Macmillan - NICR Partnership: Emergency Admissions in the Last Year of Life for People Dying of Cancer in Northern Ireland in 2015

In partnership

Macmillan-NICR Partnership:

Emergency admissions in last year of life for people dying of Cancer in Northern Ireland in 2015

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GLOSSARY

AOS Acute Oncology Service

CI Confidence Interval

CNS Central Nervous System

CUP Cancer Unknown Primary

DoH Department of Health

ED Emergency Department

ICD-10 International Classification of Diseases-Version 10

ICU Intensive Care Unit

GP General Practitioner

GRO General Register office

HCP Health Care Professional

HSC Health and Social Care

NICR Northern Ireland Cancer Registry

NHS National Health Service

NMSC Non-Melanoma Skin Cancer

PAS Patient Administration System

PPD Preferred Place of Death

SOA Super Output Area

SPC Specialist Palliative Care

FOREWORD

Macmillan Cancer Support is pleased to have facilitated this important evaluation of emergency care for people with cancer at end of life in Northern Ireland. Macmillan has had a long association with the invaluable work of the Registry, leading to the establishment of the Macmillan-NI Cancer Registry Partnership in April 2016.

Palliative and end-of-life care is a key priority for Macmillan. We believe that everyone approaching the end of their lives should get the best possible care, be involved in decision-making, and have a choice about how and where they are cared for.

This report aims to deliver insightful analysis of Northern Ireland cancer data to support improved design and implementation of better models of care to improve outcomes for people with cancer.

The findings highlight many pertinent challenges from both a patient-centred care perspective, and in terms of local service delivery. These must be addressed to ensure that there is appropriate communication and planning, and that care is coordinated, consistent and meets people's needs at end-of-life.

It is hoped that the findings will help to inform decision-making and service delivery in the future. Furthermore, the report is a reminder of the urgent need for collaboration within and across the health and social care sector, so that all stakeholders are working together to prioritise people's wishes about their care and support at end-of-life.

Heather Monteverde

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Head of Services for Macmillan in Northern Ireland

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This work would not have been possible without:

- Macmillan Cancer Support who funded this work through their partnership with the N.Ireland Cancer Registry and the Macmillan-NICR partnership Strategic group (listed in Appendix 4).

- The Public Health Agency for NI which funds the work of the Registry and Queens University, Belfast which hosts the Registry.

- Cancer Focus Northern Ireland who funded the Qualycare-NI study from which qualitative information is included in this report.

- The staff of the Registry whose knowledge, skill and dedication leads to assimilation and analysis of data provided by patients and collected by the health service as part of their care and support and which results in outputs such as this report.

And finally, Dr Victoria Cairnduff and Laura Dwyer who worked tirelessly on this project.

Anna Gavin.

Dr Anna Gavin

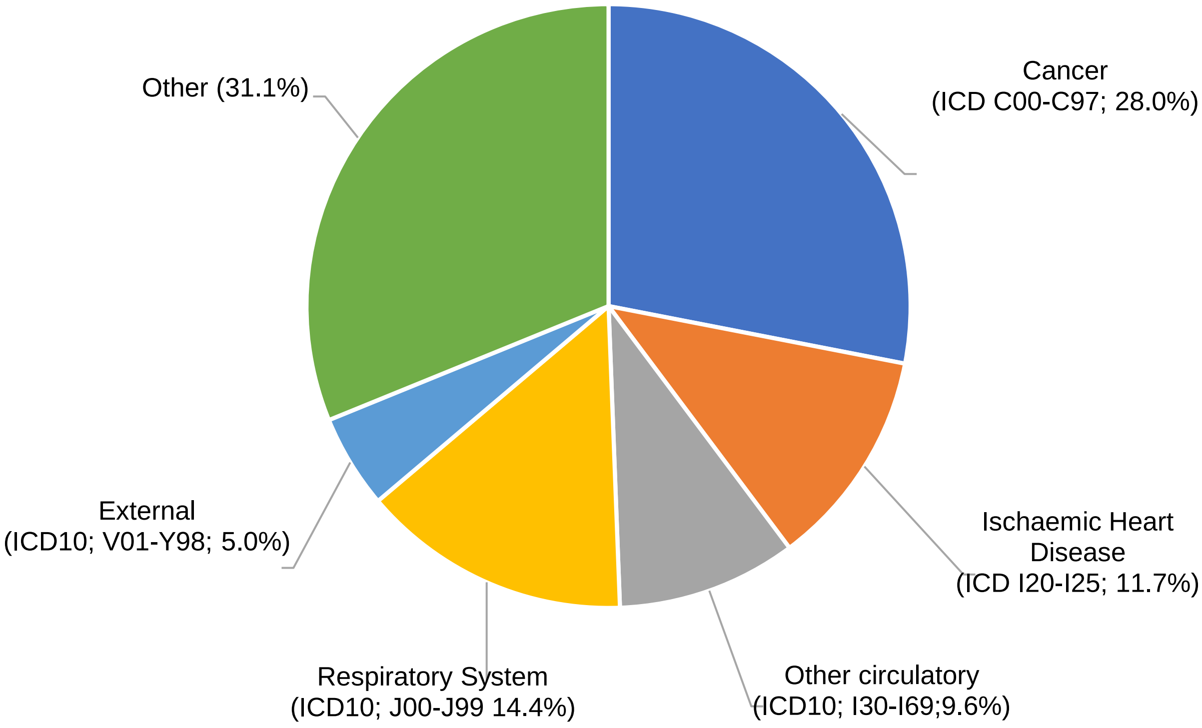
Director, NICR 2019

SECTION 1 – INTRODUCTION AND BACKGROUND

1.1 Cancer Deaths in Northern Ireland (NI)

At the end of 2017 there were approximately 63,413 people living in NI following a diagnosis of cancer made between 1993 and 2017 (NICR, 2019). Overall, 4,316, just over 1 in 4 deaths (28%), in NI in 2015 had cancer recorded as cause of death (GRO, 2017).

Figure 1.1 Causes of Death in N.Ireland 2015



In recent years, there has been increased interest in the timing and place of end-of-life care for people dying of cancer. Two previous N.Ireland Cancer Registry (NICR) reports have investigated end-of-life care in Northern Ireland.

The first report, ‘Why do cancer patients die in acute hospital: A retrospective study by note review’, found that over three quarters of patients who died in an acute hospital setting were admitted as an emergency as a result of cancer related problems (37%) or other urgent physical symptoms (34%). This suggested that patients required medical attention that could not be provided or was not currently available within a community setting. One in seven (14%) of patients in the study died within 48 hours of admission (Blaney and Gavin, 2011).

The second NICR end-of-life care report ‘Dying with Cancer: Perspectives of Bereaved Relatives and Friends’ also found that while most patients spent considerable amounts of time at home, over three quarters (78.6%) had at least one overnight stay in hospital and half (53%) attended the Emergency Department (ED) or used Ambulance Services (58%) at least once in the last three months of life (Cairnduff et al., 2015).

1.2 End-of-Life Care for people dying of cancer

The palliative and end-of-life care strategy for adults in NI entitled ‘Living Matters, Dying Matters’ (2010) has highlighted seven main features of good palliative care, including that care towards the end-of-life should:

- affirm life and regard dying as a normal process,
- intend neither to hasten nor postpone death,
- provide relief from pain and other distressing symptoms,
- integrate the psychological, emotional and spiritual aspects of patient care,
- offer a support system to help patients live as actively as possible until death,
- offer a support system to help the family cope during the patient’s illness and into bereavement,
- use a team approach to address the needs of patients and their families, including bereavement counselling if indicated and enhance quality of life.

‘Living Matters, Dying Matters’ also recognised that clinical prognostic factors can be used to assist in identifying when a person has entered the end-of-life stage. Many studies have shown that for people with cancer, approaching their end-of-life, the aspects of care considered most important are having adequate symptom relief, being able to spend time with family and friends and having access to emotional and spiritual support when needed (Smith, 2000, Teno et al., 2005, Zhang et al., 2012).

The majority of people dying of cancer prefer to be cared for and die at home (Bell et al., 2009, Higginson et al., 2010, Gomes et al., 2012, Brogaard et al., 2013). A recent systematic review of 210 studies investigating the Preferred Place of Death (PPD) of terminally ill cancer patients and changes over time concluded that over half of patients preferred to die at home (Gomes et al., 2013). Studies published have also shown that people dying of cancer also prefer to limit ‘aggressive’ care, concentrate on achieving good symptom control and plan for care needs associated with disease progression including the introduction of timely palliative care (Earle et al., 2003, Heyland et al., 2006, Zhang et al., 2012). Several studies have shown evidence of aggressive treatments towards the end-of-life linked with poorer patient and family or carer outcomes such as prolonged pain for the patient, overall dissatisfaction with care and more than three times the odds of a psychiatric illness such as anxiety and/or depression in bereaved relatives (Wright et al., 2008, Barnato et al., 2010).

Increased use of acute hospital care and in particular emergency admissions towards the end-of-life may indicate overly aggressive care as well as gaps in routine end-of-life care in the community setting. However, it has also been acknowledged that many symptoms require hospital-based care. Determining the hospital visits representing necessary care for adequate symptom relief compared to those representing aggressive care is complex and may vary from person to person depending on co-morbidities (Henson et al., 2015). Earle et al. (2003) developed a set of quality indicators which at a population-level could be used to identify healthcare systems delivering aggressive or poor-quality end-of-life care. These include, a short interval between last chemotherapy and death, a high proportion of hospital deaths vs home deaths, frequent emergency room visits, a high number of hospital and Intensive Care Unit (ICU) days near the end-of-life and, hospital admission near to death. Indicators of good-quality care include communication, shared decision making, advance directives and pain and symptom management (Earle et al. 2003).

As well as having a cost in terms of outcomes and inconvenience for people dying of cancer, overly aggressive treatment, including the use of emergency care, also has a large monetary cost. A U-shaped distribution of cancer care costs has been described within the literature, starting high around the time of diagnosis, decreasing and then peaking with the highest costs observed towards end-of-life (Yabroff et al., 2008 and Laudicella et al., 2016). A large proportion of all healthcare expenditure in developed countries is consumed by care for those in the last year of life; in the UK it has been estimated that approximately 10-20% of National Health Service (NHS) expenditure is used to care for those in the last year of their life (Georghiou et al. 2012). A statistical model which simulated the cost of caring for English cancer patients in their last year of life found that a 10% reduction in emergency admissions coupled with a three day reduction in length of stay could equate to a saving of £104 million per year (Hatziandreu et al., 2008).

In order to inform future end-of-life care services that work towards decreasing the number of avoidable emergency admissions, it is important to gain an understanding of current service use of emergency care by people dying with cancer and factors that influence this use. Knowledge of such factors could help healthcare professionals identify and support individuals at increased risk of multiple end-of-life emergency admissions.

SECTION 2- THE ACUTE ONCOLOGY SERVICE IN NI

An Acute Oncology Service (AOS) was established in NI in October 2016. This service aims to care for people who present to the Emergency Department (ED) with a suspected cancer or complications from cancer or cancer treatment including:

- Toxicity that has occurred as a result of anti-cancer treatment
- Acute complications of the patients' disease (such as malignant spinal cord compression)
- Patients admitted as an emergency with a previously undiagnosed cancer.

In NI, patients with acute cancer-related complications may present in a number of ways and to different healthcare settings. Whilst it is recognised that cancer patients may present to any acute hospital within NI, the AOS has initially been based in Altnagelvin hospital (Western Trust), Antrim Area hospital (Northern Trust), Craigavon Area hospital (Southern Trust), Royal Victoria (Belfast Trust) Hospital, and Ulster hospital (South-Eastern Trust), with each local AOS providing liaison services (by phone) to all acute hospitals within each Trust area.

The AOS provides a single point of hospital contact for advice/support and brings together expertise from the multi-disciplinary team including oncology, palliative care, haematology, acute and emergency medicine and surgery, radiology, microbiology and pathology amongst others. The patient can be referred to AOS by any member of the healthcare team and the aim is that they are referred as early as possible and usually within 24 hours of hospital admission.

The AOS currently operates across all five HSC Trusts between the hours of 9am-5pm Monday to Friday. The AOS aims to reduce length of stay, avoid unnecessary emergency admissions and improve overall patient experience by:

- Providing access to expert and timely oncology advice in order to ensure appropriate management of the complications of cancer and its treatment.
- Providing timely and appropriate access to emergency treatment and, if necessary, hospital admission.
- Ensuring that the infrastructure is in place to provide this service.
- Enhancing the management of patients with previously undiagnosed cancer or cancer of an unknown primary.
- Informing patients, where appropriate, of the potential side effects of treatment and how to deal with problems.

Although the AOS has the potential to care for people at any stage of their cancer journey, it is likely that the AOS will provide most acute care for people in their last year of life. The findings of this report provide baseline information on numbers of emergency admissions for people dying of cancer in NI prior to the introduction of the service at the end of 2016.

SECTION 3- STUDY AIM AND OBJECTIVES

3.1 Study Aim and Objectives

3.1.1 Aim: To examine the demographic, disease and environmental characteristics of people dying with cancer in 2015 who did and did not have an emergency admission recorded in the last year of life.

3.1.2 Objectives:

(a) To document the total number of emergency admissions recorded in the last year of life.

(b) To investigate demographic, disease and environmental characteristics of people dying with cancer in 2015.

(c) To assess differences in the number and timing of emergency admissions in the last year of life by rurality and socio-economic status.

(d) To investigate timelines including time from:

- diagnosis to first emergency admission.
- diagnosis to death.
- first admission to death.
- last admission to death.

(e) To examine the method of admission (i.e. through ED by timing of emergency admission).

(f) To assess length of stay in hospital following an emergency admission in the last year of life.

(g) To examine final discharge destination and investigate the characteristics of people who died before discharge following an emergency admission.

(h) To investigate place of death for those who did and did not have an emergency admission recorded.

(i) To investigate the proportion of patients who had a palliative care code recorded.

(j) To examine reasons for the last emergency admission by method of admission, and final discharge destination.

SECTION 4- STUDY METHODS

4.1 Data Sources

Data on all people dying of cancer in 2015 were obtained from the General Register Office (GRO) NI. Death data were linked with cancer registration data on the tumour of diagnosis associated with death and Patient Administration System (PAS) episodes relating to emergency admissions between 1st January 2014 and 31st December 2015.

4.2 Inclusion and Exclusion Criteria

A small number of people dying of cancer (n=54) were excluded from the study due to lack of clinical information around their time of death or being extra-regional (n=38) at the time of their cancer diagnosis and therefore information on cancer of diagnosis was not available within the NICR database.

4.3 Analysis

Analysis of the anonymised datasets was carried out in STATA (version 14, STATA Corp, LLC). Descriptive statistics were used to present characteristics of people dying of cancer who did or did not have an emergency admission recorded within PAS in the last year of life using frequency tables with numbers and valid percentages. Where applicable, data are presented with means and standard deviations. Chi-square analysis was used to test comparisons between groups. ICD-10 codes from PAS for each emergency admission episode were used as a ‘proxy’ for reason for admission due to incomplete free-text information on reason for admission being available for all patients.

4.4 Designation of Rurality and Socio-economic status

Rurality and socio-economic status were based on postcode of residence at time of death. Super output areas (SOA) are assigned to each patient based on their postcode of usual residence at time of death. The patient is then assigned, through their SOA, a socio-economic deprivation quintile based on the SOA’s 2017 Income domain of the Multiple Deprivation Measure. The 2017 Multiple Deprivation Measure is available from the NI Statistics and Research Agency (www.nisra.gov.uk).

SECTION 5- RESULTS

5.1 Patient Characteristics

Table 5.1. Demographic Characteristics for those included and excluded from the final analysis

		Excluded	Included in Analysis	Total	p
Sex	Female	42 (45.7%)	1,939 (45.9%)	1,981 (45.9%)	0.872
	Male	50 (54.3%)	2,285 (54.1%)	2,335 (54.1%)	
Age at time of death	0-49 years	6 (6.6%)	211 (5.0%)	217 (5.0%)	0.139
	50-59 years	10 (10.9%)	369 (8.7%)	379 (8.8%)	
	60-69 years	16 (17.4%)	908 (21.5%)	924 (21.4%)	
	70-79 years	18 (19.6%)	1296 (30.7%)	1314 (30.4%)	
	80+ years	42 (45.6%)	1440(34.1%)	1482 (34.3%)	
Deprivation Quintile	Quintile 1 (Least deprived)	21 (22.8%)	812 (19.3%)	833 (19.4%)	0.392
	Quintile 2	22 (23.9%)	863 (20.4%)	885 (20.5%)	
	Quintile 3	22 (23.9%)	808 (19.1%)	830 (19.2%)	
	Quintile 4	12 (13.0%)	818 (19.3%)	830(19.2%)	
	Quintile 5 (Most deprived)	15 (16.5%)	914 (21.7%)	929 (21.6%)	
	Unknown	0 (0.0%)	9 (0.2%)	9 (0.2%)	
	Total	**92 (2.1%)**	**4,224 (97.9%)**	**4,316 (100.0%)**	

- There were 4,316 cancer related deaths in 2015.
- There were no differences in sex (p=0.872), age at time of death (p=0.139) or deprivation quintile (p=0.392) between those included and excluded from the final analysis.

Table 5.2.a Demographic and Disease Characteristics of People dying with cancer in 2015 by emergency admission recorded in the last year of life

		Emergency Admission in last year of life			
		No	Yes	Total	p
Sex	Male	556 (24.3%)	1,729 (75.7%)	2,285 (54.1%)	0.018
	Female	534 (27.5%)	1,405 (72.5%)	1,939 (45.9%)	
Tumour Diagnosis	Brain and other CNS (C70-C72)	21 (20.2%)	83 (79.8%)	104 (2.5%)	<0.001
	Breast (C50)	83 (30.0%)	194 (70.0%)	277 (6.6%)	
	Colorectal and Anus (C18-C21)	128 (26.0%)	364 (74.0%)	492 (11.6%)	
	Connective Tissue (C49)	9 (45.0%)	11 (55.0%)	20 (0.5%)	
	Female Genital (C51-C55)	33 (35.9%)	59 (64.1%)	92 (2.2%)	
	Head & Neck (C00-C14, C30-C32)	49 (35.8%)	88 (64.2%)	137 (3.2%)	
	Leukaemia (C91-C95)	28 (21.5%)	102 (78.5%)	130 (3.1%)	
	Liver, Gallbladder & Bile Ducts (C22-C24)	39 (23.2%)	129 (76.7%)	168 (4.0%)	
	Lung (C33 & C34)	222 (22.0%)	788 (78.0%)	1,010 (23.9%)	
	Lymphoma (C81-C85)	26 (17.7%)	121 (82.3%)	147 (3.5%)	
	Melanoma (C43)	24 (42.9%)	32 (57.1%)	56 (1.3%)	
	Mesothelioma (C45)	8 (19.5%)	33 (80.5%)	41 (1.0%)	
	Myeloma (C90)	18 (20.0%)	72 (80.0%)	90 (2.1%)	
	NMSC (C44)	19 (54.3%)	16 (45.7%)	35 (0.8%)	
	Oesophagus, Stomach & Small Intestine (C15-C17)	85 (25.4%)	250 (74.6%)	335 (7.9%)	
	Other Digestive (C26)	12 (30.8%)	27 (69.2%)	39 (0.9%)	
	Other	23 (26.1%)	65 (73.9%)	88 (2.1%)	
	Ovarian (C56)	27 (29.4%)	65 (70.7%)	92 (2.2%)	
	Pancreas (C25)	51 (23.1%)	170 (76.9%)	221 (5.2%)	
	Prostate (C61)	65 (25.6%)	189 (74.4%)	254 (6.0%)	
	Unknown Primary (C76-C80)	58 (35.8%)	104 (64.2%)	162 (3.8%)	
	Urinary Cancer (C64-C68)	62 (26.5%)	172 (73.5%)	234 (5.6%)	

CNS: Central Nervous System, NMSC Non-melanoma Skin Cancer

- ***Sex**:* A higher proportion of males (75.7%) had at least one emergency admission recorded in the last year of life compared to females (72.5%; p=0.018).
- ***Tumour Diagnosis**:* A higher proportion of people with a diagnosis of Lymphoma (82.3%), mesothelioma (80.5%), myeloma (80.0%), brain and other CNS cancer (79.8%), leukaemia (78.5%) or lung cancer (78.0%) had at least one emergency admission recorded in the last year of life compared to those with a diagnosis of Non Melanoma Skin Cancer (NMSC) (45.7%), connective tissue cancer (55.0%), melanoma (57.1%), female genital cancer (64.1%), head and neck cancer (64.2%) or cancer of unknown primary (CUP) (64.2%). (p<0.001).

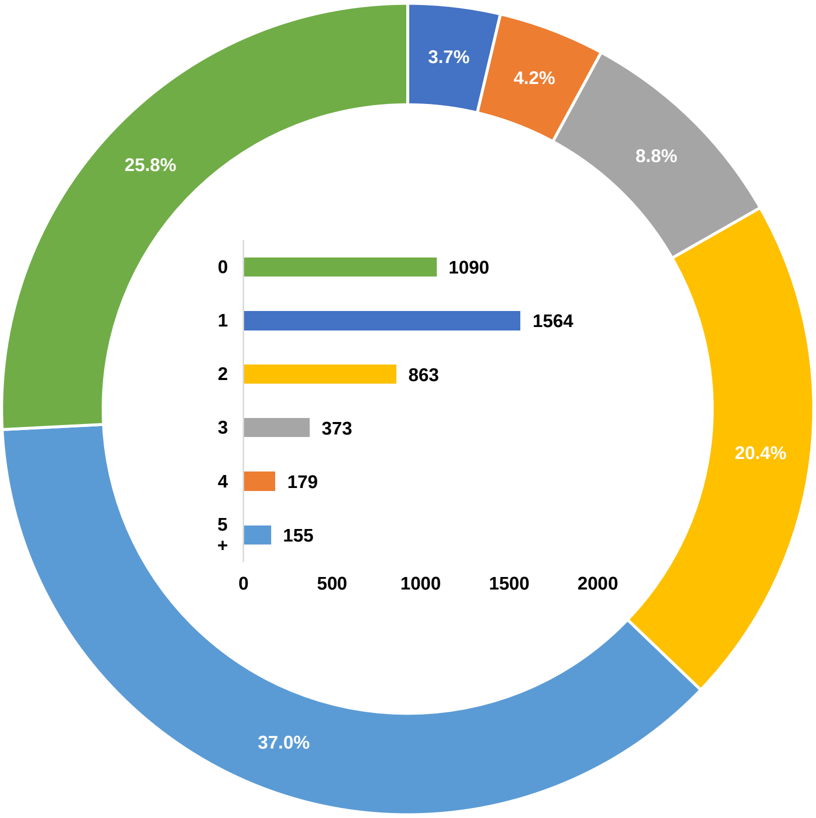
Table 5.2.b Demographic and Environmental Characteristics of People dying with cancer in 2015 by emergency admission recorded in the last year of life

		Emergency Admission in last year of life			
		No	**Yes**	**Total**	**p**
Socio-economic status	Quintile 1 (Least deprived)	219 (27.0%)	593 (73.0%)	812 (19.2%)	0.708
	Quintile 2	219 (25.4%)	644 (74.6%)	863 (20.4%)	
	Quintile 3	201 (24.9%)	607 (75.1%)	808 (19.1%)	
	Quintile 4	216 (26.4%)	602 (73.6%)	818 (19.4%)	
	Quintile 5 (Most deprived)	231 (25.3%)	683 (74.7%)	914 (21.6%)	
	Unknown	4 (44.4%)	5 (55.6%)	9 (0.2%)	
Stage at Diagnosis	Stage I	77 (32.6%)	159 (67.3%)	236 (5.6%)	<0.001
	Stage II	109 (29.6%)	259 (70.4%)	368 (8.7%)	
	Stage III	158 (22.6%)	542 (77.4%)	700 (16.6%)	
	Stage IV	306 (20.3%)	1198(79.7%)	1504 (35.6%)	
	Unknown	436(31.2%)	961 (68.8%)	1397 (33.1%)	
	Two tumours at different stages	4(21.1%)	15 (78.9%)	19 (0.4%)	
Age at time of Death	0-24 years	6 (40.0%)	9 (60.0%)	15 (0.4%)	<0.001
	25-39 years	10 (19.6%)	41 (80.4%)	51 (1.2%)	
	40-49 years	27 (18.6%)	118 (81.4%)	145 (3.4%)	
	50-59 years	60 (16.3%)	309 (83.7%)	369 (8.7%)	
	60-69 years	182 (20.0%)	726 (80.0%)	908 (21.5%)	
	70-79 years	330 (25.5%)	966 (74.5%)	1296 (30.7%)	
	80-89 years	348 (30.8%)	783 (69.2%)	1131(26.8%)	
	90+ years	127 (41.1%)	182 (58.9%)	309 (7.3%)	
Rurality	Rural	379 (27.4%)	1002 (72.6%)	1381 (32.7%)	0.082
	Urban	707 (24.9%)	2127 (75.1%)	2834 (67.1%)	
	Unknown	4 (44.4%)	5 (55.6%)	9 (0.2%)	
	Total	**1090 (25.8%)**	**3134 (74.2%)**	**4,224**	

- ***Stage at Diagnosis**:* A higher proportion of those diagnosed at stages III (77.4%) or IV (79.7%) and a lower proportion of those diagnosed at stage I (67.3%) had at least one emergency admission recorded (p<0.001).
- ***Age at Time of death***: A lower proportion of people aged 0-24 years, 80-89 years and 90 years and over had at least one emergency admission in the last year of life (p<0.001).
- ***Rurality/Deprivation**:* There were no differences by rurality (p=0.082) or deprivation (p=0.708) in the proportions of people dying with cancer who did or did not have an emergency admission.

