



Why Cancer Patients Die in Acute Hospitals

A Retrospective Study by Note Review



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2011 Report**



Why Cancer Patients Die in Acute Hospitals A Retrospective Study by Note Review

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Forewords

The Ulster Cancer Foundation is pleased to have been able to fund this research into the reasons why cancer patients die in acute hospitals. We know from our work with cancer patients, that most people want to die with dignity at home. Yet the evidence is that the majority of cancer patients die in hospital. This study looks at the reasons why cancer patients die in an acute hospital setting and explores the characteristics of these patients, as well as the factors most likely to influence and contribute to a hospital death.

We at the Ulster Cancer Foundation feel strongly that the wishes of patients are paramount and that the further development of community-based end of life services would allow the final wishes of patients to be fulfilled. Findings also indicate that a worryingly high number of patients (26%) were diagnosed with cancer on their last admission to hospital. This stresses the need for improved information on signs and symptoms of cancer, and on the importance of early diagnosis targeted at older people.

This report by the Northern Ireland Cancer Registry is based on sound data collection and analysis of patients across Northern Ireland and adds significantly to our knowledge base of the discrepancy between patients' wishes and their final experiences. It has the potential to inform and influence the implementation of the Palliative and End of Life Care Strategy for Northern Ireland (DHSSPS, 2010) and ultimately lead to improved end of life experiences for patients.



Roisin Foster
Chief Executive of Ulster Cancer Foundation, 2011

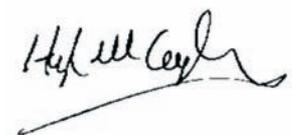
Within Northern Ireland as elsewhere in the UK, there has been a growing awareness and an increasing momentum to improve the quality of palliative and end of life care. Yet despite this, the findings of this report illustrate that a significant gap still exists between cancer patients' preferred and actual place of death.

The NICaN Supportive and Palliative Care Network have constantly placed emphasis on the need to consider the totality of the patient journey; with early identification of patients with palliative needs, good communication, and effective coordination of care, being important precursors to quality end of life care.

The findings of this study endorses this, and highlights the importance of a trained health and social care workforce who understand the importance of patient choice around preferred place of care, and can skillfully use appropriate assessment tools as well as engage in challenging conversations.

It is useful to note that the report's recommendations also add weight to the DHSSPS (2010) Palliative and End of Life Strategy, *Living Matters*, *Dying Matters* and endorse Government's priority for action with regards to improving palliative care.

In undertaking this study the NI Cancer Registry have provided useful insight into an aspect of care that has widespread implications for society, and it is to be commended for doing so. It will undoubtedly help to inform the future commissioning of services and ultimately the quality of services we offer to those affected.



Hugh McCaughey
Chair of Northern Ireland Cancer Network, 2011

Acknowledgements

I wish to acknowledge the Ulster Cancer Foundation who funded this work, the Registry staff in particular Dr. Janine Blaney who undertook the analysis and write up, Jackie Kelly and Julie McConnell who gathered the data and the late Anita Jones who was involved in the initial stages of data collection. I would also like to thank Dr. Graeme Crawford, a Macmillan GP who facilitated categorisation of data, and Dr. Denise Catney who was involved at the initiation of the project. The guidance of the Project Steering Group was invaluable for this project.

The work of the Northern Ireland Cancer Registry is funded by the Public Health Agency and supported by a Registry Steering Group and Council.



Anna Gavin
Director, NICR
2011

Layout of Report

This report has 5 sections:

Section 1:

Introduces the report and examines routine death registration data provided by the General Register Office for Northern Ireland.

Section 2:

Describes the methods undertaken during the review of hospital records to determine why cancer patients die in acute hospital settings.

Section 3:

Presents the results of the study.

Section 4:

Outlines a summary of the main findings of the study.

Section 5:

Discusses the main findings within the study, and lists recommendations.

SECTION 1 – INTRODUCTION and BACKGROUND

1.1 Introduction

It is recognised that, regardless of the site of cancer origin, many of the management concerns for cancer patients nearing end of life (EoL), as active anti-cancer treatment ends, are similar (Steinhauser et al, 2000). The Department of Health (DoH) has defined EoL care as care that “Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patients and family to be identified and met throughout the last phase of life and into bereavement. It includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support” (DoH, 2008).

In Northern Ireland, in 2005, there were 3,417 newly diagnosed cases of cancer in men and 3,537 in women (excluding non-melanoma skin cancer). In 2006, despite improving cancer survival (Donnelly and Gavin, 2007), 2,304 men and 2,082 women died of a cancer-related diagnosis. Therefore issues pertaining to EoL cancer care, such as the appropriate use of interventions, access to specialist palliative care, and dying in one’s place of choice, affect more than 4,300 patients and their wider families in Northern Ireland each year. Approximately 39% of cancer patients died in an acute hospital in 2007. Within our ageing population, projections show that institutional deaths are set to show an increase of 20% by 2030 (Gomes and Higginson, 2008). Over recent years, acute hospital settings are increasingly thought of as an inappropriate place for cancer patients to end their life. Acute hospitals have a targeted practice of diagnosis, intervention and cure and are ultimately not designed for EoL care (Al-Qurainy et al, 2009).

One feature of good EoL care is the possibility of the patient remaining at home at the time of their death, among their family, with comfort and dignity, particularly as preferences for a home death are commonly cited. Although cancer patients’ preferred place of death can change within the last days and hours of life, preferences to die at home are typically reported to be greater than 50%.

Preferences for a home death in England have ranged from 67% in Harrow (Townsend et al, 1990) to 73% in London (Karlsen and Addington-Hall, 1999). Similar preferences and percentages were reported among 62% of cancer patients in North Carolina, USA, (Hays et al, 2001), 66% in Taiwan (Tang et al, 2010) and 58% of Italian cancer patients (Beccaro et al, 2006). International estimates of the proportion of patients with cancer that actually achieve a home death are much less and range from 23% in Belgium (Schrijvers et al, 1998) and 26% in England (Higginson et al, 1998) to 55% in Australia (Hunt et al, 1991).

More recently, a large population-based study using death certificate data across 6 European countries, examined the proportion of cancer deaths occurring at home in 2002 and 2003 (Cohen et al, 2010). With the exception of Norway (12.8%), England and Wales had the lowest percentages of cancer patients dying at home (22.1% and 22.7%, respectively). Percentages of patients dying at home in the remaining European countries were slightly higher in Belgium (27.9%), but more so for Italy (35.8%) and the Netherlands (45.4%).

Latest figures for Northern Ireland (2007) show that 34.1% of cancer patients die at home, while 45.5% die in hospital, 12.5% in a hospice setting and 7.9% in nursing/residential or care homes (General Register Office). Although figures for Northern Ireland are higher than those reported in England and Wales, they are lower than

Italy and the Netherlands. Such variance indicates that home deaths among cancer patients may be influenced by cultural, social and healthcare factors that are country-specific.

A study comparing place of death in New York and London indicates that cultural and healthcare factors do play a role in place of death (Decker and Higginson, 2006). The authors report that being female lowers the odds of dying at home by 7% in London and increases the odds by 22% in New York. With regards to age and socioeconomic status, older people are less likely to die at home in London and more likely to die at home in New York, while deaths at home were less likely among lower socioeconomic groups in both cities, but more so in New York (39%) compared to London (22%). A survey of deaths registered in Belfast, Northern Ireland, over a six month period for 1977, 1987 and 1997, found that there were no associations between gender, social class and place of death (Davison et al, 2001). The authors did report however an association between both socio-demographic and disease-related variables and place of death.

Interest in the factors that influence place of death among cancer patients has increased, particularly in the context of the long term trends away from home deaths, towards institutional deaths. A systematic review conducted by Gomes and Higginson (2006) found that place of death predictors can be broadly categorised into factors relating to illness, demographic and personal variables, healthcare input, social support and historical trends. Factors such as a long length of disease, low functional status, good social conditions and support as well as preference to die at home, are all associated with home deaths. The use and intensity of homecare and living in a rural setting also influence the likelihood of dying at home. On the other hand, factors associated with hospital deaths were shown to be the availability of inpatient beds, prior hospital admissions, living in geographical areas with a greater hospital provision and being from an ethnic minority.

A further systematic review conducted by Murray and Colleagues, (2009) found similar results to those reported by Gomes and Higginson, (2006) however, the authors report inconclusive findings within the literature, particularly in relation to functional status, social class, geographical location, caregiver support, marital status and tumour type (solid/non-solid tumours).

Tumour type and place of death have been specifically explored in a more recent systematic review and meta-analysis (Howell et al, 2010) and clarified that patients with haematological cancers were more than twice as likely (Odds Ratio (OR) 2.25, 95% confidence interval (CI) 2.07-2.44) to die in hospital than other types of cancer. With regard to healthcare input, the NICE guidelines, (2004) state that improvements in the provision of community care, including the organisation of services, symptom control as well as psychological, social and spiritual support may lead to fewer crises, fewer hospital admissions, more rapid discharges and thus, more patients being enabled to die in their place of choice.

A case note review of all inpatient deaths (June 2006-May 2007) within a district general hospital in the South West of England identified that 33% of patients could have been cared for at home if excellent EoL care services were in place (Abel and Rich, 2009). Such findings are in support of the aforementioned recommendations (NICE, 2004) and highlight existing issues surrounding unnecessary hospital admissions, as well as a lack of provision of community EoL care services. Although the existing literature reports conflicting and inconclusive findings in relation to factors associated with place of death, it seems that the characteristics of healthcare systems, rather than patient preferences and needs may often drive decisions about EoL care (Murray et al, 2009) and are most likely the factors carrying the greatest influential weight.

Recognising these important EoL care issues, as well as the implications of an ageing UK population, with higher percentages developing chronic illnesses and decreasing home deaths (Gomes and Higginson, 2008), the DoH in England developed The End of Life Care Strategy (DoH, 2008). Within this strategy, recommendations were made to enable the delivery of high quality EoL care; including advanced care planning, improved discharge arrangements and co-ordination of care across all settings to enable patients who wish to die at home, achieve this. This strategy also recommends the implementation of the Liverpool Care Pathway (LCP) for the Dying Patient across all settings, particularly within acute hospitals. The LCP is an EoL care tool that provides guidance for clinicians and healthcare professionals caring for patients in the last days and hours of life, specifically in relation to patients' comfort, anticipatory prescribing, discontinuation of inappropriate interventions, psychological and spiritual care, as well as the needs of patients' families both before and after death. Round 2 of the National Care of the Dying Audit (Marie Curie Palliative Care Institute, 2009) included data from thirteen hospitals across five Health and Social Care Trusts in Northern Ireland. Findings specific to Northern Ireland showed that an average of 20% of all patients that died in one of the thirteen hospitals (1st October 2008 to 31st December 2008) were cared for using the LCP. The audit demonstrated that where the LCP for the dying patient was in place, patients were receiving a high quality of clinical care in their last hours and days of life. Recommendations within the audit included ensuring that the LCP was in place for all patients for whom it was appropriate and that all organisations should have a LCP facilitator.

A study to evaluate EoL care practices and the benefits of the LCP from the perspectives of both clinicians and the bereaved carers of patients who died in hospital, nursing home and home care settings was undertaken in the Netherlands. The study was comprised of two consecutive periods: a baseline period whereby usual practices were accessed and an intervention period during which the LCP was implemented within all settings. Findings showed that hospitalised patients are more intensively treated and patients and their carers are less involved in the medical decision making process than patients who died elsewhere. The authors also found that implementation of the LCP reduced the use of potentially life-shortening medication from 46% to 28% (van der Heide et al, 2010).

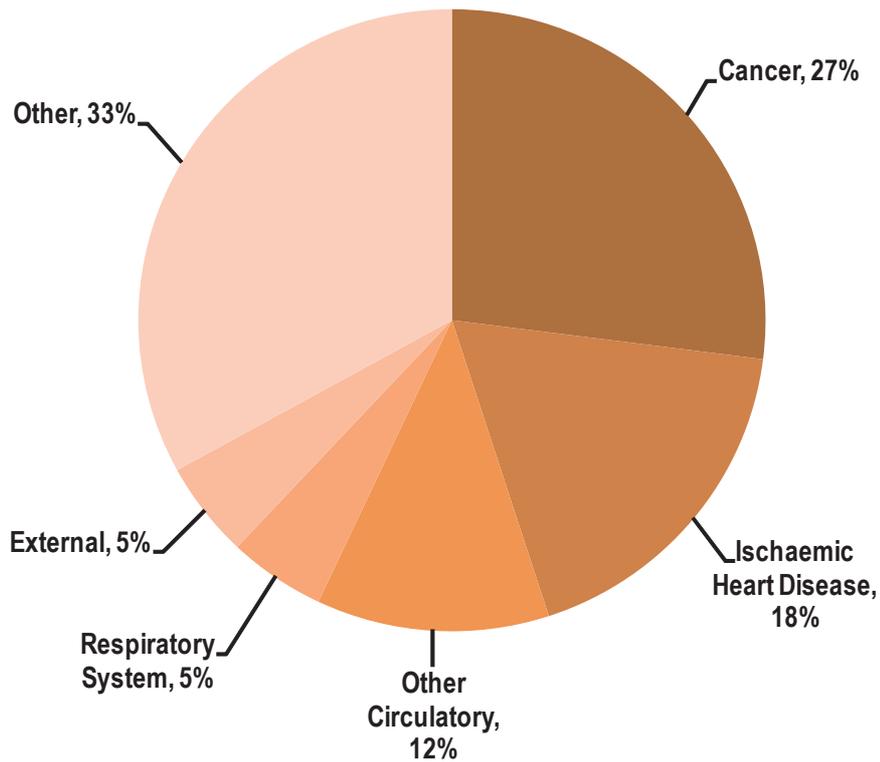
Within Northern Ireland, the Department of Health, Social Services and Public Safety (DHSSPS) published the Palliative and End of Life Care Strategy for Adults in Northern Ireland in March 2010 (DHSSPS, 2010). This strategy sets out a vision and action plan to be implemented over the next five years. Similar to the End of Life Care Strategy in England (DoH, 2008), it aims to ensure high quality palliative and EoL care within health and social care services, while offering patients informed choice as to how their care is delivered and within the setting of their preference. To achieve this, key recommendations have been made and include, the implementation of palliative and EoL care tools (e.g. LCP), developing the skills and knowledge of clinicians and healthcare professionals caring for palliative care patients and those nearing EoL, identifying the needs of patients and their families, providing choice, improving communication, as well as the continuity of patient support and care across all settings.

Although the data from the current report precedes that of the Palliative and End of Life Care Strategy for Northern Ireland (DHSSPS, 2010) and thus cannot appraise the implementation of the Strategy's recommendations, the findings will provide an insight into the factors associated with cancer patients being admitted to acute hospitals and subsequently dying there, as well as the characteristics of these patients. It is hoped that findings within this report will compliment the recommendations of the Palliative and End of Life Care strategy for Northern Ireland (DHSSPS, 2010) and aid its implementation. Additionally, this study will elicit information that will help clinicians, healthcare professionals and policy makers improve palliative and EoL care

services across Northern Ireland and act as a benchmark for future studies which will be able to evaluate and report on the progress and success of the Strategy's five year action plan.

1.2 Background Cancer Mortality Statistics

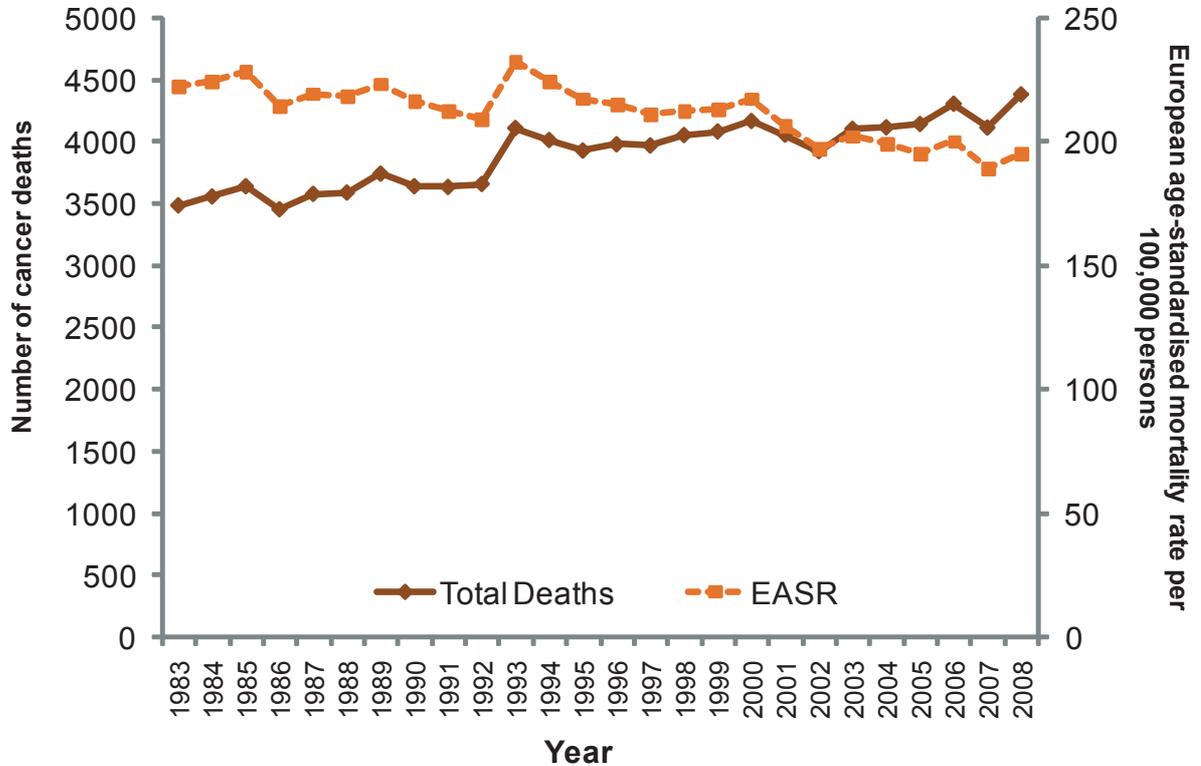
Figure 1.1: Cause of Death in Northern Ireland 2004-2008 (n=72,666; average n=18,167 per year)



Source: Northern Ireland Statistics and Research Agency 2009. Registrar General Northern Ireland Annual Report 2008. TSO, Belfast

- Cancer is the leading cause of death in Northern Ireland and accounted for 27% of all deaths between 2004 and 2008. (Figure 1.1)

Figure 1.2: Total Cancer Deaths in Northern Ireland 1983-2008 and European Age Standardised Rate (EASR) of Cancer Deaths per 100,000 Persons

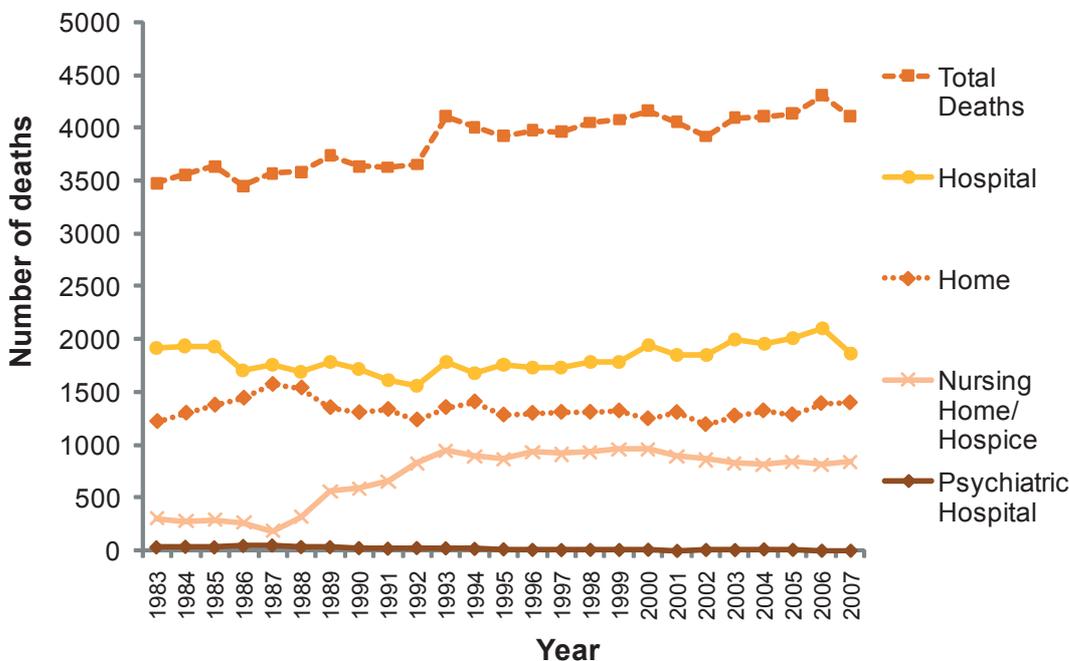


Note: EASR=European Age Standardised Rate

- Total cancer deaths increased from 3482 in 1983 to 4375 in 2008. However, taking into account our ageing population, cancer death rates are decreasing (EASR cancer deaths 1983=222/100,000; 2008=195/100,000). (Figure 1.2)

1.3 Cancer Patients' Place of Death: Routine Death Registration Data

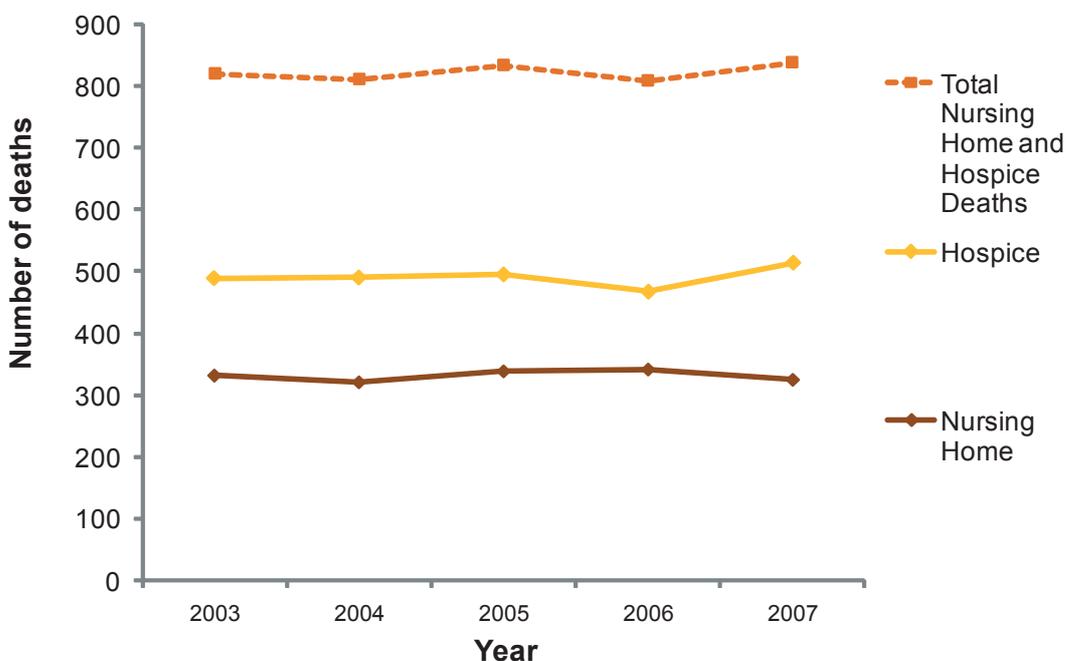
Figure 1.3 (a): All Cancer Patients Place of Death in Northern Ireland 1983-2007



Note: Source= General Register Office Files

Note: Hospital=NHS Hospitals. Nursing Home/Hospice =Nursing, residential and care homes, hospices and other hospitals.
Home=Patients home and all other places.

