 (13.5%)	25 (17.1%)	
Feel good about self				
Yes, all the time	41 (27.3%)	10 (27.0%)	38 (26.2%)	0.982
Most of the time	43 (28.7%)	11 (29.7%)	41 (28.1%)	
Sometimes	23 (15.3%)	4(10.8%)	17 (11.6%)	
Occasionally	12(8.0%)	4 (10.8%)	12 (8.2%)	
No, not at all	31 (20.7%)	8 (21.6%)	38 (26.0%)	
Wasted time appointments				
None at all	136 (90.7%)	35 (94.6%)	127 (87.0%)	0.786
Up to half a day wasted	7 (4.7%)	2(5.4%)	11 (7.5%)	
more than half a day wasted	7 (4.7%)	0 (0%)	8 (5.5%)	
Practical matters addressed				
No practical problems	40 (26.7%)	11 (29.7%)	47 (32.2%)	0.870
Practical problems were addressed	82 (54.7%)	20 (54.1%)	63 (43.2%)	
Practical problems in process of being addressed /Practical problems existed not addressed	28 (18.7%)	6(16.2%)	36 (24.7%)	

4.6.2 Quality of life (EuroQol-5D)

The EuroQol-5D scale (29) was used to assess the patient's quality of life as reported by carers in the last three months and last week of life by investigating five main areas: mobility, self-care, carrying out usual activities, pain and discomfort and anxiety and depression. The EuroQol-5D is scored out of a total of 15 with a higher score representing more problems and a poorer quality of life for the patient. The EuroQol-5D was available for 369 patients in their last three months of life and 355 patients in the last week of life.

Table 11. Mean EuroQol-5D scores in last three months and last week of life for patients who achieved preferred place of death (PPD) vs those who did not or did not have PPD

	EQ5D-3L score in last 3 months Mean (SD) n=369	EQ5D-3L score in last week Mean (SD) n=355	P
All patients	9.7 (2.1)	12.9 (1.5)	≤0.001*
Achieved PPD at home	n=166 9.6 (2.0)	n=162 13.0 (1.4)	0.118
Achieved PPD institution	n=45 10.0 (2.2)	n=41 13.1 (1.4)	
Did not achieve PPD at home	n=158 9.6 (2.2)	n=152 12.9 (1.8)	

*Note: * Significant at the p=≤0.05 level (Independent t-test analysis)*

- The mean EuroQol-5D score for patients at 3 months prior to death was 9.7 ± 2.1 and was significantly higher in last week of life with mean score of 12.9 ± 1.6; p=0.001 indicating poorer quality of life (see Table 11).

- No significant differences in EuroQol-5D scores in 3 months or last week of life between patients who achieved PPD and those who did not or did not have PPD were observed (see Table 12).

Table 12. Quality of Life as assessed by EuroQol-5D in last three months of life for patients who achieved preferred place of death (PPD) vs those who did not achieve PPD and those who did not have PPD

Last three months of Patients Life: Symptoms and feelings	Achieved PPD		Did not achieve	P
	PPD at Home (n=166)	PPD Institution (n=45)	PPD at Home (n=158)	
Mobility				0.909
No problems	43 (25.9%)	8 (17.8%)	41 (25.9%)	
Some problems walking about	112 (67.5%)	32 (71.1%)	105 (66.5%)	
Confined to bed	11 (6.6%)	5 (11.1%)	12 (7.6%)	
Self Care				0.014*
No problems with self care	52 (31.3%)	20 (44.4%)	50 (31.6%)	
Some problems with washing and dressing	78 (47.0%)	11 (24.4%)	80 (50.6%)	
Unable to wash or dress	36 (21.7%)	14 (31.1%)	28 (17.7%)	
Usual activities				0.624
No problems with performing usual activities	22 (13.3%)	4(8.9%)	30 (19.0%)	
Some problems with performing usual activities	80 (48.2%)	24 (53.3%)	72 (45.6%)	
Unable to perform usual activities	64 (38.6%)	17 (37.8%)	56 (35.4%)	
Pain/Discomfort				0.513
No pain or discomfort	24 (14.5%)	5 (11.1%)	25 (15.8%)	
Moderate pain or discomfort	112 (67.5%)	28 (62.2%)	104 (65.8%)	
Extreme pain or discomfort	30 (18.1%)	12 (26.7%)	29 (18.4%)	
Anxiety/Depression				0.787
Not anxious or depressed	71 (42.8%)	15 (33.3%)	58 (36.7%)	
Moderately anxious or depressed	85 (51.2%)	25 (55.6%)	83 (52.5%)	
Extremely anxious or depressed	10 (6.0%)	5 (11.1%)	17 (10.8%)	

- No significant differences in mobility, usual activities, pain/discomfort and anxiety/depression in the last three months of life were observed between patients who achieved PPD at home, PPD in institution and patients who did not achieve PPD at home (all p> 0.05).

Table 13. Quality of Life as assessed by EuroQol-5D in last week of life for patients who achieved preferred place of death (PPD) vs those who did not achieve PPD and those who did not have PPD

Last week of Patients Life: Symptoms and feelings	Achieved PPD		Did not achieve PPD	P
	PPD at Home (n=162)	PPD Institution (n=41)	PPD at Home (n=152)	
Mobility				0.428
No problems/Some problems walking about	24 (14.9%)	4 (9.7%)	30 (19.7%)	
Confined to bed	138 (85.2%)	37 (90.2%)	122 (80.3%)	
Self Care				0.030*
No problems with self care/ Some problems with washing and dressing	11 (6.8%)	3 (7.3%)	27(17.8%)	
Unable to wash or dress	151 (93.2%)	38 (92.7%)	125 (82.0%)	
Usual activities				0.165
No problems with performing usual activities/ Some problems with performing usual activities	3(1.9%)	0 (0.0%)	10 (6.6%)	
Unable to perform usual activities	159 (98.1%)	41 (100%)	142 (93.4%)	
Pain/Discomfort				0.328
No pain or discomfort	19 (11.7%)	5(12.2%)	21 (14.5%)	
Moderate pain or discomfort	63 (38.9%)	13 (31.7%)	45 (29.6%)	
Extreme pain or discomfort	80 (49.45)	23 (56.1%)	85 (55.9%)	
Anxiety/Depression				0.030*
Not anxious or depressed	61 (37.7%)	17 (41.5%)	47 (30.9%)	
Moderately anxious or depressed	63 (38.9%)	13 (31.7%)	63 (41.4%)	
Extremely anxious or depressed	38 (23.5%)	11 (26.6%)	42 (27.6%)	

In the last week of life relatives / carers reported that:

- 82-93% of patients had problems with self care, the highest being for those who achieved PPD at home.
- The majority of patients (88%) experienced moderate/extreme pain with no differences by achievement of PPD.
- The majority of patients experience moderate/extreme anxiety or depression (62% of patients who died at home, 58% of those achieved PPD in an institution and 69% for those who did not achieve their PPD).
- A higher proportion of patients who achieved PPD at home (93.2%) and PPD in an institution (92.7%) had problems with self-care in the last week e.g. unable to wash and dress compared with those who did not achieve PPD at home (82.0%; p=0.030).
- A lower proportion of patients who did not achieve PPD at home were not anxious or depressed in the last week when compared to those who achieved PPD at home (41.1%) or in an institution (27.6%; p=0.030).
- There were no significant differences in mobility, ability to carry out usual activities and pain/discomfort between patients who achieved PPD and those whose did not or did not have PPD.

