



Dying and Death in Ireland: What Do We Routinely Measure, How Can We Improve?



Trinity College Dublin
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**Irish
Hospice
Foundation**

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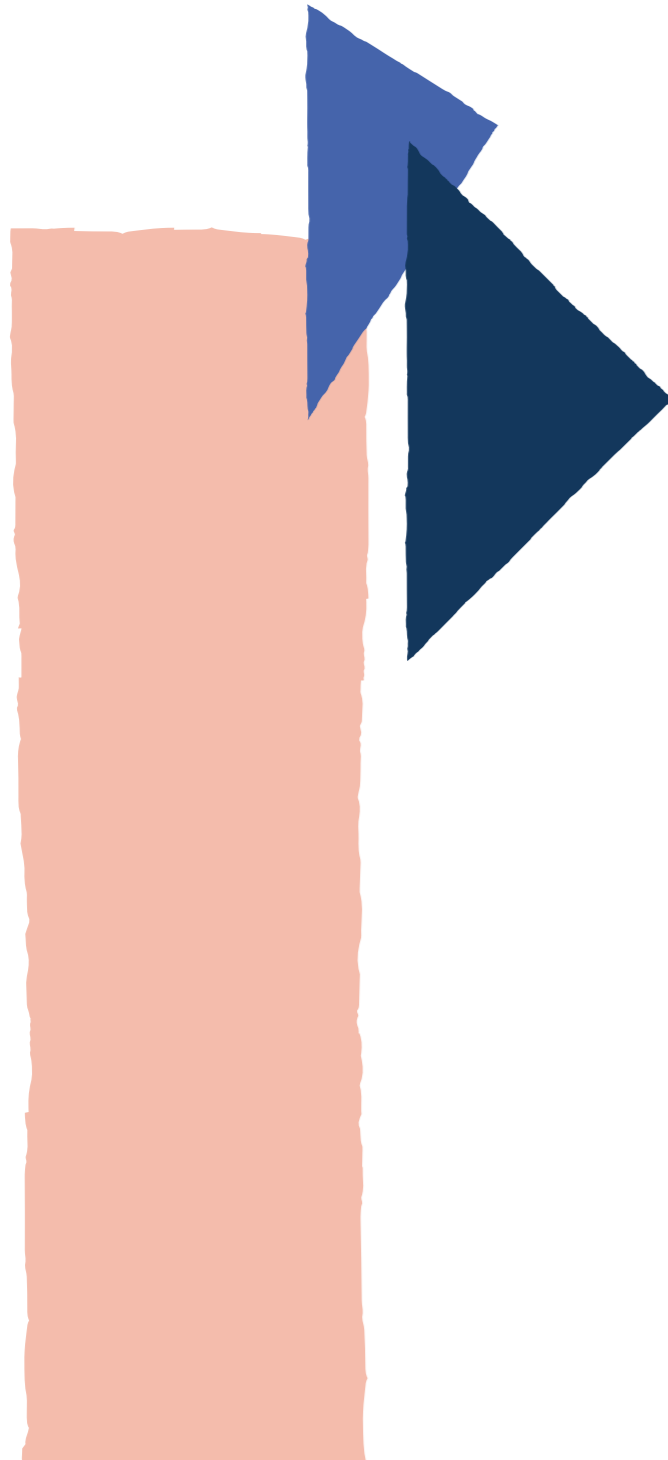
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Executive Summary

1 Background

- Death is an integral part of life. All people die, and in high-income countries like Ireland a large and growing majority die from serious chronic diseases like cancer, heart disease, organ failure and dementia. People have a right to compassion, dignity and participation in decision-making as they approach the end of life.
- The end-of-life period can impose significant challenges and burden on individuals with terminal illness and their families.
- Care delivery at the end of life involves a mix of public, private and informal health and social care providers. However, contemporary health systems are not well equipped to meet the needs of complex ageing populations with many people are living and dying with multiple serious conditions.
- The importance of reforming health and social care systems, and wider societal structures, to ensure that dying people have access to appropriate care and psychological and spiritual supports is being increasingly recognised.
- To begin to address these aims it is important to have a national overview of the existing trends in death and dying in the Republic of Ireland.
- This report is the first output of the Palliative and End-of-Life Care Ireland (PELCI) project, a secondary data analysis project, grant funded by the Health Research Board.

2 Place of death

We used Central Statistics Office (CSO) data to analyse place of death between 2013 and 2018 across hospital, home, long-stay residential care facilities (LSRCFs), hospice and elsewhere.

- *Hospitals* were consistently the most common place of death across the six-year period, accounting for approximately 40% of deaths in the State. This is lower than most similar countries in Europe, which is a positive indicator since most people state a preference for dying at home provided appropriate supports are available. Nevertheless, the proportion could almost certainly be lower still with care provision that is more responsive to people's needs and preferences.

- *Home* deaths comprised a consistent proportion of state deaths across the time period (23%) but with significant regional variations. While Dublin experienced 17% of its deaths at home, most counties had home death rates above the national average. Lower home deaths in Dublin may be due to low home care capacity and overreliance on hospitals, and/or high home deaths in rural areas may be due to improved accessibility to other services or high reliance on unpaid family carers.
- There were small increases in the number of deaths that occurred in *LSRCFs*. Within *LSRCFs*, deaths in nursing homes have increased while deaths in community hospitals have decreased.
- There was a small increase in *hospice* deaths, largely explained by the increase in the number of in-patient hospice beds between 2013 and 2018. Regional variations in hospice deaths highlight that only 8 out of the 26 counties in the State have a hospice.

3 Cause of death

We used CSO data to examine cause of death between 2013 and 2018. We grouped 1,780 different causes of death into eight main categories: cancer, diseases of the circulatory system, diseases of the respiratory system, mental and behavioural disorders, diseases of the nervous system, diseases of the digestive system, external causes of injury and poisoning, and other.

- Between 2013 and 2018, *cancer replaced diseases of the circulatory system as the leading cause of death in Ireland*, partly reflecting a long-term trend of declining heart-related mortality in Ireland. Diseases of the respiratory system were the third most common cause of death in 2018.
- Deaths caused by *mental and behavioural disorders increased 61% as both prevalence and identification of dementia grew* across the health care system.
- *Cause of death varied widely by age and gender*. Most deaths occurred among older people, with people aged 65+ accounting for 82% of all deaths in 2018. This varies across different cause of death categories, ranging from 77% for deaths caused by cancer to 99% for deaths caused by mental and behavioural diseases. Cancer mortality is higher among males, whereas deaths from diseases caused by mental and behavioural disorders are more prevalent among females.

4 Cancer as a cause of death

As cancer is the primary cause of death in the state and a term that covers multiple illnesses, we examined this in more detail. We grouped different types of cancer into nine categories using CSO data to provide an overview for different cancer deaths and how these differ by age and sex.

- *Four cancer categories accounted for over three-quarters of cancer deaths in 2018: gastrointestinal (31% of cancer deaths), respiratory and thoracic (20%), breast and gynaecological (14%), and genitourinary and testicular (12%).*
- *Cancer type varied widely by age and gender. Of the 9,466 deaths due to cancer, 7,245 (77%) were people aged 65+. This age group accounts for a minimum of half of deaths in each cancer category (56%-89%). There were important sex differences, with females accounting for a higher proportion of deaths in two categories (breast and gynaecological and cancer of unknown primary), and males accounting for the majority in all other cancer categories.*

5 Dementia as a cause of death

As international evidence is showing that deaths caused by dementia are increasing, we examined this in more detail. We grouped dementia deaths into three categories using CSO data: vascular dementia, unspecified dementia and Alzheimer's disease.

- *There was a steady increase in deaths caused by dementia between 2013 (6% of state deaths) and 2018 (8%). Of the 2,466 deaths in 2018, 64% were attributed to unspecified dementia, 23% to Alzheimer's disease and the remaining 12% to vascular dementia.*
- *Factors likely to be contributing to this rise include longer life expectancy and increasing dementia prevalence, improved diagnosis, and better reporting of dementia on death notification forms. It is highly likely that there is underreporting of deaths caused by dementia.*
- *Nearly all deaths caused by dementia were among older age groups, and the proportion of deaths in each age category increased as age increased.*
- *Women accounted for two-thirds of the deaths caused by dementia, highlighting the importance of promoting gender-sensitive approaches in end-of-life and palliative care services for people with dementia. The availability of data showing place of death for people with dementia would help inform where the focus needs to be for end-of-life and palliative care services for people with dementia.*

6 HSE Specialist Palliative Care Services Minimum Data Set (SPC MDS)

The SPC MDS is a national survey of patient activity data for specialist palliative care services in the State. We examined data from the SPC MDS between 2013 and 2019 across three main types of SPC: in-patient SPC, community SPC and day SPC.

- *While there was an upward trend in the number of new patients admitted to an in-patient SPC unit and receiving community SPC for the first time, the number of new patients receiving day SPC decreased from 2018.*
- *Nationally the number of SPC in-patient beds per 100,000 population increased to 4.7; however, this is still below the level recommended by national policy, and there is wide variation regionally.*
- *The majority of new patients receiving in-patient, community and day SPC had cancer as a primary diagnosis. However, over the seven-year period, the proportion of cancer diagnoses receiving these services has decreased, and non-cancer diagnoses have increased. This is in keeping with the principle that palliative care should be available to all, irrespective of diagnosis, which underpins national policy and the substantial work of the Irish Hospice Foundation (IHF) through its Palliative Care for All programme.*
- *With regard to place of death, two-thirds of new patients admitted to in-patient SPC units die there, with most of the remainder discharged home. The place of death for new patients receiving community SPC is varied.*

7 Hospital In-Patient Experience data

We examined Hospital In-Patient Experience (HIPE) data, the main source of data on patient activity in acute hospital settings, for indications of palliative care and end-of-life care need between 2013 and 2017.

- *People with a diagnosis of cancer, major organ failure or dementia make up approximately half of all adult emergency admissions to acute hospitals. It is clear that the volume of admissions with a serious illness far exceeds the capacity of SPC services in acute hospitals.*
- *These admissions account disproportionately for both length of stay and discharges ending in death. Patterns of length of stay and discharge locations are broadly consistent across hospital groups and over time.*

- *Death and dying are a core activity of acute public hospitals in Ireland. We estimate that among all adults in an acute public hospital in Ireland following emergency admission on a given day, one in five will die within the next 12 months.*
- *Diffusing palliative care approaches across hospital staff is essential to meet this large and growing need. Moreover, better community services could potentially reduce emergency admission of patients with serious illness to acute hospitals in the first place.*
- *Weaknesses in data recording and infrastructure mean that we do not know how many hospital in-patients receive palliative care nationally, and we cannot follow their trajectories of experience and health care use following hospital discharge.*

8 Challenges and policy implications

8.1 The need for reliable indicators and outcome measures

- *Place of death: We examined place of death, which is commonly used as an indicator of a 'good death' and as a proxy for quality of care. However, on its own, it is not necessarily a good indicator for either and the focus needs to be broadened beyond place of death as a sole indicator. It should instead be used as part of a suite of indicators of quality of care at end of life.*
- *Cause of death: As populations age, and people live and die with multiple serious conditions and limitations, the concept of a single identifiable 'cause of death' becomes increasingly flawed. Primary cause of death is recorded on the death certificate and is often a value judgement of the person reporting. Understanding total prevalence of conditions, and the co-occurrence of specific conditions, as people age and die is critical to planning and providing appropriate services.*
- *Dementia: The proportion of deaths attributed to dementia is likely to be an undercount, signalling the need for improvements in dementia diagnosis as well as better reporting of dementia on death certificates.*
- *SPC MDS: The SPC MDS does not tell us if there is an essential minimum core of professionally trained staff with recognised post-qualification specialist training in SPC services. Moreover, it does not include standardised outcome measures for use in evaluating and monitoring the quality of SPC services at national level.*

- *Not all patients who could benefit from SPC services will receive those services. Therefore, access to a broad range of data, including person-centred outcome measures, is needed to understand end-of-life care of all people with life-limiting illnesses.*
- *With respect to in-patients in acute hospitals, the lack of a reliable indicator of receipt of SPC is an important barrier to measuring access and to evaluating the effectiveness and cost-effectiveness of SPC for in-patients in acute hospital services.*

8.2 Classification and coding practices

- *The introduction of 11 place of death categories by the CSO in 2017 is a positive development and allows for reasonably accurate data that will inform regional and national trends and impact future service planning.*
- *However, clearer definitions for the included categories would be beneficial, in particular 'community hospitals' and 'nursing homes', to further aid interpretation.*
- *Each of the datasets accessed classified long-stay residential care facilities differently, and incompatibility across datasets is an issue that needs to be addressed.*
- *With respect to the SPC MDS, classification changes affected comparability over time.*

8.3 Absence of a unique patient identifier

- *The absence of a unique patient identifier in the Republic of Ireland presents challenges for secondary data analysis. For example, not being able to track people before or following a given hospital admission profoundly limits our understanding of how they came to be admitted and how they fared after discharge.*
- *Understanding how the trajectory of disease and need changes, how people use and access services throughout their illness, and how people die therefore requires linking multiple data sources over time at the individual level.*
- *The Covid-19 crisis has illustrated the limitations imposed on providers and patients by the lack of a unique identifier. Acting upon existing legislation to implement a unique identifier is a long-standing priority in the Irish health system and a pre-requisite if patients are to receive responsive, efficient, high-quality health care across multiple providers and settings as they approach end of life.*

8.4 Data limitations and gaps

- The wide regional variations with respect to use of SPC services and age disparities with respect to place of death were highlighted. However, it was not possible to show whether such disparities can be attributed to variations in need, which would be required for the purposes of demonstrating inequities that exist.