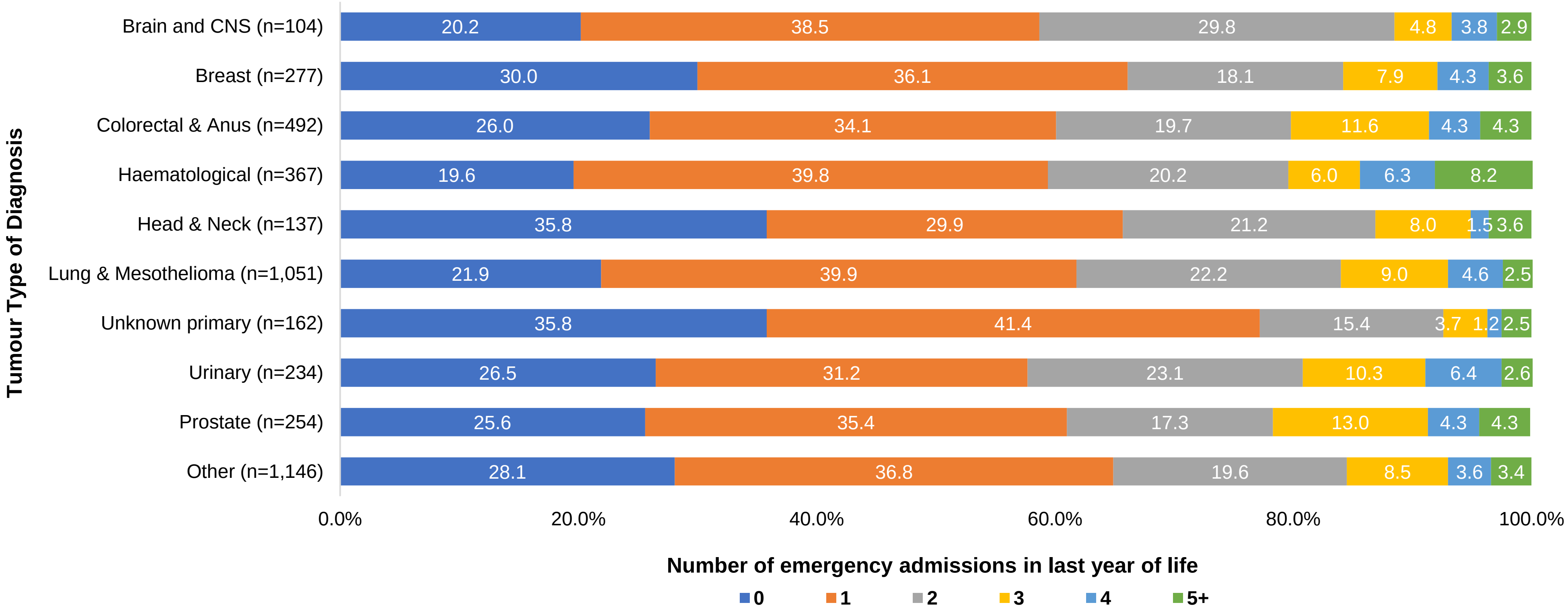
5.2 Number of Emergency admissions

Figure 5.1 Number of Emergency Admissions recorded in last year of life



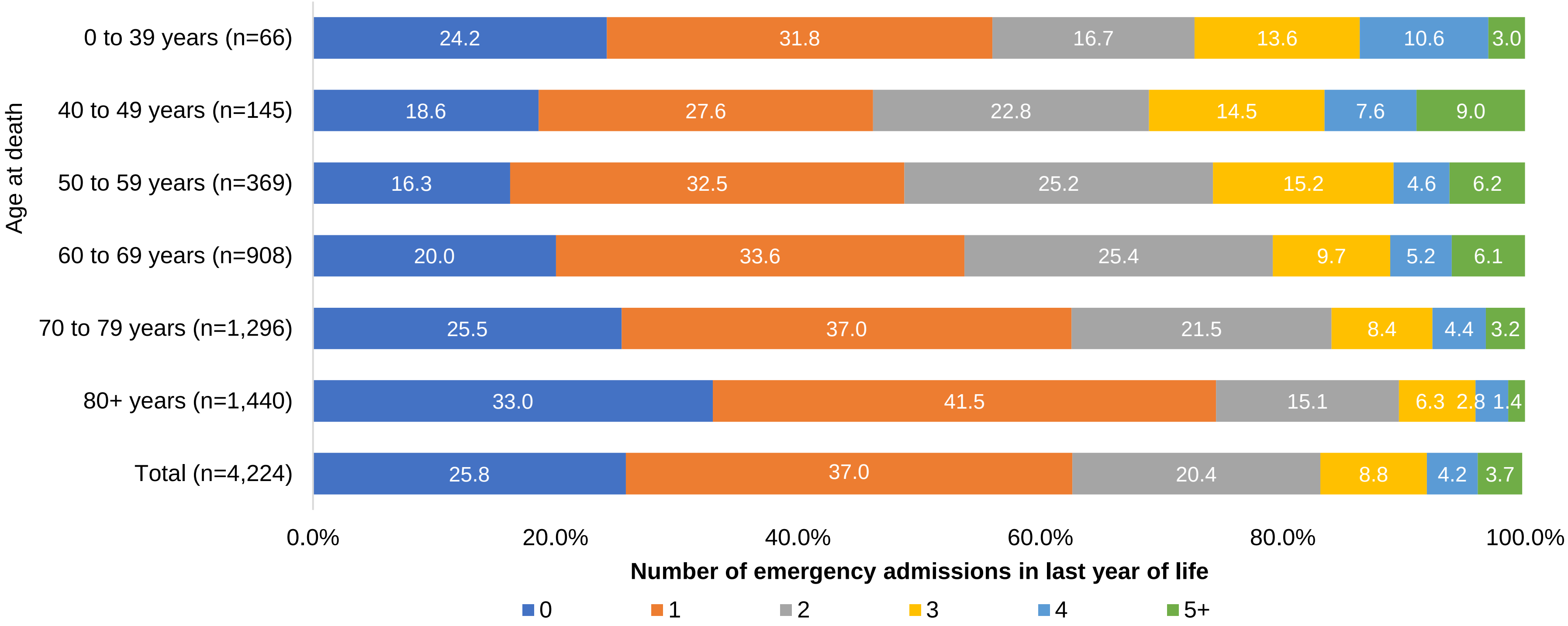
- Almost 3 in 4 (74.2%) people dying of cancer in 2015 had at least one emergency admission while 1 in 6 (16.7%) had 3 or more emergency admissions recorded in their last year of life.
- This represents a total of 6,041 emergency admissions occurring the last year of life for people dying of cancer in 2015.
- The mean number of emergency admissions in the last year of life for those who had at least one emergency admission recorded in the last year of life was 1.9 (95%CI 1.9-2.0).

Figure 5.2 Number of Emergency Admissions recorded in last year of life by tumour site of diagnosis



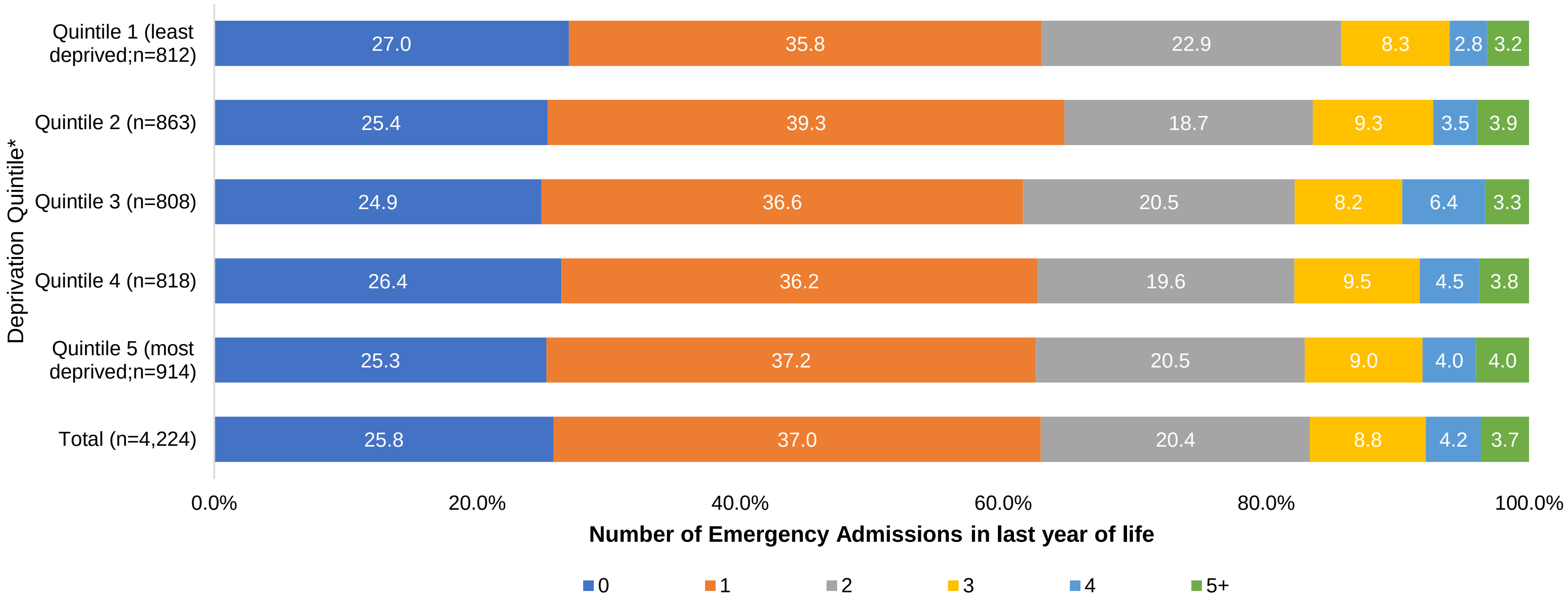
- A higher proportion of patients with a diagnosis of Prostate (21.6%), Haematological (20.5%), Colorectal or Anus (20.2%), or Urinary Cancer (19.3%) had three or more emergency admissions recorded in the last year of life compared with Cancer of Unknown Primary (CUP) (7.4%), Brain and other Central Nervous System (CNS) (11.5%) and Head and Neck cancer (13.1%). (p<0.001). See Figure 5.2.

Figure 5.3 Number of Emergency Admissions recorded in last year of life by age at time of death



- A higher proportion of patients aged 0-59 years had three or more emergency admissions recorded in their last year of life (0 to 39 years; 27.2%), (40 to 49 years; 31.1%), (50 to 59 years; 26.0%) compared with those aged 70 to 79 years (16.0%) or 80+ years (10.5%) ($p<0.001$). See Figure 5.3.

Figure 5.4 Number of Emergency Admissions recorded in last year of life by Deprivation Quintile* (based on postcode of residence at time of death)



* Super output areas (SOA), are assigned to each patient based on their postcode of usual residence at time of death. The patient is then assigned, through its SOA, to a socio-economic deprivation quintile based on the SOA's 2017 Income domain of the Multiple Deprivation Measure. The 2017 Multiple Deprivation Measure is available from the NI Statistics and Research Agency (www.nisra.gov.uk)

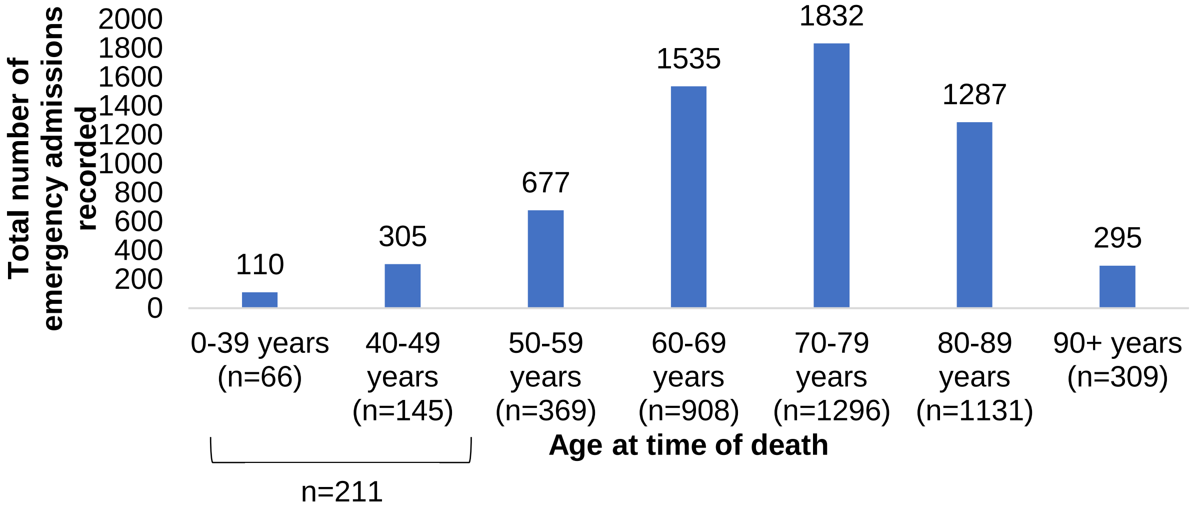
- There was no difference in the number of emergency admissions in last year of life by deprivation quintile (based on postcode of residence at time of death; p=0.440). See Figure 5.4.

Table 5.3 Average Number of Emergency Admissions (95%CI) by Age group at time of Death

Age group (number of patients)	% with emergency admission	Average number Emergency Admissions	95%CI
0 to 39 years (n=66)	75.8	1.7	1.3,2.0
40 to 49 years (n=145)	81.4	2.1	1.8, 2.4
50 to 59 years (n=369)	83.7	1.8	1.7, 2.0
60 to 69 years (n=908)	80.0	1.7	1.6, 1.8
70 to 79 years (n=1,296)	74.5	1.4	1.3,1.5
80 to 89 years (n=1,131)	69.2	1.1	1.1,1.2
90+ years (n=309)	58.9	1.0	0.8,1.1
All patients	74.2	1.4	1.4,1.5

- Emergency admissions as a proportion of cancer deaths was highest in those aged 50-59 years (83.7%) and 60 to 69 years (80.0%). See Table 5.3.

Figure 5.5. Total Number of emergency admissions recorded by age group at time of death



- More than half (56.5%) of all emergency admissions in last year of life for people dying of cancer in 2015, were recorded for people aged 70 years and over at time of death.

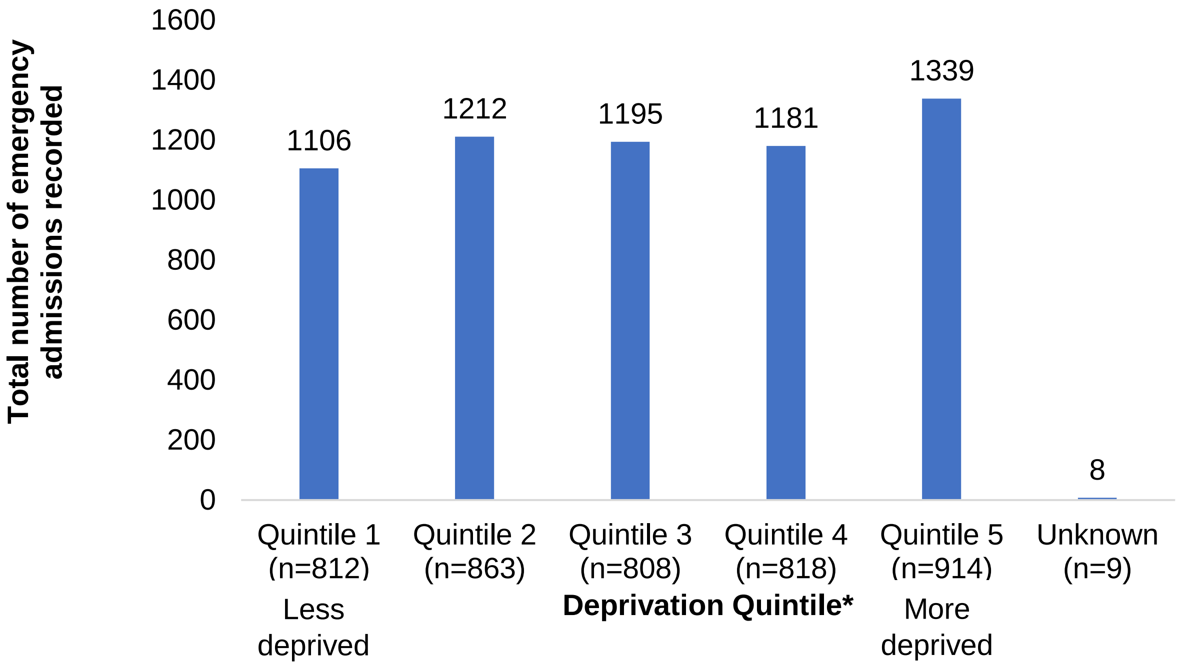
- 1 in 14 (6.9%) of emergency admissions in last year of life for people dying of cancer in 2015, occurred in people aged under 50 years at time of death. See Figure 5. 5.

Table 5.4 Mean Number of Emergency Admissions (95%CI) by Socio-economic Group

Socio-economic group (number of patients)	% with emergency admission	Average number Emergency Admissions	95%CI
Quintile 1 (least deprived) (n=812)	73.0%	1.4	1.3, 1.5
Quintile 2 (n=863)	74.6%	1.4	1.3, 1.5
Quintile 3 (n=808)	75.1%	1.5	1.4,1.6
Quintile 4 (n=818)	73.6%	1.4	1.3, 1.5
Quintile 5 (most deprived) (n=914)	74.7%	1.5	1.4, 1.6
Unknown (n=9)	55.6%	0.9	0.2, 1.6

- There was no difference in the number or average number of emergency admissions in the last year of life by socio-economic group.

Figure 5.6. Number of emergency admissions recorded by Socio-economic Group



* Super output areas (SOA), or 897 census output areas of NI, are assigned to each patient based on their postcode of usual residence at time of death. The patient is then assigned, through its SOA, to a socio-economic deprivation quintile based on the SOA's 2017 Income domain of the Multiple Deprivation Measure. The 2017 Multiple Deprivation Measure is available from the NI Statistics and Research Agency (www.nisra.gov.uk)

- Approximately 1 in 5 emergency admissions took place in each deprivation quintile, from 18.3% in Quintile 1 (least deprived) to 22.2% in Quintile 5 (most deprived).