Figure 1.3 (b): Nursing Home and Hospice Cancer Deaths 2003-2007



Note: Source= General Register Office Files

Note: Hospital=NHS Hospitals. Nursing Home/Hospice =Nursing, residential and care homes, hospices and other hospitals.
Home=Patients home and all other places.

Table 1.1 Place of Death for Cancer Patients in Northern Ireland 1983-2007

Year	Psychiatric Hospital	Hospital	Nursing Home/Hospice	Home	Total
N (%)					
1983	33 (0.9)	1925 (55.3)	303 (8.7)	1221 (35.1)	3482
1984	38 (1.1)	1940 (54.6)	274 (7.7)	1301 (36.6)	3553
1985	33 (0.9)	1939 (53.3)	287 (7.9)	1377 (37.9)	3636
1986	46 (1.3)	1703 (49.4)	257 (7.4)	1444 (41.9)	3450
1987	50 (1.4)	1766 (49.4)	183 (5.1)	1575 (44.1)	3574
1988	36 (1.0)	1695 (47.3)	313 (8.7)	1541 (43.0)	3585
1989	35 (0.9)	1789 (47.9)	559 (15.0)	1354 (36.2)	3737
1990	26 (0.7)	1719 (47.3)	585 (16.1)	1306 (35.9)	3636
1991	21 (0.6)	1623 (44.7)	650 (17.9)	1336 (36.8)	3630
1992	27 (0.7)	1564 (42.8)	827 (22.6)	1236 (33.8)	3654
Total	345 (1.0)	17,663 (49.1)	4238 (11.8)	13,691 (38.1)	35,937
1993	24 (0.6)	1782 (43.3)	943 (23.0)	1355 (33.0)	4104
1994	19 (0.5)	1685 (42.0)	896 (22.4)	1408 (35.1)	4008
1995	15 (0.4)	1759 (44.8)	866 (22.1)	1283 (32.7)	3923
1996	10 (0.3)	1732 (43.6)	931 (23.4)	1300 (32.7)	3973
1997	8 (0.2)	1734 (43.7)	913 (23.0)	1309 (33.0)	3964
1998	10 (0.2)	1787 (44.3)	931 (23.1)	1310 (32.4)	4048
1999	9 (0.2)	1789 (43.9)	957 (23.5)	1322 (32.4)	4077
2000	11 (0.3)	1947 (46.8)	955 (23.0)	1248 (30.0)	4161
2001	0	1852 (45.7)	892 (22.0)	1307 (32.3)	4051
2002	9 (0.2)	1859 (47.4)	859 (21.9)	1192 (30.4)	3919
Total	115 (0.3)	17,926 (44.6)	9143 (22.7)	13,034 (32.4)	40,218
2003	8 (0.2)	1994 (48.7)	820 (20.0)	1275 (31.1)	4097
2004	14 (0.3)	1963 (47.8)	810 (19.7)	1323 (32.2)	4110
2005	10 (0.2)	2009 (48.6)	833 (20.1)	1285 (31.1)	4137
2006	2 (<0.05)	2105 (48.9)	808 (18.8)	1392 (32.3)	4307
2007	2 (<0.05)	1869 (45.5)	838 (20.4)	1399 (34.1)	4108
Total	36 (0.2)	9940 (47.9)	4109 (19.8)	6674 (32.1)	20,759

Note: Hospital=NHS Hospitals. Nursing Home/Hospice =Nursing, residential and care homes, hospices and other hospitals. Home=Patients home and all other places.

- Figure 1.3 (a) outlines cancer patients' place of death in Northern Ireland from 1983 to 2007, while Table 1.1 details these numbers and percentages. In the years 1983-2002, it has not been possible to separate nursing home/hospice deaths due to coding of the records. This was possible however, from 2003 onwards and is graphically presented in Figure 1.3 (b).
- Only a very small proportion of cancer patients died in a psychiatric hospital across all time periods and percentages have declined significantly ($p < 0.01$) over time (See Table 1.1). There was a significant decline in the proportions of patients dying in a hospital from 49.1% in 1983-1992 to 44.6% in 1993-2002 ($p < 0.001$). This then increased to 47.9% in 2003-2007 ($p < 0.001$). Consistently since 1983, the majority of cancer patients in Northern Ireland die in hospital.
- Overall, the average proportion of patients dying at home has decreased from 38.1% in 1983-1992 to 32.4% in 1993-2002 ($p < 0.001$). For the period of 2003-2007, proportions have remained unchanged (32.1%).

- The proportions of patients dying in nursing homes/hospices increased from 11.8%, in 1983-1992 to 22.7% in 1993-2002 ($p < 0.001$). This decreased again to 19.8% in 2003-2007 ($p < 0.001$).

Table 1.2: Place of Death by Local Government District of Residence – All Cancer Patients 2003-2007

Local Government District	Place of Death N (% of total deaths)				Total
	Psychiatric Hospital	Hospital	Nursing Home/Hospice	Home	
Ards	0	434 (48.1)	215 (23.8)	254 (28.1)	903
Belfast	6 (0.1)	2038 (49.8)	875 (21.4)	1176 (28.7)	4095
Castlereagh	3 (0.3)	399 (45.8)	245 (28.1)	225 (25.8)	872
Down	0	310 (41.7)	141 (19.0)	292 (39.3)	743
Lisburn	0	541 (46.8)	236 (20.4)	380 (32.8)	1157
North Down	0	516 (47.7)	282 (26.1)	283 (26.2)	1081
Eastern HSSB	9 (0.1)	4238 (47.9)	1994 (22.5)	2610 (29.5)	8851
Antrim	5 (1.0)	287 (55.8)	58 (11.3)	164 (31.9)	514
Ballymena	1 (0.1)	407 (58.6)	74 (10.6)	213 (30.6)	695
Ballymoney	0	202 (62.9)	21 (6.5)	98 (30.5)	321
Carrickfergus	0	251 (48.2)	112 (21.5)	158 (30.3)	521
Coleraine	0	423 (57.5)	63 (8.6)	250 (34.0)	736
Cookstown	0	149 (44.1)	37 (10.9)	152 (45.0)	338
Larne	0	270 (62.2)	47 (10.8)	117 (27.0)	434
Magherafelt	0	190 (47.1)	24 (6.0)	189 (46.9)	403
Moyle	0	112 (57.4)	12 (6.2)	71 (36.4)	195
Newtownabbey	0	511 (51.6)	241 (24.3)	238 (24.0)	990
Northern HSSB	6 (0.1)	2291 (55.1)	448 (10.8)	1412 (34.0)	4157
Armagh	4 (0.7)	259 (43.0)	118 (19.6)	221 (36.7)	602
Banbridge	0	184 (45.8)	109 (27.1)	109 (27.1)	402
Craigavon	0	470 (51.3)	148 (16.2)	298 (32.5)	916
Dungannon	0	227 (42.2)	92 (17.1)	219 (40.7)	538
Newry & Mourne	0	333 (32.3)	348 (33.8)	349 (33.9)	1030
Southern HSSB	4 (0.1)	1984 (44.3)	1056 (23.6)	1434 (32.0)	4478
Derry	7 (0.6)	478 (43.3)	239 (21.6)	381 (34.5)	1105
Fermanagh	0	334 (46.5)	109 (15.2)	276 (38.4)	719
Limavady	2 (0.7)	127 (42.8)	43 (14.5)	125 (42.1)	297
Omagh	4 (0.9)	219 (47.3)	52 (11.2)	188 (40.6)	463
Strabane	3 (0.7)	155 (36.3)	90 (21.1)	179 (41.9)	427
Western HSSB	16 (0.5)	1313 (43.6)	533 (17.7)	1149 (38.2)	3011
Unknown	1 (0.4)	114 (43.5)	78 (29.8)	69 (26.3)	262
Total	36 (0.2)	9940 (47.9)	4109 (19.8)	6674 (32.1)	20,759

Note: Local Government District was determined by the postcode of patients' usual address.

Note: Hospital=NHS Hospitals. Nursing Home/Hospice =Nursing, residential and care homes, hospices and other hospitals.

Home=Patients home and all other places.

- The Local Government (LG) district of Ballymoney had the highest percentage of patients dying in hospital (62.9%), followed by Larne (62.2%), Ballymena (58.6%) and Coleraine (57.5%). LG districts with the lowest percentages of hospital deaths were Newry and Mourne (32.3%), Strabane (36.3%) and Down (41.7%). See Table 1.2.
- Magherafelt had the highest percentage of patients dying at home (46.9%), followed by Cookstown (45.0%), Limavady (42.1%), Strabane (41.9%) and Dungannon (40.7%). The lowest percentage of home deaths were within Newtownabbey (24.0%), Castlereagh (25.8%), North Down (26.2%), Larne (27.0%) and Banbridge (27.1%) LG districts.
- Newry and Mourne (33.8%), Castlereagh (28.1%) and Banbridge (27.1%) LG districts had the highest percentages of patients dying in a nursing home/hospice, whereas Magherafelt (6.0%), Moyle (6.2%) and Ballymoney (6.5%) had the lowest percentages.
- Significant ($p < 0.001$) differences existed in place of death by Health and Social Services Board (HSSB). The Northern HSSB had the highest percentage of patients dying in a hospital setting (55.1%), while the Western HSSB had the highest percentage of patients dying at home (38.2%). The Southern HSSB had the highest percentage of patients dying in a nursing home/hospice (23.6%).

Table 1.3: Place of Death by Gender - All Cancer Patients 1983-2007

Years	1983-1992			1993-2002			2003-2007		
Gender	Male	Female	Total	Male	Female	Total	Male	Female	Total
Place of Death	N (%)								
Psychiatric Hospital	188 (1.0)	157 (0.9)	345 (1.0)	58 (0.3)	57 (0.3)	115 (0.3)	14 (0.1)	22 (0.2)	36 (0.2)
Hospital	9366 (50.3)	8297 (47.9)	17,663 (49.1)	9584 (46.1)	8342 (42.9)	17,926 (44.6)	5353 (49.4)	4587 (46.2)	9940 (47.9)
Nursing Home/Hospice	1957 (10.5)	2281 (13.2)	4238 (11.8)	4257 (20.5)	4886 (25.1)	9143 (22.7)	1904 (17.6)	2205 (22.2)	4109 (19.8)
Home	7100 (38.1)	6591 (38.0)	13,691 (38.1)	6889 (33.1)	6145 (31.6)	13,034 (32.4)	3555 (32.8)	3119 (31.4)	6674 (32.1)
Total	18,611	17,326	35,937	20,788	19,430	40,218	10,826	9933	20,759

Note: Hospital=NHS Hospitals. Nursing Home/Hospice =Nursing, residential and care homes, hospices and other hospitals. Home=Patients home and all other places.

Statistics: *Binary logistic regression analysis using 2003-2007 data and controlling for age.

- There were no significant differences between the low number of males and females that died in a psychiatric hospital across all timeframes ($p > 0.05$).
- Males were 14% more likely than females to die in hospital (OR 1.14, 95% CI 1.08-1.20; $p < 0.001$) or 6% more likely to die at home (OR 1.06, 95% CI 1.01-1.13; $p = 0.04$). They were 26% less likely to die in nursing homes (OR 1.26, 95% CI 1.18-1.34; $p < 0.001$)*. This reflects the higher make up of females as nursing home residents.

Table 1.4: Place of Death by Cancer Diagnosis - All Cancer Patients 1983-2007

Years	Place of Death	Cancer Type N (%)						Total
		Digestive Organs	Respiratory & Intrathoracic Organs	Breast	Female Genital Organs	Male Genital Organs	Other	
1983-1992	Psychiatric Hospital	119 (1.0)	63 (0.8)	35 (1.0)	18 (1.0)	29 (1.5)	81 (0.9)	345 (1.0)
	Hospital	5169 (44.9)	3605 (46.2)	1429 (42.6)	947 (52.4)	943 (47.8)	5570 (58.6)	17,663 (49.1)
	Nursing Home/Hospice	1307 (11.4)	900 (11.5)	557 (16.6)	211 (11.7)	277 (14.0)	986 (10.4)	4238 (11.8)
	Home	4907 (42.7)	3228 (41.4)	1334 (39.8)	631 (34.9)	725 (36.7)	2866 (30.2)	13,691 (38.1)
	Total	11,502	7796	3355	1807	1974	9503	35,937
1993-2002	Psychiatric Hospital	32 (0.3)	13 (0.2)	13 (0.4)	5 (0.2)	16 (0.6)	36 (0.3)	115 (0.3)
	Hospital	4738 (39.5)	3592 (44.0)	1310 (37.4)	885 (44.1)	1172 (42.7)	6229 (52.8)	17,926 (44.6)
	Nursing Home/Hospice	2767 (23.1)	1626 (19.9)	1061 (30.3)	522 (26.0)	744 (27.1)	2423 (20.5)	9143 (22.7)
	Home	4466 (37.2)	2926 (35.9)	1119 (31.9)	597 (29.7)	811 (29.6)	3115 (26.4)	13,034 (32.4)
	Total	12,003	8157	3503	2009	2743	11,803	40,218
2003-2007	Psychiatric Hospital	9 (0.1)	5 (0.1)	3 (0.2)	1 (0.1)	2 (0.1)	16 (0.3)	36 (0.2)
	Hospital	2764 (45.1)	2241 (49.3)	793 (45.2)	516 (46.9)	670 (46.9)	2956 (51.1)	9940 (47.9)
	Nursing Home/Hospice	1200 (19.6)	823 (18.1)	412 (23.5)	270 (24.5)	295 (20.6)	1109 (19.2)	4108 (19.8)
	Home	2162 (35.2)	1481 (32.5)	547 (31.2)	314 (28.5)	462 (32.3)	1708 (29.5)	6674 (32.1)
	Total	6135	4550	1755	1101	1429	5789	20,759

Note: Hospital=NHS Hospitals. Nursing Home/Hospice =Nursing, residential and care homes, hospices and other hospitals. Home=Patients home and all other places.

- With the exception of 2003-2007, patients with breast cancer had the highest percentages of deaths in a nursing home/hospice compared to any other cancer diagnoses (Table 1.4).
- Patients with cancers of the digestive organs had the highest percentages for a home death than any other cancer type. This was consistent across all timeframes.

Table 1.5: Place of Death by Age - All Cancer Patients 1983-2007

Years	1983-1992	1993-2002	2003-2007
Place of Death	Age Median (IQR) and Range		
Psychiatric Hospital	78 (14) 23-98	81 (14) 36-99	76 (23) 42-96
Hospital	71 (17) 0-105	73 (16) 0-103	74 (16) 0-102
Nursing Home/Hospice	74 (15) 20-102	76 (16) 9-107	75 (18) 6-102
Home	69 (16) 0-103	71 (16) 0-100	73 (16) 0-103
Total Sample	71 (17)	73 (16)	74 (16)

Note: Hospital=NHS Hospitals. Nursing Home/Hospice =Nursing, residential and care homes, hospices and other hospitals.

Home=Patients home and all other places.

Note: IQR=Interquartile range

- At the time of death, the average age of patients increased from 71 years in 1983-1992 to 73 years in 1993-2002 and 74 years in 2003-2007 ($p < 0.001$). These findings are consistent with previous reports of an ageing cancer population and increased survival within Northern Ireland (Donnelly and Gavin, 2007).
- Compared to patients who died in hospital, those who died at home were significantly younger ($p < 0.001$), whereas those that died in a nursing home/hospice were significantly older ($p < 0.001$) and again reflective of the clientele. In both instances, these differences were observed across all timeframes.
- Patients who died in a psychiatric hospital were significantly older than patients who died in hospital (all $p < 0.001$). This was observed across all timeframes except 2003-2007 (Table 1.5).

Table 1.6: Place of Death by Socioeconomic Status - All Cancer Patients 1983-2007

Year	Place of Death	Socioeconomic Status N (%)						Total
		Quintile 1 Most Deprived	Quintile 2	Quintile 3	Quintile 4	Quintile 5 Least Deprived	Unknown	
1983-1992	Psychiatric Hospital	97 (1.1)	65 (0.9)	50 (0.8)	71 (1.4)	23 (0.5)	39 (0.9)	345 (1.0)
	Hospital	4018 (47.2)	3417 (49.0)	3203 (49.7)	2528 (49.2)	2054 (47.4)	2443 (53.9)	17,663 (49.1)
	Nursing Home/Hospice	927 (10.9)	739 (10.6)	644 (10.0)	700 (13.6)	827 (19.1)	401 (8.8)	4238 (11.8)
	Home	3469 (40.8)	2752 (39.5)	2548 (39.5)	1844 (35.9)	1427 (32.9)	1651 (35.4)	13,691 (38.1)
	Total	8511	6973	6445	5143	4331	4534	35,937
1993-2002	Psychiatric Hospital	36 (0.4)	23 (0.3)	25 (0.3)	19 (0.3)	10 (0.2)	2 (0.4)	115 (0.3)
	Hospital	4327 (44.0)	3945 (45.2)	3827 (46.0)	3067 (44.6)	2575 (42.9)	185 (40.7)	17,926 (44.6)
	Nursing Home/Hospice	2127 (21.6)	1824 (20.9)	1635 (19.7)	1761 (25.6)	1693 (28.2)	103 (22.7)	9143 (22.7)
	Home	3344 (34.0)	2944 (33.7)	2825 (34.0)	2037 (29.6)	1720 (28.7)	164 (36.1)	13,034 (32.4)
	Total	9834	8736	8312	6884	5998	454	40,218
2003-2007	Psychiatric Hospital	15 (0.3)	8 (0.2)	4 (0.1)	5 (0.1)	3 (0.1)	1 (0.4)	36 (0.2)
	Hospital	2272 (47.7)	2143 (47.7)	2040 (47.5)	1856 (49.7)	1515 (47.2)	114 (43.5)	9940 (47.9)
	Nursing Home/Hospice	880 (18.5)	825 (18.4)	741 (17.3)	794 (21.3)	791 (24.6)	78 (29.8)	4109 (19.8)
	Home	1597 (33.5)	1517 (33.8)	1509 (35.1)	1080 (28.9)	902 (28.1)	69 (26.3)	6674 (32.1)
	Total	4764	4493	4294	3735	3211	262	20,759

Note: Hospital=NHS Hospitals. Nursing Home/Hospice =Nursing, residential and care homes, hospices and other hospitals. Home=Patients home and all other places.

Note: Socioeconomic status is determined by postcode data.

Statistics:* Binary logistic regression analysis using 2003-2007 data and controlling for age.

- Across all timeframes, there were no significant differences in the percentage of patients dying in a psychiatric hospital or a hospital setting by socioeconomic status (Quintiles 1&2 compared with Quintiles 4&5; $p > 0.05$)
- Patients with higher socioeconomic status (Quintiles 4&5) were 30% more likely to die in a nursing home/hospice than those from more deprived backgrounds (Quintiles 1&2; OR 1.30, 95% CI 1.20-1.40; $p < 0.001$)*.
- Patients with a higher socioeconomic status (Quintiles 4&5) were 26% less likely to die at home compared with those with a lower socioeconomic status (Quintiles 1&2; OR 1.26, 95% CI 1.18-1.35; $p < 0.001$)*.

Table 1.7: Place of Death by Marital Status - All Cancer Patients 1983-2007

Year	Place of Death	Marital Status N (%)				
		Single	Married	Divorced	Widowed	Total
1983-1992	Psychiatric Hospital	171 (2.8)	75 (0.4)	6 (1.2)	93 (0.9)	345 (1.0)
	Hospital	3381 (55.4)	8723 (47.3)	231 (46.3)	5328 (48.8)	17,663 (49.1)
	Nursing Home/Hospice	858 (14.1)	1661 (9.0)	95 (19.0)	1624 (14.9)	4238 (11.8)
	Home	1695 (27.8)	7964 (43.2)	167 (33.5)	3865 (35.4)	13,691 (38.1)
	Total	6105	18,423	499	10,910	35,937
1993-2002	Psychiatric Hospital	55 (0.9)	14 (0.1)	2 (0.2)	44 (0.3)	115 (0.3)
	Hospital	2912 (47.7)	8889 (44.1)	537 (47.3)	5588 (43.5)	17,926 (44.6)
	Nursing Home/Hospice	1804 (29.5)	3511 (17.4)	272 (23.9)	3556 (27.7)	9143 (22.7)
	Home	1335 (21.9)	7722 (38.3)	325 (28.6)	3652 (28.4)	13,034 (32.4)
	Total	6106	20,136	1136	12,840	40,218
2003-2007	Psychiatric Hospital	15 (0.5)	8 (0.1)	2 (0.2)	11 (0.2)	36 (0.2)
	Hospital	1434 (49.9)	4973 (47.2)	435 (49.8)	3098 (47.8)	9940 (59.7)
	Nursing Home/Hospice	694 (24.1)	1788 (17.0)	195 (22.4)	1432 (22.1)	4109 (19.8)
	Home	732 (25.5)	3767 (35.7)	241 (27.6)	1934 (29.9)	6674 (32.1)
	Total	2875	10,536	873	6475	20,759

Note: Hospital=NHS Hospitals. Nursing Home/Hospice =Nursing, residential and care homes, hospices and other hospitals. Home=Patients home and all other places.

Statistics: *Binary logistic regression analysis using 2003-2007 data and controlling for age.

- Significant differences in place of death by marital status (Table 1.7) across all timeframes existed ($p < 0.001$). Patients who were single had the highest percentage of deaths in a psychiatric hospital, although this was low from 2.8% in 1983-1992 to 0.5% in 2003-2007. With the exception of the years 1983-1992, patients who were single or widowed had the highest percentage for nursing home/hospice deaths, while patients who were single or divorced had the highest percentage for hospital deaths. Married patients had the highest percentage of home deaths.
- Patients who were partnered were 40% more likely to die at home than those who were not partnered (OR 1.40, 95% CI 1.32-1.48; $p < 0.001$)*.
- In 1983-1992, patients who were partnered were 16% less likely to die in hospital than patients who were not partnered, even when controlling for age. (OR 1.16, 95% CI 1.11-1.21; $p < 0.001$). In the remaining years, marital status did not significantly alter the odds ratio of dying in hospital ($p > 0.05$)*.
- Patients who were partnered were 36% less likely to die in a nursing home/hospice than those that were not partnered, even when controlling for age (OR 1.36, 95% CI 1.27-1.46; $p < 0.001$)*.