8.5 Gaining access to data for secondary analysis is challenging

- It was intended at the outset of this report to use National Cancer Registry (NCRI) data, but access to the national dataset was not achieved due to NCRI capacity issues.
- While access to data from other sources was achieved, capacity issues contributed to delays in accessing MDS and HIPE data, and there were limits to the level of data that the CSO could produce for the research team. Getting access to or clarification about data was further hampered by the Covid-19 pandemic and in 2021 the cybersecurity attack on the HSE.
- There is increasing recognition of the power of data to inform better care, but our experience is that accessing population data for secondary data analysis is problematic. Better systems need to be put in place to facilitate researcher access to health and social care data, and capacity issues preventing access need to be addressed.

8.6 Data on impact of Covid-19 pandemic not yet available

- Data for 2020 is not yet available from any of the datasets examined and it remains to be seen how the Covid-19 pandemic has impacted trends. It is highly likely that when the data become available it will show that Covid-19 had an impact on place of death, SPC activity and utilisation, and hospital emergency admissions, as has been shown in other countries such as the UK^{3,4}.
- In the UK, concerns have been raised that without adequate support and care in the community, dying at home may not have been a positive experience during the pandemic, and many gaps in knowledge were highlighted. In Ireland, even in the absence of data, Covid-19 provides us with an opportunity to generate debate on important issues relating to dying and death.

9 Conclusions

- Population-level monitoring of end-of-life trends provides descriptive information that can help inform public health policy regarding the allocation of end-of-life care resources and support improvement strategies.
- Our results can assist provision and planning in palliative and end-of-life care by providing, for the first time, a national picture of how people die in Ireland, and how services such as acute public hospitals and SPC care for patients.
- However, our understanding is only as good as the available data. We have identified a range of issues and challenges in trying to establish the state of the nation for death and dying. These include the reliability of indicators, the absence of outcome measures, classification and coding practices, the absence of a unique patient identifier, data limitations and gaps, and problems gaining access to data, all of which need to be addressed if routine data are to be used to inform palliative and end-of-life care policy planning, resource allocation and practice.

01 Introduction

Background

Death is an integral part of life. All people die, and in high-income countries a large and growing majority die from serious chronic diseases like cancer, heart disease, organ failure and dementia. In Ireland, the number of people living and dying with serious chronic disease will approximately double over the next 30 years. People have a right to compassion, dignity and participation in decision-making as they approach the end of life. This is important not only so that people are supported as well as possible in dying, but also to support family and friends for whom death of a loved one is itself a unique and important life event. Health systems designed a century ago to provide acute, episodic care are not well equipped to meet the needs of ageing populations where many people are living and dying with multiple serious conditions.

Governments increasingly recognise these facts. Reforming health and social care systems, and wider societal structures, to ensure that dying people have access to appropriate care, and psychological and spiritual supports, is a declared priority of the European Union and its member states. A growing number of European countries have focused on data as a key component of any strategy to measure and improve end-of-life experiences for citizens. Where do people die, and what do they die from? What health care do they use? Do they access palliative and hospice care? Does experience differ by age or disease, geographical region or social class? These are important questions, and answering them requires appropriate data.

In Ireland and internationally, levels of funding for research on death, dying and end-of-life care have historically been low. If we are to improve our planning and provision of care and supports for people approaching end of life in Ireland, then we must first establish current patterns of experience. Routinely collected health and social care data – that is, data generated by administrative and clinical processes and not solely for the purposes of research – is the largest single source of relevant information.

The aim of this report is to establish what is known currently about death and dying in Ireland through major sources of routine population-level data collection. By establishing what is known, we inform ourselves about how people currently die in Ireland, we learn ways to improve experiences, and we identify gaps in current data collection that should be addressed to strengthen future planning and provision.

Data sources and chapters

We accessed data from three main sources to evaluate the circumstances surrounding how people die in the State:

- Central Statistics Office (CSO) death registration data (taken from death certificates)
- Health Service Executive (HSE) Specialist Palliative Care Minimum Dataset (SPC MDS), and
- Hospital In-Patient Experience (HIPE) database of acute public hospital admissions.

We employ the CSO data in four chapters:

- Chapter 2 examines where people died in Ireland 2013–2018.
- Chapter 3 examines the primary recorded cause of death for people in Ireland 2013–2018.
- Chapter 4 analyses in more detail deaths from cancer in Ireland 2013–2018. Cancer is the most common cause of death in Ireland according to the most recent data.
- Chapter 5 analyses in more detail deaths from dementia in Ireland 2013–2018. Dementia is the fastest-growing cause of death in Ireland according to the most recent data.

We use the SPC MDS data in one chapter:

- Chapter 6 analyses the number of specialist palliative care encounters in Ireland 2013–2019, that is, the number of people receiving specialist palliative care at home, in in-patient hospices, and in day care.

We use the HIPE data in one chapter:

- Chapter 7 analyses emergency admissions to acute public hospitals in Ireland 2013–2017. What proportion of admissions are accounted for by those with serious chronic illness, what proportion end in death, where do people go after discharge, and how do these factors vary by region?

Implications of findings

In Chapter 8, we summarise the main findings from our analysis and discuss the most important implications with respect to data access, classification and coding practices, and data gaps and limitations.

Population-level monitoring of end-of-life trends provides descriptive information that can help inform public health policy regarding the allocation of end-of-life care resources and support improvement strategies. Our results can assist provision and planning in palliative and end-of-life care by providing, for the first time, a national picture of how people die in Ireland, and how the data we collect shapes – and restricts – our understanding of these experiences.

Place of Death

1. Introduction

This chapter presents an overview of deaths in Ireland by place of occurrence for the period 2013–2018 inclusive using data from the Central Statistics Office (CSO). This is the most up-to-date data on place of death at the time of writing.

In Ireland, every death is officially recorded with the General Register Office (GRO) in the Department of Social Protection using a death registration form. These registration forms are the basis for CSO mortality statistics, which represent the definitive national dataset on all deaths in Ireland, including place of occurrence.

2. Place of death in CSO statistics

The CSO classifies place of death according to 11 categories: General and Orthopaedic Hospitals, Private Hospitals, Community Hospitals, Maternity Hospitals, Paediatric Hospitals, Oncology Hospitals, Nursing Homes, Psychiatric Hospitals, Hospices, Domiciliary and Elsewhere.

These can be grouped into five places: in a hospital, at home, in a long-stay residential care setting, in a hospice and in another place. The 11 CSO classifications include discrete categories for home, hospice and in another place, and the other eight classifications relate to hospital and long-stay residential care settings:

Hospital: Of all deaths in the State, the most common place of occurrence is general and orthopaedic hospitals. The category ‘general and orthopaedic hospitals’ refers to all major acute settings, including for example, university and other public hospitals and we look at this category separately. A low proportion of deaths occur in other hospitals and this report groups together five of these hospital types – Private Hospitals, Maternity Hospitals, Paediatric Hospitals, Oncology Hospitals and Psychiatric Hospitals.

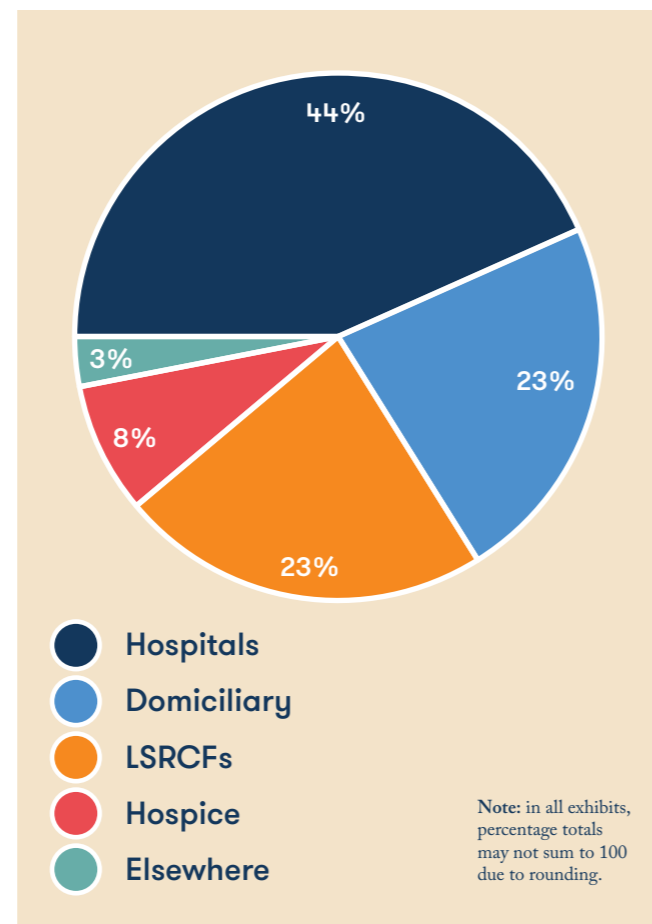
Long-stay residential care setting: Among the 11 categories is ‘community hospitals’. There is no official definition of a ‘community hospital’ in Ireland, but the convention is to differentiate it from an acute hospital if it does not have an accident and emergency department. Effectively community hospitals are long-stay residential care facilities¹. The CSO also uses ‘Nursing Homes’ as a place of death category. In Ireland nursing home definitions are broad but in general can be taken to mean services that cater for the needs of vulnerable and dependent people in residential settings². For the purposes of this report, we have combined the categories ‘community hospitals’ and ‘nursing homes’ into one category, long-stay residential care facilities.

The CSO collects data by county and we present those data accordingly. It is not possible to provide precise data by community healthcare organisation (CHO) regions as some counties overlap with more than one CHO. Deaths are presented according to the *county of residence* of the decedent, not the *county of occurrence*.

3. National overview by place of occurrence (2013–2018)

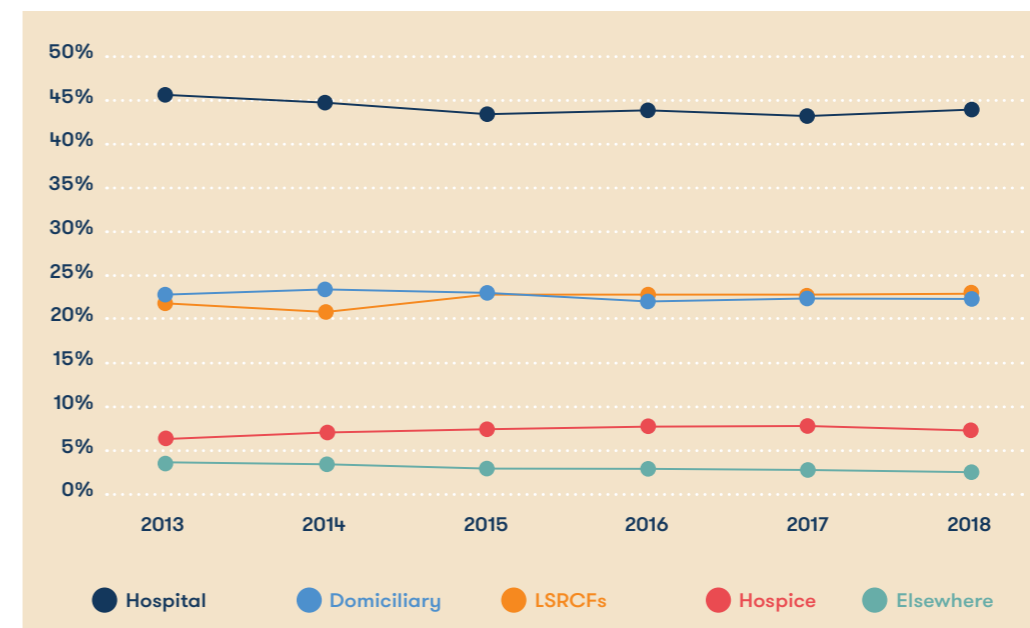
Of the 31,140 deaths that occurred in Ireland in 2018, 44% occurred in a hospital, 23% at home (domiciliary) and 23% in a long-stay residential care facility (8% in a community hospital and 16% in a nursing home). Eight per cent died in a hospice, and 3% died elsewhere (Figure 2.1).