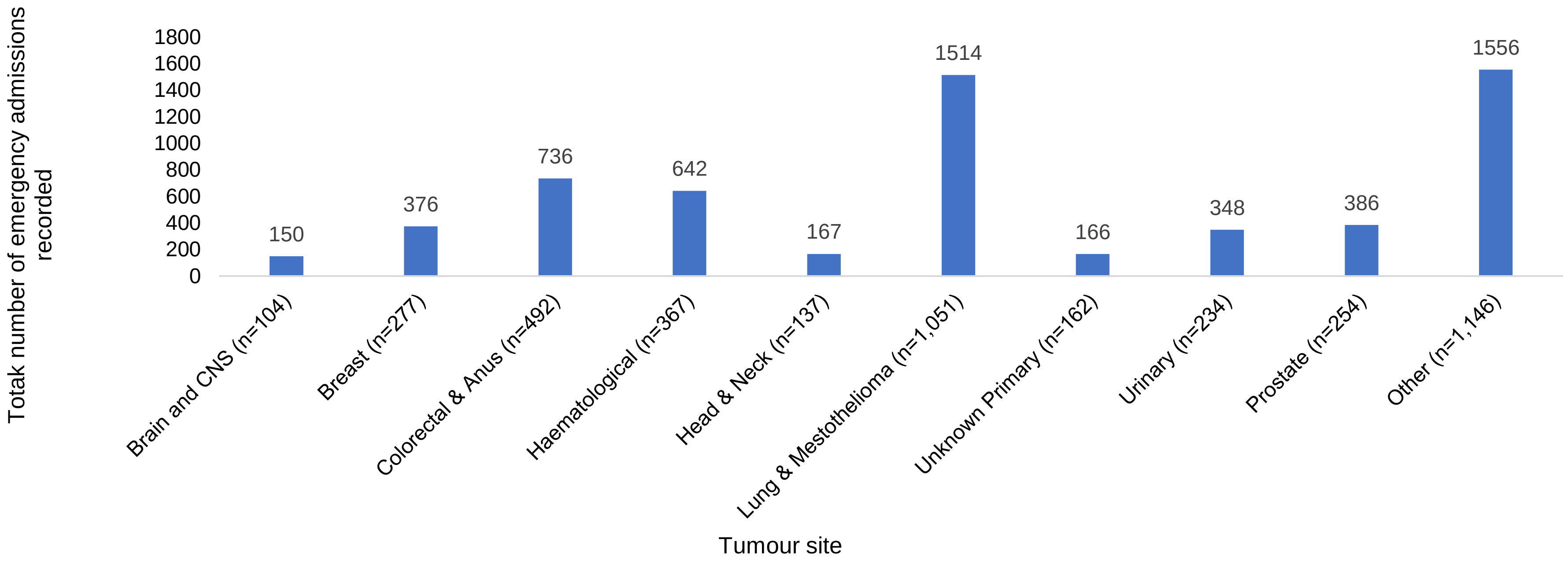
Table 5.5 Average and total number of Emergency Admissions (95%CI) by Tumour site related to the emergency admission

Cancer Type (No. of Patients)*	Total Number of Emergency Admissions	Average number Emergency Admissions	95%CI
Brain & CNS (n=104)	150	1.4	1.2, 1.7
Breast (n=277)	376	1.4	1.2,1.5
Colorectal & Anus (n=492)	736	1.5	1.4, 1.6
Head & Neck (n=137)	167	1.2	1.0, 1.4
Haematological (n=367)	642	1.7	1.6, 1.9
Lung and Mesothelioma (n=1,051)	1514	1.4	1.4, 1.5
Prostate (n=254)	386	1.5	1.3, 1.7
Unknown Primary (n=162)	166	1.0	0.8, 1.2
Urinary Cancer (n=234)	348	1.5	1.3, 1.7
Other (n=1,146)	1,556	1.4	1.3, 1.4

*Number of patients Includes those with no emergency admissions recorded

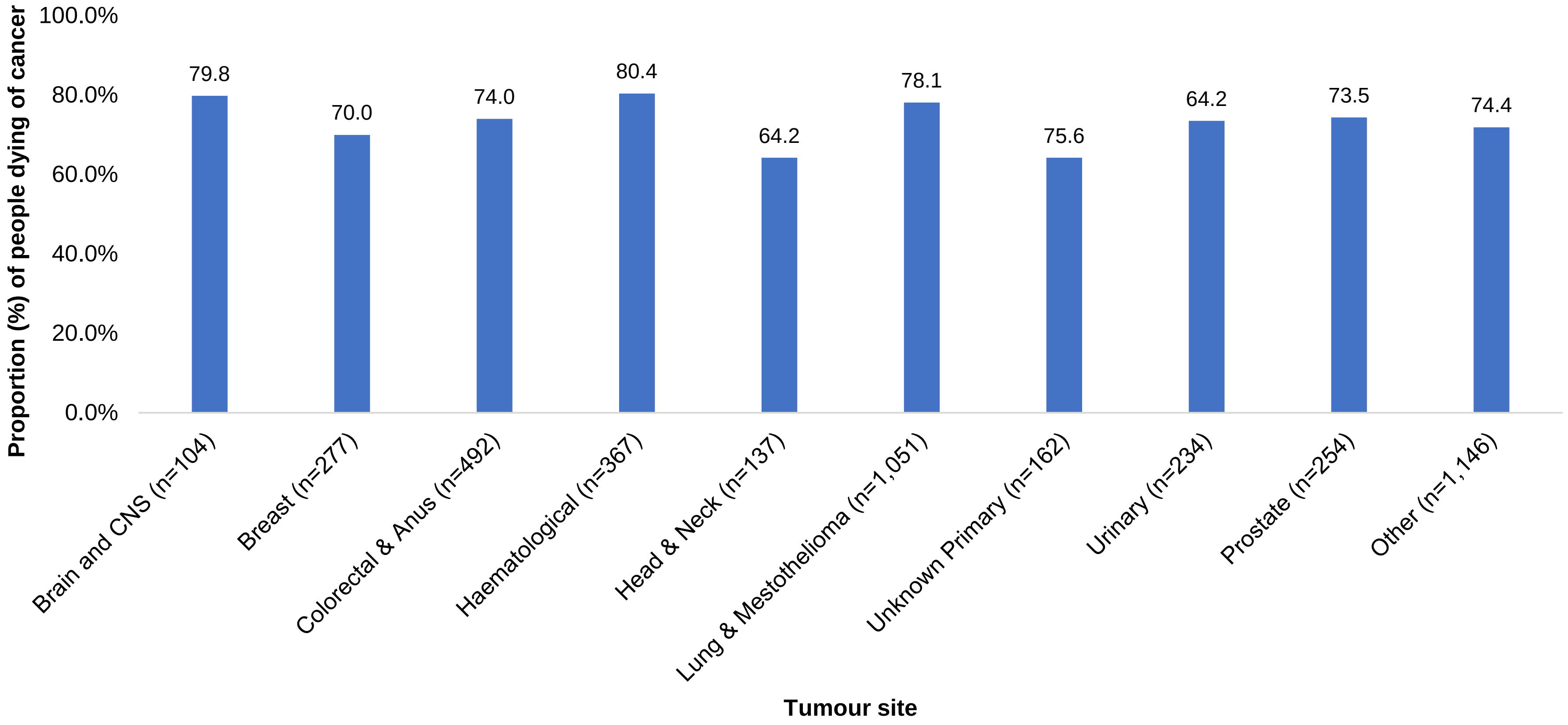
- Those with a haematological malignancy were most likely to have multiple admissions in their last year of life compared to other cancer types. See Table 5.5.

Figure 5.7. Number of emergency admissions recorded by tumour site



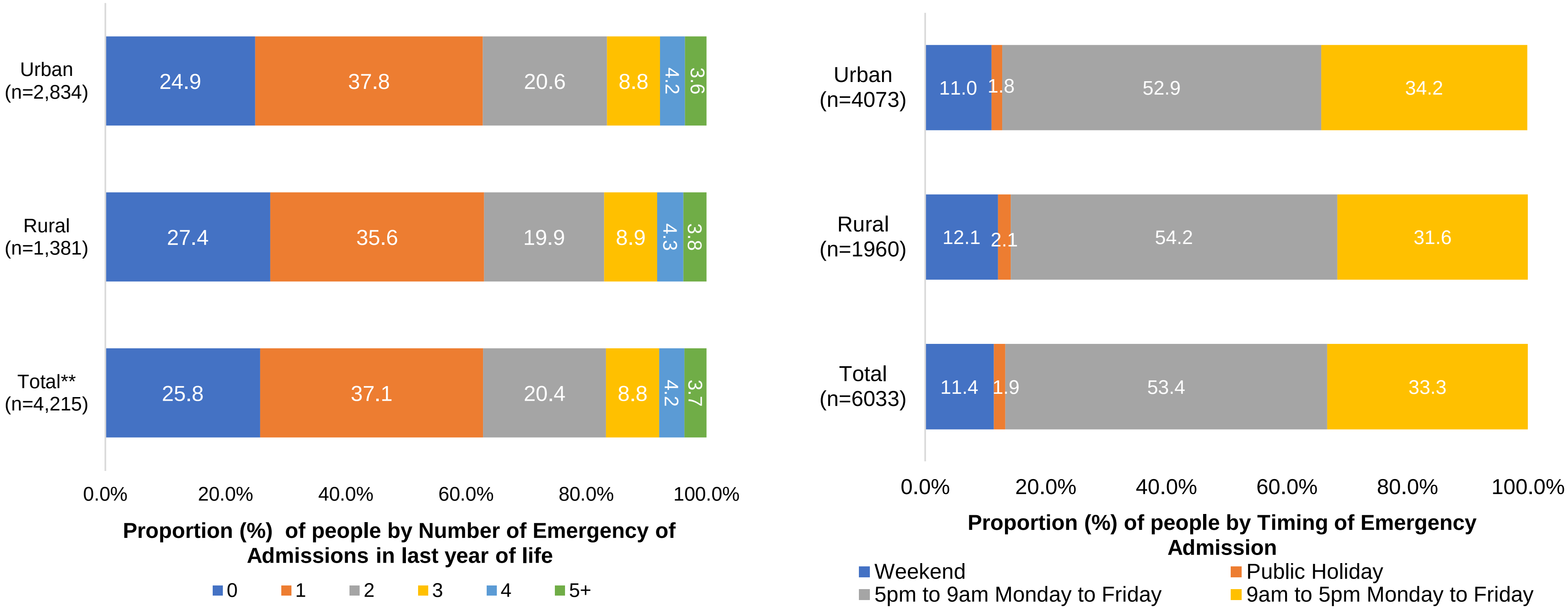
- Almost 1 in 4 (25.1%) of all emergency admissions occurred in people with a lung cancer or mesothelioma with 1 in 8 (12.2%) colorectal or anal cancer, 1 in 10 (10.6%) haematological malignancy, 1 in 16 prostate cancer (6.4%) or breast cancer (6.2%). This in part reflects the number of deaths from any one cancer. See Figure 5.7
- The rate of any emergency admissions was highest for Haematological, Brain and CNS and Lung. See Figure 5.8

Figure 5.8 Proportion (%) of people who had an emergency admission in the last year of life by tumour site



5.3 Rurality

Figure 5.9. Number and timing of emergency admissions by Rurality*

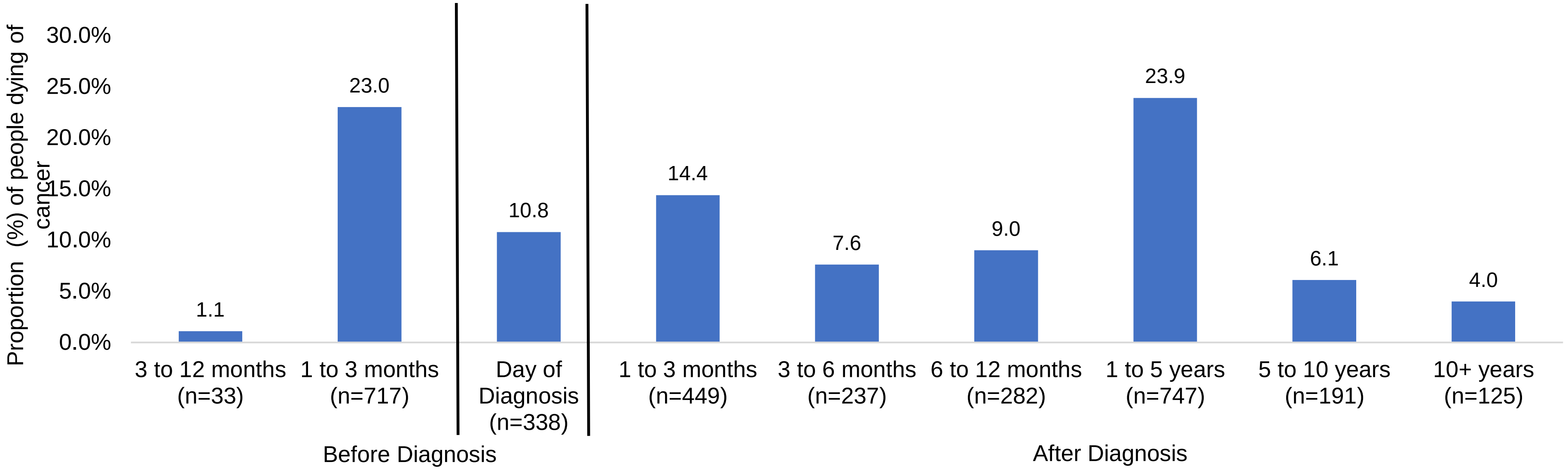


* Rurality based on post-code of residence at time of death**Please note: n=9 not presented due to lack of information on post-code of residence at time of death

- There was no difference in the number (p=0.551) or time (p=0.462) of emergency admissions in last year of life by rurality See Figure 5.9.

5.4 Timelines

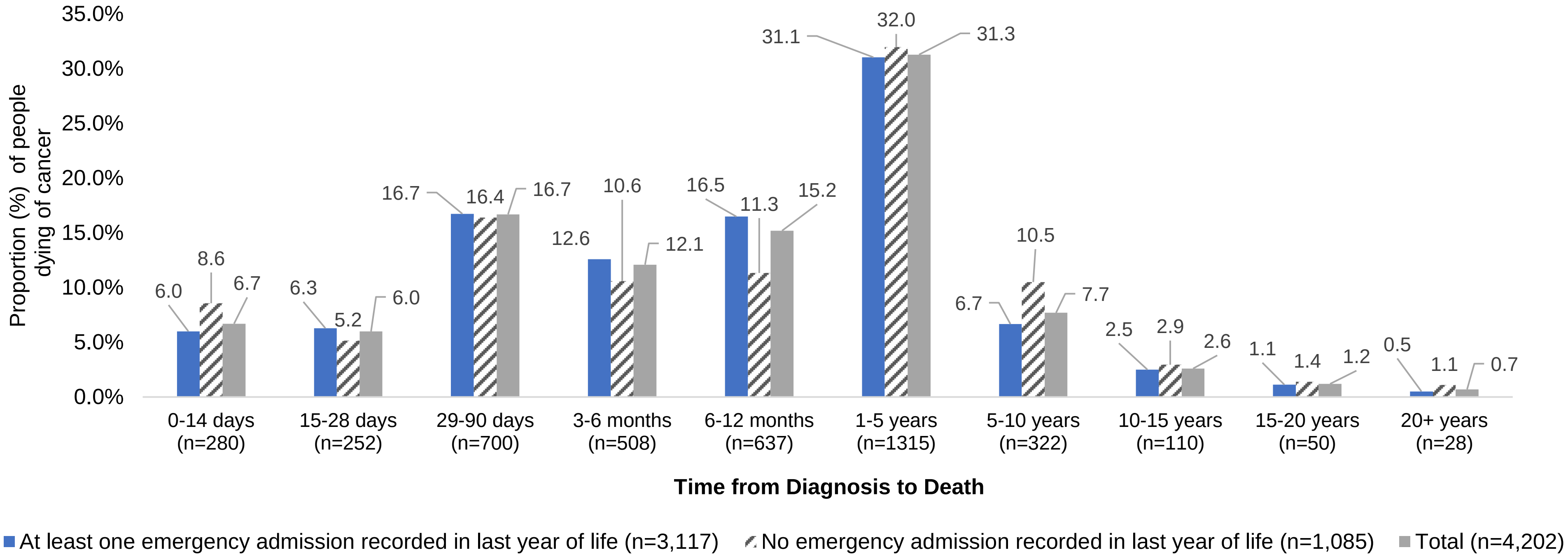
Figure 5.10. Time from Diagnosis to 1st emergency admission



***Date of diagnosis was not included for n=15 due to two tumours diagnosed**

- Almost 1 in 4 (23.0%) people were admitted as an emergency one to three months before their cancer diagnosis representing possible lost opportunities for earlier diagnosis.
- 1 in 9 (10.8%) were admitted on the day of their cancer diagnosis.
- Over 1 in 5 (22.0%) were admitted as an emergency in the six months following their cancer diagnosis with almost 1 in 4 (23.9%) between one to five years following their diagnosis and 1 in 10 (10.1%) more than five years following their cancer diagnosis. See Figure 5.10.

Figure 5.11. Time from Diagnosis to Death by existence/absence of emergency admission



- 1 in 8 (12.7%) people dying of cancer in 2015, died within 28 days of diagnosis, 1 in 6 (16.7%) within 29-90 days of diagnosis and approximately 1 in 20 (4.5%) more than 10 years following their cancer diagnosis with no differences in any group related to having had an emergency admission. See Figure 5.11.
- 1 in 15 (6.6%) people died within 14 days of diagnosis and of those people, 1 in 3 (33.2%) had at least one emergency admission recorded in the last year of life.

Figure 5.12 Time from 1st admission to Death

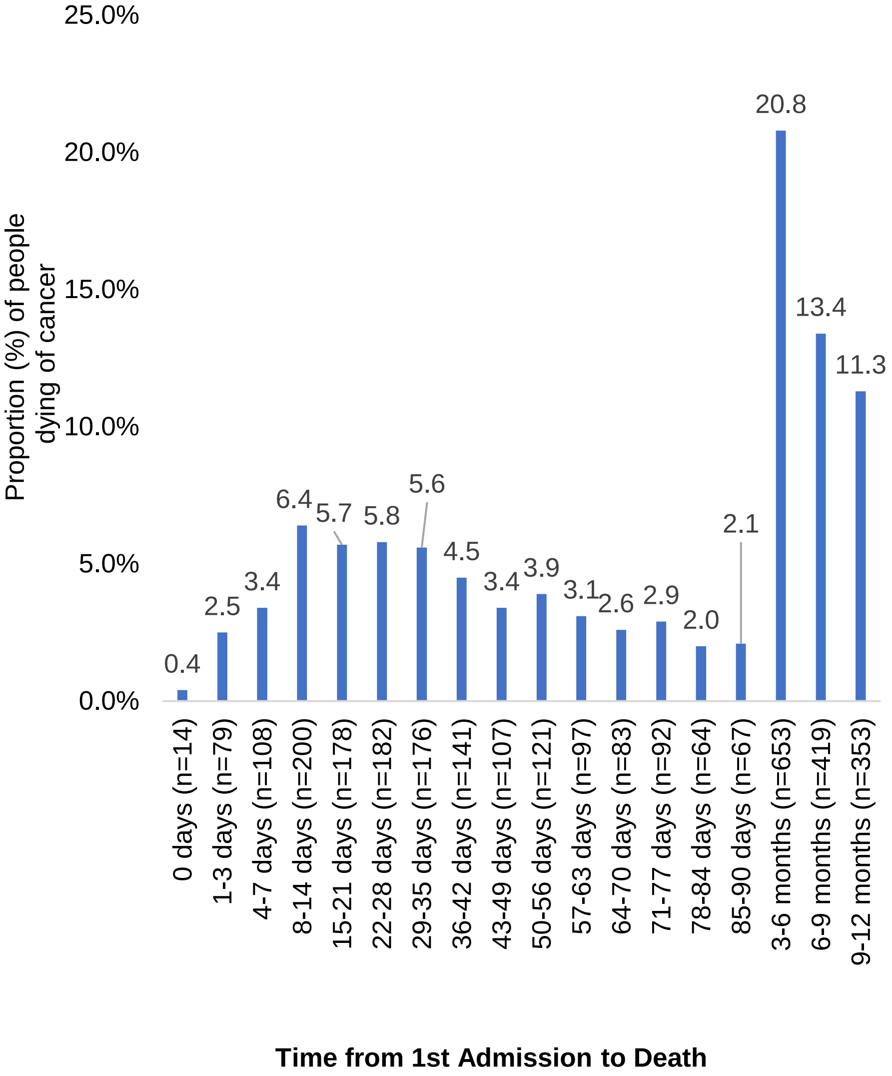
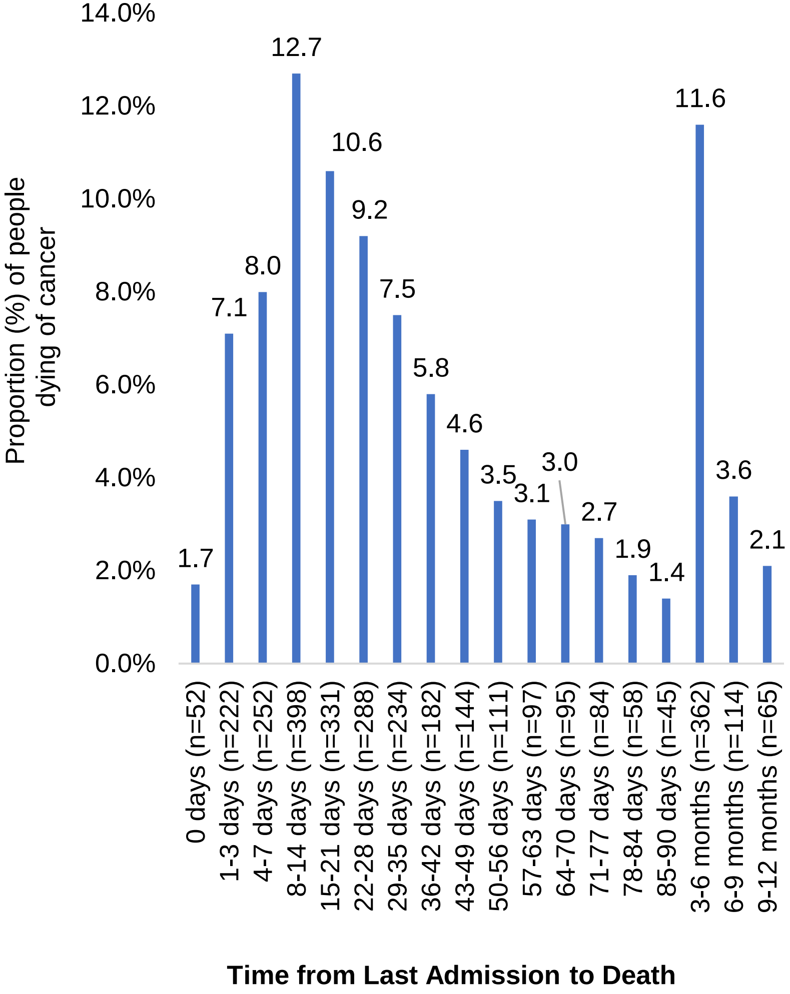


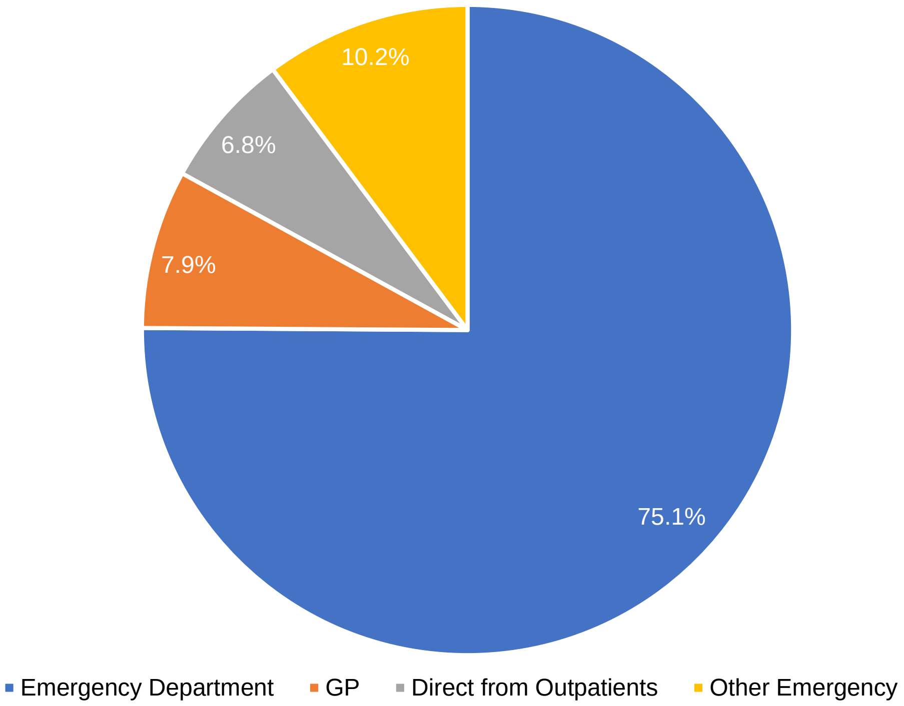
Figure 5.13 Time from last admission to Death



1 in 6 (16.8%) died within 7 days of last emergency admission, almost 1 in 3 (29.5%) within 14 days, half (49.3%) within 28 days and 1 in 6 (17.3%) within 3 to 12 months of last emergency admission. See Figure 5.13

5.5 Method of Admission

Figure 5.14. Method of admission for all emergency admissions recorded for people dying with cancer in 2015

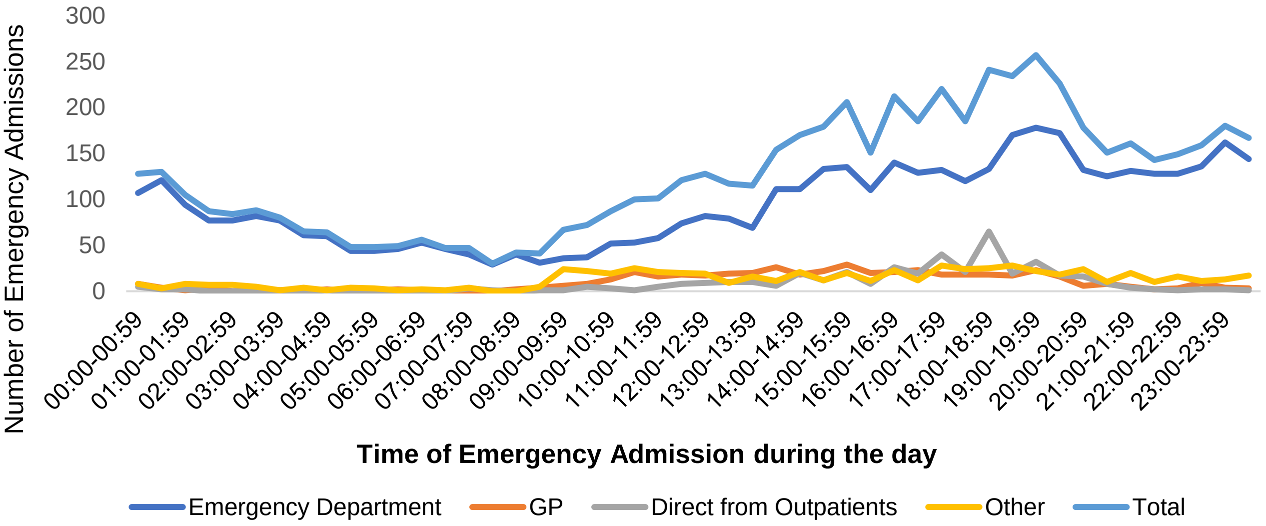


*Other emergency includes acute care at home, ambulatory assessment, critical care medical unit and paramedic admission

- 3 in 4 (75.1%) of all emergency admissions were admitted through the ED,1 in 13 (7.9%) via GP as an emergency, with 1 in 15 (6.8%) admitted direct from outpatients and 1 in 10 (10.2%) through another emergency route (such as acute care at home, ambulatory assessment, critical care medical unit or paramedic admission). See Figure 5.14.