4.6.3 Respondents Grief: Texas Revised Inventory of Grief (TRIG)

The Texas Revised Inventory of Grief (TRIG) questionnaire (30) was used to measure the level of grief experienced by the respondent. The questionnaire is made up of 2 components/sections. The first section (TRIG 1) relates to past emotional behaviour of the respondent at the time when the patient died, whilst the second section (TRIG 2) relates to their current emotional feelings at the time of questionnaire completion. TRIG1 is scored out of a total of 40 and TRIG 2 is scored out of a total of 65 with a lower score for each outcome representing a higher grief response.

Table 14. Mean TRIG scores of respondents for patients who achieved preferred place of death (PPD) vs those who did not or did not have PPD

	TRIG 1 past behaviour Mean (SD) n=342 (max 40)	TRIG 2 present behaviour Mean (SD) n= 357 (max 65)
All patients	26.0 (8.7)	32.2 (12.7)
Achieved PPD at home	n=157 26.6 (8.5)	n=156 33.4 (12.8)
Achieved PPD institution	n=38 26.3 (8.2)	n=43 29.7 (13.3)
Did not achieve PPD at home	n=146 25.2 (9.0)	n=157 31.8 (12.5)

- No significant differences in mean TRIG 1 or TRIG 2 scores were observed between the respondents of patients who achieved PPD and those who did not.

Table 15. Proportion (%) of Respondents that selected ‘Completely True’ or ‘Mostly True’ TRIG 1 past behaviour items

TRIG 1 Past Behaviour	Achieved PPD		Did not achieve PPD	P
		Frequency (%)		
	PPD at Home (n=157)	PPD Institution (n=38)	PPD at Home (n=146)	
Hard to get along with certain people	44 (28.0%)	3 (7.9%)	40 (27.4%)	0.076
Hard to work well	88 (56.1%)	18 (47.4%)	69 (47.3%)	0.400
Lost interest in my family, friends and outside activities	39 (24.8%)	8 (21.1%)	44 (30.1%)	0.660
Felt a need to do things he/she had wanted to do	64 (40.8%)	15 (39.5%)	65 (44.5%)	0.985
Usually irritable	46 (29.3%)	12 (31.6%)	52 (35.6%)	0.707
Could not keep up with normal activities	65 (41.4%)	13 (34.2%)	58 (39.7%)	0.981
Angry that he/she left me	34 (21.7%)	6 (15.8%)	43 (29.5%)	0.604
Found it hard to sleep	89 (56.7%)	14 (36.8%)	82 (56.2%)	0.454

- No significant associations between achieving PPD at home, in an institution or not achieving PPD at home and individual items for TRIG 1 past behaviour scale were observed (all p> 0.05).

Table 16. Proportion (%) of Respondents that selected ‘Completely True’ or ‘Mostly True’ TRIG 2 present behaviour items

TRIG 2 Present Behaviour	Achieved PPD		Did not achieve PPD	**P**
	Frequency (%)			
	PPD at Home (n=156)	PPD Institution (n=43)	PPD at Home (n=157)	
I still cry when I think of them	87 (55.8%)	21 (48.8%)	82 (52.2%)	0.647
I still get upset when I think about them	106 (67.9%)	28 (65.1%)	93 (59.2%)	0.324
I cannot accept their death	34 (21.8%)	7 (16.3%)	37 (23.6%)	0.659
Sometimes I miss them very much	146 (93.6%)	35 (81.4%)	140 (89.2%)	0.078
Even now it’s painful to recall memories	89 (57.1%)	18 (41.9%)	85 (54.1%)	0.322
Preoccupied with thoughts (often think about them)	89 (57.1%)	21 (48.8%)	85 (54.1%)	0.618
I hide my tears when I think about them	71 (45.5%)	18 (41.9%)	82 (52.2%)	0.316
No one will ever take the place in my life	133 (85.3%)	30 (69.8%)	128 (81.5%)	0.464
I can’t avoid thinking about them	105 (67.3%)	23 (53.5%)	105 (66.9%)	0.385
I feel it’s unfair that they died	75 (48.1%)	19 (44.2%)	70 (44.6%)	0.512
Things and people around me still remind me of them	131 (84.0%)	35 (81.4%)	126 (80.3%)	0.963
I am unable to accept their death	36 (23.1%)	7 (16.3%)	39 (24.8%)	0.564
At times I still feel the need to cry for them	110 (70.5%)	25 (58.1%)	97 (61.8%)	0.776

- No significant associations between achieving PPD at home, in an institution or not achieving PPD at home and individual items for TRIG 2 present behaviour scale were observed (all p> 0.05).

- Only 9.6% (n=45) of respondents reported that they had talked to someone from HSC Services in terms of bereavement counselling regarding the patient’s illness and death. Of those 45 respondents, 77.8% (n=35) found that seeking the professional service was helpful.

5. DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Main Discussion Points

Cancer accounts for 4050 deaths each year, over a quarter of all deaths in NI. The literature indicates that over half of cancer patients would prefer to die at home (22,31-34), however within the current study, although 75% of patients and 64% of respondents had preference for a home death, only 38% of patients achieved this.

High use of services

While most patients spent considerable amounts of time at home there was high use of services reported with over three quarters of patients having at least one overnight stay in a hospital ward and half attending Accident and Emergency or using Ambulance Services at least once in the last three months of life.

A recent report into reasons why cancer patients died in acute hospitals in NI (1) found that over three quarters of patients who died in an acute hospital were admitted as an emergency, as a result of cancer related symptoms (37%) or other urgent physical symptoms (34%) suggesting that patients required medical attention that could not be provided or was not currently available within the community setting and therefore required hospitalisation. 14% of patients in that study died within 48 hours of admission (1). This suggests that cancer patients admitted to hospital as an emergency may be more likely to die there.

The DHSSPS for NI (2010; 2) has recommended that all out of hours teams should be trained to identify patients who are approaching end of life and to provide end of life care to patients and their family and friends. Having appropriate services to meet the care needs of patients approaching end of life available within the community, may lead to a reduction in the number of cancer patients attending Accident and Emergency and being admitted as an emergency to acute hospitals. This may in turn lead to a reduction in the number of terminally ill cancer patients dying in acute hospital settings. Enabling a patient to die at home has benefits for both patients as well as for the health service. A statistical model which simulated the cost of caring for cancer patients in their last year of life (England) found that a 10% reduction in emergency admissions coupled with a three day reduction in length of hospital stay could equate to saving of £104 million per year (35). The findings of a recent report into of the National End of Life Care Intelligence Network in England (2012;36) has suggested an estimated potential net saving of £958 for each patient that achieves a death in the community rather than in an acute hospital setting. The savings that occur as a result of reduced emergency admissions and inpatient care could be redirected where necessary into end of life services within the community.