Figure 2.1
All deaths in Ireland by place of death, 2018 (%)



Over the six-year period 2013–2018 inclusive, there has been little change in the proportion of deaths that occurred in each of these settings (Figure 2.2). There was a small decrease in the proportion of deaths that occurred in hospitals (from 45% in 2013 to 44% in 2018). Small increases were recorded in the proportion of deaths that occurred in long-stay residential settings (from 22% to 23%) and hospices (from 6% to 8%). Deaths occurring in the home remained constant in proportional terms (at 23% in both 2013 and 2018).

Figure 2.2
Place of death trends in Ireland, 2013–2018



Deaths in 2018 by age group and place of death are presented in Table 2.1. Ages 65+ account for over 75% of deaths in hospital, LSRCF, hospice and home. The majority of deaths in LSRCFs are accounted for by those aged over 85 (61%), whereas in other categories the proportion of deaths across age groups is broadly similar.

Table 2.1.
State death totals by age: total, and as a proportion (%) of all place of death categories, 2018

	General & Orthopaedic Hospital	Other Hospital	LSRCF	Hospice	Domiciliary	Elsewhere
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
0–4yr	40 (<1)	138 (10)	<10 (<1)	<10 (<1)	17 (<1)	<10 (<1)
5–14yr	14 (<1)	17 (1)	<10 (<1)	<10 (<1)	14 (<1)	<10 (<1)
15–24yr	53 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	54 (1)	42 (5)
25–34yr	109 (1)	<10 (<1)	<10 (<1)	13 (1)	120 (2)	73 (9)
35–44yr	232 (2)	24 (2)	19 (<1)	58 (2)	222 (3)	95 (11)
45–54yr	549 (4)	68 (5)	54 (1)	149 (6)	456 (7)	106 (13)
55–64yr	1181 (10)	140 (10)	185 (3)	356 (15)	861 (12)	110 (13)
65–74yr	2533 (21)	275 (20)	594 (8)	642 (27)	1517 (22)	126 (15)
75–84yr	3942 (32)	419 (30)	1983 (27)	731 (31)	1796 (26)	152 (18)
85+yr	3616 (29)	299 (21)	4409 (61)	420 (18)	1954 (28)	139 (16)
State	12269	1391	7247	2373	7012	848

4. Deaths by county and place of occurrence (2013–2018)

4.1 Hospitals

4.1.1 General and orthopaedic hospitals

In 2018, 39% of all deaths in the State occurred in general and orthopaedic hospitals. There was a small reduction over the time period under review from 12,273 deaths in 2013 (42% of all deaths) to 12,269 deaths in 2018 (39% of state deaths in the state ('state deaths')). However, these overall figures conceal the large variation that exists between counties with regard to deaths in general and orthopaedic hospitals, as shown in Table 2.2.

We also present the average proportions of deaths in general and orthopaedic hospitals in each county within the five-year period (Table 2.2). This is calculated using the average number of general and orthopaedic hospital deaths (2013–2018) and the average number of total deaths within each county (2013–2018).

With respect to the national average, 40% of deaths occurred in general and orthopaedic hospitals within the time period. Table 2.2 shows that the death rate in 14 counties was higher than the national average within this setting (highlighted orange). Conversely, in ten counties the death rate was lower than the national average (highlighted blue) and in two counties it corresponded to the national average (highlighted green).

Louth was the county where the highest proportion of all deaths on average occurred in hospital (51%), followed by Roscommon (45%), Westmeath (45%), Kildare (44%) and Monaghan (44%). The counties with the smallest percentage of hospital deaths on average as a proportion of all deaths were: Limerick (31%), Clare (32%), Donegal (33%), Leitrim (34%) and Cork (35%).

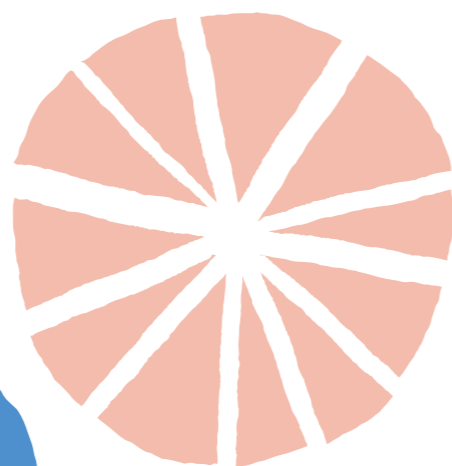


Table 2.2

General and orthopaedic hospital deaths by county: total, and as a proportion (%) of all county deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths in a G&O hospital 2013–2018*
State	12273 (42)	11311 (39)	12050 (40)	12309 (40)	12028 (40)	12269 (39)	12040 (40)
Leinster							
Dublin	3531 (47)	2839 (38)	3573 (45)	3341 (43)	3314 (41)	3228 (40)	3304 (42)
Carlow	164 (42)	162 (44)	141 (36)	154 (40)	136 (34)	151 (41)	151 (39)
Kildare	443 (48)	413 (44)	404 (44)	452 (46)	419 (42)	424 (42)	426 (44)
Kilkenny	273 (42)	200 (36)	235 (38)	262 (39)	238 (38)	286 (43)	249 (40)
Laois	187 (42)	176 (42)	180 (39)	181 (38)	177 (38)	196 (44)	183 (40)
Longford	110 (38)	113 (43)	109 (37)	103 (37)	118 (41)	102 (37)	109 (39)
Meath	381 (46)	369 (43)	382 (43)	392 (45)	399 (44)	394 (40)	386 (43)
Louth	391 (53)	354 (49)	396 (48)	411 (54)	428 (53)	402 (50)	397 (51)
Offaly	219 (46)	179 (39)	192 (40)	219 (44)	206 (44)	229 (47)	207 (43)
Wexford	420 (42)	417 (41)	400 (41)	433 (41)	427 (40)	477 (42)	429 (41)
Wicklow	354 (44)	332 (42)	337 (40)	341 (40)	326 (38)	364 (42)	342 (41)
Westmeath	270 (45)	301 (50)	251 (45)	279 (46)	244 (43)	223 (39)	261 (45)
Munster							
Cork	1224 (35)	1176 (35)	1141 (33)	1288 (34)	1298 (35)	1319 (36)	1241 (35)
Clare	249 (31)	239 (29)	281 (33)	280 (32)	283 (36)	281 (33)	269 (32)
Kerry	452 (38)	424 (36)	443 (38)	449 (37)	434 (39)	544 (45)	458 (39)
Limerick	420 (31)	430 (31)	406 (30)	459 (32)	409 (30)	475 (33)	433 (31)
Tipperary	481 (38)	458 (38)	467 (37)	502 (37)	456 (37)	459 (36)	471 (37)
Waterford	355 (44)	361 (44)	341 (43)	354 (42)	357 (47)	342 (42)	352 (43)
Connacht							
Leitrim	92 (35)	84 (34)	94 (33)	99 (34)	86 (34)	90 (32)	91 (34)
Sligo	172 (36)	180 (39)	181 (36)	195 (39)	172 (34)	179 (35)	180 (36)
Galway	653 (44)	649 (43)	656 (43)	659 (42)	621 (40)	622 (40)	643 (42)
Mayo	457 (40)	439 (41)	429 (40)	446 (41)	445 (41)	457 (41)	446 (41)
Roscommon	226 (47)	244 (47)	246 (47)	221 (43)	215 (46)	213 (40)	228 (55)
Ulster Rol							
Cavan	219 (44)	210 (41)	230 (46)	226 (43)	218 (44)	213 (42)	219 (43)
Donegal	354 (32)	373 (330)	353 (31)	395 (35)	410 (34)	398 (34)	381 (33)
Monaghan	176 (43)	189 (44)	182 (44)	168 (39)	192 (45)	201 (47)	185 (44)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.

4.1.2 Other hospitals

As well as deaths occurring in general and orthopaedic hospitals, deaths occur in a range of other hospitals including private hospitals, maternity hospitals, oncology hospitals, paediatric hospitals and psychiatric hospitals. In 2017, 4% of all deaths in the State occurred in other hospitals. Over the period under review, the proportion of deaths that occurred in other hospitals remained the same.

In Table 2.3 we present a national breakdown of the other hospital categories and their death rates across the six-year period. We do not report county-level rates for two reasons. First, low numbers of deaths in some settings for some counties undermine the anonymity of decedents. Second, these speciality hospitals are not evenly distributed across the country so county-level comparisons would be skewed by, for example, the higher prevalence of private hospitals in Dublin. Whereas private hospitals accounted for an average of 3% of deaths in the State between 2013–2018, they accounted for an average of 6.6% in Dublin. Nationally, the proportion of private hospital deaths (3%) remained

relatively unchanged across the six-year period, despite the number of deaths increasing between 2013 and 2018. There was a notable spike nationally in 2014 (1,609 deaths) whereby figures more than doubled compared to 2013 (797 deaths) and 2015 (781 deaths). To the best of our understanding this reflects a data measurement issue for the CSO (e.g. some hospices were included in the data for one year) and not a like-for-like comparison across years (e.g. private hospitals admitted double the usual number of people approaching end of life due to a policy or system factor).

The remaining ‘other hospitals’ (psychiatric, maternity, paediatric and oncology) each accounted for less than 1% of national deaths in each of the years between 2013 and 2018.

Table 2.3
Deaths in ‘Other Hospital’ categories and as a proportion of all state deaths, 2013–2018

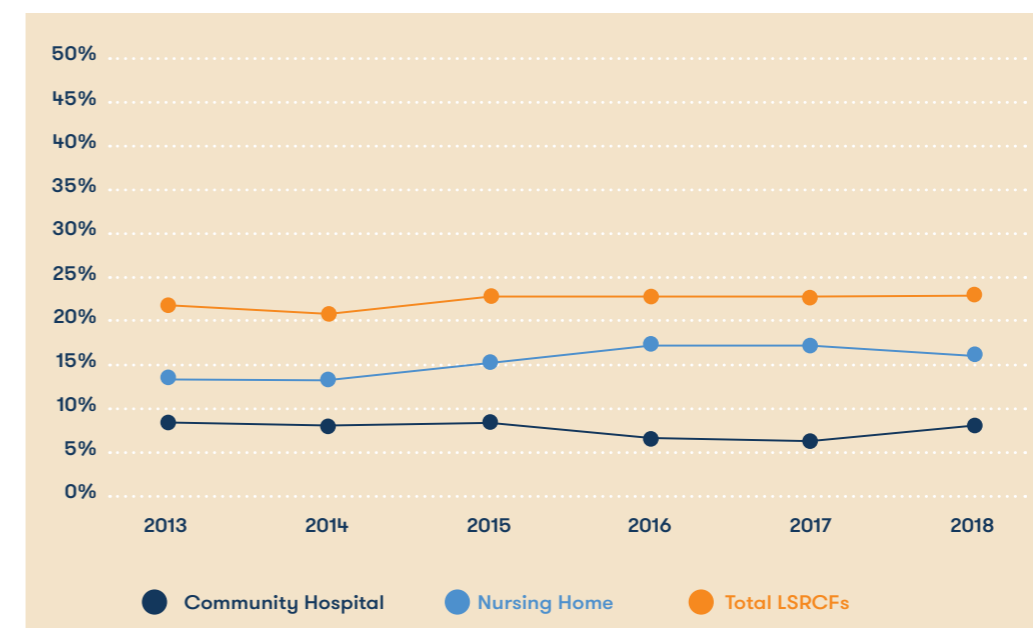
	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths in ‘Other Hospital’ categories 2013–2018
‘Other Hospitals’	1146 (4)	1891 (6)	1067 (4)	1185 (4)	1159 (4)	1391 (4)	1307 (4)
Psychiatric Hospitals	64 (<1)	48 (<1)	72 (<1)	67 (<1)	52 (<1)	79 (<1)	64 (<1)
Private Hospitals	797 (3)	1609 (6)	781 (3)	919 (3)	909 (3)	1039 (3)	1009 (3)
Maternity Hospitals	123 (<1)	102 (<1)	112 (<1)	88 (<1)	92 (<1)	100 (<1)	103 (<1)
Paediatric Hospitals	99 (<1)	97 (<1)	72 (<1)	70 (<1)	77 (<1)	146 (<1)	94 (<1)
Oncology Hospitals	63 (<1)	35 (<1)	30 (<1)	41 (<1)	29 (<1)	27 (<1)	38 (<1)

4.2 Long-stay residential care facilities

When the data on community hospitals and nursing homes are combined, just over one-fifth of deaths in Ireland occur in long-stay residential care facilities. Figure 2.3 shows that the number of deaths in long-stay residential care facilities rose from 6,417 in 2013 to 7,247 in 2018. This is an approximate increase of 13% in the absolute number of deaths when comparing 2013 to 2018. With respect to the proportion of state deaths, this corresponds to a 1% increase (22% to 23%).