SECTION 2 - STUDY METHODS

Why Cancer Patients Die in Acute Hospitals: A Retrospective Study by Note Review

2.1 Study Aim

The aim of this study was to describe the characteristics of patients with cancer that die in an acute hospital setting and ascertain the most likely factors that influence and contribute to a hospital death.

2.2 Data Collection

A project steering group (Appendix I) was established and involved in the protocol development and production of this report. Ethical approval for this study was granted by the Office for Research Ethics Committee Northern Ireland (ORECNI) in February 2009 (Reference number 09/NIR02/8). Following ethical approval, and a pilot study, data collection was undertaken by the Northern Ireland Cancer Registry (NICR) Tumour Verification Officers (TVOs) on all adult patients with cancer in Northern Ireland who had died in an acute hospital within the last six months (July-December) of 2007. The year 2007 was chosen as this was the most recent data available at that time. Information was extracted by reviewing the clinical notes of these patients, with data entered onto a secure digital Proforma. In addition to routine medical and demographic information, detailed data were collected on patients' last hospital admission, co-morbidities, socio-demographic information, treatment interventions and investigations on the last admission, recording of preferred place of death (PPD), implementation of the Liverpool Care Pathway (LCP) for the dying patient, level of specialist palliative care¹ involvement, multidisciplinary team (MDT) meetings, death predictability and implementation of 'Do Not Attempt Resuscitation' (DNAR) Orders. The number of previous hospital admissions within the last year of life was also collected for each patient.

Although this study had originally planned to also collect data on patients who died at home, in a hospice or nursing home, a pilot study revealed that the detailed information was only available within a small percentage of G.P. notes. Thus this method of planned data collection was not possible. The socioeconomic status of patients in this study was derived from postcode data.

2.3 Inclusion and Exclusion Criteria

Cancer patients (ICD-10 codes C00-C97) who were over the age of 18 years and had died within an acute hospital setting in the last 6 months of 2007 were included in the study. Patients were excluded if clinical notes were unobtainable or lacked sufficient information. A total of 9 non-acute hospitals were excluded from the study (those providing respite or palliative care) and included; Braid Valley, Banbridge, Bangor, Dalriada, Lurgan, Moyle, Mullinure, Robinson Memorial and South Tyrone Hospitals.

¹ For the purpose of this study specialist palliative and end of life care is defined as the management of unresolved symptoms and more demanding care needs including complex psychosocial, end of life and bereavement issues. This is provided by specialist personnel with expert knowledge, skills and competences (NICE, 2004). It is delivered by specialist multidisciplinary teams dedicated to palliative and end of life care (DHSSPS, 2010).

2.4 Data Analysis

Following data cleaning and validation, analysis was conducted using the Statistical Packages for the Social Sciences (SPSS) for windows, version 15. Descriptive analysis was mainly carried out on Proforma data. Since data had a non-normal distribution and did not normalise using appropriate transformations, averages are presented as medians (Interquartile range; IQR) and non-parametric tests were used to test for statistical significance. Chi-Square analysis was used for categorical data while Kruskal-Wallis and Mann-Whitney U Tests were used for continuous data. Binary logistic regression analysis was used where appropriate to test for predictors of an outcome.

SECTION 3 – RESULTS

A total of 793 adult cancer patients died in an acute hospital setting within the study timeframe. Of those patients, 97 (12.2%) patients were excluded due to lack of information within medical notes or notes being unavailable/not found. At the data extraction period, 1 (0.2%) patient was accidentally overlooked. As a result, 695 (87.6%) patients were included in the study.

3.1 Patient Characteristics

Table 3.1: Patient Characteristics - Included and Excluded

Patient Characteristics	Patients Included	Patients Excluded	p
	N (%)		
Gender			
Male	371 (53.4)	65 (67.0)	0.01*
Female	324 (46.6)	32 (33.0)	
Age			
≤45	27 (3.9)	6 (6.3)	0.14
46-60	89 (12.8)	18 (18.6)	
61-70	159 (22.9)	22 (22.7)	
71-80	237 (34.1)	22 (22.7)	
≥81	183 (26.3)	29 (30.6)	
Marital Status			
Partnered	380 (54.7)	57 (58.8)	0.40
Not Partnered	313 (45.0)	39 (40.2)	
Unknown	2 (0.3)	1 (1.0)	
Religious Background			
Roman Catholic	223 (32.1)	38 (39.2)	0.04*
Presbyterian	175 (25.2)	16 (16.5)	
Methodist	27 (3.9)	2 (2.1)	
Other Christian	189 (27.2)	15 (15.5)	
No Religion/Unknown	81 (11.7)	26 (26.8)	
Socioeconomic Status			
Quintile 1 (Most Deprived)	165 (23.7)	29 (29.9)	0.09
Quintile 2	158 (22.7)	16 (16.5)	
Quintile 3	125 (18.0)	20 (20.6)	
Quintile 4	122 (17.6)	21 (21.6)	
Quintile 5 (Least Deprived)	124 (17.8)	10 (10.3)	
Unknown	1 (0.1)	1 (0.1)	
Cancer Type (ICD-10 Codes)			
Digestive Organs (C15-C26)	182 (26.2)	28 (28.9)	0.21
Respiratory & Intrathoracic Organs (C30-C39)	170 (24.5)	19 (19.6)	
Breast (C50)	58 (8.3)	6 (6.2)	
Female Genital Organs (C51-C58)	35 (5.0)	1 (1.0)	
Male Genital Organs (C60-C63)	38 (5.5)	9 (9.3)	
Other (C00-C14, C40-C49, C64-C97)	212 (30.5)	34 (35.1)	
Total	695	97	

Note: *Significant at the $p \leq 0.05$ Level (Chi-Square analysis).

Note: p values relate to comparisons of the included and excluded sample.

Note: Socioeconomic status (deprivation quintile) has been determined by postcode data.

- There were significantly more males in the sample excluded (67.0%) from the study than those included (53.4%; $p=0.01$), see Table 3.1.
- There were significantly more categorised as other Christian that were in the included (27.2%) sample compared to those excluded (15.5%; $p=0.01$).
- There were no significant differences in those included and excluded patients for age, marital status, socioeconomic status or cancer type.
- The median age of patients was 74 (IQR 17) years. Just over half were partnered (54.7%) and 46.4% of the sample were from more deprived backgrounds (Quintiles 1&2). This 46% is higher than the expected 40% but is the usual pattern for cancer deaths.

3.1.1 Study Sample

Table 3.2: Cancer Diagnosis

Cancer Diagnosis	N (%)
Digestive Organs	182 (26.2)
Respiratory & Intrathoracic Organs	170 (24.5)
Breast	58 (8.3)
Male Genital Organs	38 (5.5)
Female Genital Organs	35 (5.0)
Other (See Below)	212 (30.5)
Lymphoid, Hematopoietic and Related Tissue	72
Other Ill-Defined Sites	50
Urinary Tract	36
Melanoma and Other Neoplasms of the Skin	15
Lip, Oral Cavity and Pharynx	14
Eye, Brain and Other Parts of the Central Nervous System	11
Mesothelial and Soft Tissue	9
Thyroid and Other Endocrine Glands	3
Bone and Articular Cartilage	2

- The most common cancer diagnoses were those of the digestive organs (26.2%) or cancers of the respiratory and intrathoracic organs (24.5%). The remaining cancer diagnoses were breast (8.3%), male genital organs (5.5%) and female genital organs (5.0%). This pattern reflects those of the cancers within the community in Northern Ireland. The remaining 30.5% of cancers were grouped as Other (Table 3.2).
- Almost two thirds (63.2%) of the study sample had either a first or last stage recorded. At best Stage, 82.0% of patients had Stage IV disease.

3.1.2 Time Since Diagnosis to Death

Table 3.3: Time Since Diagnosis to Death by Cancer Type

Cancer Diagnosis	Time Since Diagnosis to Death	
	Median Months (IQR)	Maximum Recorded Survival Months (Years)
Breast	44 (111)	395 (33 Years)
Male Genital Organs	33 (50)	219 (18 Years)
Digestive Organs	5 (19)	420 (35 Years)
Female Genital Organs	4 (18)	78 (7 Years)
Respiratory & Intrathoracic Organs	1 (6)	243 (20 Years)
Other	3 (25)	237 (20 Years)
Total	4 (24)	420 (35 Years)

- The median time since diagnosis to death (Table 3.3) was, as expected, greatest in patients with a diagnosis of breast cancer (44 months; IQR 111) and least for those diagnosed with cancers of the respiratory & intrathoracic organs (1 month; IQR 6). This reflects known survival patterns.

3.1.3 Co-morbidities

A co-morbidity is another disease recorded for the patient in addition to their cancer. It should also be noted that the type of co-morbidity and its severity would have a strong influence over the survival of patients.

Table 3.4: Co-morbidities

Co-morbidities (n=695)	N (%)
Number of Co-morbidities Recorded	
0	84 (12.1)
1	200 (28.8)
2	215 (30.9)
3+	196 (28.2)
Co-morbidity	
Alzheimer's	46 (6.6)
Arthritis	87 (12.5)
Cardiovascular Disease	120 (17.3)
Cerebrovascular Disease	57 (8.2)
COPD*	97 (14.0)
Diabetes	95 (13.7)
Hypertension	236 (34.0)
Learning Disability	7 (1.0)
Parkinson's Disease	16 (2.3)
Psychiatric Disorder	16 (2.2)
Renal Disease	30 (4.3)
Multiple Sclerosis	1 (0.1)
Other Malignancy	70 (10.1)

Note: COPD = Chronic Obstructive Pulmonary Disease

- A total of 87.9% of patients had one or more co-morbidity (Table 3.4). The most common co-morbidities were hypertension (34.0%), cardiovascular disease (17.3%), COPD (14.0%), diabetes (13.7%) and arthritis (12.5%).

- There were no significant differences in the total number of co-morbidities by cancer type and the main co-morbidities outlined previously were the same across all cancer diagnoses. Patients with cancers of the digestive organs however, were the group with the highest percentage that had diabetes recorded as a co-morbidity, whereas for patients with cancers of the respiratory and intrathoracic organs it was COPD, hypertension for patients with cancers of the female genital organs and Alzheimer's for patients with cancer of the male genital organs, possibly reflecting their older age profile. Appendix II (i) displays co-morbidity by cancer type.

3.2 Hospital Admission

3.2.1 Source, Timing and Symptoms on Admission

Table 3.5: Source and Timing of Patient Referral

Last Hospital Admission	N (%)
Source of Referral	
G.P.	321 (46.2)
Patient/Family Referral	132 (19.0)
Other Hospital	121 (17.4)
Outpatient Clinics	29 (4.2)
Nursing Home	28 (4.0)
Oncology Helpline	13 (1.9)
Community Hospital	10 (1.4)
Other	22 (3.2)
Not Recorded	19 (2.7)
Day of Admission	
Weekday	551 (79.3)
Weekend/Public Holiday	144 (20.7)
Time of Admission*	
In G.P. Practice Hours	360 (51.8)
Out of G.P. Practice Hours	330 (47.5)
Not Recorded	5 (0.7)
Type of Admission	
Emergency	547 (78.7)
Non-Emergency/Planned	148 (21.3)
Hospital and Health and Social Care Trust (HSCT) admitted to:	
Belfast HSCT	264 (38.0)
Belfast City Hospital	100 (14.4)
Northern Ireland Cancer Centre	68 (9.8)
Royal Victoria Hospital	51 (7.3)
Mater Infirmorum Hospital	45 (6.5)
South Eastern HSCT	118 (17.0)
Ulster Hospital	90 (12.9)
Lagan Valley Hospital	17 (2.4)
Downe Hospital	11 (1.6)
Northern HSCT	114 (16.4)
Antrim Area Hospital	64 (9.2)
Causeway Hospital	22 (3.2)
Whiteabbey Hospital	11 (1.6)
Mid-Ulster Hospital	17 (2.4)
Western HSCT	108 (15.5)
Altnagelvin Hospital	68 (9.8)
Erne Hospital	29 (4.2)
Tyrone County Hospital	11 (1.6)
Southern HSCT	91 (13.1)
Craigavon Area Hospital	66 (9.5)
Daisy Hill Hospital	25 (3.6)
Total	695 (100)

Note: *For the purpose of this study, G.P. practice hours are considered 8.30 am to 6.00 pm.

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

Note: Nursing home includes residential and care homes.

- Patients were mainly admitted by a G.P. (46.2%), or as a patient/family referral (19.0%). The large majority were admitted on a weekday (79.3%), as an emergency (78.7%), and over half were admitted within G.P. practice hours (51.8%).
- Patients were generally admitted to medical (61.2%) or surgical (15.1%) wards and assessed by a Senior House Officer (26.3%) or Junior House Officer (13.7%). However, in 43.7% of cases, assessor on admission was not discernable from the records.
- Patients had a median of 4 symptoms on admission with the most common being pain (48.3%), breathlessness (40.9%), anorexia (40.4%) and nausea/vomiting (33.8%). See Table 3.6.
- Most patients were admitted with either cancer-related (37.4%) or urgent physical (33.5%) symptoms. This was followed by patients admitted for further investigations/precautions (10.6%), for treatment (10.4%), treatment-related symptoms (3.2%), for palliative care (3.0%), urgent social needs (1.2%) or for rehabilitation (0.7%). A definition of how reasons for admission were categorised, with examples, is in Appendix II (ii).
- Of the 21 (3.0%) patients who were admitted for palliative care, 14 (66.7%) were admitted within G.P. practice hours. A total of 8 patients were recorded as having specialist palliative care at home and 6 out of the 8 were admitted within G.P. practice hours. PPD was recorded for 12 of these 21 patients and only 2 of these patients wished to die in hospital. The remaining patients preferred to die at home (n=8), hospice (n=1) or nursing home (n=1).
- A total of 72 (10.4%) patients had surgery within their last year of life, a median of 19 days (IQR 97) days prior to death. Of these 72 patients, 44 (61.1%) had surgery on their last admission, a median of 10 (IQR 17) days prior to death and 16 (36.4%) patients were diagnosed on their last admission.
- Surgery for patients on their last admission was mainly for symptom control (43.2%), diagnosis/treatment of cancer (38.6%), or fracture repair (18.2%). Patients who had surgery on their last admission were predominantly classified as “other” cancers (40.9%), followed by cancers of the digestive organs (25.0%), female genital organs (13.6%), male genital organs (9.1%), cancers of the respiratory & intrathoracic organs (6.8%) and breast cancer (4.5%).
- Only a very small percentage of patients had chemotherapy (3.9%) or radiotherapy (4.9%) on their last admission. Since the data collected within this study was done so from reviewing patients’ medical notes relating to their last admission, last chemotherapy and radiotherapy dates were only available for 126 (18.1%) patients. The last chemotherapy session was a median of 10 (IQR 27) weeks prior to death, a median of 7 (IQR 29) weeks for last radiotherapy session prior to death and a median of 2 (IQR 28) weeks for last surgical intervention prior to death.
- Prior to admission, 10.1% (n=70) of patients lived in a nursing home. A total of 74.3% of these patients were admitted on a weekday and 52.9% within G.P. practice hours. The majority of patients were either referred by a G.P. (44.3%) or nursing home staff (40.0%). The remainder of referrals were other hospitals (7.1%), patient/family referral (4.3%) and outpatient clinic (1.4%), with 2.8% other/missing. Reasons for admission were mainly urgent physical (62.9%), followed by cancer-related (20.0%), further investigations/precaution (10.0%), for palliative care (4.3%), or for treatment (2.9%). Median length of stay from admission until death for patients admitted from a nursing home was 9 (IQR 17) days.

Table 3.6: Main Symptoms by Cancer Diagnosis

Main Symptoms	Digestive Organs	Respiratory & Intrathoracic Organs	Breast	Female Genital Organs	Male Genital Organs	Other	Total
	N						
	182	170	58	35	38	212	695
%							
Pain	53.3	42.9	55.2	48.6	36.8	48.6	48.3
Breathlessness	24.7	73.5	48.3	28.6	34.2	29.7	40.9
Anorexia	41.2	35.9	50.0	48.6	26.3	42.0	40.4
Nausea/Vomiting	39.0	19.4	44.8	60.0	31.6	34.0	33.8
Diarrhoea/Constipation	29.1	22.9	34.5	48.6	26.3	20.8	26.3
Cough	16.5	49.4	24.1	5.7	28.9	17.0	25.5
Weight loss	31.3	29.3	13.8	8.6	7.9	24.5	24.9
Dehydration	29.1	14.1	36.2	45.7	18.4	17.9	22.9
Lethargy	19.8	22.4	25.9	20.0	13.2	27.4	22.9
Confusion	15.9	17.1	29.3	5.7	21.1	21.7	18.8

- On admission, pain was one of the main issues for the majority of cancer patients (Table 3.6), particularly patients with breast cancer (55.2%) and cancers of the digestive organs (53.3%).
- Breathlessness (73.5%) and a cough (49.4%) were the main symptoms for patients with cancers of the respiratory & intrathoracic organs.
- Gastrointestinal symptoms such as nausea/vomiting, diarrhoea/constipation, anorexia and dehydration were experienced by a higher percentage of patients with breast cancer and cancers of the female genital organs than patients with cancers of the digestive system.

3.2.2 Length of Stay: Last Hospital Admission

Table 3.7: Length of Stay

Length of Stay (n=695): Last Hospital Admission (Days)	N (%)
<1	60 (8.6)
1-3	79 (11.4)
4-7	130 (18.7)
8-14	149 (21.4)
15-21	102 (14.7)
22-28	75 (10.8)
>28	100 (14.4)
Average (Range)	11 (0-233) Days

- The duration of patients' last hospital stay ranged from 0-233 days (Table 3.7). While the median length of stay on patients' last admission was 11 (IQR 18) days, a small percentage (14%) of patients died within 48 hours of admission (See section 3.2.6).

3.2.3 Emergency Admissions

Table 3.8: Emergency Admissions by Demographic Information and Medical Information

Demographic and Medical Information	Emergency Admission N (%)		
	Yes	No	P
Age Group (Years)			
≤45	20 (3.7)	7 (4.7)	
46-60	63 (11.5)	26 (17.6)	
61-70	116 (21.2)	43 (29.1)	
71-80	195 (35.6)	42 (28.4)	
≥81	153 (28.0)	30 (20.3)	0.02*
Gender			
Male	282 (51.6)	89 (60.1)	
Female	265 (48.4)	59 (39.9)	0.06
Marital Status			
Partnered	287 (52.3)	94 (63.5)	
Not Partnered	258 (47.2)	54 (36.5)	
Unknown	2 (0.4)	0	0.02*
Reason for Admission			
Cancer-Related	225 (41.1)	35 (23.6)	
Urgent Physical	222 (40.6)	11 (7.4)	
Urgent Social	7 (1.3)	1 (0.7)	
Further Investigations/Precautions	48 (8.8)	26 (17.6)	
Treatment-Related	17 (3.1)	5 (3.4)	
For Treatment	19 (3.5)	53 (35.8)	
For Rehabilitation	0	5 (3.4)	
For Palliative Care	9 (1.6)	12 (8.1)	<0.001*
Length of Last Hospital Stay (Days)			
<24 Hours	56 (10.2)	4 (2.7)	
1-3	66 (12.1)	13 (8.8)	
4-7	105 (19.2)	25 (16.9)	
8-14	111 (20.3)	38 (25.7)	
15-21	76 (13.9)	26 (17.6)	
22-28	63 (11.5)	12 (8.1)	
>28	70 (12.8)	30 (20.3)	0.008*
Diagnosed Last Admission			
Yes	154 (28.2)	29 (19.6)	
No	393 (71.8)	119 (80.4)	0.04*
Time Since Diagnosis (Months)			
<1	160 (29.3)	44 (29.7)	
1-3	93 (17.0)	36 (24.3)	
4-6	40 (7.3)	12 (8.1)	
7-12	52 (9.5)	16 (10.8)	
13-18	39 (7.1)	7 (4.7)	
19-24	25 (4.6)	4 (2.7)	
>24	138 (25.2)	29 (19.6)	0.30
Total	547 (78.7)	148 (21.3)	

Note: *Significant at the $p \leq 0.05$ Level (Chi-Square analysis).

- A total of 547 (78.7%) patients were admitted as an emergency (Table 3.8). A significantly higher percentage of older patients were admitted as an emergency (Median 74 years, IQR 16) than those with a non-emergency/planned admission (Median 70 years, IQR 17; Mann-Whitney U Test $p=0.003$).
- A significantly higher percentage of patients admitted as an emergency were not partnered (47.2%) in contrast to patients with a non-emergency/planned admission (36.5%; $p=0.02$).
- Patients admitted as an emergency tended to be mainly admitted for cancer-related (41.1%) or urgent physical symptoms (40.6%), whereas patients with a non-emergency/planned admission were mainly admitted for treatment (35.8%), cancer-related symptoms (23.6%) or for further investigations/precautions (17.6%).
- Patients admitted as an emergency tended to die significantly earlier i.e. from admission to death (Median 10 days, IQR 17) than those that had a non-emergency/planned admission (Median 13 days, IQR 18; Mann-Whitney U Test $p=0.003$).
- No significant differences by gender or time since diagnosis to death were observed between emergency and non-emergency/planned admissions.

Table 3.9: Emergency Admissions by Source of Referral and Day and Time of Admission

Source of Referral	Emergency Admission N (%)		p
	Yes	No	
Source of Referral			
G.P.	298 (54.5)	23 (15.5)	<0.001*
Patient/Family Referral	132 (24.1)	0	
Other Hospital	18 (3.3)	103 (69.6)	
Outpatient Clinics	23 (4.2)	6 (4.1)	
Nursing Home	27 (4.9)	1 (0.7)	
Oncology Helpline	6 (1.1)	7 (4.7)	
Community Hospital	5 (0.9)	5 (3.4)	
Other	21 (3.8)	1 (0.7)	
Not Recorded	17 (3.1)	2 (1.4)	
Day of Admission			
Weekday	422 (77.1)	129 (87.2)	0.008*
Weekend/Public Holiday	125 (22.9)	19 (12.8)	
Time of Admission**			
In G.P. Practice Hours	273 (49.9)	87 (58.8)	0.16
Out of G.P. Practice Hours	270 (49.4)	60 (40.5)	
Not Recorded	4 (0.7)	1 (0.7)	
Total	547 (78.7)	148 (21.3)	

Note: *Significant at the $p \leq 0.05$ Level (Chi-Square analysis).

Note: **For the purpose of this study, G.P. practice hours are considered 8.30 am to 6.00 pm.

Note: Nursing home includes residential and care homes.