Over the past ten years in England, Marie Curie Cancer Care has established a ‘Delivering Choice’ programme which provides terminally ill patients with the choice of dying at home by preventing unnecessary admissions to hospital and accelerating discharge from hospital back into the community. The programme consists of 1. Rapid Response Teams (RRTs) which make both emergency and planned home visits to end of life care patients during out of GP practice hours and 2. District/Community Link Nurses (DCLNs) who coordinate packages of care for end of life patients in order to speed up discharge from hospital back to their preferred place of care. An evaluation of the programme in Lincolnshire was carried out by Addicott and Dewar (2008; 37) and showed that the programme was associated with a significant reduction in 999 ambulance journeys and out of hours GP and Other Nursing Care visits and more home deaths. Overall, twice as many patients (42%) that accessed the 'Delivering Choice' programme died at home compared to those who received standard palliative care (19%).

Burden on the carer

Almost nine out of ten patients received informal care from family or friends including help with personal care, medical procedures, attending appointments, household tasks and on call help. A higher proportion of patients who died at home had help with household tasks, personal care and medical procedures for 20+ hours per week and help on call all the time. Over a third of patients received help with medical procedures, personal care and household tasks from relatives/friends for more than 20 hours per week and 59.4% had help 'on call' at all times in the last three months of life. Patients who lived with the respondent or others before death were more likely to achieve preferred place of death (PPD) at home than those who lived alone, yet in our society there are increasing numbers of people living alone who may not have the support required for a home death. Also a higher proportion of respondents for patients who achieved PPD at home stopped or reduced their work hours in the last three months of life due to the patient's illness. This is reflective of previous literature which showed that whether a patient is able to receive end of life care and die at home is very often dependent on the capacity of family and friends to provide informal care at home (13,38). Though this is carried out willingly (39-40), providing informal care at home can be associated with significant emotional, social, physical and financial costs, i.e. if working hours are reduced in order to provide care (41) and has even been associated with increased mortality of the care giver (42). However, it has also been shown that accessing formal care from health services at home did not lead to a reduction in the reliance on friends and family in providing care to enable a death at home and working towards the current policy objectives of enabling patients to have the option of receiving end of life care at home would become difficult without their input (38).

Key healthcare professionals

Significantly higher proportions of patients who achieved a home death had a key healthcare worker compared to those did not achieve PPD death at home. The Palliative and End of Life Care Strategy for NI published by the DHSSPS for NI (2) in 2010 recommended that all patients with end of life care needs should have a key healthcare worker/case manager.

The role of the key healthcare worker is to provide a point of contact for the patient, to provide practical and emotional support for the family, to co-ordinate the palliative care journey in hospital, to ensure appropriate interventions are carried out in a timely way. As well as to act as a patient advocate up to and including end of life and to provide information as appropriate and to ensure that this information is timely and tailored to the patient's needs and understanding. The key healthcare worker can be a GP, District/Community Nurses, Specialist Nurse, Social Worker or Allied Health Professional. For almost two thirds of patients in the current study the key healthcare worker was their GP, either alone or together with another HCP, additionally care from a GP at home and the number of home visits by the GP were shown to be an important factor in achieving a home death. This reflects the findings of two Danish studies (43,44) which also showed District and Community Nursing visits as important. In this study overall satisfaction with GP care received at home was higher for patients who achieved PPD at home.

Poor Information and communication

Effective communication is considered an essential aspect of care for cancer patients (45). Providing cancer patients with good information on their condition and treatment has been shown to decrease levels of emotional distress and can assist in managing expectations (46) with inadequate information giving being highlighted as a main reason for patients becoming emotionally distressed (47). A study carried out by Heyland et al. (2006;6) showed that communication and information giving are considered to be important aspects of end of life care by both the patient and their family.

The End of Life Care Strategy for Northern Ireland (2) has highlighted effective communication as a key component of end of life care and that it is essential for the implementation of the recommended end of life care pathway in order to plan and co-ordinate delivery of patient centred care and bereavement care for the family. However the findings of the current study indicate that communication and information giving in current practice in end of life care could improve, as a third of respondents felt that they had not received adequate information regarding the patient’s condition and some reported avoidance of answering some questions or that information given was difficult to understand. These findings are not unique to NI (48-53). The findings of Lecoutrier et al. (1999;52) showed that timing of information received was also important.

In the current study, respondent satisfaction with communication differed across settings and health care professions with the highest rating given for those HCPs specifically trained to provide Specialist Palliative Care (SPC). Satisfaction was also high for Other Nursing care at home and in care homes, but while still high, was lowest for hospital doctors and nurses and GPs at home. This is an important finding as home and hospital represent the setting in which the majority of care was received by patients in the current study, with the majority of patients (89.4%) spending most of the last three months at home or in hospital and with more than three quarters (78.4%) of patients dying there.

The End of Life Care Strategy for Northern Ireland (2) has suggested that one of the main roles of the key healthcare worker is to co-ordinate services and to facilitate effective exchange of information between the patients, their families and carers and HSC providers.

The current study found better information giving was associated with achieving a home death. Discussions around PPD were shown to be an important factor in whether a patient achieved PPD at home. Studies investigating GP awareness of PPD in patients with non sudden deaths in Belgium (54) and Netherlands (55) have shown similar findings.

A qualitative study of GP and Nurse experiences of exploring PPD in end of life patients carried out by Munday and Petrova (2009;56) highlighted that discussions around PPD as not an easy area for HCPs and it was often not approached unless it was brought up by the patient.

Agreement between respondent and patient on PPD at home was also shown to be an important factor in achieving a home death within the current study reflecting the findings of Ishikawa et al. (2013;57).

Although achieving PPD has previously been highlighted as important it is only one aspect of a 'good death' (7). Other palliative outcomes including management of pain and other symptoms, preparation for death and the opportunity to achieve a sense of completion are other aspects of a 'good death' that both patients and their family and caregivers consider to be important in end of life care (7,58).

Is home death associated with better outcomes?

It is reassuring that both patient and respondent outcomes did not differ by place of death in the current study. In addition there were no differences in levels of reported patient/respondent anxiety, depression and patient feeling good about themselves, whether practical matters were addressed or not and level of family anxiety between patients. This is indeed a welcome finding which reflects the high quality care and commitment of staff who provide care for cancer patients in NI together with the care and support provided by informal carers.