When nursing homes and community hospitals are examined separately, distinct trends are observable. For nursing homes, the number of deaths increased from 3,976 in 2013 to 4,894 in 2018, an increase of 23% in absolute number of deaths and a 3% change in proportion of state deaths (13% to 16%). For community hospitals, the number of deaths decreased from 2,441 in 2013 to 2,352 in 2018, a decrease of 4% in absolute number of deaths, and the proportion of state deaths remained at 8% in both years.

Figure 2.3
Deaths in long-stay residential care facilities as proportion of all deaths, 2013–2018 (%)



4.2.1 Community hospitals

In Table 2.4 we present the average proportions of deaths in community hospitals in each county within the six-year period (Table 2.4). The state average showed that 7% of deaths occurred in community hospitals within the time period. In Table 2.4, 13 counties are shown (highlighted orange) as experiencing a higher death rate than the national average within this setting. Conversely, 11 counties (blue) experienced a lower death rate and two counties matched the national average (green). Over the six-year period, there is a marked variance between counties with respect to the proportion of all deaths that occur in

community hospitals, ranging from 1% (Longford, 2016) to 19% (Leitrim, 2014) of all deaths in the county. For some counties the proportion of deaths varied greatly from one year to the next.

In the six-year period, Donegal has the highest average proportion of deaths occurring in community hospitals (15%), followed by Leitrim (13%), Kerry (12%), Clare (12%) and Waterford (11%). The counties with the smallest percentage of deaths were: Galway (3%), Meath (3%), Kildare (4%), Monaghan (4%) and Dublin (5%).

Table 2.4.

Community hospital deaths by county: total, and as a proportion (%) of all county deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths in a com- munity hospital 2013–2018*
State	2441 (8)	2264 (8)	2476 (8)	1876 (6)	1782 (6)	2352 (8)	2199 (7)
Leinster							
Dublin	377 (5)	360 (5)	393 (5)	285 (4)	278 (3)	445 (5)	356 (4)
Carlow	53 (14)	42 (11)	43 (11)	28 (7)	39 (10)	31 (8)	39 (10)
Kildare	52 (6)	58 (6)	42 (5)	39 (4)	29 (3)	29 (3)	42 (4)
Kilkenny	55 (9)	46 (8)	55 (9)	50 (8)	53 (9)	50 (7)	52 (8)
Laois	41 (9)	47 (11)	39 (8)	25 (5)	36 (8)	31 (7)	37 (8)
Longford	13 (4)	15 (6)	26 (9)	<10 (1)	13 (4)	25 (9)	16 (6)
Meath	33 (4)	17 (2)	34(4)	30 (3)	15 (2)	39 (4)	28 (3)
Louth	44 (6)	35 (5)	44 (5)	28 (4)	26 (3)	46 (6)	37 (5)
Offaly	35 (7)	37 (8)	50 (10)	27 (5)	22 (5)	27 (6)	33 (7)
Wexford	102 (10)	87 (9)	77 (8)	71 (7)	73 (7)	90 (8)	83 (8)
Wicklow	40 (5)	42 (5)	53 (6)	37 (4)	32 (4)	50 (6)	42 (5)
Westmeath	64 (11)	39 (6)	46 (8)	17 (3)	<10 (1)	34 (6)	35 (6)
Munster							
Cork	381 (11)	349 (10)	413 (12)	279 (7)	371 (10)	414 (11)	368 (10)
Clare	118 (15)	107 (15)	105 (12)	123 (14)	56 (7)	99 (12)	101 (12)
Kerry	126 (11)	146 (12)	170 (15)	158 (13)	141 (13)	132 (11)	146 (12)
Limerick	96 (7)	96 (7)	114 (8)	63 (4)	48 (4)	99 (7)	86 (6)
Tipperary	126 (10)	114 (9)	150 (12)	115 (8)	85 (7)	115 (9)	118 (9)
Waterford	120 (15)	84 (10)	88 (11)	99 (12)	61 (8)	74 (9)	88 (11)
Connacht							
Leitrim	39 (15)	48 (19)	43 (15)	29 (10)	20 (8)	28 (10)	35 (13)
Sligo	66 (14)	57 (12)	57 (11)	39 (8)	36 (7)	40 (8)	49 (10)
Galway	58 (4)	55 (4)	50 (3)	31 (2)	39 (3)	75 (5)	51 (3)
Mayo	138 (12)	118 (11)	123 (12)	93 (8)	94 (9)	94 (8)	110 (10)
Roscommon	43 (9)	36 (7)	36 (7)	24 (5)	19 (4)	45 (8)	34 (7)
Ulster Rol							
Cavan	19 (4)	25 (5)	22 (4)	15 (3)	19 (4)	41 (8)	24 (5)
Donegal	174 (15)	189 (17)	196 (17)	141 (12)	155 (13)	175 (15)	172 (15)
Monaghan	28 (7)	15 (4)	<10 (2)	26 (6)	14 (3)	24 (6)	19 (4)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.

4.2.2 Nursing homes

In Table 2.5 we present the average proportions of deaths in nursing homes in each county within the six-year period. In the State, on average, 15% of deaths occurred in nursing homes over the period 2013 to 2018. Table 2.5 shows that 12 counties (highlighted orange) experienced a death rate higher than the national average within this setting. Conversely, ten counties (blue) experienced a death rate lower than and four counties corresponded with the national average (green). Similar to community hospitals, there is a marked variance between counties with respect to the proportion of all deaths that occur in nursing homes.

For example, this can range from 6% to 25% of all deaths in the county, and for some counties the proportion of deaths varied greatly from one year to the next.

Limerick has the highest average proportion of deaths occurring in nursing homes (21%), followed by Tipperary (19%), Longford (19%), Wexford (19%) and Westmeath (17%). The counties with the smallest percentage of nursing home deaths on average were: Donegal (9%), Sligo (12%), Leitrim (13%), Carlow (13%) and Clare (14%).

Table 2.5.

Nursing home deaths by county: total, and as a proportion (%) of all county deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths in a nursing home 2013–2018**
State	3976 (13)	3860 (13)	4408 (15)	5117 (17)	5201 (17)	4895 (16)	4576 (15)
Leinster							
Dublin	967 (13)	982 (13)	1114 (14)	1197 (16)	1349 (17)	1286 (16)	1149 (15)
Carlow	38 (10)	40 (11)	56 (14)	60 (16)	72 (18)	46 (12)	52 (13)
Kildare	104 (11)	135 (14)	141 (15)	142 (14)	183 (18)	168 (17)	146 (15)
Kilkenny	75 (12)	94 (17)	110 (18)	127 (19)	109 (17)	119 (18)	106 (17)
Laois	64 (14)	54 (13)	80 (17)	86 (18)	86 (18)	71 (16)	74 (16)
Longford	54 (19)	50 (19)	49 (17)	70 (25)	60 (21)	39 (14)	54 (19)
Meath	102 (12)	143 (17)	135 (15)	137 (16)	159 (18)	150 (15)	138 (16)
Louth	78 (11)	103 (14)	123 (15)	111 (15)	131 (16)	102 (13)	108 (14)
Offaly	67 (14)	48 (10)	68 (14)	83 (17)	92 (20)	66 (14)	71 (15)
Wexford	150 (15)	160 (16)	193 (20)	226 (22)	203 (19)	210 (19)	190 (19)
Wicklow	115 (14)	127 (16)	145 (17)	143 (17)	155 (18)	127 (15)	135 (16)
Westmeath	94 (16)	85 (14)	91 (16)	117 (19)	120 (21)	98 (17)	101 (17)
Munster							
Cork	441 (13)	388 (12)	427 (12)	620 (17)	498 (13)	521 (14)	483 (14)
Clare	128 (16)	102 (12)	93 (11)	96 (11)	111 (14)	144 (17)	112 (14)
Kerry	183 (15)	152 (13)	151 (13)	178 (15)	178 (16)	172 (14)	169 (14)
Limerick	283 (21)	259 (18)	281 (20)	350 (24)	308 (23)	294 (20)	296 (21)
Tipperary	216 (17)	177 (15)	228 (18)	293 (22)	286 (23)	256 (20)	243 (19)
Waterford	109 (13)	114 (14)	124 (15)	161 (19)	137 (18)	151 (18)	133 (16)
Connacht							
Leitrim	26 (10)	16 (6)	31 (11)	39 (13)	48 (19)	53 (19)	36 (13)
Sligo	36 (8)	37 (8)	61 (12)	75 (15)	73 (14)	69 (13)	59 (12)
Galway	233 (16)	203 (13)	230 (15)	252 (16)	313 (20)	260 (17)	249 (16)
Mayo	147 (13)	122 (11)	124 (12)	180 (16)	173 (16)	164 (15)	152 (14)
Roscommon	43 (9)	36 (7)	36 (7)	24 (5)	19 (4)	45 (8)	34 (7)
Ulster Rol							
Cavan	76 (15)	73 (14)	79 (16)	80 (15)	75 (15)	74 (15)	76 (15)
Donegal	85 (8)	70 (6)	110 (10)	122 (11)	134 (11)	114 (10)	106 (9)
Monaghan	44 (11)	50 (12)	70 (17)	77 (18)	59 (14)	47 (11)	58 (14)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.

4.3 Hospices

Hospices are specialist units which provide palliative care. Individuals can attend a hospice as an in-patient or an out-patient (day-care). There was a 16% increase in hospice bed capacity between 2013 (190 beds) and 2018 (221 beds).

On average, 7% of all deaths in the State occurred in hospices, increasing from 1,883 deaths in 2013 (6% of state deaths) to 2,373 deaths by 2018 (8% of state deaths) (Table 2.6). This is an approximate increase of a quarter (26%) in absolute number of hospice deaths when comparing 2018 to 2013.

We also present the average proportions of deaths in hospices in each county within the six-year period (Table 6). The state average showed that 7% of deaths occurred in hospices within the time period. In Table 2.6, eight counties (highlighted orange) experienced a death rate higher than the national average within this setting. Conversely, 17 counties (blue) experienced a death rate lower than and 1 county corresponded with the national average (green). Including this differential allows us to demonstrate which counties are diverging from national average.

Sligo has the highest average proportion of deaths occurring in hospices (16%), followed by Cork (13%), Limerick (12%), Clare (12%) and Dublin (11%). The counties with the smallest average percentage of hospice deaths were Kilkenny, Offaly, Laois and Carlow, with deaths in hospices accounting in each of these counties for less than 1% of average county deaths (see Table 2.6). This highlights the requirement for individuals to travel outside their county of residence to receive hospice care, as 18 counties in the State did not have hospices during the six-year period. Some of the variation in hospice deaths by county may be explained by changing capacity over the time period, and we return to this in Section 5.