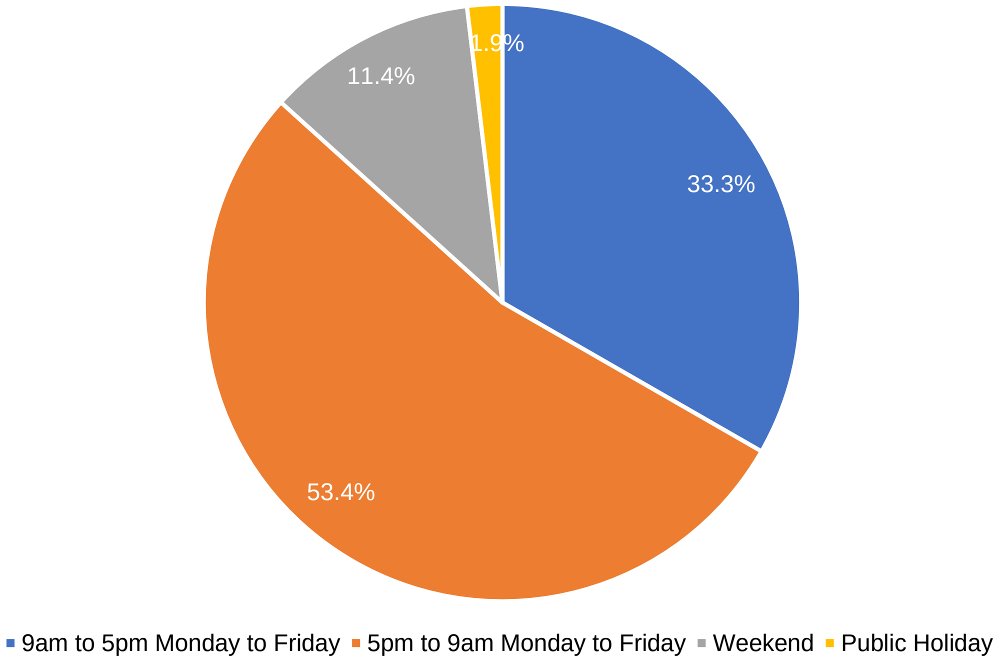
5.6 Timing of Admission

Figure 5.15. Timing of Emergency Admission (during the day) by source of admission



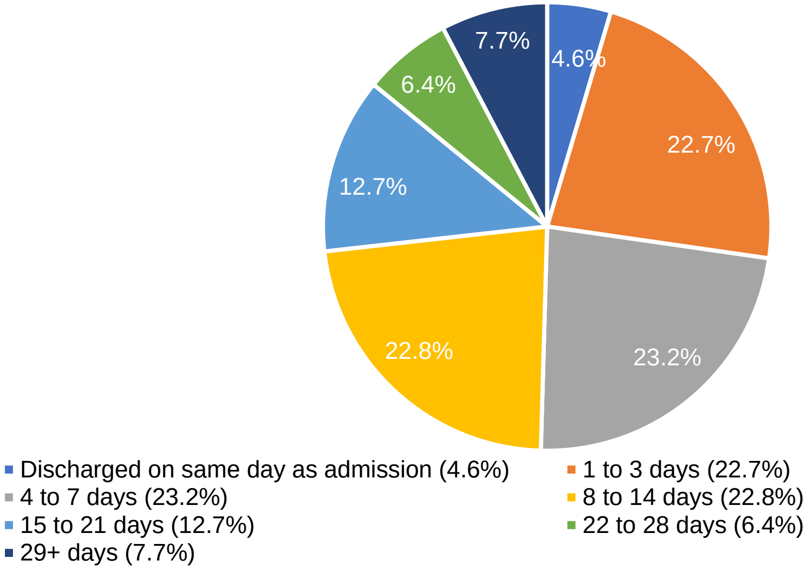
- The majority of patients were admitted via the Emergency Department (ED).
- 1 in 3 (33.3%) emergency admissions occurred between 9am and 5pm Monday to Friday with half (53.4%) 'out of hours' 5pm to 9am Monday to Friday. See Figure 5.16
- 1 in 9 (11.4%) were admitted as an emergency 'out of hours' over a weekend with 1 in 50 (1.9%) admitted 'out of hours' during a public holiday. See Figure 5.16

Figure 5.16 Time of Emergency Admission during the day



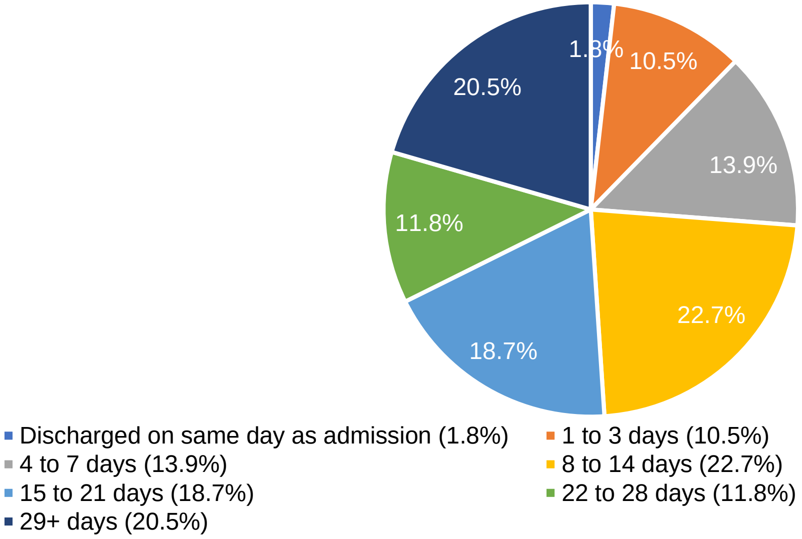
5.7 Length of stay in hospital

Figure 5.17 Number of days between admission and discharge for 1st emergency admission.



- 1 in 20 (4.6%) cancer patients who died in 2015 were discharged (or died) on the same day as their first admission, 1 in 5 (22.7%) had an inpatient stay of 1 to 3 days, 4 to 7 days (23.2%), 8 to 14 days (22.8%) with 1 in 12 (7.7%) staying more than 28 days. See figure 5.17

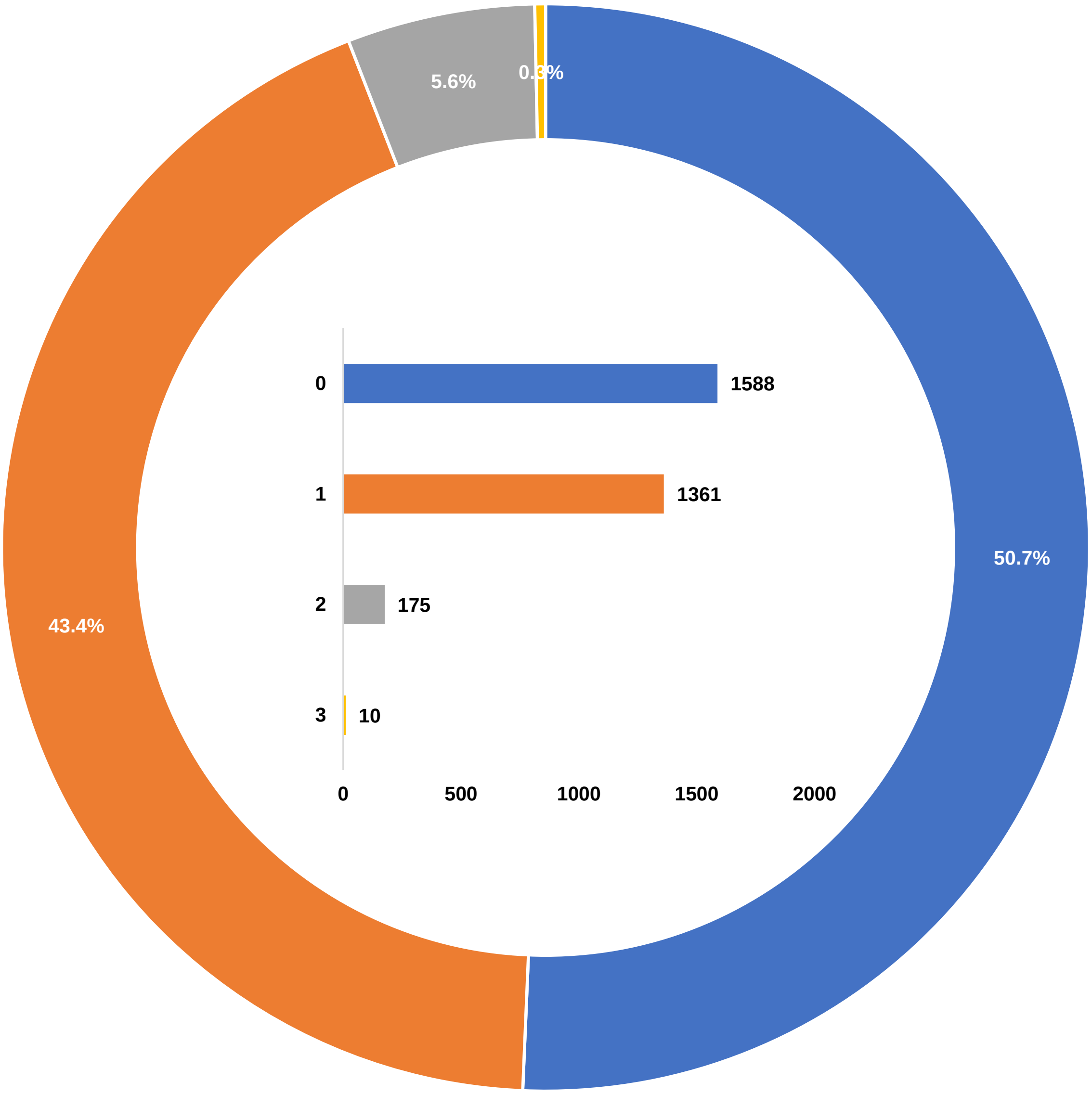
Figure 5.18 Total number of inpatient days for cancer patients with any emergency admission recorded in last year of life.



- Over 1 in 4 (26.2%) with at least one emergency admission recorded in the last year of life had a total inpatient stay of 7 days or less following their emergency admission(s). However, 1 in 5 (22.7%) had a total inpatient stay of 8 to 14 days and 1 in 5 (20.5%) more than 28 days. See Figure 5.18

5.8 Last 28 days of life

Figure 5.19 Total number of admissions in last 28 days of life



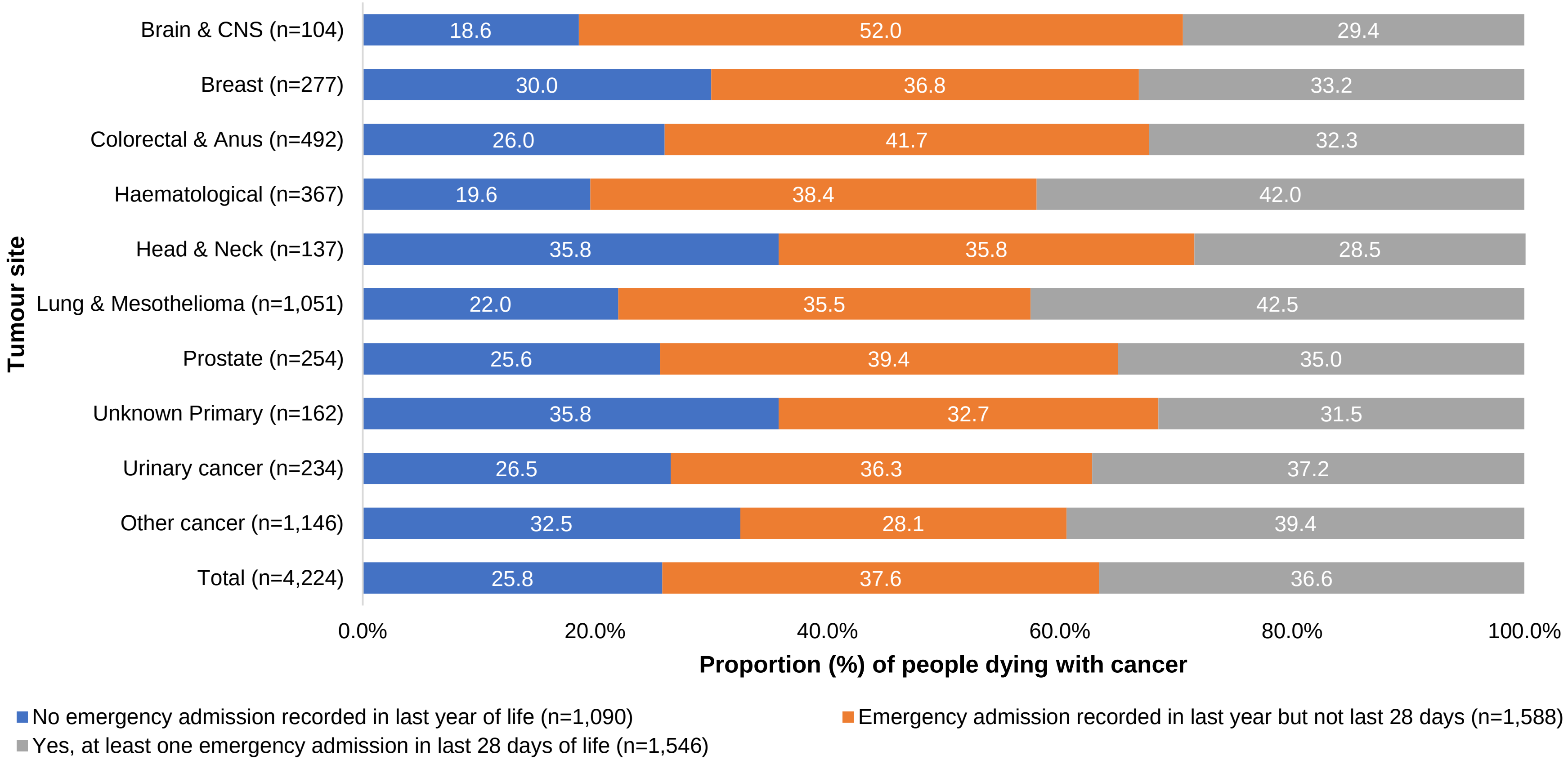
- 1 in 2 (49.3%) people who died from cancer in 2015 and with at least one emergency recorded in the last year of life, had at least one emergency admission recorded in the last 28 days of life with 1 in 18 (5.6%) having two such admissions. See Figure 5.19

Table 5.6 Demographic characteristics of patients with at least one emergency admission in the last 28 days of life compared with those who did not

	Admitted as an emergency in last 28 days of life	Emergency Admission recorded last year but not last 28 days of life	No emergency admission in last year of life	Total	p
Sex					
Female	648 (41.9%)	757 (47.7%)	534 (49.0%)	1,939 (45.9%)	<0.001
Male	898 (58.1%)	831 (52.3%)	556 (51.0%)	2,285 (54.1%)	
Age at time of Death					
0 to 49 years	89 (5.8%)	79 (5.0%)	43 (3.9%)	211 (5.0%)	<0.001
50 to 59 years	156 (10.1%)	153 (9.6%)	60 (5.5%)	369 (8.7%)	
60 to 69 years	389 (25.2%)	337 (21.2%)	182 (16.7%)	908 (21.5%)	
70 to 79 years	445 (28.8%)	521 (32.8%)	330 (30.3%)	1296 (30.7%)	
80 to 89 years	380 (24.6%)	403 (25.4%)	348 (31.9%)	1131 (26.8%)	
90 years and over	87 (5.6%)	95 (6.0%)	127 (11.7%)	309 (7.3%)	
Socio-economic Group					
Quintile 1 (Least deprived)	275 (17.8%)	318 (20.0%)	219 (20.1%)	812 (19.2%)	0.770
Quintile 2	313 (20.2%)	331 (20.8%)	219 (20.1%)	863 (20.4%)	
Quintile 3	310 (20.1%)	297 (18.7%)	201 (18.4%)	808 (19.1%)	
Quintile 4	305 (19.7%)	297 (18.7%)	216 (19.8%)	818 (19.4%)	
Quintile 5 (Most deprived)	340 (22.0%)	343 (21.6%)	231 (21.2%)	914 (21.6%)	
Unknown	3 (0.2%)	2 (0.1%)	4 (0.4%)	9 (0.2%)	
Total	**1546**	**1588**	**1090**	**4224**	

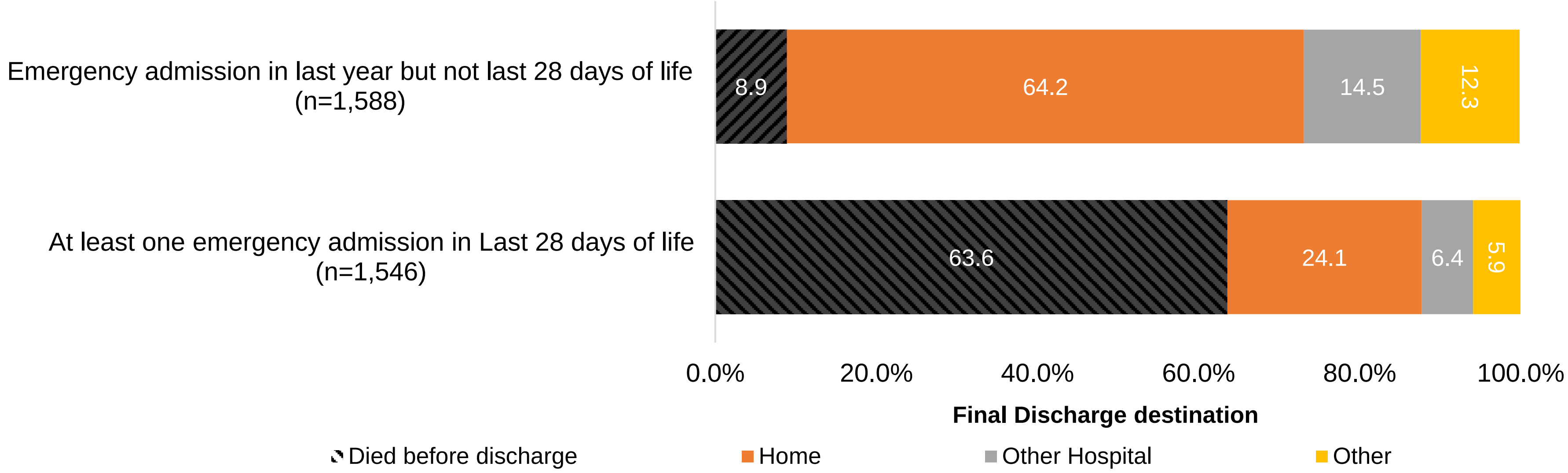
- A higher proportion of males (39.3%) than females (33.4%) had at least one emergency admission recorded in the last 28 days of life (p<0.001). The highest number of emergency admissions in last 28 days of life occurred in those aged 70-79 years.
- There were no differences in the proportion of people with or without an emergency admission in the last 28 days of life by socio-economic group (deprivation quintile) (p=0.770). See Table 5.6.

Figure 5.20 Tumour site for those who did and did not have an emergency admission in the last 28 days of life.



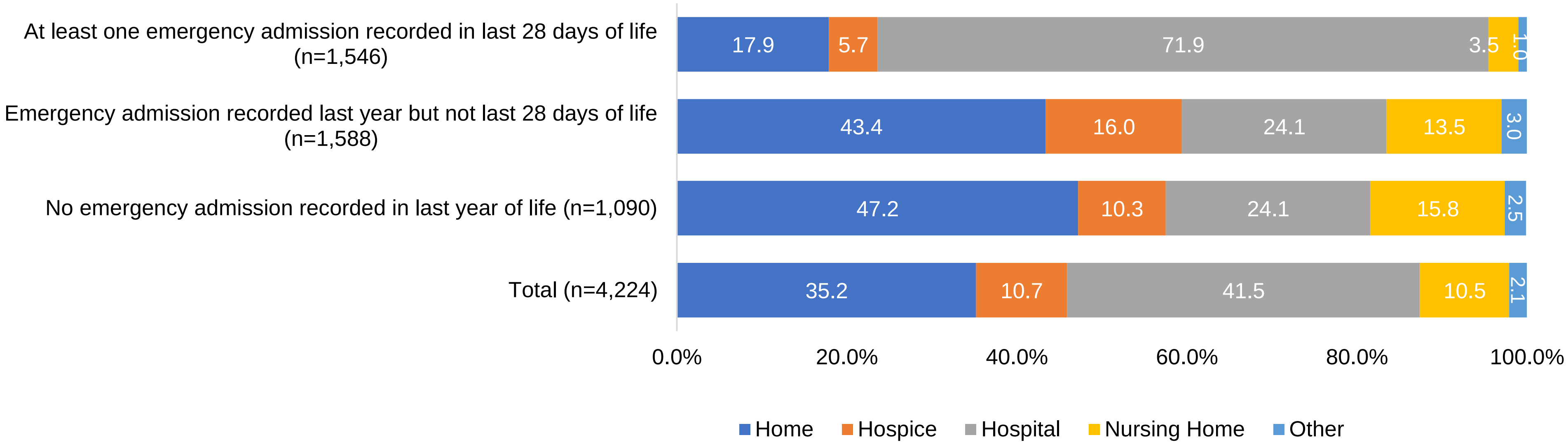
- A higher proportion of people with a diagnosis of lung cancer or mesothelioma (42.5%) and haematological cancer (42.0%) had at least one emergency admission recorded in their last 28 days of life compared with those diagnosed with Brain & CNS cancer (29.4%) or Head & Neck cancer (28.5%) (p<0.001). See Figure 5.20

Figure 5.21 Relationship between late emergency admission (last 28 days of life) and dying before discharge from hospital



- A higher proportion of people with an emergency admission recorded in the last 28 days of life died before discharge (63.6% vs 8.9%). See Figure 5.21.