Strengths and Limitations

A major strength of the current study is that it is a population based survey which has been shown to be representative of cancer patients who died in NI in 2012 with no significant differences in age, gender, diagnosis of the seven main cancers and deprivation being observed between study participants and cancer deaths that occurred and were registered in 2012 (n=4047). A further strength is that the study questionnaire incorporates instruments previously validated and used within palliative care research and the methodology used is based on that already tested and used within the Qualycare study (59).

A limitation of the current study to be taken into consideration is that it has a mortality follow back study design with information collected retrospectively from bereaved relatives on behalf of the patient rather than directly from the patient. However, using bereaved relatives as a proxy for a patient within end of life care research has been considered valuable for three main reasons (59): (1) It is the only way to gain information on patient and respondent experiences of end of life care in the last days of life, (2) Relatives' views provide a valuable insight into the care received as research has shown that they play a vital role in caring for and supporting patients in end of life, especially those patients who die at home and also (3) Relatives are recipients of end of life care and exploring their views can help us to understand how well they cope with loss and grief.

A further limitation of the study is that the information was collected retrospectively and that a relative's perceptions of the patient's palliative outcomes (such as pain, anxiety and depression) may have changed over the bereavement process. A study carried out by McPherson and Addington-Hall in 2004 (60-61) investigated agreement between relative's assessment of palliative outcomes at three to five months and seven to nine months following bereavement. The findings showed moderate agreement for the assessment of anxiety and depression in the last week of life, however, the agreement for the assessment of pain experienced in the last week of life was slight with pain frequency and severity of pain being underestimated at seven to nine months compared with three to five months (60-61). Another limitation is that due to the nature of data collection (self-completed questionnaire) there is the potential for respondent bias with respondents who had a more negative or positive experience than standard care being more likely to complete the survey. This should be considered in the interpretation of the findings.

5.2 Conclusion

- Given that the majority of cancer patients would prefer to die at home and although there has been a recent increase in proportion of cancer patients achieving this, approximately half of patients with home as PPD still die in an institutional setting.

- While achieving PPD can be considered an important end in itself, we have no evidence from this study to suggest that home death is associated with better or worse Quality of Life or Palliative Outcomes in last week of life or different grief outcomes for relatives.

- The findings have highlighted:

  - High levels of service usage including ambulance and Accident and Emergency by cancer patients in the last three months of life.
  -The importance of good communication and information giving in end of life care, in particular, relating to awareness of likelihood of death and discussions around preferred place of death between the patient, their family and Healthcare Professionals.
  -The critical role that key healthcare professionals play in communication and co-ordinating access to services.
  - That achieving preferred place of death was not associated with cancer diagnosis, stage of disease or days from diagnosis, suggesting that patient's demographic characteristics and social circumstances may be more important factors associated with achieving preferred place of death at home.
  - That while achieving preferred place of death can be considered an important end in itself, the current study provides no evidence to suggest that home death is associated with better or worse Quality of Life or Palliative Outcomes in the last week of life.
  -An undocumented burden exists on informal carers looking after cancer patients before they die exists.

5.3 Recommendations

From the findings of the current study the following recommendations have been made:

Recommendation 1: Healthcare Professionals (HCPs) caring for patients with end of life care needs should have additional training in effective communication particularly in initiating discussions about likelihood of death and preferred place of death in order to put an appropriate care plan in place and to enable patients to receive end of life care in preferred place of death wherever possible. It is also recommended that HCPs responsible for delivering end of life care in all settings should be encouraged to complete an evidence based training programme, for example the European Certificate in Essential Palliative Care (63).

Recommendation 2: Models such as the ‘Delivering Choices’ program and Rapid Response Teams should be explored and piloted for NI to reduce inappropriate ambulance use and admission to hospital.

Recommendation 3: All patients nearing end of life should have a knowledgeable key healthcare worker to provide practical and emotional support for the family and to co-ordinate end of life care according to needs of patient and family.

Recommendation 4: Further work is recommended to explore the burden that providing informal care at home puts on family and friends and to establish how best to support them in this role both practically and financially.

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APPENDICES

APPENDIX I – Project Steering Group Members

APPENDIX II - Background Data – All Cancers deaths N. Ireland

1. Place of Death for cancer patients in N. Ireland 2005-2012
2. Place of Death by Gender – All Cancer Patients NI – 2005 -2012
3. Place of Death by Cancer Diagnosis – All Cancer Patients NI – 2005 -2012
4. Place of Death by Age – All Cancer Patients NI – 2005 -2012
5. Place of Death by Socioeconomic Status – All Cancer Patients NI – 2005-2012
6. Place of Death by Marital Status – All Cancer 2005 - 2012

APPENDIX III - Supplementary Tables and Figures from Study

A. Study Patient’s Cancer Diagnosis vs NI Cancer Deaths

B. Time since diagnosis to Death by Cancer Type for Study Patients

C. Study Patients Aware vs Patients Unaware of Death

D. Respondent Characteristics

E. Factors Influencing Respondents Finding the Questionnaire Completion Upsetting

F. Informal Care provided by respondent / family and friends at home

Figure 1. Respondent’s Preferred Place of Death Over Time and if all Things in Place

APPENDIX I

List of Project Steering Group Members

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APPENDIX II: Background Data- All Cancer Deaths in NI

Table 1. Place of Death for Cancer Patients in NI 2005-2012

Place of Death	Year of Death							
	2005	2006	2007	2008	2009	2010	2011	2012
Hospital	1748 (46.7%)	1806 (46.7%)	1691 (44.1%)	1710 (43.3%)	1628 (42.1%)	1761 (43.6%)	1674 (41.3%)	1704 (42.1%)
Care home	302 (8.1%)	295 (7.6%)	301 (7.8%)	327 (8.3%)	336 (8.7%)	368 (9.1%)	375 (9.3%)	380 (9.4%)
Hospice	498 (13.3%)	462 (11.9%)	509 (13.3%)	514 (13.0%)	481 (12.4%)	478 (11.8%)	475 (11.7%)	437 (10.8%)
Home	1182 (31.6%)	1292 (33.4%)	1331 (34.7%)	1397 (35.3%)	1423 (36.8%)	1424 (35.3%)	1527 (37.7%)	1522 (37.6%)
All Other Places	10 (0.3%)	12 (0.3%)	6 (0.2%)	5 (0.1%)	3 (0.1%)	4 (0.1%)	3 (0.1%)	4 (0.1%)
All Places	**3740**	**3867**	**3838**	**3953**	**3871**	**4035**	**4054**	**4047**

Note: Source= General Register Office Files
Note: Cancer Deaths (ICD 10 codes C00-C097; WHO 2010) that occurred and were registered in the same year between 2005-2012 have been included. It is important to note that a small number of deaths that occurred in 2012 and earlier years but not registered until 2013 and are therefore not included.
Note: Hospital = NHS hospitals. Care home= Nursing homes and Residential homes, Home= Patients own home or home of relative/friend.