Table 2.6

Hospice deaths by county: total, and as a proportion (%) of all county deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths in a hospice 2013–2018*
State	1883 (6)	2074 (7)	2285 (8)	2388 (8)	2455 (8)	2373 (8)	2243 (7)
Leinster							
Dublin	724 (10)	780 (10)	884 (11)	910 (12)	1023 (13)	997 (12)	886 (11)
Carlow	<10 (<1)	<10 (<1)	<10 (<1)	<10 (1)	<10 (<1)	3 (1)	2 (<1)
Kildare	62 (7)	57 (6)	67 (7)	66 (7)	81 (8)	81 (8)	69 (7)
Kilkenny	<10 (1)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	1 (<1)	1 (<0)
Laois	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	5 (1)	2 (<1)
Longford	<10 (<1)	<10 (1)	<10 (<1)	<10 (1)	<10 (1)	1 (<1)	2 (1)
Meath	13 (2)	16 (2)	25 (3)	59 (7)	47 (5)	46 (5)	34 (4)
Louth	<10 (1)	<10 (1)	<10 (1)	<10 (1)	<10 (1)	8 (1)	6 (1)
Offaly	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	2 (<1)	2 (<1)
Wexford	<10 (1)	<10 (1)	<10 (<1)	<10 (<1)	<10 (<1)	7 (1)	5 (<1)
Wicklow	32 (4)	37 (5)	30 (4)	31 (4)	49 (6)	44 (5)	37 (4)
Westmeath	<10 (<1)	12 (2)	11 (2)	14 (2)	12 (2)	24 (4)	12 (2)
Munster							
Cork	394 (11)	406 (12)	526 (15)	531 (14)	487 (13)	399 (11)	457 (13)
Clare	53 (7)	128 (15)	118 (14)	117 (13)	119 (15)	64 (7)	100 (12)
Kerry	12 (1)	16 (1)	14 (1)	18 (1)	13 (1)	9 (1)	14 (1)
Limerick	139 (10)	169 (12)	168 (12)	172 (12)	176 (13)	181 (12)	168 (12)
Tipperary	41 (3)	40 (3)	43 (3)	33 (2)	35 (3)	42 (3)	39 (3)
Waterford	<10 (1)	<10 (1)	10 (1)	<10 (1)	<10 (1)	11 (1)	8 (1)
Connacht							
Leitrim	30 (12)	25 (10)	19 (7)	45 (15)	30 (12)	32 (11)	30 (11)
Sligo	91 (19)	77 (17)	73 (14)	63 (12)	76 (15)	87 (17)	78 (16)
Galway	100 (7)	131 (9)	129 (8)	144 (9)	120 (8)	143 (9)	128 (8)
Mayo	22 (2)	17 (2)	16 (2)	<10 (<1)	16 (1)	20 (2)	16 (1)
Roscommon	12 (2)	10 (2)	<10 (2)	<10 (2)	<10 (1)	14 (3)	10 (2)
Ulster Rol							
Cavan	19 (4)	13 (3)	10 (2)	20 (4)	21 (4)	20 (4)	17 (3)
Donegal	110 (10)	105 (9)	116 (10)	122 (11)	115 (10)	126 (11)	116 (10)
Monaghan	<10 (1)	<10 (2)	<10 (1)	<10 (1)	11 (3)	6 (1)	7 (2)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.

4.4 Domiciliary

Close to 7,000 people die at home each year, representing just under a quarter (23%) of all deaths in the State. There was an approximate increase of 5% in the absolute number when comparing 2013 to 2018, consistent with overall trends in the time period.

We also present the average proportions of domiciliary deaths in each county within the six-year period (Table 2.7). On average, 23% of all deaths were domiciliary deaths within the time period. In Table 2.7, 20 counties (highlighted orange) experienced a death rate higher than the national average within this setting. Conversely, three

counties (blue) experienced a lower death rate and three counties matched the national average (green). There is considerable variation across counties with respect to the proportion of deaths that occur at home, ranging from 17% to 34% in 2018.

Longford has the highest average proportion of domiciliary deaths (30%), followed by Kilkenny (30%), Monaghan (30%), Carlow (29%) and Offaly (29%). The counties with the smallest average percentage of domiciliary deaths were: Dublin (17%), Kildare (21%), Cork (21%), Sligo (23%) and Clare (23%) (Table 2.8).

Table 2.7

Domiciliary deaths by county: total, and as a proportion (%) of all county deaths, 2013–2018

State	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of domiciliary deaths 2013–2018*
State	6661 (23)	6788 (23)	6921 (23)	6849 (22)	6898 (23)	7012 (23)	6855 (23)
Leinster							
Dublin	1266 (17)	1310 (17)	1343 (17)	1313 (17)	1369 (17)	1352 (17)	1326 (17)
Carlow	104 (27)	97 (26)	125 (32)	117 (31)	124 (31)	109 (30)	113 (29)
Kildare	186 (20)	195 (21)	188 (20)	211 (21)	213 (21)	221 (22)	202 (21)
Kilkenny	188 (29)	181 (32)	192 (31)	189 (28)	197 (32)	181 (27)	188 (30)
Laois	112 (25)	118 (28)	138 (30)	155 (32)	139 (30)	120 (27)	130 (29)
Longford	90 (31)	65 (25)	93 (32)	80 (29)	85 (29)	92 (34)	83 (30)
Meath	249 (30)	232 (27)	262 (29)	186 (21)	225 (25)	261 (27)	236 (26)
Louth	176 (24)	169 (23)	217 (27)	170 (22)	176 (22)	200 (25)	185 (24)
Offaly	118 (25)	164 (36)	147 (31)	132 (27)	123 (26)	140 (29)	137 (29)
Wexford	264 (27)	279 (27)	248 (25)	267 (25)	285 (27)	284 (25)	271 (26)
Wicklow	177 (22)	169 (21)	196 (23)	212 (25)	222 (26)	201 (23)	196 (24)
Westmeath	140 (23)	137 (23)	132 (24)	147 (24)	153 (27)	165 (29)	146 (25)
Munster							
Cork	751 (22)	753 (22)	730 (21)	773 (21)	778 (21)	744 (20)	755 (21)
Clare	184 (23)	174 (21)	195 (23)	189 (22)	179 (22)	220 (26)	190 (23)
Kerry	288 (24)	306 (26)	311 (27)	297 (24)	269 (24)	273 (23)	291 (25)
Limerick	332 (25)	365 (26)	337 (25)	330 (23)	363 (27)	349 (24)	346 (25)
Tipperary	328 (26)	343 (28)	312 (25)	326 (24)	302 (24)	338 (27)	325 (26)
Waterford	195 (24)	213 (26)	208 (26)	185 (22)	174 (23)	203 (25)	196 (24)
Connacht							
Leitrim	56 (22)	68 (27)	83 (29)	65 (20)	56 (22)	66 (23)	66 (24)
Sligo	94 (20)	91 (20)	116 (23)	114 (23)	134 (26)	126 (24)	113 (23)
Galway	347 (23)	364 (24)	364 (24)	363 (23)	339 (22)	363 (23)	357 (23)
Mayo	304 (26)	289 (27)	299 (28)	298 (27)	293 (27)	313 (28)	299 (27)
Roscommon	113 (23)	125 (24)	122 (23)	127 (25)	115 (24)	132 (25)	122 (24)
Ulster ROI							
Cavan	129 (26)	143 (28)	129 (26)	160 (31)	128 (26)	132 (26)	137 (27)
Donegal	341 (30)	313 (28)	313 (27)	309 (27)	332 (28)	308 (26)	319 (28)
Monaghan	129 (31)	125 (29)	121 (29)	134 (31)	125 (29)	119 (28)	126 (30)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.

4.5 Elsewhere

In the CSO data, 'elsewhere' is defined as 'Deaths that occurred in locations other than those listed'. This includes deaths in hotels and similar accommodation, on roads, at rivers and lakes, in public places, etc. On average, 3% of all state deaths occurred 'elsewhere', falling from 1,124 deaths in 2013 (4% of state deaths) to 843 deaths in 2018 (3%) (Table 2.8). This is a 25% decrease in absolute number of deaths that occurred 'elsewhere' when comparing 2013 to 2018.

We also present the average proportions of deaths that occurred 'elsewhere' for each province within the six-year period (Table 2.8). Table 2.8 shows that the average proportion of deaths that occurred 'elsewhere' was higher than the national average in three provinces (highlighted orange): Ulster ROI (4%), Munster (4%) and Connacht (4%). Leinster corresponded to the national average (green) (3%). Including this differential allows us to demonstrate which counties are diverging from the national average.

Table 2.8

Elsewhere deaths by county: total, and as a proportion (%) of all province deaths, 2013–2018

State	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths elsewhere 2013–2018*
State	1124 (4)	1064 (4)	920 (3)	943 (3)	895 (3)	848 (3)	966 (3)
Leinster	455 (3)	406 (3)	362 (2)	366 (2)	375 (2)	345 (2)	385 (3)
Munster	394 (4)	420 (5)	345 (4)	350 (4)	316 (4)	296 (3)	354 (4)
Connacht	182 (5)	143 (4)	129 (3)	162 (4)	133 (3)	125 (3)	146 (4)
Ulster ROI	93 (5)	95 (5)	84 (4)	65 (3)	71 (3)	82 (4)	82 (4)

* Provinces highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.

5 Summary and policy implications

This chapter has used the CSO data on death to summarise data currently available on the place of death in Ireland for the period 2013–2018 inclusive. In this section we consider and interpret the key findings.

5.1 Hospital death rate is steady, but poorly aligned with population preferences

The CSO data show that hospital is the most common place of death in Ireland. This is the case for all age groups, apart from those aged 85+. Approximately 40% of deaths in Ireland occur in acute general and orthopaedic hospitals, highlighting the importance of continuing to expand and improve palliative care provision in hospital settings³.

The proportion of people in Ireland who die in hospital remains far in excess of the proportion of people who state a preference for dying in a hospital⁴. Moreover, deaths in hospital often offer poor-value care: acute in-patient care costs are high, and often the needs of dying patients would be met more appropriately elsewhere. Among western European countries, the hospital death rate of 40% is lower than average but far higher than countries like the Netherlands (22% in 2017⁵) and Norway (31%⁶). Ireland, like most high-income countries, must continue to reduce the in-hospital mortality rate in the context of population-level preferences, costs and future needs. The goal should be to reduce the in-hospital mortality rate without compromising the level or quality of care for a person at the end of their life.

These national data come with two important caveats. First, there are people for whom the hospital setting is appropriate to needs and preferences. For example, in a survey of 356 bereaved relatives undertaken in two acute hospitals in Dublin with established palliative care services, 81% reported that on balance hospital was the appropriate place of death and 87% rated the overall quality of end-of-life care highly⁷. Second, while the majority of people state a preference for dying outside hospital, these preferences may change during disease progression, particularly if needs are complex and there is limited homecare and family support⁸. While more research is needed to quantify how many people change preferences in this way and why, it is essential that health services are responsive to these changing needs. Given that 12% of bereaved relatives thought that hospital was not the right place of death for their relative⁷, there is some margin for reducing hospital deaths.

The CSO data also show that, as well as deaths in general and orthopaedic hospitals, an additional 4% of all deaths in Ireland occur in ‘Other Hospitals’, a figure that has remained relatively stable over the period under review. While deaths in these ‘other hospitals’ represent a small proportion of all deaths, this figure is still important. This grouping is made up of a disparate range of hospitals meeting the needs of the diverse groups of people (e.g. paediatric, maternity, psychiatric and oncology-specific hospitals, and private hospitals). These data highlight the need for optimising end-of-life and palliative care services across all hospital settings. Palliative care services in all hospital settings need to be tailored to the needs of the people being cared for at end of life in specific hospital contexts.

5.2 Deaths in nursing home rise quickly as deaths in community hospitals fall

The proportion of all deaths that occurred in long-stay residential care facilities increased from 22% to 23% in the six-year period. Although the changes are relatively small, they may be an indication that when residents of long-stay residential care facilities are dying, an increasing number are being cared for in their place of residence, rather than being transferred to a hospital to die. Long-stay residential care facilities are an important place of death for older people; 96% of all deaths in LSRCFs are of people aged 65+ and a greater proportion of people aged 85+ die in LSRCFs than in hospitals.

When the two types of long-stay residential facilities are examined separately, we observe clear and different trends. Of the places examined in this report, the fastest increase in number of deaths was in nursing homes and fastest decrease in community hospitals.

These trends raise important questions. Are nursing homes meeting the end-of-life care needs of residents better than community hospitals? Are these trends linked to a growth in the private and voluntary nursing home sector, and a reduction in the role of public sector when it comes to long-stay residential care? These questions warrant further consideration.

5.3 Hospice deaths are more commonplace but still a minority

The data show that there has been an increase in the proportion of deaths in hospices over the period under review, from 6% to 8%, reflecting the small increase in the number of in-patient hospice beds that were made available during this period, from a total of 190 beds in ten hospices across the country in 2013 to 221 beds in eleven hospices by the end of 2017. The data show marked regional variation with respect to the proportion of deaths that occur in hospices. Of the eight counties that experienced a death rate in hospices that was higher than the national average, seven were counties in which a hospice was located. This underscores the need for regional change to improve access to in-patient hospice care and reduce geographical inequity. The opening of new hospices in Mayo and Wicklow in 2021 and the planned opening of a hospice in Waterford will increase hospice bed capacity nationally and at the same time will help improve access to hospices geographically.