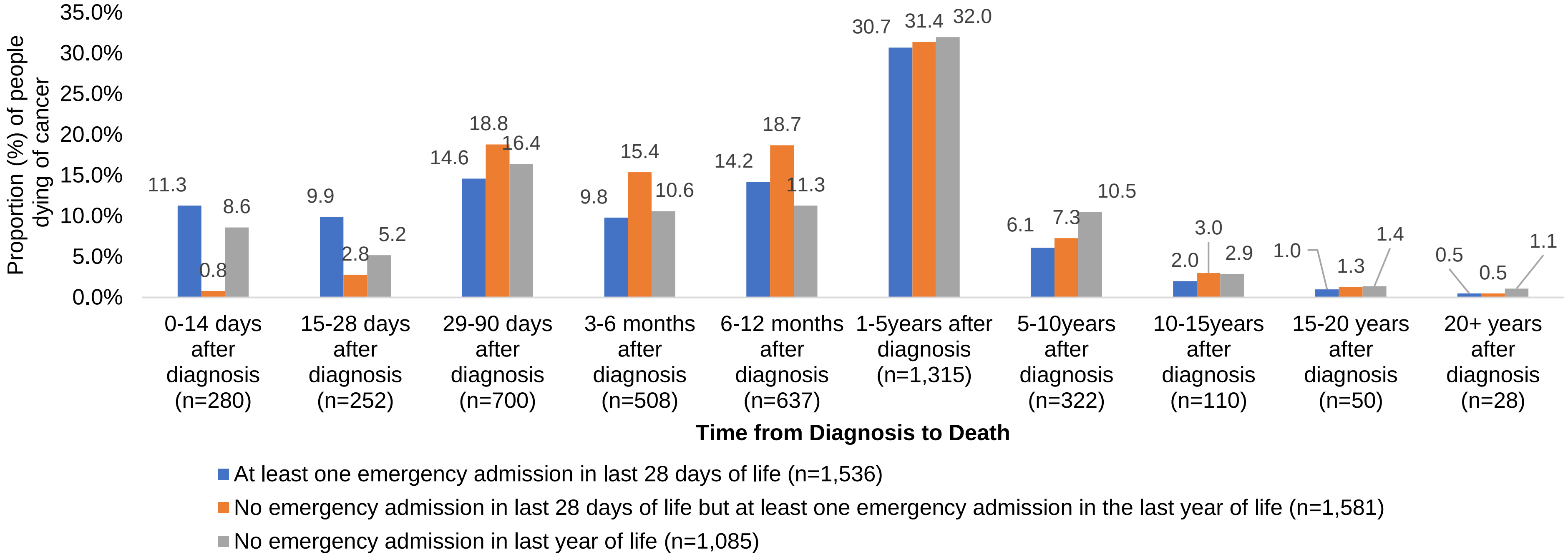
Figure 5.22 Place of Death for those with or without at least one emergency admission recorded in the last 28 days



- Almost three quarters of people (71.9%) who had at least one emergency admission recorded in the last 28 days of life died in hospital compared with less than a quarter (24.1%) of those who did not (p<0.001).

- Conversely less than 1 in 5 (17.9%) people who had at least one emergency admission recorded in the last 28 days of life died at home compared with at least 2 out of 5 (43.4%) who had an emergency admission recorded in the last year of life but not the last 28 days (p<0.001). See Figure 5.22.

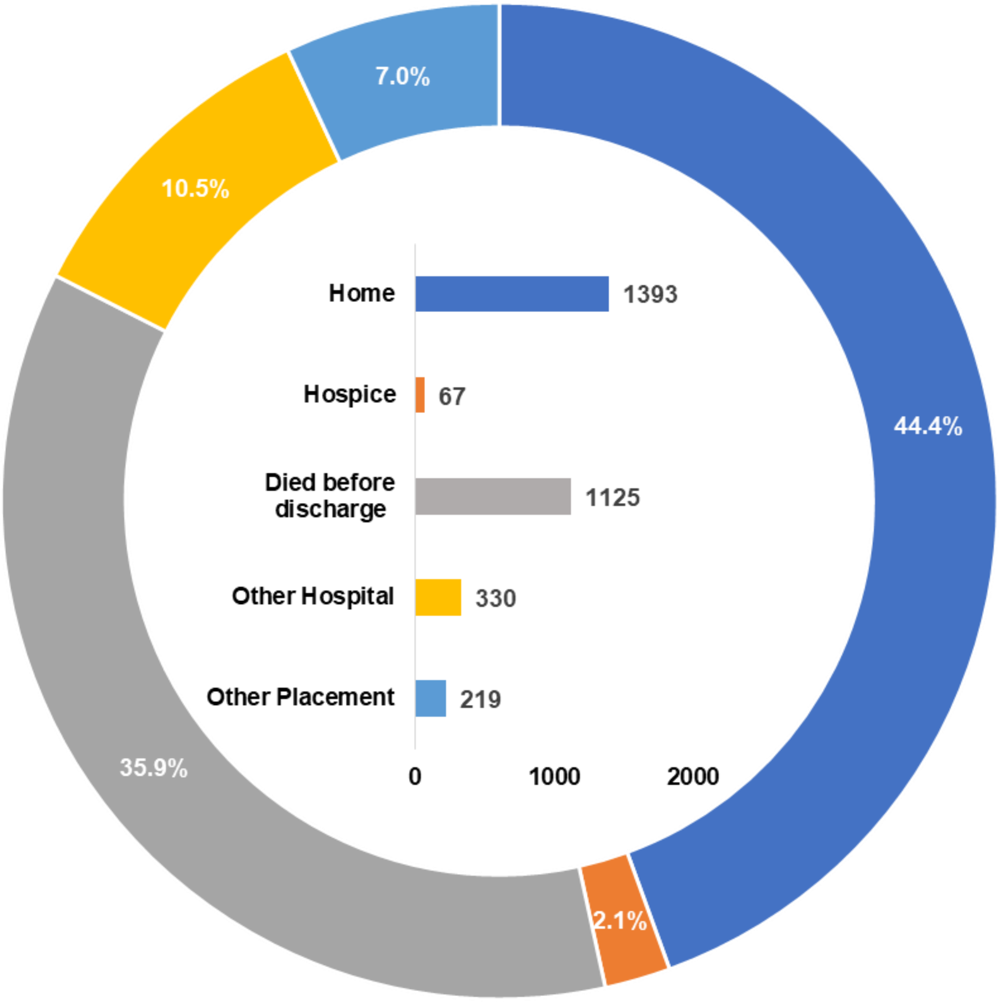
Figure 5.23. Time from Diagnosis to Death by emergency admission status in year of life.



- Overall 1 in 8 (12.7%) of people who died from cancer in 2015 died within 28 days of diagnosis
- 1 in 5 (21.2%) of those who had at least one emergency admission recorded in the last 28 days of life, died within 28 days of diagnosis.
- Approximately 3 in 10 (31.3%) people dying of cancer in 2015 died between one and five years following their cancer diagnosis. In this group, there was no relationship with having an emergency admission in the last year of life or in the last 28 days of life. See Figure 5.23.

5.9 Final Discharge Destination

Figure 5.24. Final Discharge Destination for people dying with cancer in 2015 who had at least one emergency admission recorded

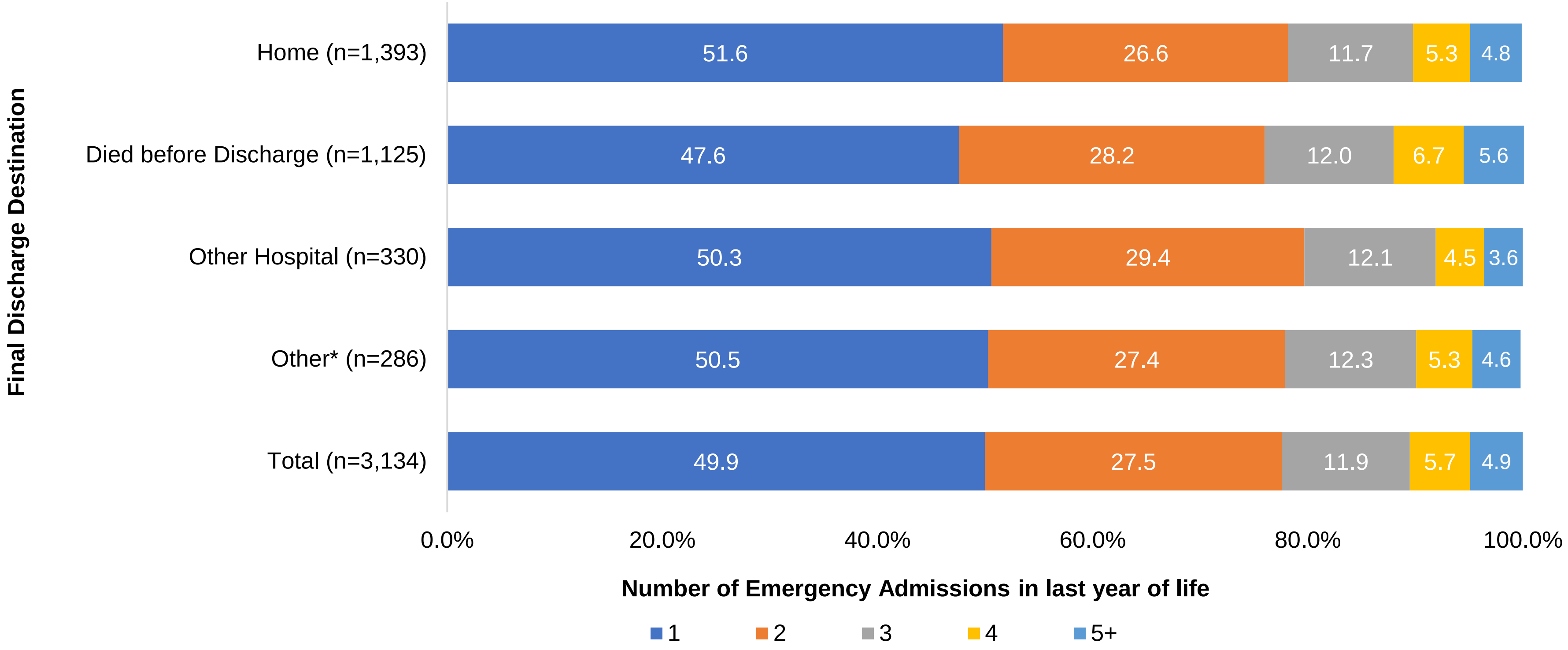


* Other placement includes: other community placement and also other category as recorded in PAS for which no further information was available.

- Over 1 in 3 (35.9%) people who died of cancer in 2015 and had at least one emergency admission recorded, died before discharge from hospital.

- Over 2 in 5 (44.4%) were discharged home following an emergency admission. See Figure 5.24.

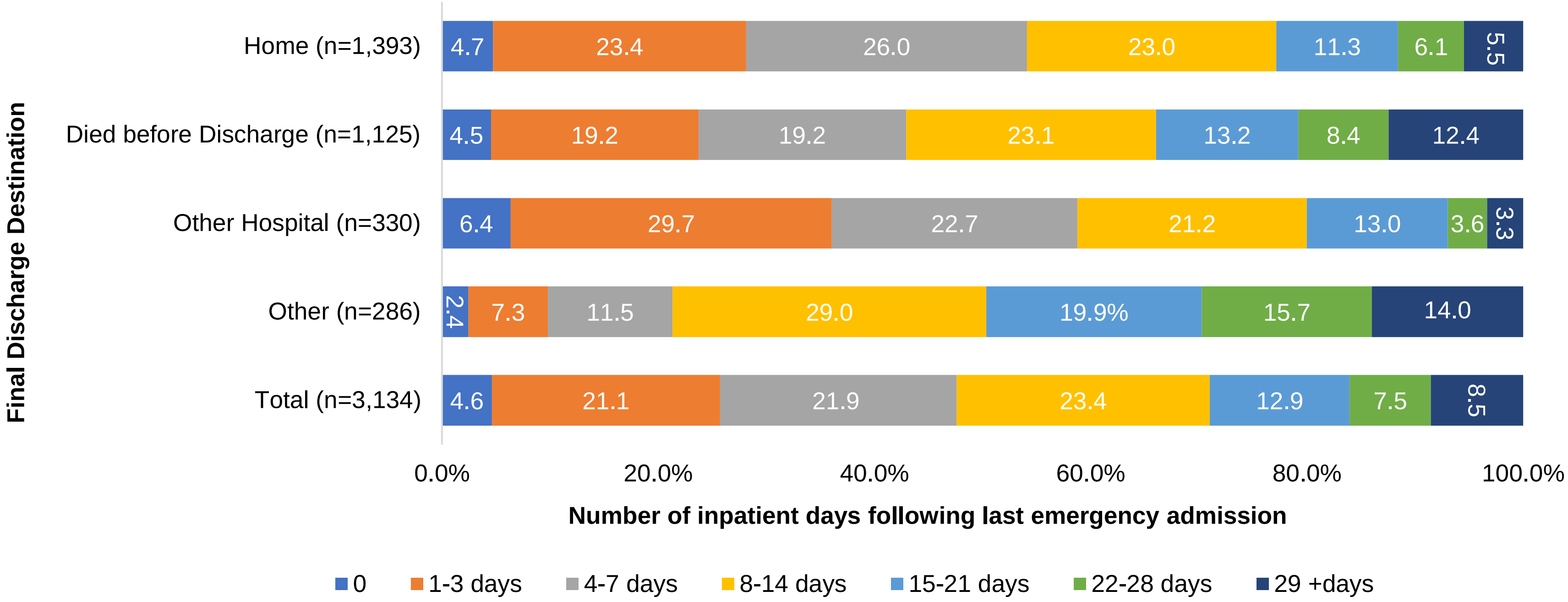
Figure 5.25. Number of Emergency Admissions in the last year of life by Final Discharge Destination



* Other placement includes: other community placement and also other category as recorded in PAS for which no further information was available.

- There were no differences in the number of emergency admissions recorded for those people who died before discharge and those who were discharged to home or other hospital (p=0.778). See Figure 5.25.

Figure 5.26 Number of Inpatient days following last emergency admission by Final Discharge Destination



- A higher proportion (12.4%) of people who died before discharge spent more than 28 days in hospital following last admission when compared with those who had a final discharge destination of home (5.5%) or other hospital (3.3%); (p<0.001). See Figure 5.26.

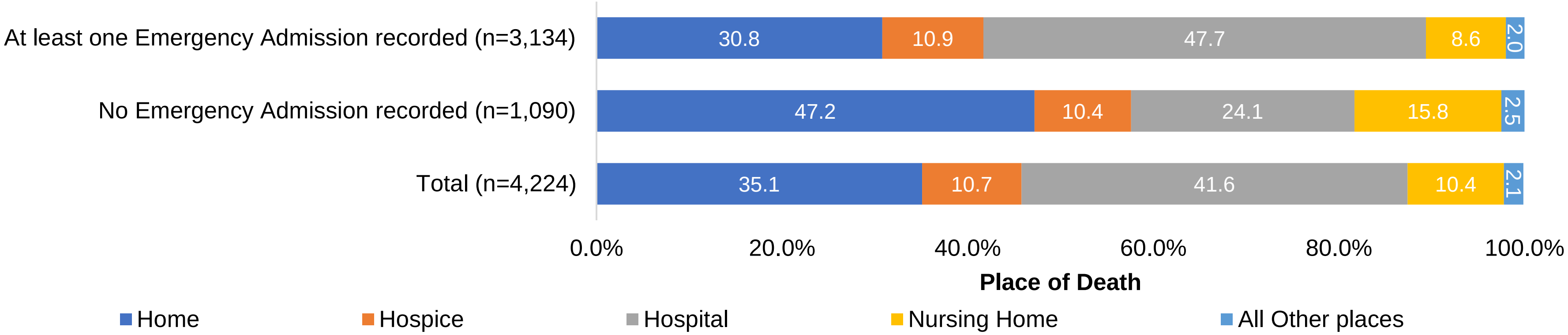
Table 5.7. Tumour type for people who died before discharge following an emergency admission in the last year of life

	Died before Discharge		
Tumour site	Yes	No	Total
Brain and CNS (C70-C72)	20 (24.1%)	63 (75.9%)	83 (2.6%)
Breast (C50)	56 (28.9%)	138 (71.1%)	194 (6.2%)
Colorectal & Anus (C18-C21)	111 (30.5%)	253 (69.5%)	364 (11.6%)
Haematological (C81-C85, C90-C95)	132 (44.7%)	163 (55.3%)	295 (9.4%)
Head & Neck (C00-C14 & C30-C32)	25 (28.4%)	63 (71.6%)	88 (2.8%)
Lung & Mesothelioma (C33-C34 & C45)	332 (40.4%)	489 (59.6%)	821 (2.6%)
Prostate (C61)	67 (35.4%)	122 (64.5%)	189 (6.0%)
Unknown Primary (C76-C80)	44 (42.3%)	60 (57.7%)	104 (3.3%)
Urinary Cancer (C64-C68)	69 (40.1%)	103 (59.9%)	172 (5.5%)
Other	269 (32.6%)	555 (67.4%)	824 (26.3%)
Total	1,125 (35.9%)	2,009 (64.1%)	3,134

- A higher proportion of people with a diagnosis of haematological cancer (44.7%), Cancer of Unknown Primary (42.3%), lung cancer or mesothelioma (40.4%) or urinary cancer (40.1%) died before discharge following an emergency admission compared with patients with cancer of the brain and other CNS (24.1%), head and neck (28.4%), breast (28.9%) or colorectal or anus (30.5%). See Table 5.7.

5.10 Place of Death

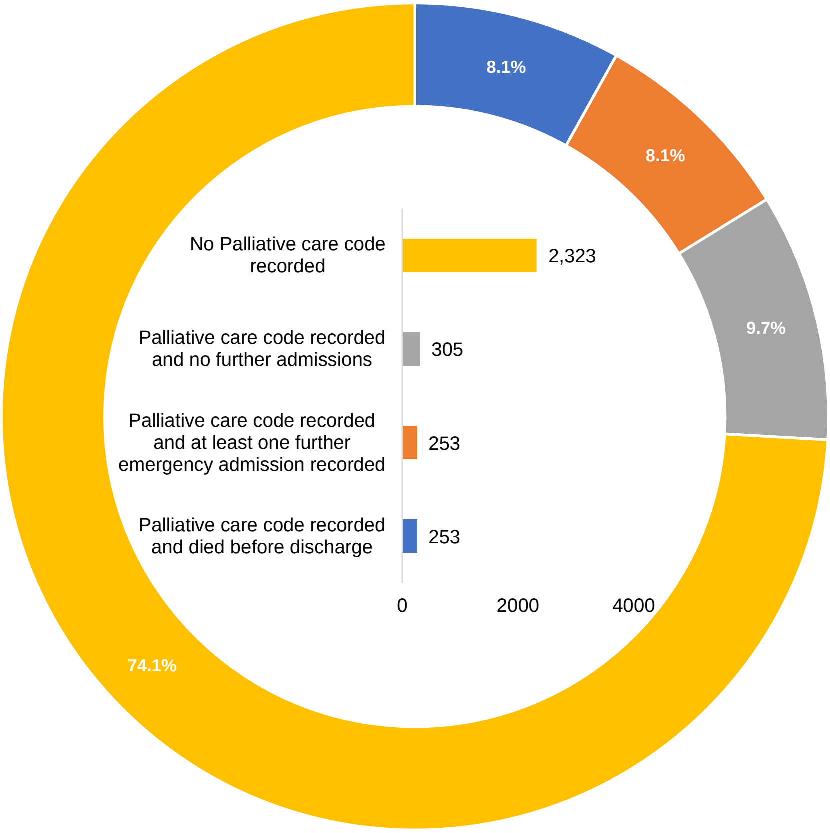
Figure 5.27. Place of death of people dying with cancer in 2015 by emergency admission recorded in the last year of life



- Those people with at least one emergency admission recorded in the last year of life were less likely to die at home and more likely to die in hospital (30.8% dying at home and 47.7% dying in hospital) when compared with those who had no emergency admissions recorded (47.2% dying at home and 24.1% dying in hospital).
- There were no differences in the proportion of people dying in a hospice for those who did (10.9%) or did not have an emergency admission recorded (10.4%).
- A lower proportion of those with at least one emergency admission recorded died in a nursing home (8.6%) compared with those who had no emergency admissions (15.8%) recorded in the last year of life. See Figure 5.27.

5.11 Palliative Care

Figure 528. Proportion of Patients (%) who had a palliative care (PC) code recorded following emergency admission in last year of life



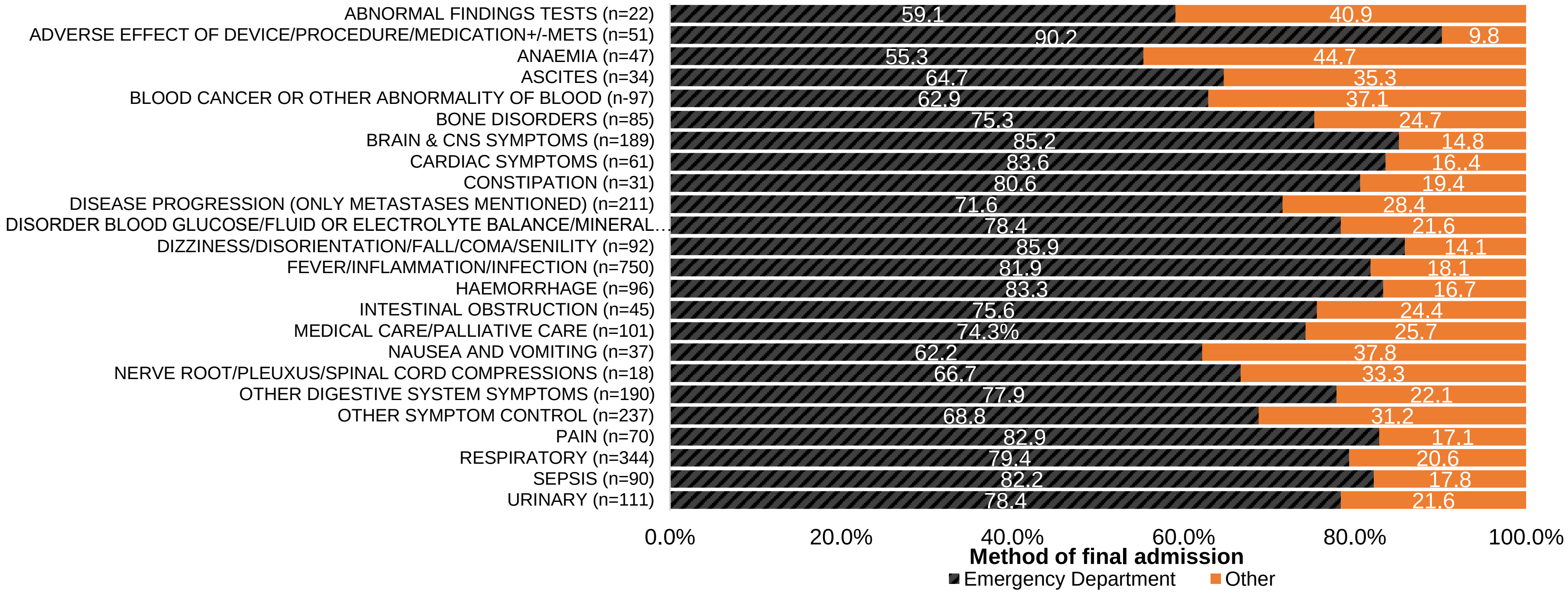
- Three quarters (74.1%) of those who had at least one emergency admission in last year of life did <u>not</u> have palliative care recorded as an ICD10 code.
- 1 in 13 (8.1%) who had palliative care recorded had at least one further emergency admission following this. See Figure 5.28

5.12 Reason for Last Emergency Admission

Table 5.8 Reason for last emergency admission* grouped	**n**	**%**
ABNORMAL FINDINGS TESTS	22	0.7%
ADVERSE EFFECT OF DEVICE/PROCEDURE/MEDICATION	51	1.6%
ANAEMIA	47	1.5%
ASCITES	34	1.1%
BLOOD CANCER OR OTHER ABNORMALITY OF BLOOD CELLS PLATELETS	97	3.1%
BONE DISORDERS (including bone metastases and Osteoporosis)	85	2.7%
BRAIN & CNS SYMPTOMS	189	6.0%
CARDIAC SYMPTOMS	61	1.9%
CIRCULATORY SYMPTOMS	26	0.8%
CONSTIPATION	31	1.0%
DISEASE PROGRESSION (ONLY METASTASES MENTIONED)	211	6.7%
DISORDER BLOOD GLUCOSE/FLUID OR ELECTROLYTE BALANCE/MINERAL METABOLISM	125	4.0%
DIZZINESS/DISORIENTATION/FALL/COMA/SENILITY	92	3.0%
FEVER/INFLAMMATION/INFECTION	750	23.9%
SEPSIS	90	2.9%
HAEMORRHAGE	96	3.1%
INTESTINAL OBSTRUCTION	45	1.4%
MEDICAL CARE/PALLIATIVE CARE	101	3.2%
NAUSEA AND VOMITING	37	1.2%
NERVE ROOT/PLEUXUS/CORD COMPRESSIONS	18	0.6%
OTHER DIGESTIVE SYSTEM SYMPTOMS	190	6.1%
OTHER SYMPTOM CONTROL	182	5.8%
PAIN	70	2.2%
RESPIRATORY	344	11.0%
TREATMENT AND REHABILITATION FOLLOWING TREATMENT	29	0.9%
URINARY SYMPTOMS	111	3.5%
Total	**3,134**	**100.0%**

- 1 in 4 (23.9%) people with at least one emergency admission in the last year of life had fever/inflammation or infection recorded as the reason for their last admission.
- 1 in 9 (11.0%) had a respiratory symptom while1 in 16 had a brain or other CNS symptom (6.0%), or a digestive symptom (6.1%). See Table 5.8.