Table 2. Place of Death by Gender- All Cancer Patients 2005-2012

Place of Death	Year of Death								
	2005-2006		2007-2008		2009-2010		2011-2012		
	Male	Female	Male	Female	Male	Female	Male	Female	Total
Hospital	1865 (47.4%)	1689 (46.2%)	1870 (45.7%)	1531 (41.5%)	1814 (43.9%)	1575 (41.7%)	1841 (43.2%)	1537 (40.0%)	13772
Care home	251 (6.4%)	346 (9.5%)	277 (6.8%)	351 (9.5%)	304 (7.5%)	400 (10.6%)	326 (7.6%)	429 (11.2%)	2684
Hospice	495 (12.6%)	465 (12.7%)	527 (12.9%)	496 (13.5%)	467 (11.3%)	492 (13.0%)	468 (11.0%)	444 (11.6%)	3854
Home	1318 (33.4%)	1156 (31.6%)	1421 (34.7%)	1307 (35.5%)	1538 (37.3%)	1309 (34.7%)	1624 (38.1%)	1425 (37.1%)	11098
Total	**3929**	**3656**	**4095**	**3685**	**4123**	**3776**	**4259**	**3835**	**31358**

Note: Source= General Register Office Files
Note: Cancer Deaths (ICD 10 codes C00-C097; WHO, 2010) that occurred and were registered in the same year between 2005-2012 have been included. It is important to note that a small number of deaths that occurred in 2012 and earlier years but not registered until 2013 and are therefore not included. Note: A small number of deaths n<10 that occurred in other places were not reported to avoid disclosure of potentially identifiable patient data Note: Hospital = NHS hospitals. Care home= Nursing homes and Residential homes, Home= Patients own home or home of relative/friend

Table 3. Place of Death by Cancer Diagnosis – All Cancer Patients 2005-2012

	Place of Death	Cancer Diagnosis (ICD10*)						
		Digestive Organs C15-C26	Respiratory & Intrathoracic Organs C30-C39	Breast C50	Female Genital Organs C51-C58	Male Genital Organs C60-C63	Leukaemia and Lymphoma C81-C95	Total
2005-2006	Hospital	854 (43.5%)	872 (49.9%)	249 (41.4%)	168 (40.9%)	185 (41.6%)	381 (66.4%)	2709
	Care home	137 (7.0%)	92 (5.3%)	81 (13.5%)	31 (7.6%)	66 (14.8%)	40 (7.0%)	447
	Hospice	237 (12.1%)	195 (11.2%)	90 (15.0%)	75 (18.2%)	53 (11.9%)	41 (7.1%)	691
	Home	735 (37.4%)	588 (32.6%)	182 (30.2%)	137 (33.3%)	141 (31.6%)	112 (19.5%)	1895
	Total	**1963**	**1747**	**602**	**411**	**445**	**574**	**5742**
2007-2008	Hospital	766 (37.6%)	804 (44.2%)	262(42.1%)	139 (36.4%)	200 (42.9%)	373 (67.6%)	2544
	Care home	161 (7.9%)	120 (6.6%)	82 (13.2%)	30 (7.9%)	60 (12.9%)	35 (6.3%)	488
	Hospice	292 (14.3%)	226 (12.4%)	77 (12.4%)	76 (19.9%)	56 (12.0%)	27 (4.9%)	754
	Home	818 (40.2%)	667 (36.7%)	202 (32.4%)	136 (35.7%)	150 (32.2%)	117 (21.2%)	2090
	Total	**2037**	**1817**	**623**	**381**	**466**	**552**	**5876**
2009-2010	Hospital	809 (40.3%)	790 (42.1%)	223 (38.6%)	161 (38.9%)	195 (41.4%)	375 (66.8%)	2553
	Care home	177 (8.8%)	123 (6.6%)	65 (11.2%)	49 (11.8%)	63 (13.4%)	39 (7.0%)	516
	Hospice	246 (12.3%)	210 (11.2%)	75 (13.0%)	66 (15.9%)	55 (11.7%)	33 (5.9%)	685
	Home	775 (38.6%)	753 (40.2%)	215 (37.2%)	138 (33.4%)	158 (33.6%)	114 (20.3%)	2153
	Total	**2007**	**1876**	**578**	**414**	**471**	**561**	**5907**
2011-2012	Hospital	739 (36.0%)	829 (43.5%)	223 (35.6%)	142 (38.0%)	201 (39.8%)	423 (65.2%)	2557
	Care home	225 (11.0%)	118 (6.2%)	85 (13.6%)	31 (8.3%)	79 (15.6%)	43 (6.6%)	581
	Hospice	213 (10.4%)	220 (11.6%)	81 (12.9%)	62 (16.6%)	51 (10.1%)	33 (5.1%)	660
	Home	876 (42.7%)	737 (38.6%)	237 (37.8%)	139 (37.2%)	174 (34.5%)	150 (23.1%)	2313
	Total	**2053**	**1904**	**626**	**374**	**505**	**649**	**6111**

Note: Source= General Register Office Files *Note: Cancer Deaths (ICD 10 codes C00-C097; WHO, 2010) that occurred and were registered in the same year between 2005-2012 have been included. It is important to note that a small number of deaths that occurred in 2012 and earlier years but not registered until 2013 and are therefore not included. Note: A small number of deaths n<10 that occurred in other places were not reported so as to avoid disclosure of potentially identifiable patient data. Note: Hospital = NHS hospitals. Care home= Nursing homes and Residential homes, Home= Patients own home or home of relative/friend. * ICD 10 codes were used to classify deaths by cancer diagnosis.