5.4 Deaths at home remain steady, well below population preferences

The CSO data show that nearly a quarter (23%) of deaths occur at home, and this proportion was steady in the period under review. Given that around two-thirds of the population in Ireland state a preference for dying at home, the data suggest that at the population-level the preferences of many people are not being met.

The reasons behind the divergence between preferred place of death and actual place of death are complex. Evidence from research consistently shows that a majority of the population favour death in their own home if appropriate supports are available^{4,9}. However, people are reluctant to face the end-of-life period at home if professional help is inaccessible or the care burden falls too heavily on family and close friends. Preferences also change as health deteriorates and needs grow.

People with complex needs and fewer family supports may therefore be more likely to spend their end-of-life period in hospital or in a long-stay residential care facility. As the population ages, this issue will become more pressing¹⁰. This highlights the need for more development of supports to enable more people with complex needs to stay at home and, where this is their preference and is appropriate, to

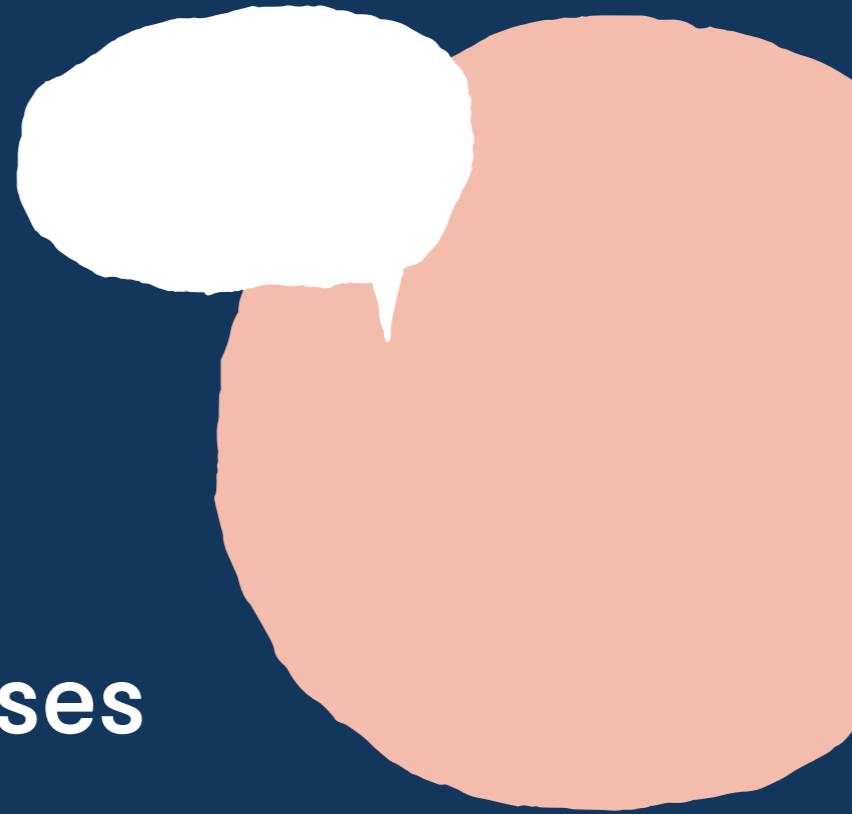
die at home. To achieve this, more investment is needed to integrate palliative care into home care services. Engagement between generalist and specialist palliative care and other health and social care services, including primary care and home-based services, is also needed. It must be remembered that place of death is often regarded as a quality indicator for evaluating end-of-life care at the population level. However, given that the quality of an individual’s end-of-life care is determined by a complex interplay of factors, some of which are not easily modified¹¹, place of death, on its own, is not necessarily a very good indicator of a ‘good death’. However, it could form part of a suite of quality of care indicators at the end of life.

5.5 Data collection practices are a challenge for interpretation

Place of death is currently classified by the CSO in 11 categories: General and Orthopaedic Hospitals, Private Hospitals, Community Hospitals, Maternity Hospitals, Paediatric Hospitals, Oncology Hospitals, Nursing Homes, Psychiatric Hospitals, Hospices, Domiciliary and Elsewhere. This 11-category classification was introduced in 2017 and its introduction is important as the previous classification, with just four categories, was considered outdated and failed for the most part to correspond in any meaningful way to where people die or may be cared for at the end of life¹². The new 11-category classification, which was applied retrospectively to data for the years 2013 to 2018 by the CSO, allows for reasonably accurate data that will inform regional and national trends of place of death and impact future service planning.

However, interpreting CSO data on place of death can still be challenging as the CSO does not provide definitions for each category. In particular, a definition is not provided for ‘community hospitals’, which is not surprising, as there is no official definition of a ‘community hospital’ in Ireland. Similarly, no definition is provided for ‘nursing homes’, which again is not surprising as in Ireland definitions of a nursing home are somewhat broad and can be open to interpretation. For the purposes of this report, we have combined the categories ‘community hospitals’ and ‘nursing homes’ into one category, i.e., long-stay residential care facilities, allowing us to report data on deaths in these facilities separately to hospital deaths. However, without clear definitions, the findings are less meaningful and open to interpretation.

03 Leading Causes of Death



1 Introduction

This chapter examines the leading causes of death in Ireland during the years 2013–2018 using mortality data from the Central Statistics Office (CSO). Every death in the State is registered with the General Register Office (GRO). Following a death, an attending physician completes a medical certificate of the primary and contributory causes of death¹ and this and other information are reported to the GRO and CSO. In this chapter, the term ‘cause of death’ is used to refer to the primary cause of death as recorded on medical certificates and reported by the GRO and CSO. Identifying a single ‘primary’ or ‘underlying’ cause of death is a challenging exercise with no ‘true’ answer. This is the

case for many deaths, and particularly deaths among older people with multiple serious illnesses¹. In addition, errors in death certificates are common^{2–4} and it is likely that there are issues with respect to data accuracy and completeness in this dataset.

The CSO data list 1,780 different causes of death and these have been grouped into eight main categories for the purposes of this chapter. The eight ‘cause of death’ categories and their corresponding ICD-10 codes⁵ are presented in Table 3.1.

Table 3.1

Cause of death categories and corresponding ICD-10 codes

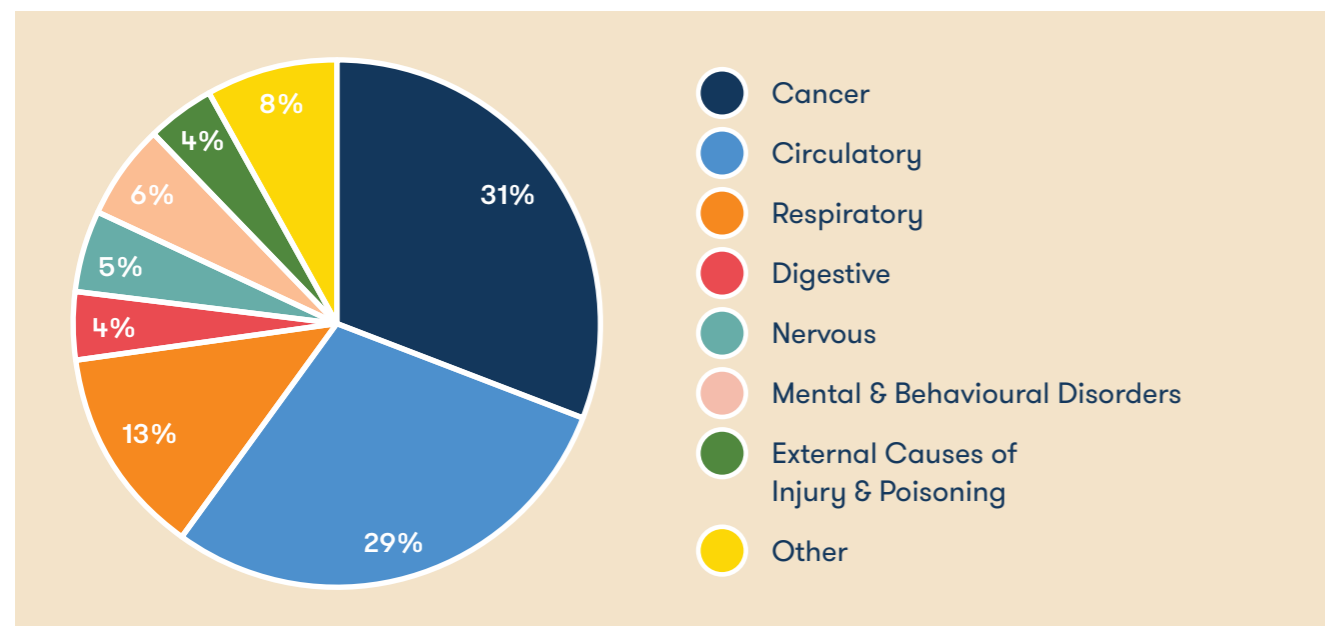
Cause of death categories	Common examples	ICD-10 Codes
Cancer	Malignant neoplasms: breast, digestive organs, genital organs, bone, skin, thyroid	C00-D48
Diseases of the circulatory system	Heart attack, chronic heart failure, angina, hypertension, arrhythmia	I00-I99
Diseases of the respiratory system	Chronic bronchitis, cystic fibrosis, chronic obstructive pulmonary disease (COPD)	J00-J99
Mental and behavioural disorders	Vascular dementia, eating disorders, abuse of non-dependence-producing substances, mental and behavioural disorders due to alcohol	F00-F99
Diseases of the digestive system	Inflammatory bowel disease, chronic liver disease, Crohn’s disease, pancreatitis	K00-K93
Diseases of the nervous system	Multiple sclerosis, Alzheimer’s, meningitis, Parkinson’s, Huntington’s, motor neuron	G00-G99
External causes of injury and poisoning	Collision, fall, accident, explosion, assault, drowning, poisoning, shooting, war, animal injury	V00-Y89
Other	Infectious & parasitic disease; diseases of blood & blood-forming organs; endocrine, nutritional & metabolic disease; diseases of eye, skin, musculoskeletal system, genitourinary system; complications of pregnancy & childbirth; conditions originating in perinatal period	A00-B99, D50-E90, H00-H95, L00-L99, M00-R99

2 National overview by cause of death (2013–2018)

Of the 31,104 deaths that occurred in Ireland in 2018, the two most common causes were cancer (31%) and diseases of the circulatory system (29%). An additional 13% of deaths were caused by diseases of the respiratory system, 5% by diseases of the nervous system illness, 6% due to mental

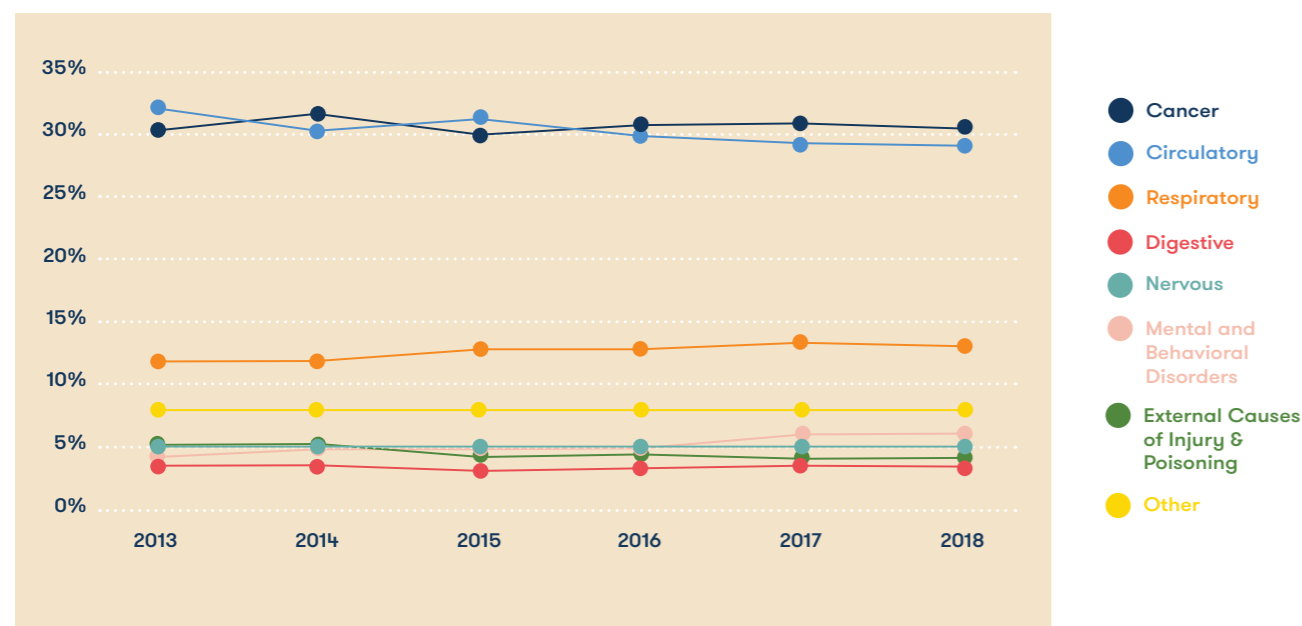
and behavioural disorders, 4% by diseases of the digestive system, and 4% were a result of external causes of injury and poisoning. In the remaining 8% of deaths, the cause of death was attributed to ‘other’ diseases or health conditions (Figure 3.1).