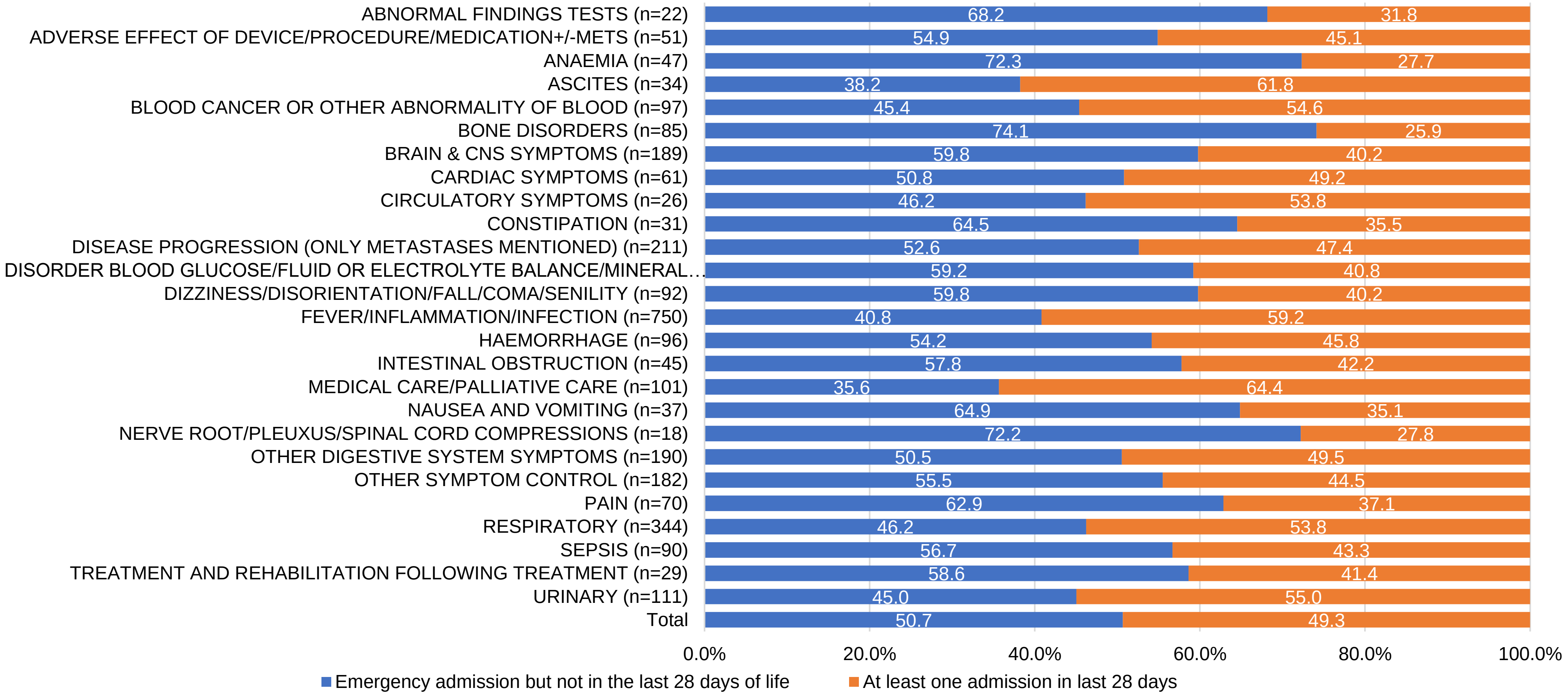
Figure 5.29 Reason for last emergency admission* by method of admission



***Reason for admission based on ICD-10 codes recorded in Patient Administration System (PAS). Please note due to cell counts less than 5, circulatory symptoms (n=26) and treatment and rehabilitation (n=29) have been included in other symptom control category**

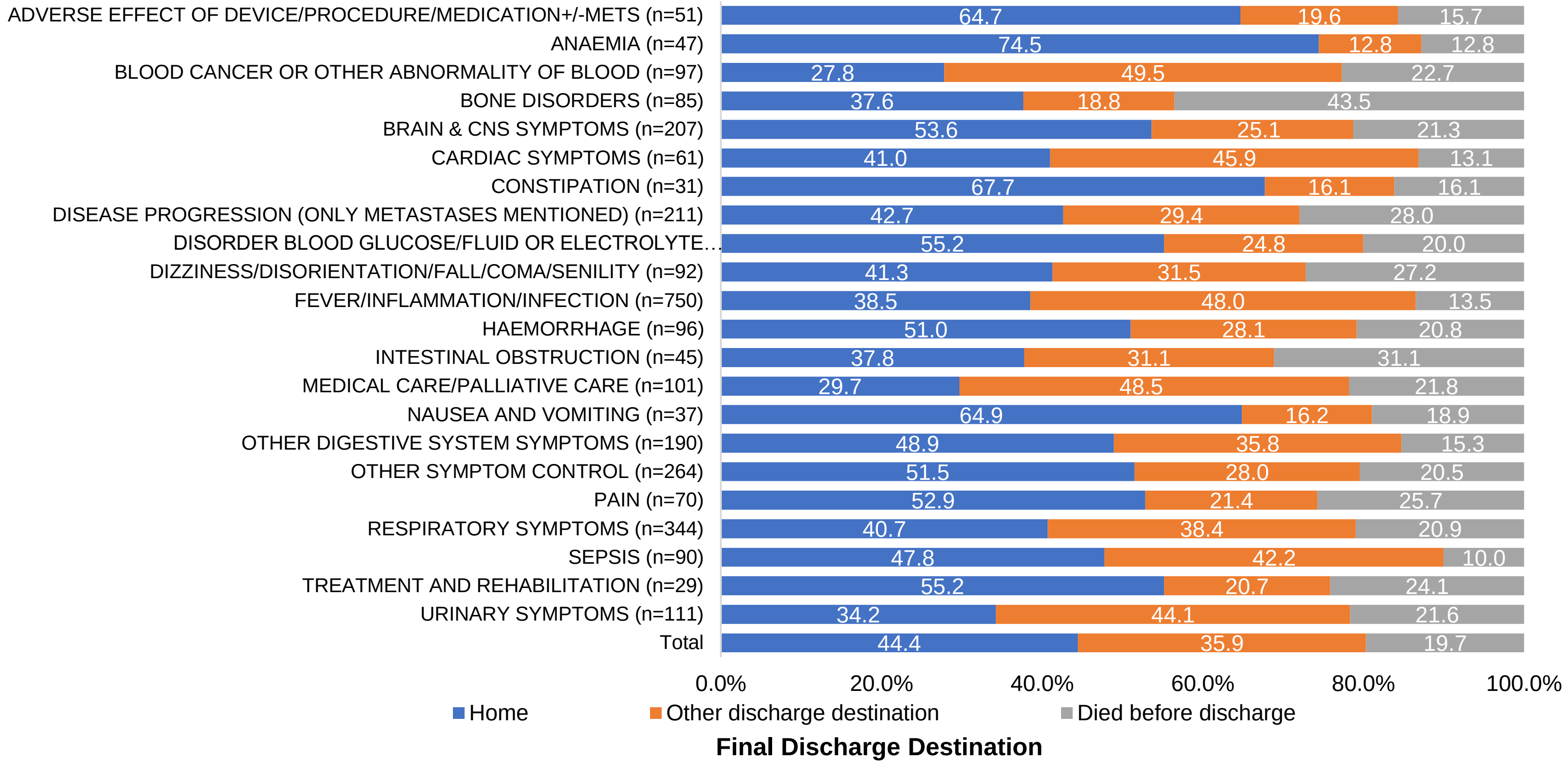
- A higher proportion of people with adverse effects of device/procedure/medication (90.2%), dizziness/disorientation/fall/coma (85.9%), brain and CNS Symptoms (85.2%), cardiac symptoms (83.6%), fever/inflammation/infection (81.9%), pain (82.9%), sepsis (82.2%), or constipation (80.6%) were admitted through the Emergency Department compared with patients presenting with anaemia (55.3%), abnormal test findings (59.1%), nerve root/plexus or spinal cord compressions (66.7%), nausea and vomiting (62.2%), blood cancer or other abnormality of blood (62.9%) or ascites (64.7%) (p<0.001). See Figure 5.29.

Figure 5.30 Reason for last emergency admission* in final 28 days of life.



***Reason for admission based on ICD-10 codes recorded in Patient Administration System (PAS)**

Figure 5.31 Reason for last emergency admission by final discharge destination



- ***Reason for admission based on ICD-10 codes recorded in Patient Administration System (PAS). Please note due to cell counts less than 5, ascites (n=34), circulatory symptoms (n=26) and abnormal test findings (n=22) have been included in other symptom control category.**

- Those with bone disorders (43.5%) or intestinal obstruction (31.1%) recorded as reason for last admission were most likely to die before discharge following their last emergency admission to hospital. See Figure 5.31.

SECTION 6 –DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

6.1 Main Discussion Points

Cancer accounts for over a quarter of all deaths in NI (4,316 deaths per year) (GRO, 2017). This population-based study has investigated factors associated with emergency admissions in the last year of life, for people dying of cancer in 2015.

Number of emergency admissions in last year of life

The findings of the current study have indicated that there is high use of emergency admissions in the last year of life with almost three quarters (74%) of people dying of cancer in 2015 having at least one emergency admission recorded and 1 in 6 (16.7%) having three or more emergency admissions. This finding is comparable to that of an Australian prospective study which showed that 70.0% presented to Emergency Department (ED) at least once in their last year of life with an average of 1.7 ED visits for people dying of cancer. The study also showed that 2 out of 3 ED visits resulted in an admission of hospital (Rosenwax et al., 2011).

The findings of the current study showed a higher proportion of males and a lower proportion of the very young and old having at least one emergency admission recorded in the last year of life. The age related findings are comparable to the work of Rosenwax et al. (2011). However, contrary to our findings the studies by Rosenwax et al. (2011) and Menec et al. (2010) found higher admissions in females. Also unlike this study where we found no difference between urban and rural areas, the Rosenwax et al. (2011) and Menec et al. (2010) studies indicated higher admissions from rural areas.

The current study showed no differences in the number of emergency admissions in the last year of life by deprivation quintile. These findings are in contrast to an economic analysis in England by Walsh and Laudicella (2017) examining if there were any differences in emergency admissions by socio-economic status.

It was postulated by Abel et al. (2015) that the greater use of emergency care by people of lower socio-economic status could be related to the higher burden of cancer types, for example, lung cancer (Abel et al. ,2015).

Our lack of difference by socio-economic status and rurality are reassuring of an equitable service in NI.

Emergency admissions on or before date of diagnosis

This study again highlighted the problem of late diagnosis of cancer with a third (33.8%) of those admitted as an emergency in the last year of life either admitted on the same day as their cancer diagnosis (10.8%) or one to three months (23.0%) before their cancer diagnosis. This represents a quarter (24.8%) of all cancer deaths in Northern Ireland in 2015. People diagnosed with cancer following an admission to hospital as an emergency tend to have a higher stage at diagnosis and poorer clinical outcomes than those diagnosed through all other routes including screening or GP referral (Zhou et al., 2017, Elliss-Brookes et al., 2012, McPhail et al., 2013, Gunnarsson et al., 2013 and Pruitt et al., 2014). Within the current study, 1 in 5 of those who had at least one emergency admission in the last 28 days of life died within 28 days of their cancer diagnosis.

Timing of Emergency admission

In the current study a third (33.4%) of emergency admissions took place during the ‘normal working’ hours of 9am and 5pm Monday to Friday. During this time access to care from other sources such as primary care is available and it is also during these hours that the Acute Oncology Service (established in Northern Ireland in late 2016) operates. However, two thirds (66.6%) of emergency admissions for people who died of cancer in 2015 took place outside of these ‘normal working’ hours during a weeknight (Monday to Friday 5pm to 8am) or during a weekend or public holiday when ‘out of hours’ care provision is in place but patients are unable to receive care required from usual treating clinicians such as family GP.

These findings are similar to those of a Norwegian study by Hjermstad et al. (2013) who found that 1 in 3 (36.0%) emergency admissions among cancer patients with palliative care needs took place Monday to Friday during usual working hours with a further 1 in 3 (38.0%) occurring ‘out of hours’ between 8pm and 5am. 3 in 4 of all ‘out hours admissions’ took place between 8pm on Friday through to Sunday night. The study also found that almost two thirds of patients (64%) stated that their symptoms had developed over several days before they sought emergency care with just 1 in 9 (12%) reporting a more acute onset of symptoms over a few hours. They reflect that if symptom management had been initiated at an earlier stage, the emergency admission could have been avoided. This may suggest an opportunity to identify symptoms requiring treatment at an earlier stage so that intervention can take place before emergency care is required.

Method of Admission

The level of admission via emergency department (75.1%) in this study is higher than observed by Hjermstad et al. (2013) in Norway, where 90.0% were admitted from home with 50% of emergency admissions initiated by a hospital doctor and 24% by a GP. Almost 1 in 2 (48%) people admitted were transferred to hospital by ambulance.

The Hjermstad et al. study also found that 66% of patients admitted to hospital stated that they preferred hospital admission to other places of care in the actual situation, with almost 1 in 5 (18%) stating that they would have preferred to have received the required medical treatment at home if resources had been available. From free-text responses, 1 in 6 (16%) felt that delays in the ED were unnecessary and tiring with a further 1 in 10 (10%) stating that they would have preferred to have been admitted directly to the appropriate hospital or palliative care unit.

Emergency admissions by tumour site of diagnosis

People with a diagnosis of haematological cancers (80.4%), brain and CNS cancer (79.8%), lung cancer or mesothelioma (78.1%) were more likely to have at least one emergency admission recorded. This may be due to more symptoms associated with progression of these cancers. These findings are comparable to that of a study by Hui et al. (2014) which found that compared to patients with solid tumours people with haematological malignancies were more likely to have at least one emergency room visit (54% vs 43%; p=0.003), two or more hospital admissions (23% vs 10%; p<0.001) and an inpatient stay of more than two weeks in the last month of life (38% vs 8%; p<0.001). It has been highlighted that people with haematological malignancies often experience significant physical symptoms such as fatigue, insomnia, drowsiness, pain, dyspnoea and neuropathy as a result of complications due to disease progression and anti-cancer treatments received (Fadul et al., 2008, Manitta et al., 2011, El-Jawahri et al., 2016). Blood abnormalities such as reduction in the number of mature blood cells and platelets and infections are especially common in people with haematological cancer, demanding frequent admission to hospital, invasive investigations, monitoring and therapies (Frachini et al., 2013). A study by Barbera et al., (2008) which investigated end-of-life care for lung cancer patients showed that the most common reasons for emergency admission were shortness of breath, pain, inability to cope at home and changed level of consciousness.

Reasons for Emergency Admission

In the current study, the main reasons for last emergency admission were infection (including pneumonia; 23.9%), respiratory symptoms (including pleural effusion and pulmonary collapse; 11.0%) and gastro-intestinal symptoms (including nausea and vomiting, intestinal obstruction and constipation; 9.8%). These findings are comparable to those of Hjermstad et al (2013) in Norway.

A study by Sadik et al. (2014) found that 96.2% were admitted for a reason related to their cancer, with the most common reasons for admission being shortness of breath (23.2%), pain (17.8%), fever (14.2%), nausea/vomiting (14.4%), confusion (5.8%) and weakness (4.6%)with over half (59.6%) subsequently admitted as an inpatient. However, in that study the proportion of people admitted to hospital varied by symptom at presentation, from one third (32%) of those with pain as main symptom admitted to two thirds (67%) of those with shortness of breath and 83% of those with fever being admitted (Sadik et al. 2014).

A study by Delgado-Guay et al. (2015) to determine the frequency of potentially avoidable ED visits and reasons for admission for people dying of cancer receiving palliative care in the community, showed that pain was a common reason for admission in both avoidable and unavoidable admission. However, all admissions due to altered mental status, shortness of breath, fever or bleeding were considered to be unavoidable. Constipation was more commonly observed as a reason for an avoidable admission.

The study by Barbera et al. (2008) investigating end-of-life care for lung cancer patients found that although less than 10% of people had pain recorded as the main reason for admission, the majority had pain recorded as a symptom during their inpatient stay.

Time spent in hospital following an emergency admission

In this NI study, almost three quarters of those who died from cancer in 2015 spent a total of more than seven days in hospital following their emergency admission(s) in the last year of life. This is comparable to the findings of Hjermstad et al., 2013 which showed a median inpatient stay of 7 days.

The introduction of regional AOS should directly address this by working to reduce average length of stay. However, initial monitoring data following the introduction of the service in 2017 have highlighted that there are still issues with length of time from presentation to referral to AOS (Burns and Mills, 2018). The average time from patient presentation to referral for people for an AOS between October 2016 and March 2018 was 2.9 days which may impede efforts to reduce unnecessary time in hospital.

Palliative care

The findings of the current study showed that three quarters of those who had at least one emergency admission in last year of life did not have palliative care recorded as an ICD10 code in the Patient Admission System (PAS) during any of their admissions and 1 in 3 of those with a note regarding palliation had at least one further emergency admission following this. However, this may be due to the way that palliative care coding was used within the PAS system rather than being indicative of those who had received a referral to palliative care teams. The main source of information on palliative care in the community would be primary care notes which were not available for access as part of the current study. However, a study by Hui et al (2014b) examined the relationship between timing of palliative care referrals and the quality of the end-of-life care received. The findings showed that having a palliative referral more than three months before death was associated with a significantly lower number of ED visits and admissions to hospital in the last month of life as well as fewer hospital deaths. A study by Capel et al. (2011) of patients known to a community palliative care team, found that 1 in 5 (19%) of those with a preferred place of death of home, died in hospital. For the majority of those people (70%) who died before discharge, the reason for admission was due to a 'new complaint' or an 'exacerbation of symptoms'. The 'new complaints' which led to the admission fell into four main categories of 'sudden events' (such as haemorrhage, seizures, obstruction), complications following treatment and sudden collapse (including stroke) and falls (including fractures).

A further study by Wright et al. (2016) assessed associations between aggressive care at the end-of-life and how family members rated the quality of end-of-life care received. The findings showed that family members of people who received no hospice care or received less than 3 days of hospice care before death were less likely to report excellent quality end-of-life care than those who received hospice care for more than 3 days before end-of-life. Also, family members of people admitted to an Intensive Care Unit (ICU) in the last month of life were less likely to report excellent quality of life when compared with those who were not.

Place of Death

The findings of the current study showed that people who had at least one emergency admission in their last year of life were twice as likely to die in hospital (48% vs 24%) compared to those with no emergency admissions recorded in the last year of life.

A quarter of people (26.6%) died prior to discharge and more than two thirds (35.9%) of people who had at least one admission in the last month of life died prior to discharge.

A study by Smith et al. (2012) showed that more than half of older adults visited the ED in the last month of life before dying of cancer. Of those that visited the ED, three-quarters (77%) were admitted and of those admitted, two thirds (67%) died before discharge. Over half of cancer patients were an inpatient in hospital on their final day of life (Rosenwax et al., 2011). When investigating hospital admissions in the last two weeks of life, it was shown that individuals aged less than 75 years old were less likely to die in hospital than those aged 75 and over (Menec et al., 2010). The indicators of quality end-of-life care developed by Earle et al. (2003) highlighted a high proportion of hospital deaths vs home deaths as a potential indicator of the quality of end-of-life care. A systematic review carried out by Gomes et al. (2013) highlighted that in three quarters (75%) of the studies investigated, more than half of people dying of cancer had a preferred place of death at home. It has been highlighted within the literature that identifying a patient's preferred place of care and death is an important part of end-of-life care (DOH, 2008). There has also been evidence to suggest that once preferred place of care and death is identified it is more likely to be realised (Detering et al. 2010).

The Marie Curie Delivering Choice Programme

After identifying that many end-of-life care patients were unable to achieve their preference to die at home through lack of choice (due to lack of communication and co-ordination between healthcare professionals and inadequate availability of services within the community), Marie Curie introduced a Delivering Choice in Lincolnshire county in England in 2004. The Marie Curie Delivering Choice Programme has worked in partnership with the NHS, the voluntary sector, social services and other community health care providers to develop patient-focused 24-hour care models that work towards ensuring that choice of place of care and death is available to all.

The Delivering Choice programme aimed to ensure:

- The best possible care for patients receiving palliative care
- Improvements in access to services
- Appropriate support services for patients receiving palliative care and their carers
- Provision of information on choice to all patients receiving palliative care
- Improvements in co-ordination of care between stakeholders

In addition to supporting existing services to provide the care required, two new services were designed as part of the delivering choice programme:

1. **Rapid Response Teams (RRT)**: This is a community-based team that provides nursing services to patients requiring palliative care and professionals during (3.00pm-10.30pm) and

out-of-hours periods (10.00pm-7.00am). The RRT make emergency and planned visits to patients in their home during the late afternoon, evening and overnight. The RRT nurses and health care assistants also provide psychological support and guidance to patients and their carers over the telephone.