- Similar to the main sample, the majority of emergency admissions came from either a G.P. (54.5%) or patient/family referral (24.1%). This is significantly different ($p < 0.001$) from those that were non-emergency/planned admissions, which were mainly referred by other hospitals (69.6%).
- The majority of emergency admissions were made on a weekday (77.1%) however, a significantly higher percentage of emergency admissions were done so over a weekend (22.9%) in contrast to non-emergency/planned admissions ($p = 0.008$). Almost half of the emergency admissions were within G.P. practice hours (49.9%). This however was not significant from the admission timing of non-emergency/planned referrals.
- Patients admitted as an emergency had on average more symptoms (5) than those admitted as a non-emergency/planned admission (3). The most common symptoms for patients with an emergency admission were pain (47.7%), breathlessness (44.6%), anorexia (42.4%), nausea/vomiting (36.9%) and a cough (28.9%). The most common symptoms for patients with a non-emergency/planned admission were pain (50.7%), anorexia (33.1%), breathlessness (27.0%), diarrhoea/constipation (24.3%) and nausea/vomiting (22.3%).

3.2.4 G.P Referrals v. Patient/Family Referrals

Table 3.10: Demographic Information and Cancer Diagnosis

Demographics and Cancer Diagnosis	G.P. Referral N (%)	Patient/Family Referral N (%)	p
Age			
≤45	7 (2.2)	7 (5.3)	0.02*
46-60	32 (10.0)	22 (16.7)	
61-70	67 (20.9)	30 (22.7)	
71-80	112 (34.9)	48 (36.4)	
>81	103 (32.1)	25 (18.9)	
Gender			
Male	170 (53.0)	76 (57.6)	0.37
Female	151 (47.0)	56 (42.4)	
Marital Status			
Partnered	174 (54.8)	71 (53.8)	0.94
Not Partnered	147 (45.8)	61 (46.2)	
Socioeconomic Status			
Quintile 1 (Most Deprived)	77 (24.0)	36 (27.3)	0.27
Quintile 2	76 (23.7)	37 (28.0)	
Quintile 3	59 (18.4)	18 (13.6)	
Quintile 4	58 (18.1)	17 (12.9)	
Quintile 5 (Least Deprived)	51 (15.9)	23 (17.4)	
Unknown	0	1 (0.8)	
Geographical Location			
Rural	109 (34.0)	35 (26.5)	0.10
Urban	212 (66.0)	96 (72.7)	
Unknown	0	1 (0.8)	
Cancers of:			
Digestive Organs	83 (25.9)	34 (25.8)	0.95
Respiratory & Intrathoracic Organs	83 (25.9)	36 (27.3)	
Breast	26 (8.1)	10 (7.6)	
Female Genital Organs	20 (6.2)	5 (3.8)	
Male Genital Organs	19 (5.9)	8 (6.1)	
Other	90 (28.0)	39 (29.5)	
Diagnosed Last Admission			
Yes	103 (32.1)	27 (20.5)	0.01*
No	218 (67.9)	105 (79.5)	
Number of Previous Admissions Last Year of Life			
0	123 (38.3)	47 (35.6)	0.48
1-2	159 (49.5)	62 (47.0)	
3-4	31 (9.7)	17 (12.9)	
5+	8 (2.5)	6 (4.5)	
Total	321 (46.3)**	132 (19.0)**	

Note: * Significant at the $p \leq 0.05$ Level (Chi-Square).

Note: ** Percentage out of all sources of referrals.

- Patients referred by a G.P. were significantly older (75 years; IQR 16) than those admitted as Patient/family referrals (72 years; IQR 17). (Mann-Whitney U Test $p=0.006$).
- A significantly higher percentage of patients who were referred by their G.P. were diagnosed on their last admission (32.3%) compared to those who were patient/family referrals (20.5%; $p=0.01$).

- No significant differences were observed between G.P. and patient/family referrals in relation to gender, marital status, socioeconomic status, geographical area or cancer diagnosis.

Table 3.11: Hospital Admission

Hospital Admission	G.P. Referral N (%)	Patient/Family Referral N (%)	p
Admission Time**			
In G.P. Practice Hours	179 (55.8)	49 (37.1)	0.001*
Out of G.P. Practice Hours	140 (43.6)	82 (62.1)	
Not Record	2 (0.6)	1 (0.8)	
Admission Day			
Weekday	262 (81.6)	88 (66.7)	0.001*
Weekend/Public Holiday	59 (18.4)	44 (33.3)	
Reason for Final Admission			
Cancer-Related	116 (36.1)	70 (53.0)	<0.001*
Urgent Physical	126 (38.9)	51 (38.6)	
Urgent Social	6 (1.9)	1 (0.8)	
Further Investigations/Precautions	46 (14.3)	3 (2.3)	
Treatment-Related	8 (2.5)	5 (3.8)	
For Treatment	17 (5.3)	2 (1.5)	
Palliative Care	3 (0.9)	0	
Total	321 (46.3)***	132 (19.0)***	

Note: * Significant at the $p \leq 0.05$ Level (Chi-Square analysis).

Note: **For the purpose of this study, G.P. practice hours are considered 8.30 am to 6.00 pm.

Note: *** Percentage out of all sources of referrals.

- A higher percentage of patients who were patient/family referrals were out of G.P. practice hours (62.1%) and over a weekend/public holiday (33.3%) in contrast to those referred by a G.P (43.6% and 18.4%, respectively). These findings were both significant ($p=0.001$). See Table 3.11.
- Significant differences between these groups also existed in relation to reason for admission. The most common reason for admission for those that were patient/family referrals was cancer-related symptoms (53.0%) whereas the most common reason for admission in patients referred by a G.P. was urgent physical symptoms (38.9%).

3.2.5 Recording of Preferred Place of Death

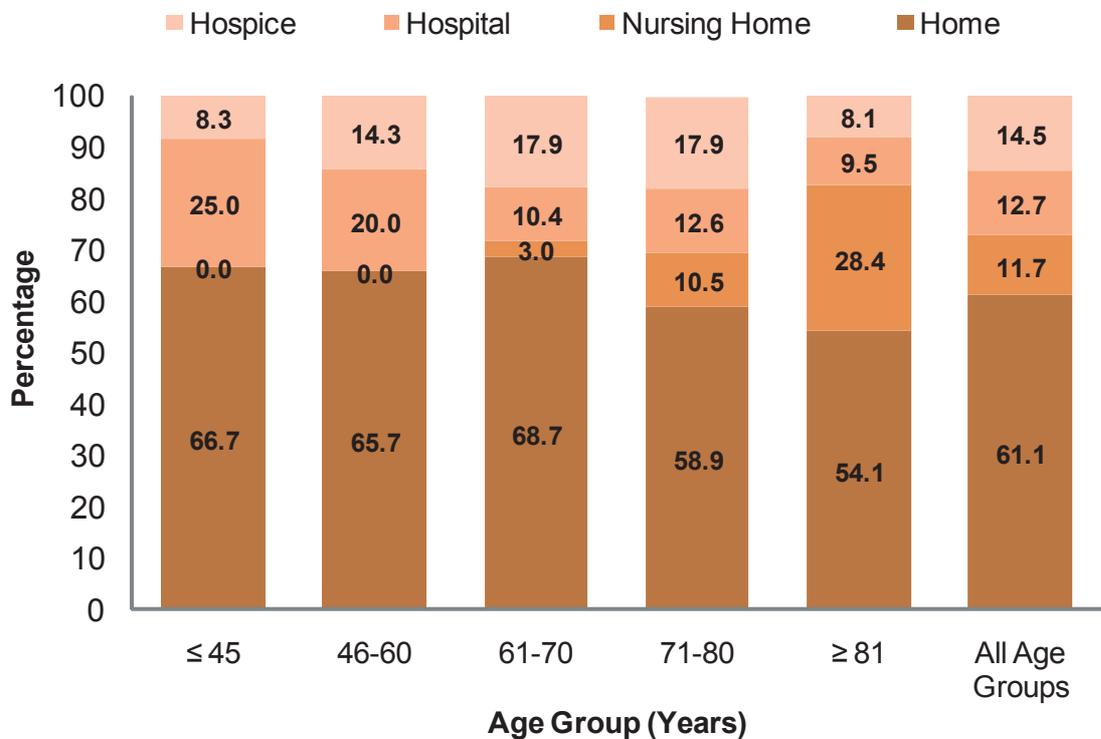
Table 3.12: Preferred Place of Death by Hospital and Health and Social Care Trust – Total Sample

Hospital and Health and Social Care Trust (HSCT)	Preferred Place of Death Recorded? N (%)		
	Yes	No	Total
Belfast HSCT	115 (43.6)	149 (56.4)	264 (38.0)
Belfast City Hospital	48 (48.0)	52 (52.0)	100
Northern Ireland Cancer Centre	37 (54.4)	31 (45.6)	68
Royal Victoria Hospital	14 (27.5)	37 (72.5)	51
Mater Infirmorum Hospital	16 (35.6)	29 (64.4)	45
Northern HSCT	47 (41.2)	67 (58.8)	114 (16.4)
Antrim Area Hospital	26 (40.6)	38 (59.4)	64
Causeway Hospital	11 (50.0)	11 (50.0)	22
Whiteabbey Hospital	3 (27.3)	8 (72.7)	11
Mid-Ulster Hospital	7 (41.2)	10 (58.8)	17
Western HSCT	47 (43.5)	61 (56.5)	108 (15.5)
Altnagelvin Hospital	34 (50.0)	34 (50.0)	68
Erne Hospital	7 (24.1)	22 (75.9)	29
Tyrone County Hospital	6 (54.5)	5 (45.5)	11
Southern HSCT	30 (33.0)	61 (67.0)	91 (13.1)
Craigavon Area Hospital	21 (31.8)	45 (68.2)	66
Daisy Hill Hospital	9 (36.0)	16 (64.0)	25
South Eastern HSCT	44 (37.3)	74 (62.7)	118 (17.0)
Ulster Hospital	36 (40.0)	54 (60.0)	90
Lagan Valley Hospital	6 (35.3)	11 (64.7)	17
Downe Hospital	2 (18.2)	9 (81.8)	11
Northern Ireland	283 (40.7)	412 (59.3)	695 (100)

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

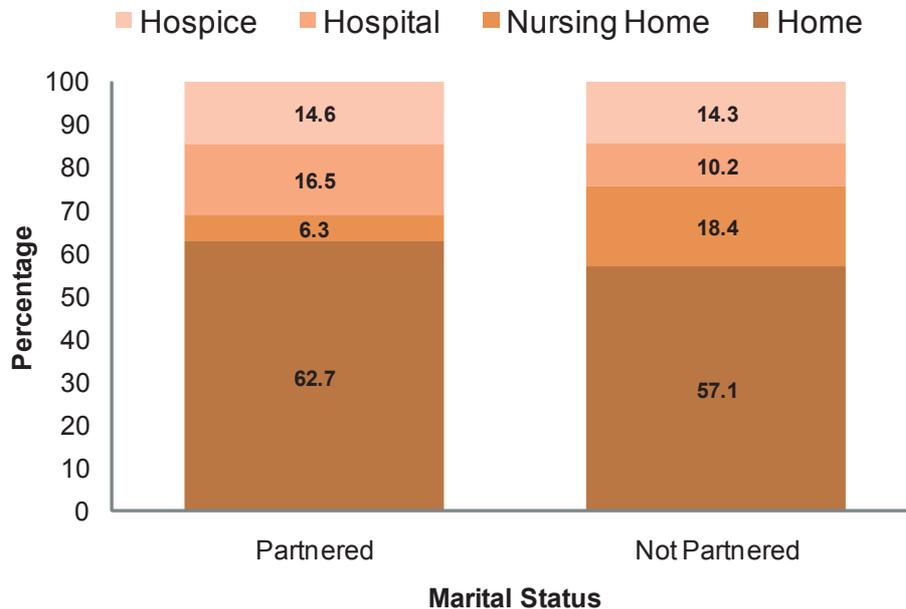
- Preferred place of death (PPD) was recorded for 283 (40.7%) patients. PPD was recorded for a similar percentage of patients (39.1%) that had a known cancer diagnosis prior to their final hospital admission. The recording of PPD varied across HSCT but not significantly. The Belfast HSCT and the Western HSCT had the highest percentages of PPD recorded (43.6% and 43.5%, respectively), while the Southern HSCT had the lowest percentage recorded (33.0%).
- Of these 283 patients, 61.1% preferred to die at home, while only 12.7% stated they preferred to die in hospital. A total of 14.5% had determined a preference to die in a hospice and 11.7% in a nursing home. The majority (66.0%) of patients admitted from a nursing home indicated that the nursing home was their PPD.
- The recording of PPD by HSCT for those with a known cancer diagnosis is tabled in Appendix II (iii) and by HSSB for the total sample in Appendix II (iv).

Figure 3.1: Preferred Place of Death by Age Group



- Recorded PPD did not vary significantly by gender, cancer type, geographical area of residence, socioeconomic status, religion or the number of previous hospital admissions (last year of life). In all scenarios, home was the highest percentage preference. The only significant differences observed, were in relation to age group ($p < 0.001$).
- As patients got older, the percentage preference for a nursing home death increased, particularly for those over 81 years of age. It should be noted however that more elderly patients may often class nursing homes as home. Conversely, younger patients had the highest percentage preference for a hospital death (≤ 45 years and 46-60 years).
- The median age of patients who preferred to die at home was 72 (IQR 16) years. This was 71 (IQR 20) years for those with a preference to die in hospital, 71 (IQR 15) years for those who preferred to die in a hospice, and 83 (IQR 11) years for those with a preference to die in a nursing home.

Figure 3.2: Preferred Place of Death by Marital Status



- Patients who were not partnered had the highest percentage of those with a preference for a nursing home death, reflecting the single/widowed status of most of the clientele. In contrast, those who were partnered had the highest percentage for having preferred a hospice/palliative care unit or hospital death. A higher percentage of patients who were partnered preferred to die at home (Figure 3.2). No significant differences marital status and PPD existed once age was taken into account.

Table 3.13: Reasons for Delay in Discharge

Reasons for Delay	N (%)
1. Condition deteriorated	203 (76.3)
2. Lack of bed (Hospice/Other Hospital/Nursing Home)	33 (12.4)
3. Care package not in place	13 (4.9)
4. Family support not available	8 (3.0)
5. Symptom control	5 (1.9)
6. Family preferred patient to die in Hospital	3 (1.1)
7. Did not meet hospice admission criteria	1 (0.4)
Total	266 (38.3)

Note: Nursing home includes residential and care homes.

- A total of 266 (38.3%) patients had specifically requested to be discharged to their usual residence, hospice or other hospital.
- The most common reasons this was not achieved (Table 3.13) was due to a deterioration in the patients' condition (76.3%), lack of bed space (12.4%) or care packages not in place (4.9%).
- Demographic and medical information was used to explore if differences existed among those who requested to be discharged but their condition deteriorated, in contrast to patients whose hospital death was due to reasons numbered 2-7 in the above table. No significant differences however were observed.

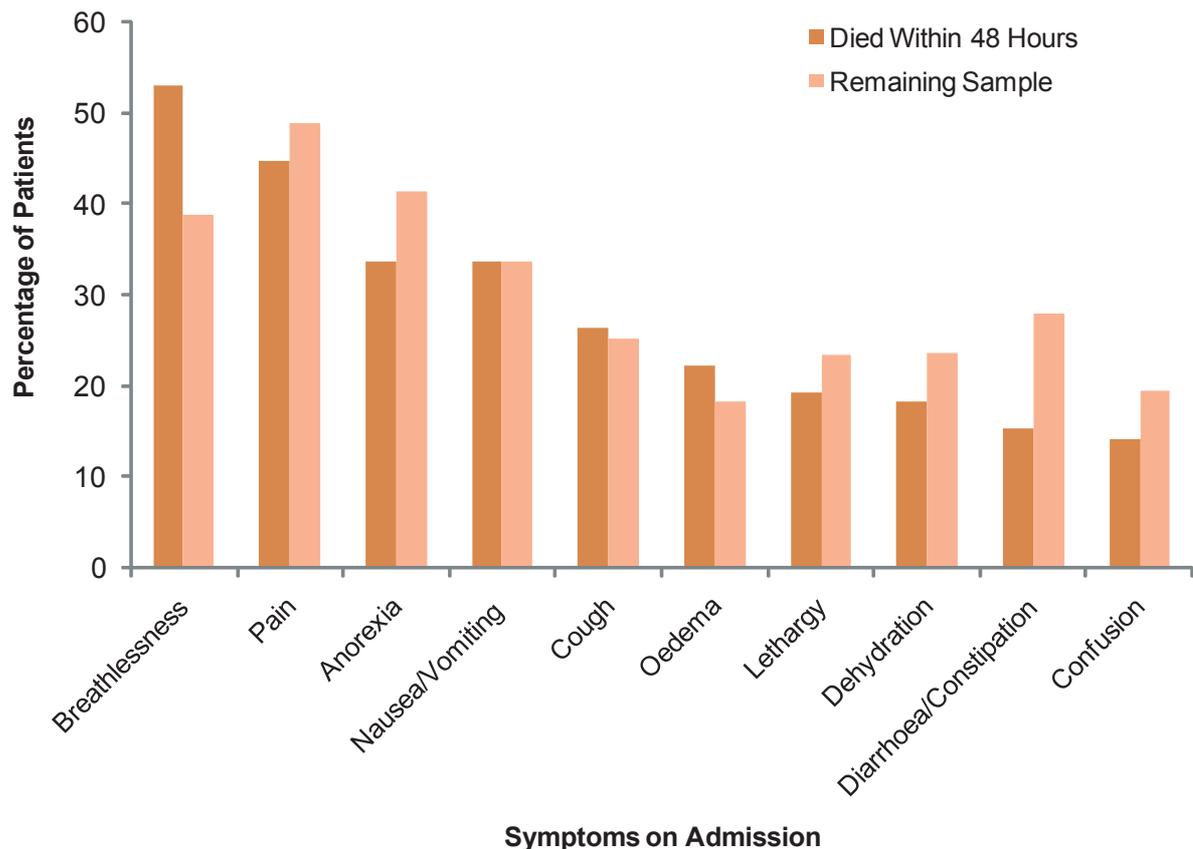
3.2.6 Deaths within 48 Hours of Hospital Admission

Table 3.14: Main Symptoms, Investigations, Interventions and Time Since Diagnosis

Deaths Within 48 hrs of Admission (n=98)	N (%)
Main Symptoms	
Breathlessness	52 (53.1)
Pain	44 (44.9)
Anorexia	33 (33.7)
Nausea/Vomiting	33 (33.7)
Cough	26 (26.5)
Oedema	22 (22.4)
Lethargy	19 (19.4)
Dehydration	18 (18.4)
Diarrhoea/Constipation	15 (15.3)
Confusion	14 (14.3)
Total Investigations	
None	6 (6.1)
1-3	71 (72.4)
4+	21 (21.4)
Investigations	
Blood Tests	83 (84.7)
ECG	80 (81.6)
Chest X-Ray	70 (71.4)
Abdominal X-Ray	13 (13.3)
CT Scan	9 (9.2)
Abdominal Ultrasound	4 (4.1)
Pleural Tap	1 (1.0)
OGD	3 (3.1)
Bronchoscopy	2 (2.0)
Total Interventions	
0	1 (1.0)
1-3	78 (79.6)
4+	19 (19.4)
Interventions	
Intravenous Fluids	84 (85.7)
Regular Oxygen	81 (82.7)
Controlled Drugs	57 (58.2)
Blood Transfusion	13 (13.3)
Resuscitation	13 (13.3)
Ventilation	6 (6.1)
Artificial Feeding	3 (3.1)
Chemotherapy	2 (2.0)
Radiotherapy	1 (1.0)
Surgery (Loop Ileostomy)	1 (1.0)
Time Since Diagnosis (Months)	
<1	15 (15.3)
1-3	27 (27.6)
4-6	8 (8.2)
7-12	4 (4.1)
13-18	9 (9.2)
19-24	4 (4.1)
>24	31 (31.6)

- A total of 14% (n=98) of patients died within 48 hours of admission. Table 3.14 outlines the main symptoms on admission, investigations and interventions conducted during patients' last admission and time since diagnosis for those patients that died within 48 hours of being admitted. Figure 3.3 shows that these patients experienced similar symptoms on admission to those in the remaining sample however, a significantly (p=0.008) higher percentage experienced breathlessness (53.1%) compared to remaining sample (38.9%).

Figure 3.3: Deaths within 48 Hours of Admission: Main Symptoms



- The large majority of patients had a cancer diagnosis prior to their final admission however, 8.2% (n=8) of patients were only diagnosed within 48 hours of their death. These were cancers of the respiratory and intrathoracic organs (n=3), digestive organs (n=1), female genital organs (n=1) and other cancers (n=3).
- The median age of those that died within 48 hours of admission was 71 (IQR 16) years, which was not statistically different from the remaining sample (74, IQR 16).
- Although there were a higher percentage of males (60.2%) than females (39.2%) that died within 48 hours of admission, these proportions were not significantly different from the rest of the sample. There were however, a significantly higher percentage of patients (70.1%) that were partnered compared to the rest of the sample (52.5%; p=0.001).
- A total of 72.4% patients that died within 48 hours of admission had between 1 and 3 (median 4) investigations and 79.6% had between 1 and 3 (median 3) interventions. These were generally routine

investigations and interventions such as blood tests (84.7%), ECGs (81.6%), chest x-rays (71.4%), IV fluids (85.7%), regular oxygen (82.7%) and controlled drugs (58.2%).

- 25 patients who died within 48 hours of admission had a chemotherapy or radiotherapy record. Their last chemotherapy session was a median of 6 (IQR 9) weeks prior to death and 8 (IQR 23) weeks for last radiotherapy session. Only a very small percentage (2.0%) of patients had chemotherapy, radiotherapy (1.0%) or surgery (1.0%) within their last 48 hours of life.
- There was no significant difference by cancer diagnosis or the number of co-morbidities for patients who died within 48 hours of admission when compared to the remaining sample.
- The median time since diagnosis until death for patients who died within 48 hours of admission was 6 (IQR 32) months compared with 4 (IQR 20) months for the remaining sample. These differences were statistically significant ($p=0.01$).
- The majority of patients (60.8%) that died within 48 hours of admission had 2-3 previous admissions in their last year of life. This was not significantly different however from the main sample.
- 42.9% of these patients had specialist palliative care services at home, which was significantly ($p=0.005$) more than the remaining sample (28.8%). Most were admitted with cancer-related (46.9%) or urgent physical (35.7%) symptoms. Significant differences existed between patients who died within 48 hours of admission and the remaining sample in terms of reasons for hospital admission. A higher percentage of patients who died within 48 hours were admitted for cancer-related symptoms (46.9%) compared to the rest of the sample (35.8%; $p=0.01$). The remaining reasons for admission were treatment-related (5.1%), for palliative care (4.1%), for treatment (3.1%), for further investigations/precautions (3.1%) or urgent social needs (2.0%).
- Of the 42.9% of patients who did have specialist palliative care at home, just over half were admitted out of G.P. practice hours (59.5%).
- During those 48 hours, death was predicted in 83.7% of cases. The LCP was in place for approximately 25.5% of patients and PPD recorded for 11.2%.
- 10.2% of patients who died within 48 hours were admitted from a nursing home.