Figure 3.1
All deaths in Ireland by cause of death, 2018 (%)



Over the six-year period, 2013–2018 inclusive, there has been little change in the proportion of deaths that occurred across each cause of death category (Figure 3.2).

Figure 3.2.
All deaths in Ireland by cause of death, 2018 (%)



Deaths in 2018 by age group and cause of death are presented in Table 3.2. Ages 65+ account for approximately three-quarters of deaths or more in each cause of death category (72%–99%), apart from external cause of injury and poisoning. There are significant differences in the causes of death for different age groups. For example, external causes of injury and poisoning is the main cause of death in

people aged 35–44 years, whereas the main causes of death for people aged 85+ are mental and behavioural disorders, diseases of the respiratory system and diseases of the circulatory system. With respect to the latter three cause of death categories, the majority of deaths relate to people aged 85+, making up 64%, 46% and 44% of all deaths respectively.

Table 3.2
State death totals by age: total, and as a proportion (%) of all place of death categories, 2018

Age Group	Neoplasms	Diseases of the Circulatory System	Diseases of the Respiratory System	Mental & Behavioural Disorders	Diseases of the Digestive System	Diseases of the Nervous System	External Cause of Injury & Poisoning	Other
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
0–4yr	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	177 (7)
5–14yr	12 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (1)	19 (1)
15–24yr	19 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	16 (1)	95 (7)	12 (<1)
25–34yr	59 (1)	27 (<1)	<10 (<1)	<10 (<1)	11 (1)	19 (1)	164 (12)	33 (1)
35–44yr	211 (2)	90 (1)	17 (<1)	<10 (<1)	41 (4)	24 (1)	215 (15)	50 (2)
45–54yr	566 (6)	310 (3)	54 (1)	<10 (<1)	102 (9)	43 (3)	217 (16)	87 (4)
55–64yr	1357 (14)	647 (7)	193 (5)	18 (1)	154 (14)	88 (5)	216 (15)	160 (7)
65–74yr	2589 (27)	1397 (15)	647 (16)	114 (6)	215 (19)	282 (18)	135 (10)	308 (13)
75–84yr	2905 (31)	2634 (29)	1273 (31)	570 (29)	290 (26)	550 (34)	145 (10)	656 (27)
85+yr	1776 (19)	3967 (44)	1851 (46)	1236 (64)	287 (26)	576 (36)	201 (14)	943 (39)
All ages	9500	9084	4051	1946	1105	1611	1398	2445

Deaths in 2018 by sex and cause of death are presented in Table 3.3. Males accounted for a higher proportion of deaths in the following categories: cancer (53.3%), diseases of the circulatory system (52.9%), diseases of the digestive system (53.9%), and external causes of injury and poisoning

(67.8%). Conversely, females accounted for a higher proportion of deaths in the following categories: diseases of the respiratory system (52.6%), mental and behavioural disorders (61.4%), diseases of the nervous system (51.0%), and ‘other’ (52.3%).

Table 3.3
State death totals by sex: total, and as a proportion (%) of all cause of death categories, 2018

	Neoplasms	Diseases of the Circulatory System	Diseases of the Respiratory System	Mental & Behavioural Disorders	Diseases of the Digestive System	Diseases of the Nervous System	External Cause of Injury & Poisoning	Other	Total
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Total	9500 (31)	9084 (29)	4051 (13)	1946 (6)	1105 (4)	1611 (5)	1398 (4)	2445 (8)	31140
Male	5065 (16)	4809 (15)	1920 (6)	751 (2)	596 (2)	789(3)	948 (3)	1167 (4)	16045 (52)
Female	4435 (14)	4275 (14)	2131 (7)	1195 (4)	509 (2)	822 (3)	450 (1)	1278 (4)	15095 (48)

3 Deaths by county and cause of death (2013–2018)

3.1 Cancer

Cancer is an umbrella term to describe a group of illnesses that share common characteristics, including an over-growth of cells to form a tumour. According to the National Cancer Registry Ireland (NCRI), approximately 43,000 people are diagnosed with cancer in the Republic of Ireland each year. This includes both invasive and non-invasive tumours, as well as non-melanoma skin cancers⁶. In 2018, 31% of all deaths in the State were caused by cancer. There was a small increase over the time period under review in both the number and proportion of deaths caused by cancer from 8,961 deaths in 2013 (30% of all deaths) to 9,500 deaths in 2018 (31% of state deaths). These overall figures conceal the variation that exists between counties with regard to cancer deaths, as shown in Table 3.4.

Table 3.2 shows that in 2018, cancer was the leading cause of death in 9,500 cases, and that, when examined by age, the death rate increased by age group up to 75–84 years and declined again for aged 85+: <1% of all deaths caused by cancer were at 0–24 years, 9% at 25–54 years, 14% at 55–64 years, 27% at 65–74 years, 31% at 75–84 years, and 19% at 85+. Cancer was the leading cause of death for both males and females. However, as Table 3.3 shows, males account for a greater proportion of cancer deaths than females (males: 16% of all deaths; female: 14% of all deaths).

We also present the average proportion of deaths due to cancer for each county within the six-year period (Table 3.4). This is calculated using the average number of cancer deaths (2013–2018) and the average number of total deaths within each county (2013–2018). The state average showed that 31% of deaths occurred due to cancer within the time period. In Table 3.4, seven counties (highlighted orange) experienced a higher death rate than the national average within this setting. Conversely, 17 counties (highlighted blue) experienced a lower death rate than the national average and two counties matched the national average (highlighted green).

Meath was the county where the highest proportion of all deaths on average occurred due to cancer (33%), followed by Kildare (33%), Waterford (33%), Louth (32%) and Carlow (32%). The counties with the smallest percentage of cancer deaths on average as a proportion of all deaths were: Monaghan (28%), Roscommon (29%), Leitrim (29%), Kerry (28%), and Offaly (29%).

Table 3.4
Cancer deaths by county: total, and as a proportion (%) of all county deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths due to cancer 2013–2018*
State	8961 (30)	9218 (32)	9072 (30)	9408 (31)	9361 (31)	9500 (31)	9253 (31)
Leinster							
Dublin	2409 (32)	2499 (33)	2443 (31)	2472 (32)	2495 (31)	2565 (31)	2481 (32)
Carlow	129 (33)	111 (30)	130 (33)	136 (36)	110 (28)	116 (31)	122 (32)
Kildare	319 (35)	283 (30)	299 (33)	343 (35)	329 (33)	323 (32)	316 (33)
Kilkenny	206 (32)	170 (30)	183 (29)	174 (26)	214 (34)	190 (28)	190 (30)
Laois	114 (26)	133 (31)	141 (30)	155 (32)	137 (29)	131 (30)	135 (30)
Longford	78 (27)	86 (32)	93 (32)	69 (25)	77 (26)	91 (33)	82 (29)
Meath	255 (31)	285 (33)	294 (33)	298 (34)	308 (34)	330 (34)	295 (33)
Louth	251 (34)	236 (33)	247 (30)	255 (34)	252 (31)	246 (31)	248 (32)
Offaly	125 (26)	144 (31)	151 (31)	142 (29)	153 (33)	124 (26)	140 (29)
Wexford	295 (30)	345 (34)	298 (30)	322 (31)	351 (33)	318 (28)	322 (31)
Wicklow	260 (33)	266 (34)	236 (28)	290 (34)	275 (32)	277 (32)	268 (32)
Westmeath	161 (27)	176 (29)	179 (32)	176 (29)	182 (32)	178 (31)	175 (30)
Munster							
Cork	1050 (30)	1000 (30)	1044 (30)	1096 (29)	1135 (31)	1091 (30)	1069 (30)
Clare	225 (28)	254 (31)	253 (29)	259 (30)	229 (29)	264 (31)	247 (30)
Kerry	341 (29)	341 (29)	331 (28)	350 (29)	316 (28)	360 (30)	340 (29)
Limerick	376 (28)	429 (31)	378 (27)	419 (29)	420 (31)	456 (31)	413 (29)
Tipperary	384 (30)	389 (32)	361 (29)	398 (29)	372 (30)	403 (32)	285 (30)
Waterford	288 (35)	309 (38)	258 (32)	250 (30)	246 (32)	228 (28)	263 (33)
Connacht							
Leitrim	82 (32)	73 (29)	83 (29)	91 (31)	70 (28)	67 (24)	78 (29)
Sligo	159 (33)	136 (29)	161 (32)	146 (29)	155 (30)	155 (30)	152 (31)
Galway	424 (28)	485 (32)	465 (31)	483 (31)	441 (29)	481 (31)	463 (30)
Mayo	308 (27)	320 (30)	320 (30)	302 (28)	326 (30)	336 (30)	319 (29)
Roscommon	136 (28)	157 (31)	153 (29)	139 (27)	133 (28)	148 (28)	144 (29)
Ulster Rol							
Cavan	141 (28)	142 (28)	144 (29)	169 (32)	159 (32)	141 (28)	149 (30)
Donegal	331 (29)	331 (30)	325 (28)	359 (32)	346 (29)	356 (30)	341 (30)
Monaghan	114 (28)	118 (28)	102 (25)	115 (27)	130 (31)	125 (29)	117 (28)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.

3.2 Diseases of the circulatory system

Diseases of the circulatory system, which refers to diseases of the heart and circulation, is the second leading cause of death in the State after cancer. The most common examples include coronary heart disease, heart failure, cerebral brain conditions (e.g. stroke) and other blood vessel diseases⁷. In 2018, 29% of all deaths in the State were recorded as circulatory-related. Although figures fluctuated, there was a decrease between 2013 (9,473 deaths, 32% of state deaths) and 2018 (9,084 deaths, 29% of state deaths). The absolute number of deaths due to circulatory illness decreased by 4% between 2013 and 2018 (See Table 5).

Table 3.2 shows that 9,084 deaths were caused by diseases of the circulatory system in 2018, and that these deaths were age-related: <1% of deaths were at 0–24 years, 4% at 25–54 years, 7% at 55–64 years, 15% at 65–74 years, 29% at 75–84 years, and 44% at 85+. Diseases of the circulatory system are the second leading cause of death for both males and females. Table 3.3 shows that of the 31,140 deaths in 2018, male circulatory system deaths accounted for 15% and female circulatory system deaths accounted for 14%.

We also present the average proportion of deaths caused by diseases of circulatory system for each county within the six-year period (Table 3.5). On average, 30% of all deaths were caused by diseases of the circulatory system within the time period. In Table 3.5, 18 counties (highlighted orange) experienced a higher death rate than the national average within this setting. Conversely, five counties (blue) experienced a lower death rate and three counties matched the national average (green). Including this differential allows us to demonstrate which counties are diverging from national average.

Leitrim has the highest average proportion of deaths occurring caused by diseases of the circulatory system (35%), followed by Mayo (33%), Kerry (33%), Monaghan (32%) and Roscommon (32%). The counties with the smallest average percentage of circulatory deaths were Louth (27%), Wicklow (28%), Meath (28%), Dublin (28%) and Kildare (29%) (Table 3.5).