2. **Discharge Community Link Nurses (DCLNs):** This programme appointed two dedicated discharge nurses to facilitate speedy discharge of patients receiving palliative care to their preferred place of care. The DCLNs facilitate discharge by co-ordinating package of home care, providing support and advice to patients and their carers, communicating patient needs to community health care teams and, if necessary, accompanying patients to their home and help with getting them settled. Part of their role is to provide the necessary information and support to patients, carers and their families, as well as to relevant primary care professionals (Addicott and Dewar, 2008).

Summarising the Problem

A study carried out by Gott et al. (2013) to investigate possible reasons for ‘potentially inappropriate’ hospital admissions identified three main factors: 1. Family Carers could no longer cope, 2.The ‘rescue culture’ of modern medicine and 3. Availability of community services. Further studies within the literature have highlighted a lack of communication and availability of patient notes for all healthcare providers as a potential reason for inappropriate emergency admissions at the end-of-life as it makes it more difficult for ‘out of hours’ and emergency care providers such as ambulance staff to make decisions regarding best place of care for the person. However, it has also been highlighted within the literature that the sudden onset of severe unexpected symptoms may necessitate the need for an emergency admission to hospital at the end-of-life.

The findings of the current study have shown that the use of emergency admissions in the last year of life for people dying with cancer is high and can lead to inpatient stays of more than one week, with certain cohorts of people being more likely to have an admission recorded. Also the majority of emergency admissions occur outside of usual working hours and those who had an emergency admission recorded in the last 28 days of life were more likely to die in hospital which may be different to their preferred place of death. It is beyond the scope of this study to determine whether or not the emergency admissions recorded were inappropriate or avoidable. However, this is an area that has been widely discussed within the literature and is considered to be complex with many factors in play.

A. Family carers could no longer cope- Inability to cope at home

It was recognised by Gott el al. (2013) that many end-of-life admissions took place due to a perceived inability by the family to manage symptoms at home. The GPs ‘reflected’ that this may have resulted from an increase in institutionalisation of death over time. As the focus shifts back to end-of-life care in community-based settings, it will require more input from informal (family) carers and therefore more emotional and practical support for families caring for end-of-life patients at home may be required. Several studies within the literature have provided evidence to support this. Conclusions have included informal carers feeling unprepared to manage symptoms (Lawson et al., 2008), emotional demands exceeding the resources available for coping (Waldrop et al., 2015) and support from GP and Specialist Palliative care (SPC) services being an important factor in preventing ‘unnecessary’ emergency admissions (Hjermsted et al., 2013).

B. The ‘rescue culture’ of modern medicine

It was recognised that many families would typically phone for an ambulance when the person’s condition deteriorated rather than seeking advice from GP. It was identified that a lack of clear communication to discuss the patient’s prognosis may be a possible reason for this. ‘As long as life-sustaining techniques and pathways exist, they will be wanted and chosen’ (Kaufman and Morgan, 2005), in other words, an acute hospital admission will be desired.

C. Availability of community services

The lack of availability of appropriate community services especially during ‘out of hours’ to care for people once they enter the final stages of life may lead to increased use of acute hospital services. A study by Henson et al. (2016) identified difficulties accessing community healthcare services especially urgently and/or ‘out of hours’ as one the main reasons influencing the decision to seek emergency care. Hjermsted et al. (2013) also highlighted that support from GP and Specialist Palliative care services at home as an important factor in preventing ‘unnecessary’ emergency admissions.

Also the qualitative study carried out by Hoare et al. (2017) identified limited availability and accessibility of additional care in the community as a key factor leading to an emergency admission towards the end-of-life.

The Carer's Voice

Thematic analysis of previously unpublished qualitative information written in the free text sections of Qualycare-NI study questionnaires (2013) used to collect information for the Cancer Focus funded 'Dying with Cancer: Perspectives of Bereaved Relatives and Friends' report (relevant themes identified are available in appendix 3) has been included to provide a further insight into the experience of end-of-life care (including emergency care) received by people dying with cancer and their families in NI. The findings showed that although in some cases the family felt that they received enough support in the community to care for their relative at home it also identified that a number of relatives also felt that:

- They required 24/7 access to Specialist Palliative Care (SPC) and a GP who was knowledgeable of palliative care needs of the person at home which wasn't always available.

'On call GP was not helpful during 'out of hours' at weekend regarding advice needed due to raised temperature and confusion'

'There was a short window of time between the district nursing team time and the SPC teams time when I was unable to get help (6pm-8pm). It was during this time that Mum died. They would not have been able to prevent that but I needed support and felt panicked when I couldn't contact help.'

'Twilight nurses were excellent but not on duty all night when needed support.'

- GPs were often reluctant to visit at home despite severe symptoms or deterioration of the patient's condition.

'GP's were never willing to do home visits'

'The GP did not visit until I demanded a visit about 2 weeks before he died'

'Took GP 6 hours to arrive, after several phone calls to surgery-reluctant to do a home visit'

- Lack of access to pain relief and anti-sickness medication at home especially 'out of hours'

'Administration of pain relief and medication would not have been there when she needed it, e.g. at night in the early stages, and anti-sickness medication was not stepped up enough to control symptoms, so she went into hospital after a few days at home as she felt more comfortable and help would be on hand 24/7'.

D. Onset of Severe unexpected symptoms

The study carried out by Hoare et al. (2017) showed that most participants agreed that when an uncontrollable acute medical situation occurs (e.g. an obstruction, sudden massive bleeding or uncontrollable pain) and a diagnosis or specific comfort treatment is needed, a hospital admission is considered justified. Also, participants indicated that such acute medical situations are generally justified because they cannot always be anticipated. Many participants also suggested that if a hospital admission is necessary for an acute medical problem, unnecessary additional tests and treatments should be avoided. The problem at hand should be remedied so the patient can return quickly and safely to his or her familiar surroundings (Reyniers et al., 2014). A qualitative study exploring clinician's views of providing ED care for patients with advanced cancer emphasized the often legitimate need for such patients to present to the ED, as they frequently experience episodes of acute unexpected deterioration (Jelinck et al., 2013). Such research acknowledges the need for an emergency service in the management of 'unpredictable crises' among patients with palliative care needs. This is backed up by findings of studies within the literature assessing the appropriateness of patients with palliative care needs attending the ED which showed that between 52-83% of ED attendances were not avoidable and required urgent investigations and/or interventions that were not available within the community (Delgado-Guay et al., 2015, Wallace et al., 2012, Green et al., 2017). In NI, the Department of Health requires that at least 95% of patients are reviewed and either admitted or discharged from the ED within four hours. This may be considered insufficient time to meet the complex needs of patients requiring palliative care and therefore may lead to the person being admitted.

E. Lack of communication about end-of-life care options/patient's history and wishes

A study by Stone et al. (2009) highlighted the need for increased numbers of people with palliative care needs having written advance directives on when to withhold aggressive care and resuscitation as well as increased training for ambulance staff on how to discuss death and stages of the dying process with families of end-of-life care patients as important factors in helping to prevent unnecessary or inappropriate hospital admissions. A study by Lupari et al. (2011) also highlighted that advance written care directives on management of symptoms at home may play an important role in helping to achieve good palliative care at home while preventing unnecessary or inappropriate hospital admissions towards the end-of-life.

Reyniers et al. 2017 found that admissions were more likely to be considered potentially inappropriate by GPs who have received palliative care training at basic, post-grad or post-academic level. The findings also showed the GPs considered 8 out of 10 (80.3%) terminal hospital admissions to be unavoidable or appropriate. They were more likely to be considered potentially inappropriate and potentially avoidable when the admission lasted less than 10 days and when the admission was initiated by the patient, the patient's partner or other family members. Of the 26 terminal hospital admissions that were considered to be potentially avoidable, GPs considered that 12 could have been prevented by informing the patient earlier about their limited life expectancy and about palliative care and 12 by providing better support to the family caregivers (Reyniers et al., 2017).

The qualitative study carried out by Hoare et al. (2017) identified limited information about the patient and their condition as a key challenge for ambulance staff in deciding about an emergency admission towards the end-of-life.

While 8 out of 10 (79%) ambulance staff interviewed felt that it is important to communicate the likelihood of death to the patient's family, less than half (48%) felt prepared to do so (Stone et al., 2009 and Smith et al., 2010). Further attention should be placed on enhancing communication skills during times of the intense emotions of an end-of-life crisis.

The Carer's Voice

The thematic analysis of qualitative information written in the free text section of Qualycare-NI study questionnaires showed that although in some cases good communication at end-of-life was identified, a number of relatives also felt that discussions around likelihood of death could have been handled in a more sensitive manner and were often too close to end-of-life to allow family to prepare.

'It was less than 24 hours before the death that I was told that the next 24-48 hours were critical. Until then I believed she would make a full recovery.'

'In the last week of his life we encountered a doctor that we had never met before who told us he would be dead in 24 hours and that's exactly how he put it.'

The relatives also often felt that they were not provided with enough information about the patient's condition and how it would progress and what to expect from end-of-life care.

'He was clearly not very well, but we were not aware of what help was available, so we didn't know what to expect or ask for help.'

'I am sure the doctors would have known her condition could have deteriorated quite suddenly or quickly. We were not informed what to expect until quite near the end.'

‘Professionals must know how this awful disease progresses and should suggest to families some options [of aids to help at end-of-life]’

‘We were visited 4 times by SPC nurse, not once were we given any information on the signs of ‘end of life’, nor was it explained.’

‘I would (in retrospect) have liked to have been informed of the possible scenarios as the tumour progressed. He died much sooner than I expected and I feel so sad about this that I neglected this symptom and he could have needed medication sooner.’

Family members felt they had to ask questions or arrange appointments to receive information and sometimes they were not sure what to ask.

‘We had to wait on doctors doing their rounds daily to ask questions and often they didn’t come. I feel had to chase everything up to find out what was happening’

The thematic analysis of qualitative information written in free text section of Qualycare-NI study questionnaires highlighted often very long waits to be seen in ED and to be admitted to a ward when needed.

‘When dad had to go to A&E – the waiting time to be seen was too long.’

‘When the GP referred her to hospital, we had to wait three hours in A&E before a doctor would look at her.’

‘My husband was taken into hospital by ambulance. He was in A&E all day Tuesday. They found him a bed on Tuesday night’

‘We spent hours with mum in a wheelchair before and after triage and before she was put on a trolley down the back of A&E for the rest of night and early morning’

‘She was taken to A&E department and was kept on a trolley for 13 hours before being transferred to a ward’

‘My father was admitted to hospital some weeks before his passing. He arrived by ambulance and had a 15 hour trolley/A&E wait before finally getting a bed’

‘He was in extreme discomfort with extreme difficulty breathing and had to remain on a trolley and then an A&E treatment for almost 24 hours. This totally drained and exhausted an already weak man.’

’16 hours waiting in A&E for a bed when Dad was very ill.’

Strengths and Limitations

A major strength of the current study is that it is a population-based study of people dying of cancer in NI in 2015 with no significant differences in sex, deprivation or age at time of death for those included and excluded from the final analysis.

This study presents a number of limitations due to:
(a) The use of secondary data sources of routinely collected healthcare data from the Patient Administration System (PAS) for information on the emergency admissions which makes it more difficult to assess the appropriateness of emergency admissions.
(b) Lack of access to primary care data which is very often where information on palliative care and whether a person is on the palliative care register is recorded.

(c) The quantitative rather than qualitative nature of data available within the current study makes it difficult to explore the decision making of family members and healthcare professionals (including GPs, 'out of hours' care staff and secondary care clinicians) regarding their help-seeking behaviours and care provided and also makes it difficult to assess the appropriateness of emergency admissions.

6.2 Conclusion

The findings highlight that:

- Late diagnosis of cancer continues to be an issue.
- The burden of emergency admissions for cancer patients in the last year of life is high
- A higher proportion of those with an emergency admission in last 28 days of life, died in hospital.
- Only one in three emergency admissions takes place during 'normal working hours' of 9am-5pm Monday to Friday with two in three taking place outside 'normal working' hours.
- A higher proportion of people with a diagnosis of lung or haematological cancer had at least one emergency admission recorded in the last year of life. However, many of these admissions may be unavoidable due to the nature of the disease and treatments/interventions required to relieve symptoms.
- Half (54.6%) of people who died from cancer in 2015 spent more than seven days in hospital following an emergency admission in their last year of life and almost three quarters (73.7%) had a total inpatient stay of more than seven days following their emergency admission(s) in last year of life. The introduction of regional Acute Oncology service (AOS) should directly address this but initial monitoring data have shown that there are still issues with length of time from presentation to referral to AOS, and this will impede efforts to reduce unnecessary time in hospital.

6.3 Recommendations

Recommendation 1: Work needs to continue to promote early detection of cancer through public awareness campaigns and encouraging uptake of established screening programmes.

Recommendation 2: Early identification of patients in their last year of life who would benefit from supportive and palliative care.
Recommendation 3: Additional training for healthcare professionals (in both primary and secondary care) in effective communication and care planning with emphasis on initiating discussions about likelihood of death and preferred place of death. This will facilitate appropriate care planning to enable patients to receive end-of-life care in preferred place of death wherever possible.

Recommendation 4: Establishing a clear point of contact for patients and their carers through which they can be provided with information on how to identify and self-manage consequences of cancer and its treatment and be signposted to the most appropriate places to seek early support for problems (GP, District Nurse, Clinical Nurse Specialist, Specialist Palliative Care etc).

Recommendation 5: Pilot extended hours for the Acute Oncology Service (AOS) from the current AOS hours of 9am to 5pm Monday to Friday and define pathways within the AOS for patients presenting via ED.

Recommendation 6: The further development of community based programmes such as 'Delivering Choice' which includes services such as Rapid response teams and district community link nurses.

Further research which could be undertaken in these areas to:

- Undertake an economic analysis of the cost of emergency admissions for cancer patients in last year of life.
- Determine the optimal time and method to provide information on likelihood of death and advance care planning for people with palliative care needs following a cancer diagnosis.
- Assess the best way to support the emotional and practical needs of informal carers.
- Investigate the appropriateness of emergency admissions for people dying with cancer to provide an estimate of 'appropriate' and 'inappropriate' admissions which potentially could have been managed in a community setting after increased education and support from existing community services.
- Qualitatively explore the needs and decision making of family members and healthcare professionals when considering an emergency admission for people dying of cancer in Northern Ireland.

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SECTION 8-APPENDICES

Appendix 1. Reason for Last Emergency Admission for ICD10 codes listed in PAS

Reason for Last Emergency Admission for ICD10 codes listed in PAS	n	%
ABDOMINAL PAIN +/- METS/NAUSEA AND VOMITING/GASTROENTERITIS AND COLITIS/HYPONATRAEMIA	25	0.8
ABNORMAL FINDINGS BLOOD CHEMISTRY, IMAGING OR LFTS +/- MALAISE AND FATIGUE OR METS	22	0.7
ABSCESS OF MOUTH/LIVER/LUNG	7	0.2
ACUTE LOWER RESPIRATORY INFECTION +/- METS OR PALLIATIVE CARE	124	3.9
ACUTE MYOCARDIAL INFARCTION	8	0.3
ACUTE PANCREATITIS/PERITONITIS +/- INTESTINAL OBSTRUCTION OR METS	6	0.2
ACUTE RENAL FAILURE +/- UTI, NAUSEA AND VOMITING, GASTROENTERITIS AND COLITIS, ELECTROLYTE IMBALANCE, CHRONIC KIDNEY DISEASE, METS	71	2.3
ADVERSE EFFECT OF DEVICE/ PROCEDURE/MEDICATION +/- METS	22	0.7
ANAEMIA +/- BLOOD TRANSFUSION/INFECTION/ABNORMAL HAEMORRHAGE/METS	47	1.5
ASCITES+/- ACUTE LOWER RESPIRATORY INFECTION/DEHYDRATION/PLEURAL EFFUSION/CONSTIPATION/JAUNDICE	34	1.1
ATRIAL FIBRILLATION +/- CHEST PAIN/PLEURAL EFFUSION	14	0.4
BONE METS + OTHER CONDITION	25	0.8
BRAIN CANCER	12	0.4
BRAIN CANCER AND OTHER CONDITION	13	0.4
BRAIN CANCER OR BRAIN METS + ACUTE INFECTION	13	0.4
BRAIN HAEMORRHAGE +/-DEHYDRATION/METS/DISORDER OF BLOOD CHEMISTRY	8	0.3
BRAIN METS	39	1.2
BRAIN METS AND FRACTURE/OTHER DISORDER OF BONE	5	0.2
BRAIN METS AND OTHER SYMPTOM	19	0.6
BRAIN/CNS TUMOUR AND PALLIATIVE CARE	6	0.2
BRONCHOPNEUMONIA +/- PLEURAL EFFUSION/PULMONARY COLLAPSE/RESPIRATORY FAILURE/PULMONARY EMBOLISM/OTHER INFECTION/SYNCOPE AND COLLAPSE+/- METS	96	3.1
CALCULUS OF BLADDER/LIVER/KIDNEY/GALLBLADDER	5	0.2

Reason for Admission for ICD10 codes listed in PAS	n	%
CARDIAC ARREST +/- METS	8	0.3
CELLULITIS +/- METS	12	0.4
CEREBRAL HAEMORRHAGE +/- BRAIN CANCER OR BRAIN METS	10	0.3
CEREBRAL INFARCTION/TRANSIENT ISCHAEMIC ATTACK +/- METS	26	0.8
CHEMOTHERAPY SESSION +/- METS	5	0.2
CHEST PAIN +/- LOWER RESPIRATORY INFECTION OR METS	14	0.4
CHRONIC KIDNEY DISEASE	6	0.2
COMPRESSION OF VEIN	8	0.3
CONSTIPATION +/- ADVERSE EFFECTS OPIOIDS/PAIN/NAUSEA AND VOMITING/DEHYDRATION/METS	31	1.0
CONVULSIONS +/- BRAIN CANCER OR BRAIN METS	30	1.0
COPD +/- ACUTE LOWER RESPIRATORY INFECTION OR METS	70	2.2
COLORECTAL CANCER	5	0.2
DEHYDRATION +/- ABDOMINAL PAIN, CONSTIPATION, ACUTE RENAL FAILURE OR METS	23	0.7
DELERIUM +/- DIZZINESS AND GIDDINESS	8	0.3
DIABETES WITH OR WITHOUT COMPLICATIONS	9	0.3
DISORDER OF BLOOD GLUCOSE/ELECTROLYTE BALANCE +/- METS	44	1.4
DISORDER OF MINERAL METABOLISM +/- METS	44	1.4
DISORIENTATION +/- RESTLESSNESS AND AGITATION	23	0.7
DEEP VEIN THROMBOSIS	12	0.4
DYSPHAGIA +/- PALLIATIVE CARE OR METS	10	0.3
EMBOLISM OF OTHER ARTERY/VEIN +/- METS	6	0.2
EMPHYSEMA	5	0.2
ENLARGED LIVER/SPLEEN/LYMPH NODES	7	0.2
ENTEROCOLITIS DUE TO C DIFF	6	0.2
FALL AND INJURY OF HEAD/ABDOMEN	7	0.2
FALL AND SUPERFICIAL INJURY ARM/HEAD/LEG/HIP +/- METS	15	0.5
FEVER +/- COUGH/ADVERSE EFFECTS OF ANTI-NEOPLASTIC DRUGS	16	0.5

Reason for Admission for ICD10 codes listed in PAS	n	%
FITTING OF/ISSUE WITH COLOSTOMY/ILEOSTOMY/GASTROSTOMY +/- METS	13	0.4
FRACTURE OF OTHER BONE +/- BONE METS +/- FALL	39	1.2
FRACTURE/COLLAPSED VERTEBRAE OR LUMBAR SPINE	11	0.3
GASTRITIS OR GASTROENTERITIS AND COLITIS	31	1.0
GI HAEMORRHAGE +/- METS OR PALLIATIVE CARE	29	0.9
HAEMATEMESIS +/- METS	13	0.4
HAEMATURIA +/- METS	15	0.5
HAEMOPTYSIS	7	0.2
HEAD AND NECK CANCER	13	0.4
HIP FRACTURE +/- FALL, REHABILITATION OR INFECTION	16	0.5
HYDRONEPHROSIS +/- DISORIENTATION OR METS	11	0.3
HYPERTROPHIC PYLORIC STENOSIS +/- METS	5	0.2
INAPPROPRIATE SECRETION OF ANTI-DIURETIC HORMONE +/- METS OR ELECTROLYTE IMBALANCE	6	0.2
INFECTION FOLLOWING PROCEDURE/TRANSFUSION OR DUE TO INTERNAL GRAFT/DEVICE/IMPLANT	17	0.5
INFLAMMATION OF BILE DUCT OR GALLBLADDER +/- PNEUMONIA OR METS	26	0.8
INTESTINAL OBSTRUCTION +/- FEVER/INFECTION/ASCITES/ STOMA STATUS/ GI HAEMORRHAGE	45	1.4
JAUNDICE +/- DEHYDRATION OR METS OR PALLIATIVE CARE	10	0.3
LEUKAEMIA/LYMPHOMA/MYELOMA	86	2.7
LIVER CANCER	53	1.7
LIVER FAILURE +/- ACUTE RENAL FAILURE AND METS	8	0.3
LOBAR PNEUMONIA +/- PLEURAL EFFUSION, PULMONARY COLLAPSE, CONSTIPATION, DELERIUM	134	4.3
LUNG CANCER	24	0.8
LUNG METS +/ BONE AND/OR BRAIN METS	69	2.2
MALAENA	7	0.2
MALAISE AND FATIGUE +/- PALLIATIVE CARE OR METS	6	0.2
MALFUNCTION OF EXTERNAL STOMA OF URINARY TRACT	5	0.2
MECHANICAL COMPLICATION OF URINARY DEVICE	6	0.2

Reason for Admission for ICD10 codes listed in PAS	n	%
MEDICAL CARE +/- METS	5	0.2
MENTAL HEALTH SYMPTOMS +/- METS OR EXCESS USE TOBACCO/ALCOHOL	22	0.7
NAUSEA AND VOMITING +/- CONSTIPATION OR DEHYDRATION OR METS	37	1.2
NERVE ROOT/PLEUXUS/CORD COMPRESSIONS AND BONE METS +/- RADIOTHERAPY SESSION	18	0.6
NO ICD10 CODES RECORDED	16	0.5
OBSTRUCTION OF BILE DUCT +/- METS	8	0.3
OESOPHAGEAL CANCER	8	0.3
OESOPHAGEAL OBSTRUCTION OR OESOPHAGITIS +/-METS	6	0.2
ONLY METS MENTIONED (BONE METS) +/- PALLIATIVE CARE	6	0.2
ONLY METS MENTIONED +/- PALLIATIVE CARE	163	5.2
OTHER	73	2.3
OTHER ABNORMALITY OF BLOOD	11	0.3
OTHER BACTERIAL/VIRAL INFECTION	16	0.5
OTHER BONE DISORDER	5	0.2
OTHER BRAIN/CNS DISORDER +/- HALLUCINATIONS	15	0.5
OTHER CHRONIC HEART DISEASE/HEART FAILURE/CARDIAC ARRHYMIAS	15	0.5
OTHER COPD WITH ACUTE EXACERBATION	7	0.2
OTHER DISORDER OF BLADDER AND URINARY +/- METS	9	0.3
OTHER DISORDER OF DIGESTIVE TRACT/ORGAN	28	0.9
OTHER DISORDER OF MUSCULOSKELETAL SYSTEM/ SOFT TISSUE	8	0.3
OTHER HAEMORRHAGE +/- HAEMATOMA	8	0.3
OTHER HEART DISEASE INCLUDING VALVES +/-METS	11	0.3
OTHER PAIN +/- ACUTE LOWER RESPIRATORY INFECTION, DISORDER OF MINERAL METABOLISM OR METS	6	0.2
OTHER RESPIRATORY DISORDER/SYMPTOM +/- PNEUMONIA	14	0.4
OVARIAN CANCER +/- METS AND PALLIATIVE CARE	15	0.5
PAIN (LOW BACK)+/- METS	15	0.5
PAIN IN LIMB/JOINT	10	0.3