3.2.7 Patients Diagnosed with Cancer within Last Month of Life

Table 3.15: Diagnosed Last Month of Life - Demographic Information

Demographic Information	Diagnosed Last Month of Life		p
	Yes N (%)	No N (%)	
Age			
≤45	2 (1.0)	25 (5.2)	<0.001*
46-60	11 (5.2)	78 (16.1)	
61-70	41 (19.5)	118 (24.3)	
71-80	83 (39.5)	154 (31.8)	
≥81	73 (34.8)	110 (22.7)	
Gender			
Male	113 (53.8)	258 (53.2)	0.88
Female	97 (46.2)	227 (46.8)	
Marital Status			
Partnered	108 (51.4)	273 (56.3)	0.22
Not Partnered	102 (48.6)	210 (43.3)	
Unknown	0	2 (0.4)	
Geographical Area			
Urban	158 (75.2)	334 (68.9)	0.20
Rural	52 (24.8)	150 (30.9)	
Unknown	0	1 (0.2)	
Socioeconomic Status			
Quintile 1 (Most Deprived)	52 (24.8)	112 (23.1)	0.69
Quintile 2	50 (23.8)	108 (22.3)	
Quintile 3	39 (18.6)	86 (17.7)	
Quintile 4	39 (18.6)	84 (17.3)	
Quintile 5 (Least Deprived)	30 (14.3)	94 (19.4)	
Unknown	0	1 (0.2)	
Total	210 (30.2)	485 (69.8)	
Median Age	78 (13)	71 (17)	<0.001**

Note: *Significant at the $p \leq 0.05$ Level (Chi-Square analysis).

Note: ** Significant at the $p \leq 0.05$ Level (Mann-Whitney U Test).

Note: Geographical area and Socioeconomic Status determined by the postcode of patients' usual address.

- A total of 210 (30.2%) patients died within one month of their cancer diagnosis (Table 3.15), 315 (45.3%) patients within 3 months of diagnosis and 369 (53.1%) within 6 months of diagnosis.
- In relation to patients that died within one month of diagnosis, with the exception of being older, these patients had similar demographic characteristics to the main group (Table 3.15).
- The median age of patients who died within one month of diagnosis was 78 years, which was significantly older than the remaining sample (71 years; $p < 0.001$).

Table 3.16: Diagnosed Last Month of Life - Medical Information

Medical Information	Diagnosed Last Month of Life		p
	Yes N (%)	No N (%)	
Cancer Type			
Digestive Organs	54 (25.7)	128 (26.4)	
Respiratory and Intrathoracic Organs	67 (31.9)	103 (21.2)	
Breast	5 (2.4)	53 (10.9)	
Female Genital Organs	10 (4.8)	25 (5.2)	
Male Genital Organs	1 (0.5)	37 (7.6)	
Other	73 (34.8)	139 (28.7)	<0.001*
Reason for Admission			
Cancer-Related	31 (14.8)	229 (47.2)	
Urgent Physical	112 (53.3)	121 (24.9)	
Urgent Social	3 (1.4)	5 (1.0)	
Further Investigations/Precautions	38 (18.1)	36 (7.4)	
Treatment Related	4 (1.9)	18 (3.7)	
For Treatment	17 (8.1)	55 (11.3)	
Rehabilitation	1 (0.5)	4 (0.8)	
Palliative	4 (1.9)	17 (3.5)	<0.001*
Number of Co-morbidities			
0	18 (8.6)	66 (13.6)	
1	49 (23.3)	151 (31.1)	
2	69 (32.9)	146 (30.1)	
3+	74 (35.2)	122 (25.2)	0.008*
Number of Admissions in Last Year			
1	102 (48.6)	125 (25.8)	
2-3	101 (48.1)	255 (52.6)	
4-5	6 (2.9)	79 (16.3)	
6+	1 (0.5)	26 (5.4)	<0.001*
Investigations on Last Admission			
None	1 (0.5)	9 (1.9)	
1-3	54 (25.7)	227 (46.8)	
4-6	120 (57.1)	222 (45.8)	
7+	35 (16.7)	27 (5.6)	<0.001*
Total	210 (30.2)	485 (69.8)	
Median (IQR) Length of Stay	14 (18) Days	9 (16) Days	<0.001**

Note: *Significant at the $p \leq 0.05$ Level (Chi-Square analysis).

Note: ** Significant at the $p \leq 0.05$ Level (Mann-Whitney U Test).

- Exploring the percentage of patients diagnosed/not diagnosed with cancer within their last month of life (not presented above) showed that 39.4% of patients with cancers of the respiratory & intrathoracic organs were diagnosed within their last month of life. 29.7% of patients with cancers of the digestive organs and 28.6% of patients with cancers of the female genital organs, died within 1 month of their diagnosis. Being diagnosed within the last month of life was much rarer for patients with breast cancer (8.3%) or cancers of the male genital organs (2.6%).
- A significantly higher percentage of patients diagnosed in their last month of life were admitted with urgent physical symptoms (53.3%) and for further investigations/precautions (18.1%) in contrast to the remaining sample (24.9% and 7.4%, respectively).
- Patients diagnosed in their last year of life had significantly more co-morbidities (reflecting their older age), less previous hospital admissions, and as expected more investigations on their last admission ($p < 0.001$).

Patients that died within one month of diagnosis also had a significantly longer hospital stay (14 days; $p < 0.001$, Mann-Whitney U Test).

3.2.8 Patients Diagnosed with Cancer on Last Hospital Admission

Table 3.17: Demographic Information

Demographic Information	Diagnosed Last Admission		p
	Yes N (%)	No N (%)	
Age			
≤45	1 (0.5)	26 (5.1)	<0.001*
46-60	7 (3.8)	82 (16.0)	
61-70	27 (14.8)	132 (25.8)	
71-80	72 (39.3)	165 (32.2)	
≥81	76 (41.5)	107 (20.9)	
Gender			
Male	94 (51.4)	277 (54.1)	0.52
Female	89 (48.6)	235 (45.9)	
Marital Status			
Partnered	79 (43.2)	302 (59.0)	<0.001*
Not Partnered	103 (56.3)	209 (40.8)	
Unknown	1 (0.5)	1 (0.2)	
Geographical Area			
Urban	141 (77.0)	351 (68.6)	0.09
Rural	42 (23.0)	160 (31.3)	
Unknown	0	1 (0.2)	
Socioeconomic Status			
Quintile 1 (Most Deprived)	44 (24.0)	120 (23.4)	0.77
Quintile 2	37 (20.2)	121 (23.6)	
Quintile 3	38 (20.8)	87 (17.0)	
Quintile 4	34 (18.6)	89 (17.4)	
Quintile 5 (Least Deprived)	30 (16.4)	94 (18.4)	
Unknown	0	1 (0.2)	
Total	183 (26.3)	512 (73.7)	

Note: * Significant at the $p \leq 0.05$ Level (Chi-Square analysis).

- A high percentage of patients (26.3%) were diagnosed on their last admission (Table 3.17) and had similar characteristics to those patients who died within one month of diagnosis (Table 3.16).
- These patients were significantly older (79 years; IQR 13) than those with a prior diagnosis (71 years; IQR 16, $p < 0.001$).
- A significantly larger percentage of patients diagnosed on their last admission were not partnered (56.3%), in contrast to those with a prior diagnosis (40.8%). This however did not remain significant once age was controlled for (Binary Logistic Regression).
- 35.7% (n=25) of patients admitted from a nursing home were diagnosed on their last admission.
- No significant differences between groups were observed for gender or socioeconomic status.

Table 3.18: Medical Information

Medical Information	Diagnosed Last Admission		p
	Yes (n=183) N (%)	No (n=512) N (%)	
Cancer Type			
Digestive Organs	45 (24.6)	137 (26.8)	
Respiratory & Intrathoracic Organs	53 (29.0)	117 (22.9)	
Breast	5 (2.7)	53 (10.4)	
Female Genital Organs	9 (4.9)	26 (5.1)	
Male Genital Organs	1 (0.5)	37 (7.2)	
Other	70 (38.3)	142 (27.7)	<0.001*
Reason for Admission			
Cancer-Related	14 (7.7)	246 (48.0)	
Urgent Physical	116 (63.4)	117 (22.9)	
Urgent Social	3 (1.6)	5 (1.0)	
Further Investigations/Precautions	42 (23.0)	32 (6.3)	
Treatment Related	0	22 (4.3)	
For Treatment	7 (3.8)	65 (12.7)	
Rehabilitation	1 (0.5)	4 (0.8)	
Palliative	0	21 (4.1)	<0.001*
Symptoms on Admission			
Anorexia	93 (50.8)	188 (36.7)	0.001*
Pain	92 (50.3)	244 (47.7)	0.54
Weight loss	84 (45.9)	89 (17.4)	<0.001*
Breathlessness	76 (41.5)	208 (40.6)	0.83
Nausea/Vomiting	60 (32.8)	175 (34.2)	0.73
Cough	50 (27.3)	127 (24.8)	0.50
Lethargy	49 (26.8)	110 (21.5)	0.14
Diarrhoea/Constipation	45 (24.6)	138 (27.0)	0.53
Dehydration	41 (22.4)	118 (23.0)	0.86
Confusion	35 (19.1)	96 (18.8)	0.91
Number of Co-morbidities			
None	11 (6.0)	73 (14.3)	
1	39 (21.3)	161 (31.4)	
2	65 (35.5)	150 (29.3)	
3+	68 (37.2)	128 (25.0)	<0.001*
Number of Previous Admissions in Last Year			
0	103 (56.3)	126 (24.6)	
1-2	76 (41.5)	278 (54.3)	
3-4	3 (1.6)	84 (16.4)	
5+	1 (0.5)	24 (4.7)	<0.001*
Investigations on Last Admission			
None	0	10 (2.0)	
1-3	26 (14.2)	255 (49.8)	
4-6	119 (65.0)	223 (43.6)	
7+	38 (20.8)	24 (4.7)	<0.001*
Median (IQR) Length of Stay	19 (18) Days	8 (14) Days	<0.001**

Note: * Significant at the $p \leq 0.05$ Level (Chi-Square analysis).

Note: ** Significant at the $p \leq 0.05$ Level (Mann-Whitney U Test).

- The highest percentages of cancers diagnosed on the last admission (Table 3.18) were cancers of the respiratory & intrathoracic organs (29.0%) and those of the digestive organs (24.6%).

- There were also significant differences between the groups with regard to reason for hospital admission. Those diagnosed on their last admission tended to be admitted due to urgent physical symptoms (63.4%) or for further investigations/precautions (23.0%) compared to the rest of the sample (22.9%, 6.3% respectively; $p < 0.001$).
- The most common symptoms on admission were similar to that of the remaining sample however there were a significantly higher percentage of patients diagnosed on their last admission that experienced anorexia (50.8%) and weight loss (45.9%) compared to the rest of the sample (36.7%, 17.4% respectively).
- Patients diagnosed on their last admission had significantly more co-morbidities yet, significantly less admissions in their last year of life (both $p < 0.001$). For 56.3% of patients, their last admission was their only admission within that year. 75.4% of patients who had a prior diagnosis had previous hospital admissions (last year of life).
- Patients diagnosed on their last admission had significantly more investigations and they had a longer hospital stay in contrast to the rest of the sample (both $p < 0.001$).
- The median time from admission to diagnosis was 6 (IQR 10) days, while median survival from diagnosis until death was 11 (IQR 15) days.
- The LCP was in place for 54.1% of patients who were diagnosed on their last admission and PPD recorded for 45.4%, with 55.4% preferring to die at home.

3.2.9 Hospital Admissions: Last Year of Life – Total Sample

Table 3.19: Number of Admissions

Number of Admissions in Last Year of Life (n=695)	N (%)
1 (Final Admission)	227 (32.7)
2-3	356 (51.2)
4-5	85 (12.2)
6+	27 (3.9)
Median (Range)	2 (1-15)

- For 227 (32.7%) patients, their final admission was their only admission within their last year of life.
- The median number of hospital admissions was 2 (IQR 2) in that last year.

Table 3.20: Prior Hospital Admissions by Preferred Place of Death, Demographics and Medical Information

Preferred Place of Death, Demographics and Medical Information	Prior Admissions in Last Year of Life		p
	Yes	No	
Preferred Place of Death			
Home	113 (24.1)	60 (26.4)	0.63
Hospital	23 (4.9)	13 (5.7)	
Hospice/Palliative Care Unit	31 (6.6)	10 (4.4)	
Nursing Home	22 (4.7)	11 (4.8)	
Not Recorded	279 (59.6)	133 (58.6)	
Age			
≤45	21 (4.5)	6 (2.6)	0.001*
46-60	70 (15.0)	19 (8.4)	
61-70	114 (24.4)	45 (19.8)	
71-80	161 (34.4)	76 (33.5)	
≥81	102 (21.8)	81 (35.7)	
Gender			
Male	256 (54.7)	115 (50.7)	0.32
Female	212 (45.3)	112 (49.3)	
Marital Status			
Partnered	278 (59.4)	103 (45.4)	0.001*
Not Partnered	189 (40.4)	123 (54.2)	
Unknown	1 (0.2)	1 (0.4)	
Cancer Diagnosis			
Digestive Organs	134 (28.6)	48 (21.1)	0.009*
Respiratory and Intrathoracic Organs	112 (23.9)	58 (25.6)	
Breast	28 (6.0)	30 (13.2)	
Female Genital Organs	23 (4.9)	12 (5.3)	
Male Genital Organs	30 (6.4)	8 (3.5)	
Other	141 (30.1)	71 (31.3)	
Socioeconomic Status			
Quintile 1 (Most Deprived)	118 (25.2)	46 (20.3)	0.07
Quintile 2	116 (24.8)	42 (18.5)	
Quintile 3	75 (16.0)	50 (22.0)	
Quintile 4	79 (16.9)	44 (19.4)	
Quintile 5 (Least Deprived)	80 (17.1)	44 (19.4)	
Unknown	0	1 (0.4)	
Geographical Location			
Urban	330 (70.5)	162 (71.4)	0.34
Rural	138 (29.5)	64 (28.2)	
Unknown	0	1 (0.4)	
Co-Morbidities			
0	60 (12.8)	24 (10.6)	0.20
1	143 (30.6)	57 (25.1)	
2	143 (30.6)	72 (31.7)	
≥3	122 (26.1)	74 (32.6)	
Total	468 (67.3)	227 (32.7)	

Note: * Significant at the $p \leq 0.05$ Level (Chi-Square analysis).

Note: Missing data was removed for Chi-Square analysis.

Note: Nursing home includes residential and care homes.

- Patients 81 years or older were more commonly noted to have only one (final) hospital admission in the last year of life, whereas patients who were 45 years or younger were those most commonly admitted 4 or more

times in the past year. Patients who were partnered were also more commonly observed to have multiple admissions.

- Similar to patients diagnosed on their last admission, patients who had no prior admissions were significantly older (77 years) than those with prior admissions (72 years; $p < 0.001$).
- Patients with cancers of the male genital organs (78.9%) and digestive organs (73.6%) had the highest percentages of prior admissions in their last year of life, whereas breast cancer (48.3%) patients had the lowest. The differences observed with previous admissions and cancer diagnosis were significant ($p = 0.009$).

Table 3.21: Hospital Bed Days in Last Year of Life by Hospital and Health and Social Care Trust

Hospital and Health and Social Care Trust (HSCT)	Bed Days Last Year of Life (n=695)		
	Median	IQR	Range
Belfast HSCT	23	32	0-233
Belfast City Hospital	25	34	0-165
Northern Ireland Cancer Centre	20	28	0-142
Royal Victoria Hospital	21	34	2-233
Mater Infirmorum Hospital	25	31	0-179
Northern HSCT	18	22	0-97
Antrim Area Hospital	18	20	1-86
Causeway Hospital	14	23	0-81
Whiteabbey Hospital	23	31	5-87
Mid-Ulster Hospital	19	32	2-97
Western HSCT	20	19	1-87
Altnagelvin Hospital	20	18	1-87
Erne Hospital	18	22	1-84
Tyrone County Hospital	20	18	4-44
Southern HSCT	22	25	0-147
Craigavon Area Hospital	22	31	0-147
Daisy Hill Hospital	22	24	2-99
South Eastern HSCT	24	24	0-153
Ulster Hospital	25	25	1-153
Lagan Valley Hospital	20	20	5-53
Downe Hospital	22	30	0-55
Northern Ireland	21	25	0-233

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

- Cancer patients spent a median of 21 (IQR 25) days in hospital in their last year of life, with 11 (IQR 18) during their last admission (Table 3.21). The pattern by Trust reflects patient numbers and case mix.
- Hospital bed days in patients' last year of life were compared by age, gender, marital status, geographical location, socioeconomic status and cancer diagnosis. Significant differences were only observed in relation to marital status. Patients who were not partnered had spent significantly more days in hospital in their last year of life (25, IQR 30) than patients who were partnered (20, IQR 24; $p = 0.004$).
- Total hospital bed days (patients last year of life) by HSSB are tabled in Appendix II (v).

3.3 The Liverpool Care Pathway for the Dying Patient

The Liverpool Care Pathway (LCP)² for the dying patient was developed by the Specialist Palliative Care Team at the Royal Liverpool and Broadgreen University Hospitals NHS Trust and the Marie Curie Hospice, Liverpool in 1997. The aim of the LCP is to ensure that dying patients and their relatives and carers are provided with a high standard of care in the last hours and days of life. The LCP is used when the multidisciplinary team has agreed that the patient is dying and all reversible causes for the current situation have been considered. It enables healthcare professionals to focus on patient care and to stop, think, assess and change care appropriately for each individual patient and their family. All care plans are reviewed and inappropriate interventions are stopped, particularly when these outweigh the benefits (Marie Curie Palliative Care Institute, 2010). The results presented in the following tables relate to the initiation of the LCP for patients' final admission only.

3.3.1 Liverpool Care Pathway

Table 3.22 (a): Liverpool Care Pathway by Hospital and Health and Social Care Trust – Total Sample

Hospital and Health and Social Care Trust (HSCT)	Liverpool Care Pathway in Place? N (%)		
	Yes	No	Total
Belfast HSCT	154 (58.3)	110 (41.7)	264 (38.0)
Belfast City Hospital	56 (56.0)	44 (44.0)	100
Northern Ireland Cancer Centre	46 (67.6)	22 (32.4)	68
Royal Victoria Hospital	26 (51.0)	25 (49.0)	51
Mater Infirmorum Hospital	26 (57.8)	19 (42.2)	45
Northern HSCT	66 (57.9)	48 (42.1)	114 (16.4)
Antrim Area Hospital	31 (48.4)	33 (51.6)	64
Causeway Hospital	17 (77.3)	5 (22.7)	22
Whiteabbey Hospital	8 (72.7)	3 (27.3)	11
Mid-Ulster Hospital	10 (58.8)	7 (41.2)	17
Western HSCT	52 (48.1)	56 (51.9)	108 (15.5)
Altnagelvin Hospital	32 (47.1)	36 (52.9)	64
Erne Hospital	12 (41.4)	17 (58.6)	29
Tyrone County Hospital	8 (72.7)	3 (27.3)	11
Southern HSCT	37 (40.7)	54 (59.3)	91 (13.1)
Craigavon Area Hospital	37 (56.1)	29 (43.9)	66
Daisy Hill Hospital	0	25 (100)	25
South Eastern HSCT	77 (65.3)	41 (34.7)	118 (17.0)
Ulster Hospital	63 (70.0)	27 (30.0)	90
Lagan Valley Hospital	8 (47.1)	9 (52.9)	17
Downe Hospital	6 (54.5)	5 (45.5)	11
Northern Ireland	386 (55.5)	309 (44.5)	695

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

Note: At the time of data collection, the Liverpool Care Pathway, facilitators and staff training was not in place within the Southern Health and Social Care Trust and was not fully implemented in the Western Health and Social Care Trust.

- The Liverpool Care Pathway (LCP) was in place for 386 (55.5%) patients. Of those identified as dying and entered onto the LCP, PPD was recorded for 176 (45.6%) patients.

² Also known as the Care Pathway for the Dying, Care of the Dying Pathway, or Integrated Care Pathway for the Dying Phase.

- Implementation of the LCP varied significantly across Trusts ($p=0.003$) in some ways reflecting the stage of implementation at the time of the study.
- The Causeway Hospital had the highest percentage of patients on the LCP at 77.3%. This was followed by Whiteabbey Hospital (72.7%), Tyrone County Hospital (72.7%), the Ulster Hospital (70.0%) and the Northern Ireland Cancer Centre (67.6%). Daisy Hill Hospital had no patients on the LCP and the Southern Health and Social Care Trust had the lowest percentage of patients entered onto the LCP, this however was related to funding for the implementation of the LCP (See table footnote above).
- With the exception of the Southern HSCT, the Erne, Altnagelvin and Lagan Valley Hospitals had the lowest percentage of patients on the LCP (41.4%, 47.1% and 47.1%, respectively).
- Appendix II (vi) outlines the LCP by HSSB for the total sample.

Table 3.22 (b): Liverpool Care Pathway by Health and Social Care Trust - Excluding Patients Diagnosed on Last Admission

Health and Social Care Trust (HSCT)	Liverpool Care Pathway in Place? N (%)		
	Yes	No	Total
Belfast HSCT	112 (58.3)	80 (41.7)	192 (37.5)
Northern HSCT	53 (63.1)	31 (36.9)	84 (16.4)
Western HSCT	44 (48.9)	46 (51.1)	90 (17.6)
Southern HSCT	27 (42.9)	36 (57.1)	63 (12.3)
South Eastern HSCT	51 (61.4)	31 (38.6)	83 (16.1)
Northern Ireland	287 (56.1)	225 (43.9)	512

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

Note: At the time of data collection, the Liverpool Care Pathway, facilitators and staff training was not in place within the Southern Health and Social Care Trust and was not fully implemented in the Western Health and Social Care Trust.

- The 183 (26.3%) patients who were diagnosed on their last admission were removed from the analysis in Table 3.22 (b). This however did not greatly alter the percentage of patients on the LCP. Overall, the percentage increased by 1.1%.
- On an individual HSCT level, percentages were also similar. Removing those diagnosed on their last admission increased the percentage of patients on the LCP within the Northern HSCT by 5.2% and decreased the percentage within the South Eastern HSCT by 3.9%.
- Differences in the implementation of the LCP across HSCTs remained significant ($p=0.05$).

3.3.2 Investigations and Interventions

Data were not collected on when patients had entered onto the LCP and the information below most likely relates to pre-commencement and was used to inform clinicians' decision to enter patients onto the pathway.