Table 4. Place of Death by age- All Cancer Patients 2005-2012

	Place of Death	Age (years)						
		18-49	50-59	60-69	70-79	80-89	90+	
2005-2006	Hospital	166 (41.9%)	362 (45.5%)	744 (44.8%)	1178 (48.6%)	932 (49.3%)	165 (41.0%)	3547
	Care home	0 (0.0%)	6 (0.8%)	35 (2.1%)	143 (5.9%)	276 (14.6%)	137 (34.1%)	597
	Hospice	76 (19.1%)	135 (17.0%)	250 (15.0%)	305 (12.6%)	173 (9.2%)	21 (5.2%)	960
	Home	154 (38.9%)	293 (36.7%)	633 (38.1%)	797 (32.9%)	508 (26.9%)	79 (19.7%)	2464
	Total	**396**	**796**	**1662**	**2423**	**1889**	**402**	**7568**
2007-2008	Hospital	179 (43.1%)	340 (42.0%)	735 (44.3%)	1065 (42.8%)	912 (45.1%)	153 (42.7%)	3384
	Care home	4 (1.0%)	8 (1.0%)	36 (2.2%)	149 (6.0%)	333 (16.4%)	98 (27.5%)	628
	Hospice	83 (20.0%)	154 (19.0%)	239 (14.4%)	334 (13.4%)	192 (9.5%)	20 (5.6%)	1022
	Home	149 (35.9%)	308 (36.2%)	648 (39.1%)	940 (37.8%)	586 (28.9%)	86 (24.1%)	2717
	Total	**415**	**810**	**1658**	**2488**	**2023**	**357**	**7751**
2009-2010	Hospital	164 (41.1%)	343 (42.2%)	769 (43.9%)	1068 (42.8%)	883 (43.9%)	156 (38.0%)	3383
	Care home	5 (1.3%)	15 (1.8%)	50 (2.9%)	160 (6.4%)	337 (16.7%)	137 (33.3%)	704
	Hospice	82 (20.6%)	145 (17.8%)	238 (13.6%)	304 (12.2%)	168 (8.3%)	19 (4.6%)	956
	Home	148 (37.1%)	310 (38.1%)	693 (39.6%)	961 (38.5%)	625 (31.0%)	99 (24.1%)	2836
	Total	**399**	**813**	**1750**	**2493**	**2013**	**411**	**7879**
2011-2012	Hospital	195 (48.5%)	355 (43.8%)	724 (43.0%)	1079 (42.3%)	852 (39.7%)	168 (34.5%)	3373
	Care home	0 (0.0%)	17 (2.1%)	41 (2.4%)	167 (6.6%)	365 (17.0%)	163 (33.5%)	753
	Hospice	60 (14.9%)	127 (15.7%)	261 (15.5%)	284 (11.2%)	164 (7.7%)	13 (2.7%)	909
	Home	145 (36.0%)	311 (38.4%)	656 (39.0%)	1016 (39.9%)	763 (35.5%)	143 (29.4%)	3034
	Total	**400**	**810**	**1682**	**2546**	**2144**	**487**	**8069**

Note: Source= General Register Office Files Note: Cancer Deaths (ICD 10 codes C00-C097; WHO, 2010) that occurred and were registered in the same year between 2005-2012 have been included. It is important to note that a small number of deaths that occurred in 2012 and earlier years but not registered until 2013 and are therefore not included. Note: A small number of deaths n <10 that occurred in other places were not reported so as to avoid disclosure of potentially identifiable patient data
Note: Hospital = NHS hospitals. Care Home= Nursing homes and Residential homes Home= Patients own home or home of relative/friend

Table 5. Place of Death by Socioeconomic status- All Cancer Patients 2005-2012

	Place of Death	Deprivation Quintile					
		Quintile 1 (least deprived)	Quintile 2	Quintile 3	Quintile 4	Quintile 5 (most deprived)	Total
2005-2006	Hospital	601 (46.4%)	671 (48.7%)	665 (45.7%)	773 (45.4%)	844 (48.0%)	3554
	Care home	145 (11.2%)	109 (7.9%)	122 (8.4%)	132 (7.8%)	89 (5.1%)	597
	Hospice	194 (15.0%)	164 (11.9%)	174 (12.0%)	191 (11.2%)	237 (13.5%)	960
	Home	355 (27.4%)	433 (31.5%)	493 (33.9%)	605 (35.5%)	588 (33.4%)	2474
	Total	**1295**	**1377**	**1454**	**1701**	**1758**	**7585**
2007-2008	Hospital	596 (43.4%)	619 (45.3%)	659 (43.1%)	730 (42.7%)	797 (44.1%)	3401
	Care home	136 (9.9%)	118 (8.6%)	119 (7.8%)	140 (8.2%)	115 (6.4%)	628
	Hospice	214 (15.6%)	143 (10.5%)	180 (11.8%)	196 (11.5%)	290 (16.1%)	1023
	Home	426 (31.1%)	485 (35.5%)	570 (37.4%)	643 (37.6%)	604 (33.4%)	2728
	Total	**1372**	**1365**	**1528**	**1709**	**1806**	**7780**
2009-2010	Hospital	589 (43.5%)	671 (44.8%)	662 (42.4%)	730 (41.6%)	737 (42.5%)	3389
	Care home	163 (12.0%)	141 (9.4%)	136 (8.7%)	151 (8.6%)	113 (6.5%)	704
	Hospice	184 (13.6%)	167 (11.1%)	170 (10.9%)	185 (10.6%)	253 (14.6%)	959
	Home	417 (30.8%)	519 (34.6%)	591 (37.9%)	687 (39.1%)	633 (36.5%)	2847
	Total	**1353**	**1498**	**1559**	**1753**	**1736**	**7899**
2011-2012	Hospital	600 (41.9%)	605 (40.8%)	669 (40.2%)	721 (42.0%)	783 (43.6%)	3378
	Care home	186 (13.0%)	125 (8.4%)	170 (10.2%)	159 (9.3%)	115 (6.4%)	755
	Hospice	189 (13.2%)	162 (10.9%	175 (10.5%)	165 (9.6%)	221 (12.3%)	912
	Home	457 (32.0%)	592 (39.9%)	652 (39.1%)	671 (39.1%)	677 (37.7%)	3049
	Total	**1432**	**1484**	**1666**	**1716**	**1796**	**8094**

Note: Source= General Register Office Files Note: Cancer Deaths (ICD 10 codes C00-C097; WHO, 2010) that occurred and were registered in the same year between 2005-2012 have been included. It is important to note that a small number of deaths that occurred in 2012 and earlier years but not registered until 2013 and are therefore not included. Note: A small number of deaths n<10 that occurred in other places were not reported so as to avoid disclosure of potentially identifiable patient data. Note: Hospital = NHS hospitals. Care home= Nursing homes and Residential homes Home= Patients own home or home of relative/friend.

Table 6. Place of Death by Marital status- All Cancer Patients 2005-2012

	Place of Death	Marital Status				
		Single	Married	Widowed	Divorced	
2005-2006	Hospital	544 (51.6%)	1767 (45.5%)	1073 (46.3%)	170 (51.7%)	3554
	Care home	157 (14.9%)	94 (2.4%)	326 (14.1%)	20 (6.1%)	597
	Hospice	142 (13.5%)	517 (13.3%)	255 (11.0%)	46 (14.0%)	960
	Home	212 (20.1%)	1508 (38.8%)	661 (28.6%)	93 (28.3%)	2474
	Total	**1055**	**3886**	**2315**	**329**	**7585**
2007-2008	Hospital	486 (46.8%)	1750 (43.1%)	997 (43.7%)	168 (41.9%)	3401
	Care home	147 (14.1%)	121 (3.0%)	327 (14.3%)	33 (8.2%)	628
	Hospice	161 (15.5%)	528 (13.0%)	238 (10.4%)	96 (23.9%)	1023
	Home	245 (23.6%)	1659 (40.9%)	720 (31.5%)	104 (25.9%)	2728
	Total	**1039**	**4058**	**2282**	**401**	**7780**
2009-2010	Hospital	459 (47.5%)	1765 (42.2%)	962 (41.6%)	203 (46.5%)	3389
	Care home	163 (16.9%)	118 (2.8%)	379 (16.4%)	44 (10.1%)	704
	Hospice	127 (13.1%)	519 (12.4%)	237 (10.3%)	76 (17.4%)	959
	Home	217 (22.4%)	1784 (42.6%)	732 (31.7%)	114 (26.1%)	2847
	Total	**966**	**4186**	**2310**	**437**	**7899**
2011-2012	Hospital	458 (45.7%)	1822 (42.6%)	568 (40.9%)	530 (37.3%)	3378
	Care home	163 (16.3%)	133 (3.1%)	217 (15.6%)	242 (17.0%)	755
	Hospice	125 (12.5%)	507 (11.8%)	155 (11.2%)	125 (8.8%)	912
	Home	257 (25.6%)	1819 (42.5%)	448 (32.3%)	525 (36.9%)	3049
	Total	**1003**	**4281**	**1388**	**1422**	**8094**