Reason for Admission for ICD10 codes listed in PAS	n	%
PALLIATIVE CARE +/- METS/CARDIAC ARRTHYMIA AND COPD	96	3.0
PANCREATIC CANCER	11	0.3
PERFORATION OF INTESTINE/OESOPHAGUS	8	0.3
PERICARDIAL EFFUSION +/- PLEURAL EFFUSION OR METS	5	0.2
PLEURAL EFFUSION +/- PULMONARY COLLAPSE OR METS	59	1.9
PNEUMONIA +/- METS, RESPIRATORY FAILURE, PLEURAL EFFUSION OR ACUTE RENAL FAILURE	153	4.9
PNEUMONITIS DUE TO SOLIDS AND LIQUIDS +/- METS	31	1.0
POSTSURGICAL COMPLICATION/WOUND DISRUPTIONS +/-METS	5	0.2
PULMONARY COLLAPSE +/- METS OR OTHER PULMONARY DISEASE	9	0.3
PULMONARY EMBOLISM +/- METS, PLEURAL EFFUSION, PULMONARY COLLAPSE, PORTAL HYPERTENSION, ASCITES AND ANAEMIA	45	1.4
RADIOTHERAPY SESSION +/- METS AND ACUTE FAILURE	15	0.5
REHABILITATION/CONVALESENCE/FOLLOW-UP AFTER TREATMENT	9	0.3
RESPIRATORY FAILURE (INCLUDING RESPIRATORY ARREST) +/- METS	19	0.6
RETENTION OF URINE +/- ACUTE RENAL FAILURE OR METS	8	0.3
SENILITY	6	0.2
SEPSIS (INCLUDING SEPTIC SHOCK) +/- ACUTE RENAL FAILURE OR METS	90	2.9
SHORTNESS OF BREATH +/- ABNORMAL WEIGHT LOSS AND METS	23	0.7
SKIN CHANGES/RASH +/- METS	5	0.2
SOMNOLENCE, STUPOR AND COMA	5	0.2
STOMACH CANCER	8	0.3
SYNCOPE (BLACKOUT) AND COLLAPSE	17	0.5
TENDENCY TO FALL	11	0.3
ULCER OF MOUTH/OESOPHAGUS/LIMB/ANUS RECTUM+/-PAIN OR METS	8	0.3
UTI +/- ACUTE RENAL FAILURE, DELERIUM, DISORIENTATION, PALLIATIVE CARE OR METS	106	3.4
WIDESPREAD METS	42	1.3
Total	**3,134**	**100.0**

Appendix 2. Reason for Last Admission Groups

ABNORMAL FINDINGS/TESTS

ABNORMAL FINDINGS BLOOD CHEMISTRY, IMAGING OR LIVER FUNCTION TESTS +/- MALAISE AND FATIGUE OR METS

ADVERSE EFFECT OF DEVICE/PROCEDURE/MEDICATION

ADVERSE EFFECT OF DEVICE/PROCEDURE/MEDICATION +/- METS

FITTING OF/ISSUE WITH COLOSTOMY/ILEOSTOMY/GASTROSTOMY +/- METS

MALFUNCTION OF EXTERNAL STOMA OF URINARY TRACT

MECHANICAL COMPLICATION OF URINARY DEVICE

POSTSURGICAL COMPLICATION/WOUND DISRUPTIONS +/- METS

BLOOD CANCER AND OTHER ABNORMALITY BLOOD CELLS/PLATELETS

LEUKAEMIA/LYMPHOMA/MYELOMA

OTHER ABNORMALITY OF BLOOD (i.e. disseminated intravascular coagulation, agranulocytosis, thrombocytopenia)

BONE DISORDERS

BONE METS + OTHER CONDITION

FRACTURE OF OTHER BONE +/- BONE METS +/- FALL

HIP FRACTURE +/- FALL, REHABILITATION OR INFECTION

OTHER BONE DISORDER (i.e. including osteoporosis, disorder of bone)

BRAIN & CNS SYMPTOMS

BRAIN CANCER

BRAIN CANCER AND OTHER CONDITION

BRAIN CANCER OR BRAIN METS + ACUTE INFECTION

BRAIN METS

BRAIN METS AND FRACTURE/OTHER DISORDER OF BONE

BRAIN METS AND OTHER SYMPTOM

BRAIN/CNS TUMOUR AND PALLIATIVE CARE

CEREBRAL INFARCTION/TRANSIENT ISCHAEMIC ATTACK +/- METS

CONVULSIONS +/- BRAIN CANCER OR BRAIN METS

OTHER BRAIN/CNS DISORDER (i.e. oedema, hemiplegia) +/- HALLUCINATIONS OR DISORIENTATION

FRACTURE/COLLAPSED VERTEBRAE OR LUMBAR SPINE

NERVE ROOT/PLEUXUS/CORD COMPRESSIONS AND BONE METS +/- RADIOTHERAPY SESSION (SEPARATE CATEGORY)

CARDIAC SYMPTOMS

ACUTE MYOCARDIAL INFARCTION

ATRIAL FIBRILLATION +/- CHEST PAIN/PLEURAL EFFUSION/HEART FAILURE/DEHYDRATION/DVT

CARDIAC ARREST +/- METS

OTHER CHRONIC HEART DISEASE/HEART FAILURE/CARDIAC ARRTHYMIAS (i.e. Aortic Stenosis, congestive heart failure, chronic ischaemic heart disease, myocardial degeneration, bradycardia, sick sinus syndrome)

PERICARDIAL EFFUSION +/- PLEURAL EFFUSION OR METS

CIRCULATORY SYMPTOMS

COMPRESSION OF VEIN
DVT

EMBOLISM OF OTHER ARTERY/VEIN +/- METS

ASCITES+/- ACUTE LOWER RESPIRATORY INFECTION/DEHYDRATION/PLEURAL EFFUSION/CONSTIPATION/JAUNDICE

CONSTIPATION +/- ADVERSE EFFECTS OPIODS/PAIN/NAUSEA AND VOMITING/DEHYDRATION/METS

OTHER DIGESTIVE SYSTEM SYMPTOMS

COLORECTAL CANCER

GASTRITIS OR GASTROENTERITIS AND COLITIS +/- DISORDERS OF FLUID/ACID BASE/ELECTROLYTE BALANCE/METS/PALLIATIVE CARE

HYPERTROPHIC PYLORIC STENOSIS +/- METS

INTESTINAL OBSTRUCTION +/- FEVER/INFECTION/ASCITES/STOMA STATUS/GI HAEMORRHAGE

JAUNDICE +/- DEHYDRATION OR METS OR PALLIATIVE CARE

LIVER CANCER

LIVER FAILURE +/- ACUTE RENAL FAILURE AND METS

NAUSEA AND VOMITING +/- CONSTIPATION OR DEHYDRATION OR METS

OBSTRUCTION OF BILE DUCT +/- METS

OESOPHAGEAL CANCER

OESOPHAGEAL OBSTRUCTION OR OESOPHAGITIS +/- METS

OTHER DISORDER OF DIGESTIVE TRACT/ORGAN (i.e. cirrhosis of liver, fistula of intestine, polyp, gastric ulcer, diverticular disease)

PANCREATIC CANCER

PERFORATION OF INTESTINE/OESOPHAGUS

STOMACH CANCER

DISORDER BLOOD GLUCOSE/FLUID OR ELECTROLYTE BALANCE/ MINERAL METABOLISM

CALCULUS OF BLADDER/LIVER/KIDNEY/GALLBLADDER

DEHYDRATION +/- ABDOMINAL PAIN, CONSTIPATION, ACUTE RENAL FAILURE OR METS

DIABETES WITH OR WITHOUT COMPLICATIONS

DISORDER OF BLOOD GLUCOSE/ELECTROLYTE BALANCE +/- METS

DISORDER OF MINERAL METABOLISM +/- METS

DIZZINESS/DISORIENTATION/FALL/COMA/SENILITY

DELERIUM +/- DIZZINESS AND GIDDINESS

DISORIENTATION +/- RESTLESSNESS AND AGITATION

FALL AND INJURY OF HEAD/ABDOMEN

FALL AND SUPERFICIAL INJURY ARM/HEAD/LEG/HIP +/- METS

SENILITY

SOMNOLENCE, STUPOR AND COMA

SYNCOPE AND COLLAPSE

TENDENCY TO FALL

FEVER/INFLAMMATION/INFECTION

ABSCESS OF MOUTH/LIVER/LUNG

ACUTE LOWER RESPIRATORY INFECTION +/- METS OR PALLIATIVE CARE

ACUTE PANCREATITIS/PERITONITIS +/- INTESTINAL OBSTRUCTION OR METS

BRONCHOPNEUMONIA +/- PLEURAL EFFUSION/ PULMONARY COLLAPSE/RESPIRATORY FAILURE/PULMONARY EMBOLISM/OTHER INFECTION/SYNCOPE (BLACKOUT) AND COLLAPSE/ METS

CELLULITIS +/- METS

ENTEROCOLITIS DUE TO C DIFF

FEVER +/- COUGH/ADVERSE EFFECTS OF ANTI-NEOPLASTIC DRUGS

INFECTION FOLLOWING PROCEDURE/TRANSFUSION OR DUE TO INTERNAL GRAFT/DEVICE/IMPLANT

INFLAMMATION OF BILE DUCT OR GALLBLADDER +/- PNEUMONIA OR METS

LOBAR PNEUMONIA +/- PLEURAL EFFUSION, PULMONARY COLLAPSE, CONSTIPATION, DELERIUM

OTHER BACTERIAL/VIRAL INFECTION (i.e. pyothorax, kidney infection, viral infection, other bacterial infection)

PNEUMONIA +/- METS, RESPIRATORY FAILURE, PLEURAL EFFUSION OR ACUTE RENAL FAILURE

PNEUMONITIS DUE TO SOLIDS AND LIQUIDS +/- METS

SEPSIS (INCLUDING SEPTIC SHOCK) +/- ACUTE RENAL FAILURE OR METS

UTI +/- ACUTE RENAL FAILURE, DELERIUM, DISORIENTATION, PALLIATIVE CARE OR METS

HAEMORRHAGE

ANAEMIA +/- BLOOD TRANSFUSION/INFECTION/ABNORMAL HAEMORRHAGE/METS

BRAIN HAEMORRHAGE +/-DEHYDRATION/METS/DISORDER OF BLOOD CHEMISTRY

CEREBRAL HAEMORRHAGE +/- BRAIN CANCER OR BRAIN METS

GI HAEMORRHAGE +/- METS OR PALLIATIVE CARE

HAEMATEMESIS +/- METS

HAEMATURIA +/- METS

HAEMOPTYSIS

MELAENA

OTHER HAEMORRHAGE (i.e. nose bleed, abnormal vaginal bleeding) +/- HAEMATOMA

MEDICAL CARE/PALLIATIVE CARE

MEDICAL CARE +/- METS

PALLIATIVE CARE +/- METS/CARDIAC ARRTHYMIA AND COPD

DISEASE PROGRESSION (ONLY METASTASES MENTIONED)

ONLY METS MENTIONED (BONE METS) +/- PALLIATIVE CARE

ONLY METS MENTIONED +/- PALLIATIVE CARE

WIDESPREAD METS

OTHER

DYSPHAGIA +/- PALLIATIVE CARE OR METS

ENLARGED LIVER/SPLEEN/LYMPH NODES

HEAD AND NECK CANCER

MALAISE AND FATIGUE +/- PALLIATIVE CARE OR METS

MENTAL HEALTH SYMPTOMS +/- METS OR EXCESS USE TOBACCO/ALCOHOL

OTHER

OTHER DISORDER OF MUSCULOSKELETAL SYSTEM/ SOFT TISSUE (i.e. myopathy, polymyalgia rheumatic)

OVARIAN CANCER +/- METS AND PALLIATIVE CARE

SKIN CHANGES/RASH +/- METS

ULCER OF MOUTH/OESOPHAGUS/LIMB/ANUS/RECTUM +/- PAIN OR METS

PAIN

ABDOMINAL PAIN +/- METS/NAUSEA AND VOMITING/GASTROENTERITIS AND COLITIS/HYPONATRAEMIA

CHEST PAIN +/- LOWER RESPIRATORY INFECTION OR METS

OTHER PAIN +/- ACUTE LOWER RESPIRATORY INFECTION, DISORDER OF MINERAL METABOLISM OR METS

PAIN (LOW BACK) +/- METS

PAIN IN LIMB/JOINT

RESPIRATORY

COPD +/- ACUTE LOWER RESPIRATORY INFECTION OR METS

EMPHYSEMA

LUNG CANCER

LUNG METS +/- BONE AND/OR BRAIN METS

OTHER COPD WITH ACUTE EXACERBATION

OTHER RESPIRATORY DISORDER/SYMPTOM (i.e. bronchitis, bronchiectasis, interstitial pulmonary disorder) +/- PNEUMONIA

PLEURAL EFFUSION +/- PULMONARY COLLAPSE OR METS

PULMONARY COLLAPSE +/- METS OR OTHER PULMONARY DISEASE

PULMONARY EMBOLISM +/- METS, PLEURAL EFFUSION, PULMONARY COLLAPSE, PORTAL HYPERTENSION, ASCITES AND ANAEMIA

RESPIRATORY FAILURE +/- METS

SHORTNESS OF BREATH +/- ABNORMAL WEIGHT LOSS AND METS

TREATMENT AND REHABILITATION FOLLOWING TREATMENT

CHEMOTHERAPY SESSION +/- METS

RADIOTHERAPY SESSION +/- METS AND ACUTE RENAL FAILURE

REHABILITATION/CONVALESENCE/FOLLOW-UP AFTER TREATMENT

URINARY

ACUTE RENAL FAILURE +/- UTI, NAUSEA AND VOMITING, GASTROENTERITIS AND COLITIS, ELECTROLYTE IMBALANCE, CHRONIC KIDNEY DISEASE, METS

CHRONIC KIDNEY DISEASE

HYDRONEPHROSIS +/- DISORIENTATION OR METS

INAPPROPRIATE SECRETION OF ANTI-DIURECTIC HORMONE +/- METS OR ELECTROLYTE IMBALANCE

OTHER DISORDER OF BLADDER AND URINARY TRACT +/- METS

RETENTION OF URINE +/- ACUTE RENAL FAILURE OR METS

Appendix 3. Findings of thematic analysis of qualitative information from the Qualycare-NI study

1. Communication

(a) Likelihood of death conversation

- **Insensitive, didn't happen or was too close to end of life to give time family time to prepare**

'My mother's terminal diagnosis was explained to us as a family by the junior doctor who had difficulty in informing us of mother's terminal diagnosis and vague when asked questions'

'I feel it was discussed very bluntly, at the time our world was being shattered and I feel the oncologist especially was not very sensitive'

'It was less than 24 hours before he death that I was told that the next 24-48 hours were critical. Until then I believed she would make a full recovery.'

'The last week of his life we encountered a doctor that we had never met before told us he would be dead in 24 hours and that's exactly how he put it.'

- **Took place on busy ward**

'During his last stay in hospital staff informed us he had been put on a palliative care plan which I had never heard of before. It was explained in a sensitive way, although the conversation took place at the nurse's station, which in hindsight was hardly suitable.'

- **Family felt were not given an accurate estimation of time left**

'My mum was told in December that he would get a 'good few years' he died at start of January.'

- **Lack of communication between medical staff/hospital wards**

'Impaired continuity and feeling of someone having ownership. The hospital admission was deemed essential by team but bed situation [lack of beds available] was not resolved to facilitate this'

'When my mum was transferred to the ward she had to answer numerous questions for about 3rd or 4th time as they did not have her notes.'

'Each doctor who came contradicted each other. Not one person agreed on what to do'

'We were never informed of anything from doctors, which was very frustrating and distressing. Not one professional offered to sit down and explain how horrible his death would be.'

(b) Raised expectations/care previously promised

- **Raised expectation about specialist palliative care at home which was never received**

'SPC promised they would visit and discuss options but never did, we had to rely on our GP for pain relief and help and support to get her admitted into A&E when the pain became too bad.'

'When I met with her specialist doctor I was led to believe that palliative care would be arranged when needed. She eventually needed this when transferred to her nursing home but when contacted the hospital nothing was known about palliative care.'

- ***Person was told that would be admitted directly to cancer ward when needed but had very long waits in ED to be admitted with no input from cancer ward whilst in ED***

'We were told she was only to go to the cancer ward. I rang the number on and off for 30 minutes the night I took her in, to be told that someone would be right down to see her when we arrived, triage and A&E doctor phoned but no one came.'

(c) Lack of information about patient's condition and how would progress

- **Family had to ask questions/arrange appointments to receive information and were not always sure what to ask**

'We had to wait on doctors doing their rounds daily to ask questions and often they didn't come. I feel had to chase everything up to find out what was happening'

- **Family felt did not receive enough information on how illness would progress and what to expect from end of life care**
  'Dad was clearly not very well, but we were not aware of what help was available, so we didn't know what to expect or ask for help.'

'I am sure the doctors would have known her condition could have deteriorated quite suddenly or quickly. We were not informed what to expect until quite near the end.'

‘Professionals must know how this awful disease progresses and should provide or suggest to families some options [of aids to help at end-of-life]’

‘we were visited 4 times by SPC nurse, not once were we given any information on the signs of ‘end of life’, nor was it explained.’

‘I would (in retrospect) have liked to have been informed of the possible scenarios as the tumour progressed. He died much sooner than I expected and I feel so sad about this that I neglected this symptom and he could have needed medication sooner.’

- **Lack of communication about the seriousness of the patient’s condition.**

‘The whole time he was in hospital he wanted to go home. It’sall he said the whole week. Had we realised this was his last week we would have brought him home immediately.’

2. Delay/Lack of Access to care needed

(a) <u>Delays in access to care needed</u>

- **Long wait in ED for bed**

‘My husband was taken into hospital by ambulance. He was in A&E all day Tuesday. They found him a bed on Tuesday night’

‘We spent hours with mum in a wheelchair before and after triage and before she was put on a trolley down the back of A&E for the rest of night and early morning’

‘She was taken to A&E department and was kept on a trolley for 13 hours before being transferred to a ward’

‘My father was admitted to hospital some weeks before his passing. He arrived by ambulance and had a 15 hour trolley/A&E wait before finally getting a bed’

‘He was in extreme discomfort with extreme difficulty breathing and head to remain on a trolley and then an A&E treatment for almost 24 hours. This totally drained and exhausted an already weak man.’

’16 hours waiting in A&E for a bed when Dad was very ill.’

- **Long wait in ED to be seen**

‘When dad had to go to A&E – the waiting time to be seen was too long.’

‘When the GP referred her to hospital, we had to wait three hours in A&E before a doctor would look at her.’

- **Lack of co-ordination of admissions through ED**

'My father was admitted on a few occasions vis A&E, this process was very slow, not very efficient and did not seem to be well co-ordinated.'

(b) Hospital care

- **Excessive number of ward moves following admission to hospital**

'Three wards over 12 days in hospital'

'My Dad was moved around several times in the last ten days he was alive.'

'When she did get a bed in a ward she was moved 3 times in a week.'

- **Getting access to adequate pain relief in hospitals slow (i.e. during the admission process, on busy ward)**

'Had to wait four hours in A&E in a wheelchair with crippling cancer of the spine before a bed was found-painkillers took far too long to get…the writing up process by a doctor/nurse was far too long'

Care on general ward rather than cancer ward and staff unfamiliar with specialised care needed

'Nurses in stroke unit did not seem to understand myeloma or how to care for a dying cancer patient.'

- **End-of-life patient place on main ward rather than a side room**

'After receiving diagnosis and being made aware of how terminally ill she was, we expected to have a single room but was kept in a four bed ward with difficult patients'

'In my father's last hours when we were sent for our whole family were made to get around his bed in the middle of a ward where there was another 5 men at 2 o'clock in the morning trying to sleep only when we asked was there somewhere we could have a bit of privacy they moved him to a side ward'

'Ambulance staff excellent when they arrived three hours after an emergency referral'

- **Transfers between place of care close to death**

'I wish he had been taken to the hospice sooner that's all he wanted. But we went from hospital ward after a terrible night at 12 noon and he died later that afternoon.'

(c) Treatment/appointments in last few weeks of life

- **Expected to attend for appointments/ treatments**

'Despite the hospital persuading him to have stents put in to help him on Friday, he was dead on Saturday'

Delays in being seen at outpatients/treatments

'Long waits at outpatient appointments'

(d) Community Care

- **'Out of hours' GP at weekend did not give enough advice support to help family deal with symptoms adequately**

'On call GP was not helpful during 'out of hours' at weekend regarding advice due to raised temperature and confusion'

- **Lack of support from GP or D/C Nurse at home**

'Inadequate GP support-Lack of empathy and poor control over medication'

'The night my mother died, I rang the district nurse to ask for help to move mum and the nurse refused to come as had already been earlier in the evening. I was alone and it was 1.45am. My mother died that night. I am still upset about this.'

- **GP reluctant to visit at home despite severe symptoms/ deterioration**

'GP's were never willing to do home visits'

'The GP did not visit until I demanded a visit about 2 weeks before he died'

'Took GP 6 hours to arrive, arrived at several phone calls to surgery-reluctant to do a home visit'

- **Need for 24/7 access to Nursing care/SPC/GP at home**

'There was short window of time between the district nursing team time and the SPC teams time when I was unable to get help (6pm-8pm). It was during this time that Mum died. They would not have been able to prevent that but I needed support and felt panicked when I couldn't contact help.'

'Twilight nurses were excellent but not on duty all night when needed support.'

- **No help offered at home**

‘At home always key to him, but needed strong morphine injections, no way for us to administer it at home, no help from other agencies- just had to go to hospital’

- **Lack of access to pain relief and anti-sickness medication at home especially ‘out of hours’**

‘Administration of pain relief and medication would not have been there when she needed it, e.g. at night in the early stages and anti-sickness medication was not stepped up enough to control symptoms, so she went into hospital after a few days at home as she felt more comfortable and help would be on hand 24/7’.

Appendix 4. Macmillan-NICR partnership Strategic group members 2018-2019

Heather Monteverde, Head of Macmillan Services for Northern Ireland (*co-chair*)

Anna Gavin, Director, N.Ireland Cancer Registry (*co-chair*)

Cara Anderson, Assistant Director, Health and Social Care Board

Clodagh O’Brien, Northern Ireland Cancer Network Manager

Gerry Millar, Macmillan GP Advisor for Northern Ireland

Moyra Mills, Macmillan Service Improvement Lead, Northern Health and Social Care Trust

Julie Flynn, Macmillan Strategic Data and Influencing Lead

Kelly Shiell-Davis, Macmillan Senior Evidence Officer

Gregory Fallica, Macmillan Health Data Analyst

Colm Burns, Macmillan, Macmillan Evidence Officer (until March 2019)

Victoria Cairnduff, Researcher, N.Ireland Cancer Registry