Table 3.23: Investigations Conducted with Patients on and not on the Liverpool Care Pathway

Total Investigations	Liverpool Care Pathway		p
	On LCP (n=386) N (%)	Off LCP (n=309) N (%)	
Investigations During Last Admission			
None	6 (1.6)	4 (1.3)	
1-3	137 (35.5)	144 (46.6)	
4-6	202 (52.3)	140 (45.3)	
7+	41 (10.6)	21 (6.8)	0.02*
Main Investigations			
Blood Tests	369 (95.6)	295 (95.5)	0.94
Chest X-Ray	318 (82.4)	258 (83.5)	0.70
ECG	294 (76.2)	253 (81.9)	0.07
CT Scan	178 (46.1)	110 (35.6)	0.005*
Abdominal US	112 (29.0)	59 (19.1)	0.003*
Abdominal X-Ray	107 (27.7)	80 (25.9)	0.59
OGD	35 (9.1)	29 (9.4)	0.89
Pleural Tap	27 (7.0)	8 (2.6)	0.008*
MRI	24 (6.2)	12 (3.9)	0.17
Bone Scan	18 (4.7)	15 (4.9)	0.91
Bronchoscopy	6 (1.6)	11 (3.6)	0.09
PET Scan	4 (1.0)	1 (0.3)	0.27
Other Investigations	115 (29.8)	81 (26.2)	0.30

Note: * Significant at the $p \leq 0.05$ Level (Chi-Square analysis).

- Interventions and investigations for patients on and off the LCP were compared for differences (Table 3.23). Patients who were on the LCP had significantly more investigations on their last admission than those who were not on the pathway ($p=0.02$).
- Patients both on and off the LCP had similar investigations with the exception of CT scans, abdominal ultrasounds and pleural taps. A significantly higher percentage of patients on the LCP had undergone these investigations ($p=0.005$, $p=0.003$ and $p=0.008$ respectively).

Table 3.24: Timing of Investigations Before Death

Investigations	Days Before Death		p
	On LCP (n=386) Median (IQR)	Off LCP (n=309) Median (IQR)	
Abdominal X-Ray	13 (15)	7 (15)	0.004*
Chest X-Ray	13 (18)	6 (15)	<0.001*
MRI	18 (17)	19 (21)	1.0
CT Scan	13 (15)	6 (13)	<0.001*
US Scan	16 (19)	12 (17)	0.01*
ECG	13 (18)	6 (15)	<0.001*
Blood Tests	14 (17)	7 (16)	<0.001*
Pleural Tap	12 (28)	8 (7)	0.4
Bone Scan	13 (11)	7 (13)	0.09*
OGD	18 (16)	13 (16)	0.01*
Bronchoscopy	25 (18)	5 (8)	0.007*

Note: PET scan data was omitted due to small numbers.

Note: *Significant at the $p \leq 0.05$ Level (Mann-Whitney U Test).

- As expected, Table 3.24 demonstrates that on average, patients on the LCP had their last investigation much longer before death than those who were not on the LCP. This was highly significant in relation to chest x-rays, CT scans, ECGs and blood tests ($p < 0.001$) and would again indicate that all unnecessary investigations were withdrawn once the patient entered onto the LCP.

Table 3.25: Interventions

Data were not collected on when patients had entered onto the LCP and the data below could relate to the time prior to patients entering onto the LCP.

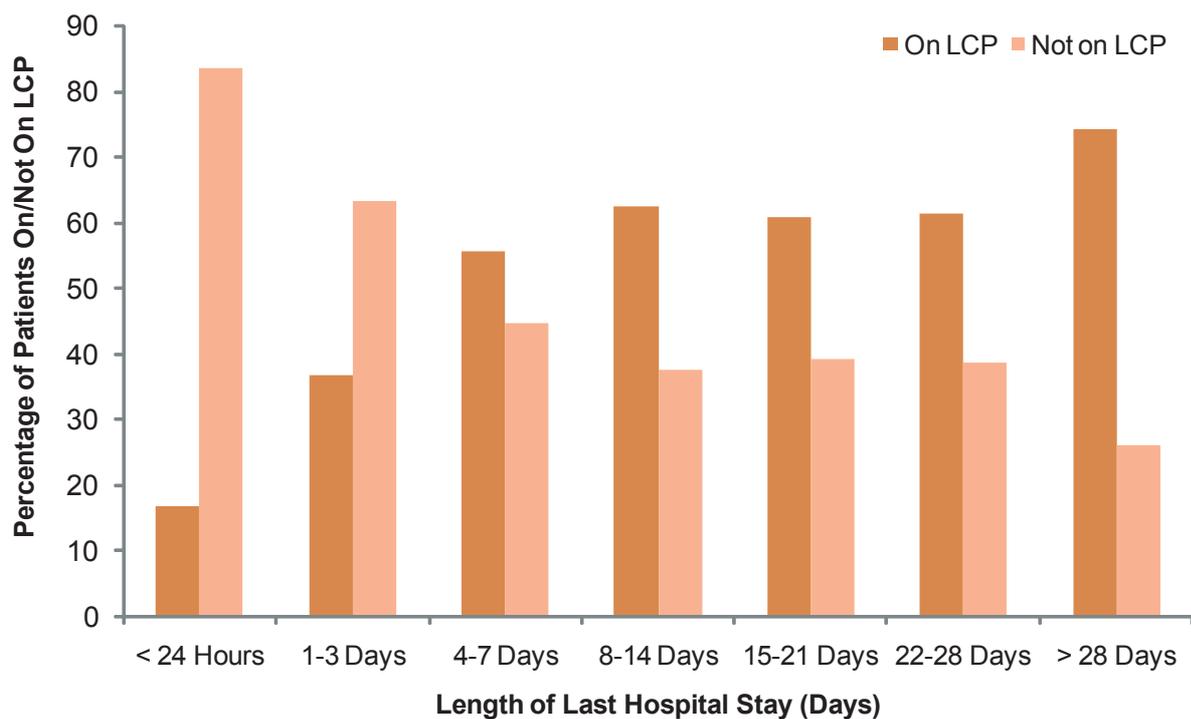
Total Interventions	Liverpool Care Pathway (LCP)		p
	On LCP (n=386) N (%)	Off LCP (n=309) N (%)	
Interventions During Last Admission			
None	0	3 (1.0)	
1	14 (3.6)	14 (4.5)	
2	58 (15.0)	55 (17.8)	
3	134 (34.7)	108 (35.0)	
4	110 (28.5)	79 (25.6)	
5+	70 (18.1)	50 (16.2)	0.32
Main Interventions			
IV Fluids	353 (91.5)	279 (90.3)	0.60
Controlled Drugs	352 (91.2)	225 (72.8)	<0.001*
Regular Oxygen	304 (78.8)	255 (82.5)	0.21
Blood Transfusion	97 (25.1)	73 (23.6)	0.65
Resuscitation	7 (1.8)	32 (10.4)	<0.001*
Surgery	26 (6.7)	18 (5.8)	0.62
Artificial Feeding	29 (7.5)	27 (8.7)	0.56
Ventilation	6 (1.6)	22 (7.1)	<0.001*
Chemotherapy	15 (3.9)	12 (3.9)	0.99
Radiotherapy	25 (6.5)	9 (2.9)	0.03*
Paracentesis	20 (5.2)	8 (2.6)	0.08
Other Treatments	113 (29.3)	80 (25.9)	0.32

Note: * Significant at the $p \leq 0.05$ Level (Chi-Square analysis).

- Table 3.25 compares interventions by patients on and off the LCP for the total sample. A significantly higher percentage of patients on the LCP were prescribed controlled drugs (91.2%) compared to those who were not on the LCP (72.8%; $p < 0.001$). There was also a significantly higher percentage who had undergone radiotherapy on their last admission (6.5%; $p = 0.03$).
- As expected, a significantly lower percentage of patients on the LCP had been resuscitated and ventilated ($p < 0.001$).
- There was no difference between patients who were on the LCP and those who were not in relation to the number of interventions.
- It is worthy to note that a total of 25.5% of patients on the LCP were diagnosed on their last admission.

3.3.3 Length of Stay on Last Hospital Admission

Figure 3.4: Length of Stay on Last Hospital Admission for Patients on and off the Liverpool Care Pathway



- There were significant differences in the length of stay in relation to those who were on and who were not on the LCP.
- The median length of stay for patients on the LCP was 14 (IQR 17) days, whereas it was 7 (IQR 15; $p < 0.001$) days for those not on the LCP.
- Figure 3.4 demonstrates that as duration of stay increased, the percentage of those on the LCP also increased. Pearson product-moment correlation co-efficient indicates that there is a significant small ($r = 0.28$; $p < 0.001$) positive correlation between the LCP and the duration of last hospital stay. This most likely relates

to there being greater time to identify that patients are entering into the dying phase of end of life as opposed to the prolonging of life.

3.4 Specialist Palliative Care Involvement and Multidisciplinary Team Meetings

3.4.1 Specialist Palliative Care

Table 3.26 (a): Hospital Specialist Palliative Care by Hospital and Health and Social Care Trust – Total Sample

Hospital and Health and Social Care Trust (HSCT)	Specialist Palliative Care Involved in Hospital N (%)		
	Yes	No	Total
Belfast HSCT	170 (64.4)	94 (35.6)	264 (38.0)
Belfast City Hospital	57 (57.0)	43 (43.0)	100
Northern Ireland Cancer Centre	49 (72.1)	19 (27.9)	68
Royal Victoria Hospital	31 (60.8)	20 (39.2)	51
Mater Infirmorum Hospital	33 (73.3)	12 (26.7)	45
Northern HSCT	75 (65.8)	39 (34.2)	114 (16.4)
Antrim Area Hospital	40 (62.5)	24 (37.5)	64
Causeway Hospital	14 (63.6)	8 (36.4)	22
Whiteabbey Hospital	7 (63.6)	4 (36.4)	11
Mid-Ulster Hospital	14 (82.4)	3 (17.6)	17
Western HSCT	79 (73.1)	29 (26.9)	108 (15.5)
Altnagelvin Hospital	48 (70.6)	20 (29.4)	68
Erne Hospital	21 (72.4)	8 (27.6)	29
Tyrone County Hospital	10 (90.9)	1 (9.1)	11
Southern HSCT	59 (64.8)	32 (35.2)	91 (13.1)
Craigavon Area Hospital	41 (62.1)	25 (37.9)	66
Daisy Hill Hospital	18 (72.0)	7 (28.0)	25
South Eastern Health HSCT	83 (70.3)	35 (29.7)	118 (17.0)
Ulster Hospital	60 (66.7)	30 (33.3)	90
Lagan Valley Hospital	16 (94.1)	1 (5.9)	17
Downe Hospital	7 (63.6)	4 (35.4)	11
Northern Ireland	466 (67.1)	229 (32.9)	695

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

Note: These results represent only what was recorded in patients' medical notes. Specialist palliative care may have been provided but no record made.

- A total of 67.1% (n=466) of patients had a record of having received specialist palliative care in hospital. See Table 3.26 (a).
- The Western HSCT and the South Eastern HSCT had the highest percentages of specialist palliative care involvement in a hospital setting (73.1% and 70.3%, respectively). No significant differences were observed across Trusts.
- Appendix II (vii) outlines specialist palliative care involvement in hospital by HSSB for the total sample.

Table 3.26 (b): Hospital Specialist Palliative Care by Health and Social Care Trust – Excluding Patients Diagnosed on Last Admission

Health and Social Care Trust (HSCT)	Specialist Palliative Care Involved in Hospital N (%)		
	Yes	No	Total
Belfast HSCT	124 (64.6)	68 (35.4)	192 (37.5)
Northern HSCT	59 (70.2)	25 (29.8)	84 (16.4)
Western HSCT	66 (73.3)	24 (26.7)	90 (17.6)
Southern HSCT	44 (69.8)	19 (30.2)	63 (12.3)
South Eastern Health HSCT	59 (71.1)	24 (28.9)	83 (16.2)
Northern Ireland	352 (68.8)	160 (31.2)	512

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

Note: These results represent only what was recorded in patients' medical notes. Specialist palliative care may have been provided but no record made.

- In Table 3.26 (b) above, patients diagnosed on their last admission were removed from the analysis (n=183). Overall, this did not greatly affect the percentage of patients receiving specialist palliative care in hospital, with an increase of 1.7%.
- On an individual HSCT level, for this subsample of patients, there were small increases in the percentages of patients receiving specialist palliative care within the Northern HSCT (+4.4%) and the Southern HSCT (+5.0%).

Table 3.27: Home Specialist Palliative Care Involvement by Hospital and Health and Social Care Trust – Excluding Patients Diagnosed on Last Admission

Hospital and Health and Social Care Trust (HSCT)	Home Specialist Palliative Care N (%)		
	Yes	No	Total
Belfast HSCT	76 (39.6)	116 (60.4)	192 (37.5)
Belfast City Hospital	27 (38.6)	43 (61.4)	70
Northern Ireland Cancer Centre	30 (45.6)	36 (54.4)	66
Royal Victoria Hospital	6 (17.6)	28 (82.4)	34
Mater Infirmorum Hospital	13 (59.1)	9 (40.9)	22
Northern HSCT	22 (26.2)	62 (73.8)	84 (16.4)
Antrim Area Hospital	15 (32.6)	31 (67.4)	46
Causeway Hospital	3 (17.6)	14 (82.4)	17
Whiteabbey Hospital	2 (25.0)	6 (75.0)	8
Mid-Ulster Hospital	2 (15.4)	11 (84.7)	13
Western HSCT	47 (52.2)	43 (47.8)	90 (17.6)
Altnagelvin Hospital	26 (51.0)	25 (49.0)	51
Erne Hospital	11 (39.3)	17 (60.7)	28
Tyrone County Hospital	10 (90.9)	1 (9.1)	11
Southern HSCT	27 (42.9)	36 (57.1)	63 (12.3)
Craigavon Area Hospital	25 (51.0)	24 (49.0)	49
Daisy Hill Hospital	2 (14.3)	12 (85.7)	14
South Eastern HSCT	31 (37.3)	52 (62.7)	83 (16.2)
Ulster Hospital	25 (40.3)	37 (59.7)	62
Lagan Valley Hospital	6 (50.0)	6 (50.0)	12
Downe Hospital	0	9 (100)	9
Northern Ireland	203 (39.6)	309 (60.4)	512

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

Note: These results represent only what was recorded in patients' medical notes. Specialist palliative care may have been provided at home, but no record made.

- A total of 39.6% (n=203) of patients (with a known cancer diagnosis) had specialist palliative care involvement at home/nursing home or community setting (Table 3.27). Patients were attended by the specialist palliative care team a median of 6 (IQR 11) days prior to death.
- Palliative care at home varied significantly by HSCT ($p < 0.001$). Just over half (52.2%) of the patients within the Western HSCT had specialist palliative care at home. The Trust with the least patients receiving palliative care at home was the Northern HSCT, with 26.2%.
- Appendix II (viii) displays home specialist palliative care involvement by HSSB for those with a known cancer diagnosis, while Appendix II (ix) outlines home specialist palliative care by Local Government district for those with a known cancer diagnosis.

3.4.2 Multidisciplinary Team Meetings: Last Year of Life

Table 3.28 (a): Multidisciplinary Team Meetings by Hospital and Health and Social Care Trust – Total Sample

Hospital and Health and Social Care Trust (HSCT)	Discussed at Multidisciplinary Team Meeting? N (%)		
	Yes	No	Total
Belfast HSCT	111 (42.0)	153 (58.0)	264 (38.0)
Belfast City Hospital	46 (46.0)	54 (54.0)	100
Northern Ireland Cancer Centre	28 (41.2)	40 (58.8)	68
Royal Victoria Hospital	24 (47.1)	27 (52.9)	51
Mater Infirmorum Hospital	13 (28.9)	32 (71.1)	45
Northern HSCT	30 (26.3)	84 (73.7)	114 (16.4)
Antrim Area Hospital	16 (25.0)	48 (75.0)	64
Causeway Hospital	7 (31.8)	15 (68.2)	22
Whiteabbey Hospital	3 (27.3)	8 (72.7)	11
Mid-Ulster Hospital	4 (23.5)	13 (76.5)	17
Western HSCT	67 (62.0)	41 (38.0)	108 (15.5)
Altnagelvin Hospital	51 (75.0)	17 (25.0)	68
Erne Hospital	13 (44.8)	16 (55.2)	29
Tyrone County Hospital	3 (27.3)	8 (72.7)	11
Southern HSCT	36 (39.6)	55 (60.4)	91 (13.1)
Craigavon Area Hospital	32 (48.5)	34 (51.5)	66
Daisy Hill Hospital	4 (16.0)	21 (84.0)	25
South Eastern HSCT	40 (33.9)	78 (66.1)	118 (17.0)
Ulster Hospital	28 (31.1)	62 (68.9)	90
Lagan Valley Hospital	10 (58.8)	7 (41.2)	17
Downe Hospital	2 (18.2)	9 (81.8)	11
Northern Ireland	284 (40.9)	411 (59.1)	695

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

- Discussion at an oncology Multidisciplinary Team (MDT) meeting during their last year of life was recorded for 40.9% (n=284) of patients. A total of 54.6% (n=155) of these patients were discussed at an oncology MDT during their last admission.
- MDT meetings varied significantly ($p < 0.001$) by Trust with the Western HSCT having the highest percentage (62.0%) and the Northern HSCT the lowest (26.3%). This reflects the status of MDT implementation in Northern Ireland in 2007.

Table 3.28 (b): Multidisciplinary Team Meetings by Health and Social Care Trust – Excluding Patients Diagnosed on Last Admission

Health and Social Care Trust (HSCT)	Discussed at Multidisciplinary Team Meeting? N (%)		
	Yes	No	Total
Belfast HSCT	79 (41.1)	113 (58.9)	192 (37.5)
Northern HSCT	23 (27.4)	61 (72.6)	84 (16.4)
Western HSCT	58 (64.4)	32 (35.6)	90 (17.6)
Southern HSCT	26 (41.3)	37 (58.7)	63 (12.3)
South Eastern HSCT	32 (38.6)	51 (61.4)	83 (16.2)
Northern Ireland	218 (42.6)	294 (57.4)	512

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

- In Table 3.28 (b) patients diagnosed on their last admission were removed from the analysis (n=183). Overall, this increased the percentage of patients discussed at an oncology MDT meeting by 1.7%.
- Significant (p=<0.001) differences in the percentage of patients discussed at an oncology MDT remained across HSCT. On an individual HSCT level, the highest percentage increase in patients discussed at a MDT meeting was within the South Eastern HSCT (+4.7%).
- Multidisciplinary Team Meetings by HSSB for those with a known cancer diagnosis prior to last hospital admission is tabulated in Appendix II (x).

Table 3.29: Discussed at Multidisciplinary Team Meeting by Health and Social Care Trust: Weeks Before Death

Health and Social Care Trust (HSCT)	Discussed at Multidisciplinary Team Meeting: Weeks Before Death (n=218)		
	Median	IQR	Range
Belfast HSCT	15	28	0-310
Northern HSCT	5	16	0-73
Western HSCT	9	48	0-182
Southern HSCT	4	24	0-81
South Eastern HSCT	3	9	0-45
Northern Ireland	7	25	0-310

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

- Patients were discussed at a MDT meeting a median of 7 (IQR 25) weeks prior to death. This varied significantly by Trust (p=0.02).

3.5 Do Not Attempt Resuscitation Orders

Table 3.30 (a): Do Not Attempt Resuscitation Order by Health and Social Care Trust – Total Sample

Health and Social Care Trust (HSCT)	Do Not Attempt Resuscitation Order in Place? N (%)		
	Yes	No	Total
Belfast HSCT	241 (91.3)	23 (8.7)	264 (38.0)
Northern HSCT	101 (88.6)	13 (11.4)	114 (16.4)
Western HSCT	101 (93.5)	7 (6.5)	108 (15.5)
Southern HSCT	82 (90.1)	9 (9.9)	91 (13.1)
South Eastern HSCT	108 (91.5)	10 (8.5)	118 (17.0)
Northern Ireland	633 (91.1)	62 (8.9)	695

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

Note: DNAR=Do Not Attempt Resuscitation Order. An order for which patients/their next of kin have consented that the medical team should not attempt to resuscitate the patient in the event of sudden cardiac or respiratory arrest.

- DNAR orders were in place for 633 (91.1%) patients, with no significant differences being observed across Trusts. See Table 3.30 (a)
- DNAR orders by HSSB for the total sample are presented in Appendix II (xi).

Table 3.30 (b): Do Not Attempt Resuscitation Order by Health and Social Care Trust – Excluding Patients Diagnosed on Last Admission

Health and Social Care Trust (HSCT)	Do Not Attempt Resuscitation Order in Place? N (%)		
	Yes	No	Total
Belfast HSCT	174 (90.6)	18 (9.4)	192 (37.5)
Northern HSCT	73 (86.9)	11 (13.1)	84 (16.4)
Western HSCT	83 (92.2)	7 (7.8)	90 (17.6)
Southern HSCT	55 (87.3)	8 (12.7)	63 (12.3)
South Eastern HSCT	75 (90.4)	8 (9.6)	83 (16.2)
Northern Ireland	460 (89.8)	52 (10.2)	512

Note: Results are presented by Health and Social Care Trust (HSCT) which came into effect in April 2007. Patients were thus treated under both the former Health and Social Services Board (HSSB) structure and the new HSCT structure. Under that structure, the Belfast HSCT and the South-Eastern HSCT were part of the Eastern HSSB while the Northern, Western and Southern HSCTs were the same as the Northern, Western and Southern HSSBs respectively.

Note: DNAR=Do Not Attempt Resuscitation Order. An order for which patients/their next of kin have consented that the medical team should not attempt to resuscitate the patient in the event of cardiac failure.

- Overall, excluding patients diagnosed on last admission from the analysis (n=183) decreased the percentage of patients with a DNAR order by 1.3%. See Table 3.30 (b). No significant differences existed across HSCT.

3.6 Distance from Usual Residence to Nearest Hospice

Figure 3.5: Miles from Usual Residence to Nearest Hospice – Excluding Patients Diagnosed on Last Admission

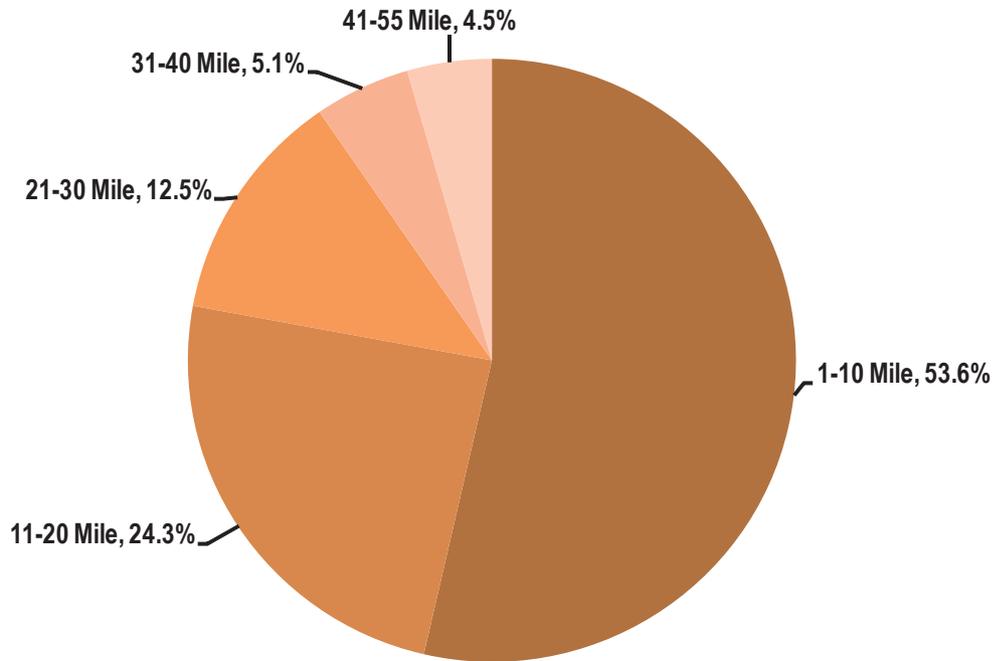


Table 3.31: Specialist Palliative Care at Home by Distance to Nearest Hospice - Excluding Patients Diagnosed on Last Admission

Usual Residence to Hospice (Miles)	Received Specialist Palliative Care at Home N (%)		Total N (%)
	Yes	No	
1-10	110 (40.1)	164 (59.9)	274 (53.6)
11-20	50 (40.3)	74 (59.7)	124 (24.3)
21-30	22 (34.4)	42 (65.6)	64 (12.5)
31-40	14 (53.8)	12 (46.2)	26 (5.1)
41-55	7 (30.4)	16 (69.6)	23 (4.5)
Total	203 (39.6)	309* (60.4)	512*

Note: Distance from usual residence to nearest hospice (Newry, Foyle, Northern Ireland or Marie Curie Hospice) was calculated using postcode data.