Note: Source= General Register Office Files Note: Cancer Deaths (ICD 10 codes C00-C097; WHO, 2010) that occurred and were registered in the same year between 2005-2012 have been included. It is important to note that a small number of deaths that occurred in 2012 and earlier years but not registered until 2013 and are therefore not included. Note: A small number of deaths n<10 that occurred in other places were not reported so as to avoid disclosure of potentially identifiable patient data. Note: Hospital = NHS hospitals. Care home= Nursing homes and Residential homes Home= Patients own home or home of relative/friend.

APPENDIX III: Supplementary Tables and Figures

(A) Study Patient's Cancer Diagnosis vs NI Cancer Deaths

Cancer Diagnosis	Patients Frequency (%) (n=467)	NI Cancer deaths 2012 Frequency (%) (n=4,047)
Digestive Organs (C15-C26)	**124 (26.5%)**	**1210 (29.9%)**
Respiratory &Intrathoracic Organs (C30-C39)	**112 (24.0%)**	**958 (23.7%)**
Breast (C50)	**35 (7.5%)**	**288 (7.1%)**
Female Genital Organs (C51-C58)	**22 (4.7%)**	**175 (4.3%)**
Male Genital Organs (C60-C63)	**35 (7.5%)**	**266 (6.5%)**
Other (C00-C14, C40-C49, C64-C97, D41.4, D47.1, D48)	**139 (29.8%)**	**1488 (35.7%)**
Oral Cavity (C00-C14)	10 (2.1%)	58 (1.4%)
Malignant Melanoma (C43)	5 (1.1%)	43 (1.1%)
Non-Malignant Melanoma (C44)	4 (0.9%)	20 (0.5%)
Kidney (C64-65, C68)	13 (2.8%)	105 (2.6%)
Bladder (C67)	12 (2.6%)	116 (2.9%)
Eye (C69)	1 (0.2%)	2 (0.0%)
Brain and Other CNS (C70-72)	13 (2.8%)	111 (2.7%)
Thyroid (C73)	3 (0.6%)	15 (0.4%)
Ill Defined Sites (C76-80)	22 (4.7%)	255 (6.3%)
Leukaemia and Lymphoma (C81-96)	31 (6.6%)	307 (7.6%)
Other Malignant (excluding ill-defined sites)	14 (3.0%)	118 (2.9%)
Other Non-Malignant Neoplasm (D41.4, D47.1, D48)	11 (2.4%)	-----

(B) Time Since Diagnosis to Death by Cancer Type for Study Patients

Cancer Diagnosis	Time Since Diagnosis to Death	
	Median Months (IQR)	Maximum Recorded Survival Months (Years)
Breast	54 (81)	296 (25 Years)
Male Genital Organs	48 (82)	177 (15 Years)
Digestive Organs	6 (16)	152 (13 Years)
Female Genital Organs	36 (43)	84 (7 Years)
Respiratory & Intrathoracic Organs	5 (13)	127 (11 Years)
Other	8 (19)	144 (12 Years)
Total	9(25)	296(5 Years)

APPENDIX III: Supplementary Tables and Figures

(C) Study Patients Aware vs. Patients Unaware of Death

Last three Months of Life Spent, Length of Illness, Place of Death	Patients Aware of Likelihood of Death Frequency (%) Yes	No	Total	p
Where patient spent most of last 3 months of life	**(n=380)**	**(n=43)**	**(n=423)**	**0.002***
Own Home	303 (92.4%)	25 (7.6%)	328 (100%)	
Home of a Relative/Friend	13 (92.9%)	1 (7.1%)	14 (100%)	
Hospice	8 (100%)	0 (0%)	8 (100%)	
Hospital	30 (76.9%)	9 (23.1%)	39 (100%)	
Care home	26 (76.5%)	8 (23.5%)	34 (100%)	
Length of time the patient was ill before death?	**(n=383)**	**(n=44)**	**(n=427)**	**≤0.001***
Less than 1 week	1 (33.3%)	2 (66.7%)	3 (100%)	
Less than 1 Month	23 (71.9%)	9 (28.1%)	32 (100%)	
Less than 6 Months	111 (91.0%)	11 (9.0%)	122 (100%)	
Less than1 Year	71 (87.7%)	10 (12.3%)	81 (100%)	
Less than 3 Years	118 (94.4%)	7 (5.6%)	125 (100%)	
More than 3 Years	57 (91.9%)	5 (8.1%)	62 (100%)	
Place of Death	**(n=383)**	**(n=44)**	**(n=427)**	**0.001***
Home	159 (95.2%)	8 (4.8%)	167 (100%)	
Hospital	144 (84.7%)	26 (15.3%)	170 (100%)	
Hospice	51 (96.2%)	2 (3.8%)	53 (100%)	
Care home	29 (78.4%)	8 (21.6%)	37 (100%)	

Note: Significant at the p=≤0.05 level (Chi-Square analysis)

APPENDIX III: Supplementary Tables and Figures

(D) Respondent Characteristics

Respondent characteristics	Frequency (n=467)	Percentage (%)
Gender		
Female	282	60.4%
Male	185	39.6%
Age Group		
20-39	42	9.0%
40-49	120	25.7%
50-59	142	30.4%
60-69	100	21.4%
70-79	46	9.9%
80-89	10	2.1%
Unknown	7	1.5%
Ethnicity		
White	462	98.9%
Unknown	5	1.1%
Relationship to Patient		
Son/Daughter	246	52.7%
Spouse/Partner	117	25.1%
Brother/Sister	39	8.4%
Parent	5	1.1%
Other relative	54	11.6%
Friend/Neighbour	5	1.1%
Other Official	1	0.2%
Religion		
Roman Catholic	173	37.0%
Presbyterian	115	24.6%
Church of Ireland	85	18.2%
Methodist	18	3.9%
Other Christian	40	8.6%
No Religion	33	7.1%
Other	1	0.2%
Unknown	2	0.4%

APPENDIX III: Supplementary Tables and Figures

(E) Factors Influencing Respondents Finding the Questionnaire Completion Upsetting

Respondent Demographics and Factors Relating to Patient's End of Life	Respondent Find Questionnaire Completion Upsetting Frequency (%) Yes (n=183)	No (n=280)	Total (n=463)	p
Gender				**≤0.001***
Female	129 (70.5%)	150 (53.6%)	183 (39.5%)	
Male	54 (29.5%)	130 (46.4%)	280 (60.5%)	
Respondents reduce/stop work	**(n=104)**	**(n=160)**	**(n=264)**	**0.001**
Yes	84 (80.8%)	98 (61.3%)	182 (68.9%)	
No	20 (19.2%)	62 (38.89%)	82 (31.1%)	
Relationship with Patient	**(n=183)**	**(n=280)**	**(n=463)**	**≤0.001***
Spouse/Partner	57 (48.7%)	60 (51.3%)	117 (25.3%)	
Son/Daughter	98 (40.5%)	144 (59.5%)	242 (52.3%)	
Brother/Sister	17 (43.6%)	22 (56.4%)	39 (8.4%)	
Parent	3 (60.0%)	2 (40.0%)	5 (1.1%)	
Other Relative	6 (11.1%)	48 (88.9%)	54 (11.7%)	
Friend/Neighbour	2 (40.0%)	3 (60.0%)	5 (1.1%)	
Other Official	0	1 (100%)	1 (0.2%)	
Patient spend time at home in the last 3 months				**0.02***
Yes	172 (94.0%)	245 (87.5%)	417 (90.1%)	
No	11 (6.0%)	35 (12.5%)	46 (9.9%)	
Where Patient Lived Before Death	**(n=178)**	**(n=276)**	**(n=454)**	**0.001***
Alone	35 (30.2%)	81 (69.8%)	116 (25.6%)	
With Respondent	51 (44.7%)	63 (55.3%)	114 (25.1%)	
With Respondent and Others	55 (52.9%)	49 (47.1%)	104 (22.9%)	
With Other People	35 (33.0%)	71 (67.0%)	106 (23.3%)	
In a Care home	2 (14.3%)	12 (85.7%)	14 (3.1%)	

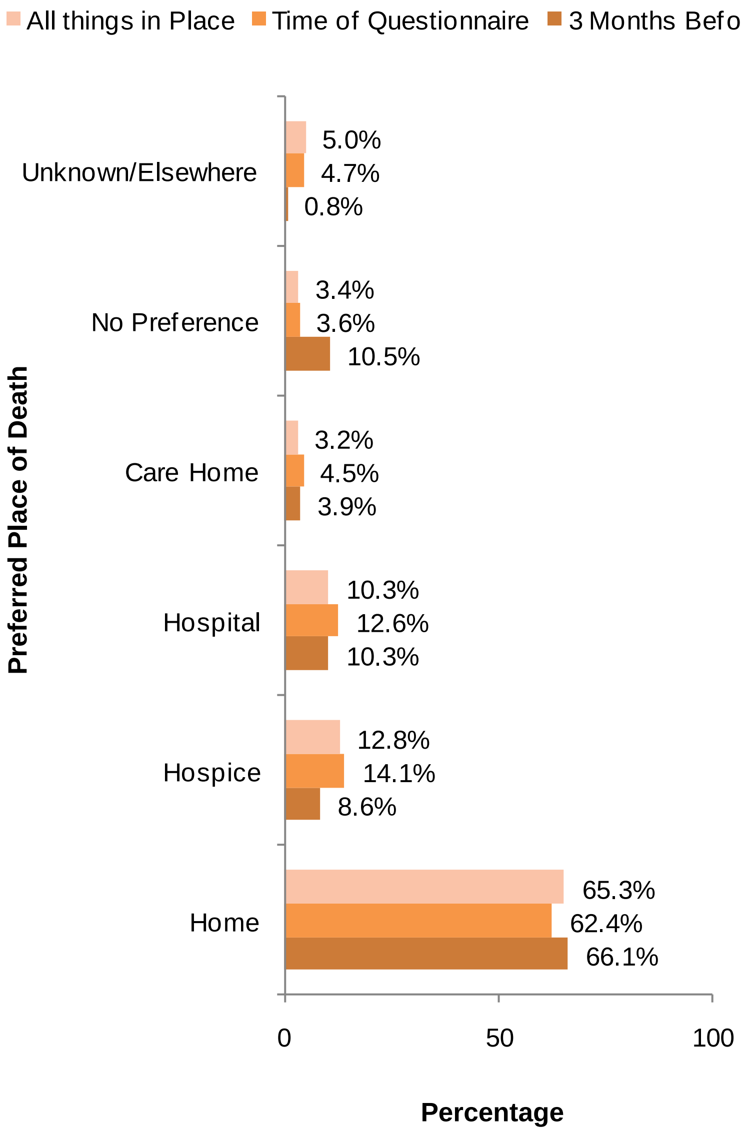
Note: Significant at the p=≤0.05 level (Chi-Square analysis)

APPENDIX III: Supplementary Tables and Figures

(F) Informal care provided by respondent/family and friends at home

Informal Care Received at Home	Frequency		Percentage %
Personal Care n=461	Yes	339	73.5
	No	122	26.5
Hours of Personal Care provided n=330	less than 5 hours/week	59	17.9
	5-9 hours/week	60	18.2
	10-19 hours/week	64	19.4
	20-49 hours/week	51	15.5
	more than 50 hours/week	96	29.1
Medical Procedures n=461	Yes	326	70.7
	No	135	29.3
Hours of assistance with medical procedures provided n=314	less than 5 hours/week	96	20.6
	5-9 hours/week	85	18.2
	10-19 hours/week	39	8.4
	20-49 hours/week	36	7.7
	more than 50 hours/week	58	12.4
Going to Appointments/treatments n=460	Yes	383	83.3
	No	77	16.7
Hours going to Appointments/treatments n=356	less than 5 hours/week	189	53.1
	5-9 hours/week	97	27.2
	10-19 hours/week	45	12.6
	20-49 hours/week	13	3.7
	more than 50 hours/week	12	3.4
Household Tasks n=461	Yes	381	82.6
	No	80	17.4
Hours going to assisting with household tasks n=364	less than 5 hours/week	53	14.6
	5-9 hours/week	69	19.0
	10-19 hours/week	82	22.5
	20-49 hours/week	82	22.5
	more than 50 hours/week	78	21.4
Time spent 'on call' n=460	Yes	421	91.5
	No	39	8.5
Hours spent ' On Call' n=419	less than 5 hours/week	31	7.4
	5-9 hours/week	28	6.7
	10-19 hours/week	38	9.1
	20-49 hours/week	44	10.5
	more than 50 hours/week	29	6.9
	all the time	249	59.4
Time spent with patient n=460	Yes	446	97.0
	No	14	3.0
Hours spent with patient n=440	less than 5 hours/week	30	6.8
	5-9 hours/week	43	9.8
	10-19 hours/week	66	15.0
	20-49 hours/week	60	13.6
	more than 50 hours/week	48	10.9
	all the time	193	43.9

Appendix III Figure 1. Respondent's Preferred Place Death Over Time and If all Things in Place



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