Note: *Postcode missing for n=1.

- The median distance from patients usual residence to the nearest hospice was 9.4 (IQR=16) miles and 53.6% of patients lived within 10 miles of a hospice and 90.4% within 30 miles.
- Specialist palliative care at home was provided for 39.6% of patients. Differences in the provision of palliative care by distance from usual residence to hospice was not significant.

SECTION 4 - SUMMARY OF FINDINGS

4.1 Background Cancer Mortality and Place of Death Statistics

Currently, 27% of deaths in Northern Ireland are due to cancer. However, taking into account our ageing population, cancer deaths have declined from 222 per 100,000 persons in 1983 to 195 per 100,000 persons in 2008.

The proportion of cancer patients dying at home has decreased significantly from 38.1% (1983-1992) to 32.1% in 2003-2007 ($p < 0.001$).

Cancer deaths occurring at home varied significantly across Local Government Districts and ranged from 24.0% in Newtownabbey to 46.9% in Magherafelt ($p < 0.001$). There was a similar significant variability in the proportion of hospital deaths by Local Government District, which ranged from 32.3% in Newry and Mourne to 62.9% in Ballymoney ($p < 0.001$).

A cancer death at home was more likely for males, patients that were partnered, patients from more deprived backgrounds and younger patients.

4.2 Study Patients' Characteristics

A total of 793 cancer patients died in hospital in the last 6 months of 2007. The 695 cancer patients included in this study died within 1 of 16 acute hospitals across Northern Ireland, representing all Health and Social Care Trusts.

The median age of cancer patients who died in hospital was 74 (IQR 17) years and 53.4% were male. Just over half (54.7%) were partnered and the highest percentage (46.4%) of patients were from more deprived areas (40% would be expected if equal among all socioeconomic groups).

The majority of patients had been diagnosed with cancers of the digestive organs (26.2%) or respiratory & intrathoracic organs (24.5%). Breast cancer patients represented 8.3%, cancers of the male genital organs 5.5% and cancers of the female genital organs accounted for 5.0% of the sample.

Although staging in general was poorly recorded within patients' medical notes, 63.2% had either a first or last stage recorded for their cancer. At best staging, 82.0 % had Stage IV disease.

The median time from diagnosis to death was 4 months, with 30.2% dying within 1 month of diagnosis. Patients that died within 1 month of diagnosis were significantly older than the rest of the sample ($p < 0.001$).

4.3 Hospital Admission

46.2% of patients were admitted to hospital by a G.P. and 78.7% as an emergency. A total of 47.5% of patients were admitted outside of G.P. practice hours.

Patients had multiple symptoms (median of 4) on admission which were most commonly pain (48.3%), breathlessness (40.9%), anorexia (40.4%) and nausea/vomiting (33.8%).

Patients were admitted with cancer-related (37.4%) or urgent physical (33.5%) symptoms, for further investigations/precautions (10.6%), for treatment (10.4%), treatment-related symptoms (3.2%), for palliative care (3.0%), urgent social needs (1.2%) or for rehabilitation (0.7%).

The median age of patients admitted as an emergency was 74 years. This was significantly older than those with a non-emergency/planned admission (70 years). In addition, a significantly higher percentage was not partnered (47.2%).

Of the patients admitted as an emergency, 54.5% were referred by a G.P. and almost half of these (49.9%) within G.P. practice hours.

65.9% of admissions that were patient/family referrals were out of G.P. practice hours with one third (33.3%) over a weekend/public holiday.

10.1% of patients (n=70) were admitted from a nursing home. 74.3% of those admitted from a nursing home were admitted on a weekday and 52.9% within G.P practice hours. Most were either referred by a G.P. (44.3%) or nursing home staff (40.0%). Reasons for admission were mainly urgent physical (62.9%).

In general, patients had routine investigations and interventions on their last hospital admission, with only a very small percentage of patients undergoing chemotherapy (3.9%) or radiotherapy (4.9%).

10.4% patients (n=72) had surgery within their last year of life, a median of 19 days before death. 44 out of the 72 patients had surgery during their last admission, a median of 10 days before death. 16 of these patients were diagnosed on their last admission.

Surgical interventions were mainly for symptom control (43.2%), diagnosis/treatment of cancer (38.6%), or fracture repair (18.2%).

On last admission, patients had a median length of stay of 11 (range 0-233) days. Patients admitted as an emergency died sooner than those with a non-emergency/planned hospital admission and thus had a significantly shorter length of stay (10 days) than those with a non-emergency/planned admission (13 days).

Median length of stay from admission until death for patients admitted from a nursing home was 9 (IQR 17) days.

The median number of hospital admissions within the last year of life was 2. However, for 227 (32.7%) patients, their final admission was their only admission that year. These patients were more commonly partnered and significantly older (77 years) than those with previous admissions (72 years). Patients with cancers of the male genital organs and digestive organs had the highest percentages of previous admissions in the last year of life, whereas patients with breast cancer had the lowest.

On average, patients spent a median of 21 days in hospital in their last year of life and there were no significant differences observed by hospital or Trust.

Patients who were not partnered had spent significantly more days in hospital in their last year of life (25 days) than patients who were partnered (20 days).

4.4 Recording of Preferred Place of Death

Overall, preferred place of death (PPD) was recorded for 283 (40.7%) patients (39.1% when excluding those diagnosed with cancer on last admission), with no significant differences between Trusts.

Where recorded, 61.1% preferred to die at home, 14.5% in a hospice, 12.7% in hospital and 11.7% in a nursing home (which is often the patient's home). The majority (66.0%) of patients admitted from a nursing home indicated that the nursing home was their PPD.

Home was therefore the PPD for the majority. The only significant differences observed, were in relation to age group. As patients got older, the percentage preference for a nursing home death increased, particularly for those aged 81 years or older. This however may be classed as home for more elderly patients. Younger patients (60 years or younger) had the highest percentage preference for a hospital death.

A total of 266 (38.3%) patients who died in hospital, had specifically requested to be discharged to their usual residence, hospice or other hospital. For three quarters (76.3%) of cases, their condition deteriorated and discharge was not possible. There was a lack of suitable beds for 12.4% and the necessary care package was not in place for 4.9%. 3.0% lacked the required family support to enable them to return to their usual residence.

4.5 Deaths within 48 Hours of Hospital Admission

During the study period (July-December, 2007), 14% (n=98) of cancer patients died in hospital within 48 hours of admission. These patients had cancers of the respiratory and intrathoracic organs (30.6%), digestive organs (24.5%), male genital organs (9.2%), female genital organs (6.1%), breast (2.0%) and other cancers (27.6%).

The median age of those that died within 48 hours of admission was 71 years, which was not statistically different from the remaining sample.

A significantly higher percentage of these patients experienced breathlessness (53.1%) and were not partnered (70.1%) compared to the rest of the sample.

Patients had a median of 4 investigations and 3 interventions within their last 48 hours of life. These were generally routine investigations and interventions. The last chemotherapy session was a median of 6 (IQR 9) weeks prior to death and 8 (IQR 23) weeks for last radiotherapy. 2 patients had chemotherapy one day prior to death, 1 patient had radiotherapy and 1 patient had surgery on the same day that they died.

The median time between diagnosis and death for patients who died within 48 hours of admission was 6 (IQR 32) months. This was significantly different to the rest of the sample (4 months; IQR 20). No significant differences in cancer diagnosis or the numbers of co-morbidities were observed. 8.2% of patients who died within 48 hours of admission had their cancer diagnosis established for the first time. These were cancers of the respiratory and intrathoracic organs (n=3), digestive system (n=1), female genital organs (n=1) and the remaining 3 patients were grouped under other cancers.

60.8% of patients that died within 48 hours of admission had 2-3 previous hospital admissions in their last year of life, which was not significantly different from the rest of the sample.

A significantly higher percentage of patients (42.9%) had specialist palliative care services at home in contrast to 28.8% within the remaining sample and just over half were admitted out of normal G.P. practice hours (59.5%).

Death was expected in 83.7% of patients who died within 48 hours of admission. The Liverpool Care Pathway was in place for 25.5%, with preferred place of death recorded for 11.2%. 10.2% of patients who died within 48 hours were admitted from a nursing home.

4.6 Patients Diagnosed on Last Hospital Admission

26.3% of patients were diagnosed on their last admission. These patients tended to be significantly older (79 v. 71 years) and not partnered (56.3% v. 40.8%) compared to the remaining sample. There were no statistical differences by gender, geographical area of residence or socioeconomic status.

The highest percentages of cancers diagnosed on the last admission were cancers of the respiratory & intrathoracic organs (29.0%) and those of the digestive organs (24.6%). Diagnosis on last admission was much rarer for patients with breast cancer (8.6% of all patients with breast cancer) and those with cancers of the male genital organs (2.7% of all patients with cancers of the male genital organs).

A significantly higher percentage of patients diagnosed on their last admission were admitted with urgent physical symptoms (63.4%) or for further investigations/precautions (23.0%) compared to the remaining sample (22.9%, 6.3% respectively). Additionally, significantly higher percentages experienced anorexia (50.8%) and weight loss (45.9%) compared to patients with a known cancer diagnosis (36.7%, 17.4% respectively).

Patients diagnosed on their last admission also had significantly more co-morbidities and significantly less admissions in their last year of life. For 56.3% of patients, their last admission was their only admission within that year. However, there may have been a potential for earlier diagnosis in the remaining 43.6%.

35.7% (n=25) patients admitted from a nursing home were diagnosed on their last admission.

Since patients that died on their last admission were similar to those that died within 1 month of diagnosis, routine Cancer Registry data was used to explore this further between the years of 1993-2008 (Appendix III). 2007-2008 data shows that approximately one in eleven (9%) cancer patients (excluding non-melanoma skin cancer) died within one month of diagnosis.

For patients diagnosed on their last hospital admission the average time from admission to diagnosis was 6 days and 11 days from diagnosis until death.

8.2% of cancer patients who died in hospital were diagnosed within 48 hours of their death.

The Liverpool Care Pathway was in place for 54.1% of patients diagnosed on their last admission and preferred place of death was recorded for 45.4%. Home was preferred by 55.4% and a nursing home by 21.7% (often classed as home by elderly patients).

4.7 The Liverpool Care Pathway for the Dying Patient

The Liverpool Care Pathway (LCP) was in place for 386 (55.5%) patients and preferred place of death was recorded for 176 (45.6%) patients that were on the pathway.

The implementation of the LCP varied significantly by each Trust. The highest percentages of cancer patients who died in hospital and were entered onto the LCP were observed within the Causeway Hospital (77.3%), Tyrone County Hospital (72.7%), Whiteabbey Hospital (72.7%) and the Ulster Hospital (70.0%). With the exception of the Southern HSCT, where funding was not in place for the implementation of the LCP, the Erne, Altnagelvin and Lagan Valley Hospitals had the lowest percentage of patients on the LCP (41.4%, 47.1% and 47.1%, respectively; $p=0.003$). It should also be noted however that the implementation of the LCP had only begun in the Western HSCT during the study period.

Patients who were on the LCP had significantly more investigations on their last admission than those who were not on the pathway. However, since data was not collected on when patients were entered onto the LCP, investigations may have been pre-initiation of the pathway and were used to inform clinicians identifying those entering into the dying phase.

There were no differences between patients who were on the LCP and those who were not in relation to the number of interventions. However, a significantly higher percentage of patients on the LCP were prescribed controlled drugs (91.2%) and had undergone radiotherapy on their last admission (6.5%). These were interventions to palliate symptoms and provide comfort.

The median length of last hospital stay for patients on the LCP was significantly longer (14 days; range 0-233 days) than those not on the LCP (7 days; range 0-100 days). As duration of stay increased, the percentage of those on the LCP also increased. This most likely reflects there being greater time to identify patients that are entering into the dying phase of life as opposed to the prolonging of life.

4.8 Specialist Palliative Care Involvement and Multidisciplinary Team Meetings

67.1% ($n=466$) of all patients and 68.8% of patients with a known cancer diagnosis, received specialist palliative care in hospital. There were no statistically significant differences across Trusts.

39.6% ($n=203$) of patients with a known cancer diagnosis had specialist palliative care involvement at home/nursing home or community setting. This varied significantly by HSCT and ranged from 26.2% in the Northern HSCT to 52.2% in the Western HSCT ($p<0.001$).

Discussion at an oncology Multidisciplinary Team (MDT) meeting was recorded for 40.9% ($n=284$) of patients and of these 54.6% ($n=155$) were discussed at an oncology MDT on their last admission. The removal of patients diagnosed on their last admission left those discussed at an oncology MDT at 42.6%.

Oncology MDT meetings varied significantly by Trust with the Western HSCT having the highest percentage recorded (62.0%) and the Northern HSCT the lowest (26.3%).

Patients were discussed at an oncology MDT a median of 7 (IQR 25) weeks prior to death and varied significantly by HSCT.

4.9 Do Not Attempt Resuscitation Orders

Do Not Attempt Resuscitation (DNAR) orders were in place for 633 (91.1%) of patients, with no significant differences across Trusts.

Considering the implementation of a DNAR order would confirm that death was expected for a large percentage of patients, only 41.1% of these patients had a preferred place of death recorded. This notwithstanding, date of commencement of DNAR orders were not collected as part of the study and may have only been put in place when death was imminent. Thus time constraints and the medical condition of the patient may have influenced the recording of PPD and discharge.

4.10 Distances from Usual Residence to Nearest Hospice

Median distance from patients' usual residence to the nearest hospital was 9.4 (IQR=16) miles. 53.6% of patients lived within 10 miles of a hospice and 90.4% within 30 miles.

Differences in the provision of palliative care by distance from usual residence to hospice was not significant.

SECTION 5 – DISCUSSION, CONCLUSIONS and RECOMMENDATIONS

5.1 Main Discussion Points

Cancer is a major burden on our society. Over a quarter of all deaths in Northern Ireland are due to cancer, accounting for approximately 4150 deaths per year. The literature indicates that well over 50% of cancer patients would prefer to die at home (Beccaro et al, 2006; Hays et al, 2001; Karlsen and Addington-Hall, 1999; Tang et al, 2010; Townsend et al, 1990), yet in Northern Ireland the majority of cancer deaths (47.9%, n=1988) occurred in hospital and a third (32.1%, n=1335) at home.

Of the patients studied, almost one third (30.2%) were diagnosed within the last month of life and just over one quarter (26.3%) during their last hospital admission. Cancer Registry data shows that in 2007, one in eleven cancer patients died within one month of diagnosis (Appendix III), which points to a problem of late diagnosis of cancers. Although earlier diagnosis may not result in cure, it will allow interventions to be put in place to alleviate symptoms and enable palliative and general care services to be involved.

Most of the late diagnoses were cancers of the respiratory and intrathoracic or digestive organs and were more likely to occur in older, non-partnered patients. A recent study (Brewster et al, 2011) which investigated the characteristics of patients dying within 30 days of a diagnosis of breast or colorectal cancer in Scotland (2003-2007) found that patients had significantly more hospital admissions in the last 10 years of life compared to controls and a significantly higher percentage had previous admissions for chronic respiratory disease. In agreement with the findings of the current study, Brewster et al, (2011) found that patients that die within one month of diagnosis are significantly older than those with a longer survival and have a history of additional co-morbidities.

Over three quarters of patients in the current study were admitted as an emergency, with cancer-related symptoms (37.4%) and urgent physical symptoms (33.5%); suggesting that patients were requiring medical attention which necessitated hospitalisation. Patients had a median length of stay of 11 (range 0-233) days with 14% of patients dying within 48 hours of admission. The median number of hospital admissions within the last year of life was 2 and patients spent a median of 21 days in hospital in their last year of life. The DHSSPS in Northern Ireland, (2010) recommend that all out-of-hours teams should be trained in providing generalist and end of life care to patients, their carers and family, as well as being able to identify patients who are approaching end of life. With the availability of appropriate community services, this may decrease the number of patients being admitted as an emergency to acute hospitals, the number of deaths occurring in acute hospital settings, as well as a reduction in the number of hospital admissions in the last year of life. Achieving the patients wish for a home death has benefits for both the patient and for the 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 3 day reduction in length of hospital stay could equate to a saving of £104 million per year (Hatziaandreu et al, 2008). Savings from reduced emergency admissions could be redirected where necessary into community and end of life care services.

The implementation of the Liverpool Care Pathway for patients nearing end of life varied by Health and Social Care Trust. Almost all, 92.1%, of patient deaths were anticipated during their last hospital admission, suggesting that a higher percentage of patients may have been eligible to be entered onto the care pathway. An audit which

investigated the implementation of the Liverpool Care Pathway for all patients that died across 8 hospitals within the Eastern Health and Social Care Board (May 2007) in Northern Ireland, found that 27% of patients that were deemed eligible, were not entered onto the pathway (Johnston, 2008). These patients were noted to have poorly controlled symptoms, 50% continued to receive antibiotics, 41% blood tests and 38% x-rays or scans until death. A study conducted in the Netherlands also found that patients on the Liverpool Care Pathway were less likely to be prescribed potentially life-shortening medication (van der Heide et al, 2010). Additional studies report better symptom management and improvements in the documentation of care (Veerbeek et al, 2008) as well as improvements in healthcare professionals confidence in delivering care to dying patients (Jack et al, 2003; Gambles et al, 2006).

Studies such as these highlight the importance of the identification of the dying patient and where appropriate, the implementation of the Liverpool Care Pathway in ensuring patient needs are being met and optimum comfort obtained. Additionally, implementation of the Liverpool Care Pathway could act as a trigger for appropriate end of life care discussions with patients, their carers and family, including preferred place of care and Do Not Attempt Resuscitation orders.

Well over one third (38.3%) of patients had specifically requested to be discharged to their usual residence, hospice or other hospital and this was not possible. In 76.3% of cases this was due to deterioration in the patient's condition. However, for 17.3%, facilities were not available (lack of suitable bed 12.4%; care package not in place 4.9%), and 3.0% lacked the required family support. Preferred place of death was recorded for 40.7% of patients and 39.7% of those diagnosed on their last admission. The large majority of patients (61.1%) indicated that they preferred to die at home, with only 12.7% of the sample indicating a preference to die in hospital. The implementation of rapid discharge services as recommended within the UK's End of life Care Strategy (DoH, 2008), may enable patients to end their life in their preferred place of care while also decreasing hospital stay. Enabling patients to die at home, if this is their preference, is however complex and the factors associated with a home death have not been firmly established and are likely to be intrinsically linked. Identifying dying and communication with patients and their carers are important factors in the facilitation of achieving preferred place of death. Although the available research is often conflicting, it appears that having good social conditions and support as well as the availability, use and intensity of homecare are important factors (Gomes and Higginson, 2006). In support of this, two studies conducted in Denmark found that home deaths were highly associated with G.P. home visits and to a lesser extent, with community nurse home visits (Aabom et al, 2005; Neergaard et al, 2009). Both studies however conclude that future research should examine the exact mechanisms of their involvement and the exact role of the G.P. particularly the interface between G.Ps and other healthcare providers.

Marie Curie Cancer Care has launched a "Delivering Choice" programme which provides terminally ill patients with the choice of dying at home. The project provides rapid response teams which make emergency and planned home visits to palliative care patients in the community during twilight and out of G.P. practice hours. The project also incorporates dedicated discharge nurses who facilitate the speedy discharge of patients receiving palliative care to their preferred place of care. A report was published in 2008 which evaluated the programme and the benefits of these services in Lincolnshire, England (Addicott and Dewar, 2008). Findings showed that the programme was associated with an increase in the percentage of patients dying at home. More specifically, 42% of patients that accessed the services died at home, which was much lower (19%) for those who did not access the service.

Prior to final hospital admission, 10% of patients within the current study lived in a nursing home and two thirds of these indicated that the nursing home was their preferred place of death. A total of 36% of the patients admitted from a nursing home had their cancer diagnosis made on their last hospital admission and 10% of patients who died within 48 hours were admitted from a nursing home. Educational awareness programmes promoting the early diagnosis of cancer should be targeted at nursing home residents and staff. In support of this, a population based study carried out in Nova Scotia, Canada (O'Brien et al, 2007) reported that nursing home residents are over 4 times more likely to have a death certificate only (DCO) cancer diagnosis, meaning their cancer was diagnosed only at the time of death.

Nursing homes residents would also benefit from staff implementing strategies to record preferred place of death as part of routine care. These findings highlight once again, the importance of identifying dying and communicating end of life care issues with patients and their families.

5.2 Conclusion

Given that the majority of cancer patients die in hospital, yet prefer to die at home and the certainty that the future holds an ageing population with an increase in chronic illnesses, it seems that there will need to be a shift toward caring for more patients in the community. This study examined in detail the cancer patients who died in acute hospitals in Northern Ireland in the last six months of 2007 and findings support and will help inform the implementation of the recommendations within the Palliative and End of Life Care Strategy for Northern Ireland, (2010). Findings also highlight the need to improve earlier recognition and diagnosis of cancer within the population. Further studies examining the factors which result in a home death are required.

5.3 Recommendations

In general, the findings within this report highlight the importance of the recommendations made within the 2010 Palliative and End of Life Care Strategy for Northern Ireland (DHSSPS, 2010) and these should be included in training and in appropriate protocols for professionals who work with cancer patients.

All patients nearing end of life should have an advanced care plan in place which incorporates patients preferred place of death.

A major initiative to improve earlier recognition of cancer symptoms among both the public and healthcare professionals is required.

Nursing homes should be specifically targeted for training in early recognition of cancer symptoms and have strategies developed to enable residents with cancer to die in their preferred place of death.

For the approximate 20% of patients whose condition would have allowed them to be discharged to die in their place of preference, efforts should be enhanced to ensure facilities and resources in the community are available to support patients and their carers in their choices.

The implementation of the Liverpool Care Pathway should be reinforced across all Trusts.

Further work is recommended to study what helps to facilitate a home death for cancer patients nearing end of life.

REFERENCES

Aabom B, Kragstrup J, Vondeling H, Bakketeig LS, Stovring H (2005) Population-based study of place of death of patients with cancer: implications for GPs. *British Journal of General Practice* 55: 684-689

Abel J, Rich A (2009) End-of-life care in hospital: A descriptive study of all inpatients deaths in 1 year. *Palliative Medicine* 23: 616-622

Addicott R, Dewar S (2008) Improving choice at the end of life: a descriptive analysis of the impact and cost of the Marie Curie delivering choice programme in Lincolnshire, King's Fund. Available at: http://www.kingsfund.org.uk/publications/improving_choice_at.html

Al-Qurainy R, Collis E, Feuer D (2009) Dying in an acute hospital setting: the challenges and solutions. *The International Journal of Clinical Practice* 63: 508-515

Beccaro M, Costantini M, Giorgi Rossi P, Miccinesi G, Grimaldi M, Bruzzi P; ISDOC Study Group (2006) Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). *Journal of Epidemiology and Community Health* 60: 412-416

Brewster DH, Clark DI, Stockton DL, Munro AJ, Steele RJC (2011) Characteristics of patients dying within 30 days of diagnosis of breast or colorectal cancer in Scotland, 2003-2007. *British Journal of Cancer* 104: 60-67

Cohen J, Houttekier D, Onwuteaka-Philipsen B, Miccinesi G, Addington-Hall J, Kaasa S, Bilsen J, Deliens L (2010) Which patients with cancer die at home? A study of six European countries using death certificate data. *Journal of Clinical Oncology* 13: 2267-2273

Davison D, Johnston G, Reilly P, Stevenson M (2001) Where do patients with cancer die in Belfast? *Irish Journal of Medical Science* 170: 18-23

Decker SL, Higginson IJ (2006) A tale of two cities: Factors affecting place of cancer death in London and New York. *European Journal of Public Health* 17: 285-290

Department of Health, Social Services and Public Safety (DHSSPS) Living matters, dying matters. A palliative and end of life care strategy for adults in Northern Ireland (2010). Available at: <http://www.endoflifecareforadults.nhs.uk/publications/living-matters-dying-matters-a-palliative-and-end-of-life-care-strategy-for-adults-in-northern-ireland>

Department of Health (DoH) End of Life Care Strategy. Promoting high quality care for all adults at the end of life. Department of Health (2008). Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

Donnelly DW, Gavin AT (2007) Survival of cancer patients in Northern Ireland: 1993-2004. Northern Ireland Cancer Registry, Queens University, Belfast. Available at: <http://www.qub.ac.uk/research-centres/nicr/FileStore/PDF/Survival/Filetoupload,81422,en.pdf>

- Gambles M, Stirzacker S, Jack B, Ellershaw JE (2006) The Liverpool care pathway in hospices: an exploratory study of doctor and nurse perceptions. *International Journal of Palliative Nursing* 12: 414-421
- Gomes B, Higginson IJ (2006) Factors influencing death at home in terminally ill patients with cancer: systematic review. *British Medical Journal* doi: 10.1136/bmj.38740.614954.55
- Gomes B, Higginson IJ (2008) Where people die (1974-2030): Past trends, future projections and implications for care. *Palliative Medicine* 22: 33-41
- Hatziafreu E, Archontakis F, Daly A (2008) The potential saving of greater use of home and hospice based end of life care in England. National Audit Office, available at:
http://www.nao.org.uk/publications/0708/end_of_life_care.aspx
- Hays JC, Galanos AN, Palmer TA, Mc Quoid DR, Flint EP (2001) Preference for place of death in a continuing care retirement community. *Gerontologist* 41: 123-128
- Higginson IJ, Astin P, Dolan S (1998) Where do cancer patients die? Ten year trends in place of death of cancer patients in England. *Palliative Medicine* 12: 353-363
- Howell DA, Roman E, Cox H, Smith AG, Patmore R, Garry AC, Howard MR (2010) Destined to die in hospital? Systematic review and meta-analysis of place of death in haematological malignancy. *BMC Palliative Care* 9: 9 doi: 10.1186/1472-684X-9-9
- Hunt RW, Bond MJ, Groth RK, King P (1991) Place of death in South Australia: patterns from 1910-1987. *The Medical Journal of Australia* 155:549-553
- Jack B, Gambles M, Murphy D, Ellershaw JE (2003) Nurses' perceptions of the Liverpool care pathway for the dying patient in the acute hospital setting. *International Journal of Palliative Nursing* 9: 375-381
- Johnston G (2008) An audit of the implementation of the care pathway for the dying in the Eastern Health and Social Services Board, Northern Ireland. Eastern Health and Social Services Board, Belfast
- Karlsen S, Addington-Hall J (1999) How do cancer patients who die at home differ from those who die elsewhere? *Palliative Medicine* 13: 169-170
- Marie Curie Palliative Care Institute (2009) National Care of the dying audit – hospitals (NCDAH) Round 2 (2008/2009) Audit report Northern Ireland pilot. Marie Curie Palliative Care Institute, Liverpool.
- Marie Curie Palliative Care Institute (2010) What is the Liverpool Care Pathway for the Dying Patients (LCP)? Information for healthcare professionals. Marie Curie Palliative Care Institute, Liverpool. Available at :
http://www.mcpcil.org.uk/liverpool-care-pathway/Updated%20LCP%20pdfs/What_is_the_LCP_-_Healthcare_Professionals_-_April_2010.pdf
- Murray MA, Fiset V, Young S, Kryworuchko J (2009) Where do the dying live: A systematic review of determinants of place of end of life cancer care. *Oncology Nursing Forum* 36: 69-77

National Institute for Clinical Excellence NICE (2004) Improving supportive and palliative care for patients with cancer. National Institute for Clinical Excellence, London. Available at: <http://www.nice.org.uk/nicemedia/live/10893/28816/28816.pdf>

Neergaard MA, Vedsted P, Olesen F, Sokolowski I, Jensen AB, Sondergaard J (2009) Associations between home death and GP involvement in palliative cancer care. *British Journal of General Practice* 59: 671-677

Northern Ireland Statistics and Research Agency (2009) Registrar General Northern Ireland Annual Report 2008. Available at: http://www.nisra.gov.uk/archive/demography/publications/annual_reports/2009/RG2009.pdf

O'Brien MB, Johnston GM, Gao J, Dewar R (2007) End-of-life care for nursing home residents dying from cancer in Nova Scotia, Canada, 2000-2003. *Supportive Care in Cancer* 15: 1015-1021

Schrijvers D, Joosens E, Vandebroek J, Verhoeven A (1998) The place of death of cancer patients in Antwerp. *Palliative Medicine* 12: 133-134.

Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA (2000) Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association* 284: 2476-2482

Tang ST, Chen CC, Tang WR, Liu TW (2010) Determinants of patient-family caregiver congruence on preferred place of death in Taiwan. *Journal of Pain and Symptom Management* 40: 235-245

Townsend J, Frank AO, Fermont D, Dyer S, Karran O, Walgrove A, Piper M (1990) Terminal cancer care and patients' preference for place of death: A prospective study. *British Medical Journal* 301: 415-417

van der Heide A, Veerbeek L, Swart S, van der Rijit C, van der Maas PJ, van Zuylen L (2010) End-of-life decision making for cancer patients in different settings and the impact of the LCP. *Journal of Pain and Symptom Management* 39: 33-43

Veerbeek L, van Zuylen L, Swart SJ, van der Maas PJ, de Vogel-Voogt E, van der Rijit CCD, van der Heide A (2008) The effect of the Liverpool care pathway for the dying: a multi centre study. *Palliative Medicine* 22: 145-151

APPENDICES I-III

APPENDIX I

Project Steering Group Members

APPENDIX II

Supplementary tables

- (i) Co-morbidities by Cancer Type for Study Patients
- (ii) Summary of Reasons for Admission Categories
- (iii) Recording of Preferred Place of Death by Health and Social Care Trust – Excluding Patients Diagnosed on Last Admission
- (iv) Recording of Preferred Place of Death by Health and Social Services Board – Total Sample
- (v) Total Hospital Bed Days in Last Year of Life by Health and Social Services Board
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- (vii) Hospital Specialist Palliative Care by Health and Social Services Board – Total Sample
- (viii) Home Specialist Palliative Care by Health and Social Services Board Excluding Patients Diagnosed on Last Admission
- (ix) Home Specialist Palliative Care by Local Government District – Excluding Patients Diagnosed on Last Admission
- (x) Patients Discussed at Multidisciplinary Meeting (Last Year of Life) by Health and Social Services Board – Excluding Patients Diagnosed on Last Admission
- (xi) Do Not Attempt Resuscitation Orders by Health and Social Services Board – Total Sample

APPENDIX III

Patients that Died within 1 Month, 3 Months and 6 Months of Cancer Diagnosis: All Places of Death (1993-2008)

Appendix I: Project Steering Group Members

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Appendix II: Supplementary Tables

(i) Co-morbidities by Cancer Type for Study Patients

Co-morbidities	Cancer Type N (%)					
	Digestive Organs	Respiratory And Intrathoracic Organs	Breast	Female Genital Organs	Male Genital Organs	Other
Alzheimer's	15 (8.2)	9 (5.3)	6 (10.3)	3 (8.6)	5 (13.2)	8 (3.8)
Arthritis	18 (9.9)	18 (10.6)	7 (12.1)	3 (8.6)	3 (7.9)	38 (17.9)
Cardiovascular Disease	30 (16.5)	33 (19.4)	6 (10.3)	7 (20.0)	12 (31.6)	32 (15.1)
Cerebrovascular Disease	17 (9.3)	16 (9.4)	5 (8.6)	1 (2.9)	4 (10.5)	17 (8.0)
COPD	14 (7.7)	53 (31.2)	2 (3.4)	1 (2.9)	2 (5.3)	25 (11.8)
Diabetes	34 (18.7)	20 (11.8)	6 (10.3)	4 (11.4)	5 (13.2)	26 (12.3)
Hypertension	68 (37.4)	52 (30.6)	22 (37.9)	15 (42.9)	13 (34.2)	66 (31.1)
Learning Disability	2 (1.1)	1 (0.6)	2 (3.4)	1 (2.9)	0	1 (0.5)
Parkinson's Disease	5 (2.7)	3 (1.8)	2 (3.4)	0	1 (2.6)	5 (2.4)
Psychiatric Disorder	6 (3.3)	3 (1.8)	0	1 (2.9)	1 (2.6)	4 (1.9)
Renal Disease	9 (4.9)	5 (2.9)	3 (5.2)	2 (5.7)	5 (13.2)	6 (2.8)
Other Malignancy	11 (6.0)	13 (7.6)	5 (8.6)	5 (14.3)	5 (13.2)	31 (14.6)

(ii) Summary of Reasons for Admission Categories

Due to the number of reasons for each patient’s last admission a criteria was applied to summarise reasons for admission. These took into account the assessment of symptoms on admission, the content of the G.P. letter (were available/appropriate), the hospitals recorded reasons for admission, whether or not the patient had a known cancer/previous diagnosis, cancer diagnosis, patient’s age, gender, existing co-morbidities, reasons for previous hospital admissions and cause of death. Involved in the decision making process and categorisations of symptoms were the Registry’s Tumour Verification Officers who collected the data and a palliative care G.P. (Dr. Graeme Crawford). Categories and summarised reasons for admission are tabulated below.

Reason for Admission Categories	Explanation and Examples
1. Cancer-related	These symptoms were generally intrinsically linked with having a cancer diagnosis. Examples are outlined below. Lung cancer: shortness of breath, haemoptysis and weight loss Colon cancer: abdominal distension, bowel obstruction and nausea/vomiting.
2. Urgent Physical	Patients who presented with urgent physical symptoms were often those without a prior diagnosis of cancer i.e. those who were diagnosed on their last admission. Typical examples of urgent physical admissions were: Urinary tract infections, lower respiratory tract infections, cardiac symptoms and respiratory distress.
3. Urgent Social	These admissions were related to the patient’s or their carer’s lack of ability to cope at home.
4. Further Investigations/Precautions	Mixtures of patients with both a known and unknown diagnosis of cancer were admitted for further investigations. Those admitted as a precaution had symptoms which could potentially escalate or if further deterioration was expected.
5. Treatment-related	These admissions were due to symptoms which were as a direct result of a treatment or an intervention e.g. post-operative complication, neutropenic sepsis.
6. For Treatment	The sole purpose of these admissions were for a specific treatment e.g. fracture repair, blood transfusion, pleural tap.
7. Rehabilitation	For patients categorised as being admitted for rehabilitation, this was specifically stated in the patient’s notes or G.P. letter.
8. Palliative Care	As above, it was specifically stated in either the patient’s medical notes or in their G.P. letter that that they were being admitted for palliative care.

(iii) Recording of Preferred Place of Death by Health and Social Care Trust – Excluding Patients Diagnosed on Last Admission

Health and Social Care Trust (HSCT)	Preferred Place of Death Recorded? N (%)		
	Yes	No	Total
Belfast HSCT	81 (42.2)	111 (57.8)	192 (37.5)
Northern HSCT	33 (39.3)	51 (60.7)	84 (16.4)
Western HSCT	36 (40.0)	54 (60.0)	90 (17.6)
Southern HSCT	21 (33.3)	42 (66.7)	63 (12.3)
South Eastern HSCT	29 (34.9)	54 (65.1)	83 (16.2)
Northern Ireland	200 (39.1)	312 (60.9)	512

(iv) Recording of Preferred Place of Death by Health and Social Services Board – Total Sample

Health and Social Services Board (HSSB)	Preferred Place of Death Recorded? N (%)		
	Yes	No	Total
Belfast HSSB	159 (41.6)	223 (58.4)	382 (55.0)
Northern HSSB	47 (41.2)	67 (58.8)	114 (16.4)
Western HSSB	47 (43.5)	61 (56.5)	108 (15.5)
Southern HSSB	30 (33.0)	61 (67.0)	91 (13.1)
Northern Ireland	283 (40.7)	412 (59.3)	695

(v) Total Hospital Bed Days in Last Year of Life by Health and Social Services Board

Health and Social Services Board (HSSB)	Total Bed Days		
	Median	IQR	Range
Belfast HSSB	23	28	0-233
Northern HSSB	18	22	0-97
Western HSSB	20	19	1-87
Southern HSSB	22	25	0-147
Northern Ireland	21	25	0-233

(vi) Liverpool Care Pathway by Health and Social Services Board – Total Sample

Health and Social Services Board (HSSB)	Liverpool Care Pathway in Place? N (%)		
	Yes	No	Total
Belfast HSSB	231 (60.5)	151 (39.5)	382 (55.0)
Northern HSSB	66 (57.9)	48 (42.1)	114 (16.4)
Western HSSB	52 (48.1)	56 (51.9)	108 (15.5)
Southern HSSB	37 (40.7)	54 (59.3)	91 (13.1)
Northern Ireland	386 (55.5)	309 (44.5)	695

(vii) Hospital Specialist Palliative Care by Health and Social Services Board – Total Sample

Health and Social Services Board (HSSB)	Specialist Palliative Care in Hospital? N (%)		
	Yes	No	Total
Belfast HSSB	253 (66.2)	129 (33.8)	382 (55.0)
Northern HSSB	75 (65.8)	39 (34.2)	114 (16.4)
Western HSSB	79 (73.1)	29 (26.9)	108 (15.5)
Southern HSSB	59 (64.8)	32 (35.2)	91 (13.1)
Northern Ireland	466 (67.1)	229 (32.9)	695

(viii) Home Specialist Palliative Care by Health and Social Services Board - Excluding Patients Diagnosed on Last Admission

Health and Social Services Board (HSSB)	Specialist Palliative Care at Home N (%)		
	Yes	No	Total
Belfast HSSB	107 (38.9)	168 (61.1)	275 (53.7)
Northern HSSB	22 (26.2)	62 (73.8)	84 (16.4)
Western HSSB	47 (52.2)	43 (47.8)	90 (17.6)
Southern HSSB	27 (42.9)	36 (57.1)	63 (12.3)
Northern Ireland	203 (39.6)	309 (60.4)	512

(ix) Home Specialist Palliative Care by Local Government District - Excluding Patients Diagnosed on Last Admission

Local Government District	Specialist Palliative Care at Home		
	N (%)		
	Yes	No	N
Antrim	5 (38.5)	8 (61.5)	13 (2.5)
Ards	3 (15.0)	17 (85.0)	20 (3.9)
Armagh	7 (43.8)	9 (56.3)	16 (3.1)
Ballymena	5 (35.7)	9 (64.3)	14 (2.7)
Ballymoney	4 (40.0)	6 (60.0)	10 (2.0)
Banbridge	5 (50.0)	5 (50.0)	10 (2.0)
Belfast	43 (41.7)	60 (58.3)	103 (20.1)
Carrickfergus	2 (14.3)	12 (85.7)	14 (2.7)
Castlereagh	8 (36.4)	14 (63.5)	22 (4.3)
Coleraine	2 (16.7)	10 (83.3)	12 (2.3)
Cookstown	2 (18.2)	9 (81.8)	11 (2.1)
Craigavon	12 (50.0)	12 (50.0)	24 (4.7)
Derry	17 (56.7)	13 (43.3)	30 (5.9)
Down	4 (20.0)	16 (80.0)	20 (3.9)
Dungannon	7 (58.3)	5 (41.7)	12 (2.3)
Fermanagh	7 (30.4)	16 (69.6)	23 (4.5)
Larne	2 (33.3)	4 (66.7)	6 (1.2)
Limavady	3 (37.5)	5 (62.5)	8 (1.6)
Lisburn	13 (46.4)	15 (53.6)	28 (5.5)
Magherafelt	2 (28.6)	5 (71.4)	7 (1.4)
Moyle	0	0	0
Newry & Mourne	3 (20.0)	12 (80.0)	15 (2.9)
Newtownabbey	10 (34.5)	19 (65.5)	29 (5.7)
North Down	18 (51.4)	17 (48.6)	35 (6.8)
Omagh	12 (75.0)	4 (25.0)	16 (3.1)
Strabane	7 (53.8)	6 (46.2)	13 (2.5)
Missing	0	1 (100)	1 (0.1)
Total	203 (39.6)	309 (60.4)	512

Note: Local Government District determined by the postcode of patients' usual address.

(x) Patients Discussed at Multidisciplinary Meeting (Last Year of Life) by Health and Social Services Board – Excluding Patients Diagnosed on Last Admission

Health and Social Services Board (HSSB)	Discussed at Multidisciplinary Meeting? (Last Year of Life) N (%)		
	Yes	No	Total
Belfast HSSB	111 (40.4)	164 (59.6)	275 (53.7)
Northern HSSB	23 (27.4)	61 (72.6)	84 (16.4)
Western HSSB	58 (64.4)	32 (35.6)	90 (17.6)
Southern HSSB	26 (41.3)	37 (58.7)	63 (12.3)
Northern Ireland	294 (57.4)	218 (42.6)	512

(xi) Do Not Attempt Resuscitation Orders by Health and Social Services Board – Total Sample

Health and Social Services Board (HSSB)	Do Not Resuscitate Order in Place? N (%)		
	Yes	No	Total
Belfast HSSB	349 (91.4)	33 (8.6)	382 (55.0)
Northern HSSB	101 (88.6)	13 (11.4)	114 (16.4)
Western HSSB	101 (93.5)	7 (6.5)	108 (15.5)
Southern HSSB	82 (90.1)	9 (9.9)	91 (13.1)
Northern Ireland	633 (91.1)	62 (8.9)	695

Appendix III - Patients that Died within 1 Month, 3 Months and 6 Months of Cancer Diagnosis: All Places of Death (1993-2008)

Year	Total Cases Diagnosed	Died Within 1 Month of Diagnosis	Died Within 3 Months of Diagnosis	Died Within 6 Months of Diagnosis
	N	N (%)		
1993	6319	1013 (16.0)	1716 (27.2)	2234 (35.4)
1994	6222	895 (14.4)	1600 (25.7)	2137 (34.3)
1995	6231	885 (14.2)	1554 (24.9)	2058 (33.0)
1996	6446	945 (14.7)	1589 (24.7)	2117 (32.8)
1997	6314	860 (13.6)	1564 (24.8)	2072 (32.8)
1998	6452	802 (12.4)	1559 (24.2)	2089 (32.4)
1999	6366	862 (13.5)	1536 (24.1)	1985 (31.2)
2000	6535	781 (12.0)	1477 (22.6)	1971 (30.2)
2001	6596	798 (12.1)	1499 (22.7)	2002 (30.4)
2002	6813	826 (12.1)	1573 (23.1)	2084 (30.6)
2003	7057	795 (11.3)	1511 (21.4)	2015 (28.6)
2004	7201	759 (10.5)	1440 (20.0)	1967 (27.3)
2005	7257	722 (9.9)	1392 (19.2)	1878 (25.9)
2006	7469	782 (10.5)	1499 (20.1)	2027 (27.1)
2007	7942	719 (9.1)	1435 (18.1)	1917 (24.1)
2008	8162	721 (8.8)	1453 (17.8)	1989 (24.4)
Total	109,382	13,165 (12.0)	24,397 (22.3)	32,542 (29.8)

Note: Data is excluding patients diagnosed with Non-Melanoma Skin Cancer (C44) as this type of cancer is rarely fatal.

ABBREVIATIONS

CI	Confidence Interval
CT	Computerised Tomography
COPD	Chronic Obstructive Pulmonary Disease
DCO	Death Certificate Only
DHSSPS	Department of Health Social Services and Public Safety
DNAR	Do Not Attempt Resuscitation Order*
DoH	Department of Health
EASR	European Age Standardised Rate
ECG	Electrocardiogram
EoL	End of Life
G.P.	General Practitioner
GRO	General Register Office, Northern Ireland
HSCT	Health and Social Care Trust
HSSB	Health and Social Services Board
ICD-10	International Classification of Diseases – Version 10
IQR	Interquartile Range
LCP	Liverpool Care Pathway for the Dying Patient**
LG	Local Government
MDT	Multidisciplinary Team
NHS	National Health Service
NICaN	Northern Ireland Cancer Network
NICE	National Institute of Clinical Excellence
NICR	Northern Ireland Cancer Registry
OGD	Oesophogastroduodenoscopy
OR	Odds Ratio
ORECNI	Office for Research Ethics Committee, Northern Ireland
PET	Positron Emission Tomography
PPD	Preferred Place of Death
SPSS	Statistical Packages for the Social Sciences
TVO	Tumour Verification Officer
UK	United Kingdom
v.	Versus

* Also known as Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) or Allow Natural Death (AND) orders.

**Also known as the Care Pathway for the Dying, Care of the Dying Pathway, or Integrated Care Pathway for the Dying Phase.

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