Table 3.5
Circulatory deaths by county: total, and as a proportion (%) of all county deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths due to circulatory illness 2013–2018*
State	9473 (32)	8852 (30)	9371 (31)	9237 (30)	8889 (29)	9084 (29)	9151 (30)
Leinster							
Dublin	2196 (29)	2122 (28)	2351 (30)	2123 (28)	2273 (28)	2271 (28)	2223 (28)
Carlow	118 (30)	112 (30)	127 (32)	101 (27)	131 (33)	124 (34)	119 (31)
Kildare	263 (28)	301 (32)	269 (29)	282 (29)	298 (30)	286 (28)	283 (29)
Kilkenny	213 (33)	172 (31)	206 (33)	210 (32)	182 (29)	202 (30)	198 (31)
Laois	170 (38)	128 (30)	146 (31)	142 (30)	131 (28)	112 (25)	138 (30)
Longford	107 (37)	68 (26)	87 (30)	93 (34)	85 (29)	78 (28)	86 (31)
Meath	274 (33)	244 (28)	269 (30)	247 (28)	232 (26)	247 (25)	252 (28)
Louth	207 (28)	190 (26)	253 (31)	202 (27)	204 (25)	205 (25)	210 (27)
Offaly	168 (35)	149 (32)	148 (31)	143 (29)	138 (29)	140 (29)	148 (31)
Wexford	327 (33)	295 (29)	306 (31)	350 (33)	327 (31)	376 (33)	330 (32)
Wicklow	234 (29)	225 (28)	226 (27)	255 (30)	222 (26)	231 (26)	232 (28)
Westmeath	216 (36)	210 (35)	161 (29)	186 (31)	175 (31)	165 (29)	186 (32)
Munster							
Cork	1109 (32)	1072 (32)	1115 (32)	1187 (32)	1127 (30)	1122 (31)	1122 (31)
Clare	283 (36)	272 (33)	289 (34)	271 (31)	229 (29)	244 (28)	265 (32)
Kerry	405 (34)	400 (34)	369 (31)	382 (31)	365 (32)	382 (32)	384 (33)
Limerick	472 (35)	447 (32)	458 (33)	449(31)	373 (27)	400 (27)	433 (31)
Tipperary	419 (33)	370 (30)	427 (34)	447 (33)	381 (31)	376 (30)	403 (32)
Waterford	268 (33)	239 (29)	248 (31)	249 (30)	211 (28)	240 (29)	243 (30)
Connacht							
Leitrim	96 (37)	86 (34)	90 (32)	95 (32)	91 (36)	115 (41)	96 (35)
Sligo	166 (35)	148 (32)	171 (34)	174 (34)	157 (31)	142 (28)	160 (32)
Galway	482 (32)	444 (29)	473 (31)	463 (30)	468 (31)	459 (29)	465 (30)
Mayo	405 (35)	325 (31)	356 (34)	356 (32)	345 (32)	349 (32)	365 (33)
Roscommon	186 (38)	165 (32)	172 (33)	157 (31)	133 (28)	166 (31)	163 (32)
Ulster Rol							
Cavan	167 (34)	168 (33)	162 (32)	159 (30)	140 (29)	143 (28)	157 (31)
Donegal	381 (34)	363 (32)	364 (32)	359 (32)	338 (28)	380 (32)	364 (32)
Monaghan	141 (34)	137 (32)	128 (31)	155 (36)	133 (31)	129 (30)	137 (32)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.



3.3 Diseases of the respiratory system

Diseases of the respiratory system cover both common and rare conditions that affect the lungs and other parts of the respiratory system. Chronic obstructive pulmonary disease (COPD) is one of the most common respiratory illnesses in the State in terms of prevalence and mortality⁸. Deaths due to infectious diseases such as pneumonia are also included in this cause of death category. In 2018, 13% of all deaths in the State were recorded as being caused by diseases of the respiratory system. There was an increase between 2013 (3,504 deaths, 12% of state deaths) and 2018 (4,051 deaths, 13% of state deaths). The absolute number of deaths caused by diseases of the respiratory system increased by 16% between 2013 and 2018 (See Table 3.6).

Table 3.2 shows that 4,051 deaths were caused by diseases of the respiratory system in 2018 and that these deaths are age-related: <1% of deaths were at 0–24 years, 1% at 25–54 years, 5% at 55–64 years, 16% at 65–74 years, 31% at 75–84 years, and 46% at 85+. Table 3.3 shows that of the 31,140 deaths in 2018, male respiratory system deaths accounted for 6% and female respiratory system deaths accounted for 7%.

We also present the average proportion of deaths caused by diseases of the respiratory system for each county within the six-year period (Table 3.6). On average, 13% of deaths were caused by diseases of the respiratory system within the time period. In Table 3.6, eight counties (highlighted orange) experienced a higher death rate than the national average within this setting. Conversely, 13 counties (blue) experienced a lower death rate and five counties matched the national average (green).

Longford has the highest average proportion of respiratory deaths (17%), followed by Kilkenny (14%), Roscommon (14%), Limerick (14%) and Meath (14%). The counties with the smallest average percentage of respiratory deaths were Cork (11%), Waterford (12%), Cavan (12%), Carlow (12%) and Leitrim (12%) (Table 3.6).

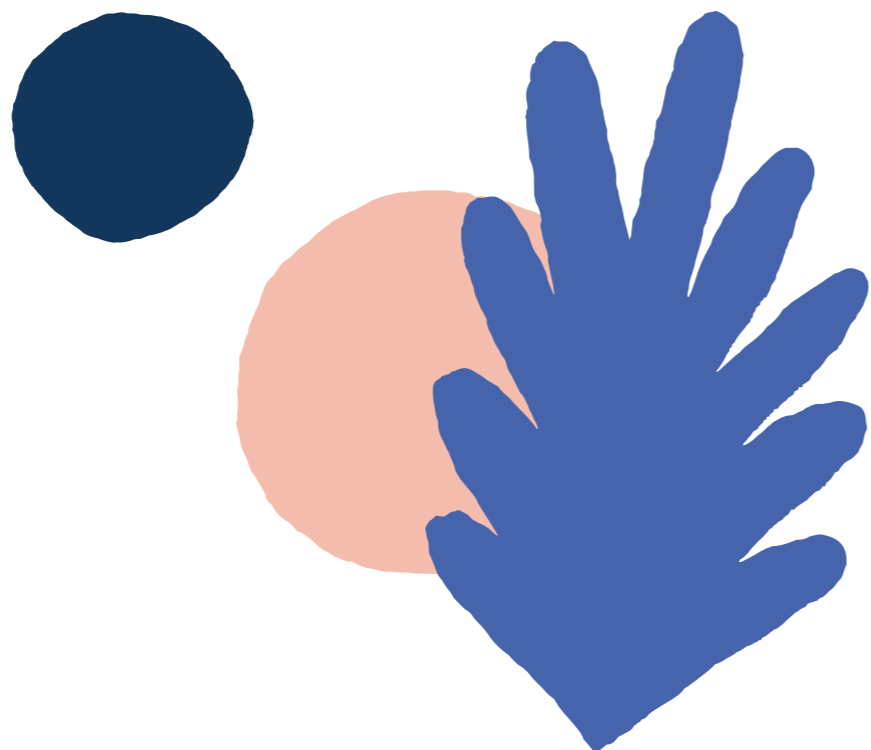


Table 3.6
Respiratory deaths by county: total, and as a proportion [%] of all county deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths due to respiratory illness 2013–2018*
State	3504 (12)	3492 (12)	3865 (13)	3935 (13)	4059 (13)	4051 (13)	3818 (13)
Leinster							
Dublin	891 (12)	857 (11)	977 (12)	975 (13)	1068 (13)	1060 (13)	971 (12)
Carlow	47 (12)	44 (12)	49 (12)	45 (12)	55 (14)	38 (10)	46 (12)
Kildare	113 (12)	106 (11)	123 (13)	117 (12)	131 (13)	135 (13)	121 (13)
Kilkenny	88 (14)	69 (12)	85 (14)	120 (18)	84 (13)	97 (14)	91 (14)
Laois	53 (12)	54 (13)	56 (12)	60 (13)	63 (13)	70 (16)	59 (13)
Longford	43 (15)	47 (18)	49 (17)	50 (18)	56 (19)	44 (16)	48 (17)
Meath	115 (14)	114 (13)	122 (14)	119 (14)	125 (14)	153 (16)	125 (14)
Louth	88 (12)	91 (13)	102 (12)	120 (16)	130 (16)	98 (12)	105 (14)
Offaly	74 (16)	60 (13)	59 (12)	67 (14)	57 (12)	69 (14)	64 (13)
Wexford	105 (11)	127 (12)	123 (12)	131 (12)	137 (13)	151 (13)	129 (12)
Wicklow	90 (11)	95 (12)	127 (15)	93 (11)	102 (12)	111 (13)	103 (12)
Westmeath	81 (13)	76 (13)	75 (13)	81 (13)	71 (13)	83 (14)	78 (13)
Munster							
Cork	374 (11)	357 (11)	403 (12)	415 (11)	457 (12)	412 (11)	403 (11)
Clare	93 (12)	106 (13)	100 (12)	137 (16)	124 (16)	136 (16)	116 (14)
Kerry	137 (12)	130 (11)	152 (13)	160 (13)	160 (14)	150 (12)	148 (13)
Limerick	166 (12)	182 (13)	224 (16)	220 (15)	188 (14)	198 (14)	196 (14)
Tipperary	159 (12)	143 (12)	145 (11)	169 (12)	163 (13)	160 (13)	157 (12)
Waterford	64 (8)	90 (11)	88 (11)	102 (12)	105 (14)	112 (14)	94 (12)
Connacht							
Leitrim	25 (10)	30 (12)	38 (13)	36 (12)	32 (13)	38 (14)	33 (12)
Sligo	46 (10)	64 (14)	66 (13)	68 (13)	65 (13)	61 (12)	62 (12)
Galway	189 (13)	185 (12)	213 (14)	173 (11)	178 (12)	205 (13)	191 (12)
Mayo	173 (15)	141 (13)	135 (13)	168 (15)	148 (14)	143 (13)	151 (14)
Roscommon	63 (13)	61 (12)	78 (15)	82 (16)	76 (16)	72 (14)	72 (14)
Ulster ROI							
Cavan	60 (12)	51 (10)	69 (14)	57 (11)	56 (11)	66 (13)	60 (12)
Donegal	120 (11)	150 (13)	150 (13)	130 (11)	168 (14)	140 (12)	143 (12)
Monaghan	47 (11)	62 (14)	57 (14)	40 (9)	60 (14)	49 (12)	53 (12)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.

3.4 Mental and behavioural disorders

Mental and behavioural disorders refer to clinical conditions characterised by disturbances in thinking, mood or behaviour associated with personal distress or impaired functioning. The majority of deaths in this category are due to dementia, but other examples include mental disorders due to known physiological conditions, and mental and behavioural disorders due to alcohol use or other psychoactive substance use⁵. In 2018, 6% of all deaths in the State were recorded as being caused by mental or behavioural disorders. There was a steady increase between 2013 (1,207 deaths, 4% of state deaths) and 2018 (1,946 deaths, 6% of state deaths). Of the 1,946 deaths in 2018, dementia was the cause of death in the vast majority (96.6%) of cases. The absolute number of deaths due to mental and behavioural disorders increased by 61% between 2013 and 2018 (See Table 3.7).

Table 3.2 shows that 1,946 deaths in 2018 were caused by mental and behavioural disorders, and when examined by age, it is striking that almost two-thirds of these deaths were aged 85+: <1% of deaths were at 0–54 years, 1% at 55–64 years, 6% at 65–74 years, 29% at 75–84 years, and 64% at 85+. As Table 3.3 shows, of the 31,140 deaths in 2018, deaths caused by mental and behavioural disorders were much more prevalent among females than males.

We also present the average proportion of deaths caused by mental and behavioural disorders for each county within the six-year period (Table 3.7). On average, 5% of deaths were caused by mental and behavioural disorders within the time period. In Table 3.7, three counties (highlighted orange) experienced a higher death rate than the national average within this setting. Conversely, 14 counties (blue) experienced a lower death rate and nine counties matched the national average (green).

Dublin has the highest average proportion of mental and behavioural disorder deaths (7%), followed by Wicklow (7%), Cork (6%), Laois (5%) and Kilkenny (5%). The counties with the smallest average percentage of mental and behavioural disorder deaths were Longford (2%), Westmeath (3%), Monaghan (4%), Wexford (4%) and Sligo (4%) (Table 3.7).

Table 3.7

Mental and behavioural disorder deaths by county: total, and as a proportion [%] of all county deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths due to mental & behavioural disorders 2013–2018*
State	1207 (4)	1352 (5)	1557 (5)	1679 (5)	1759 (6)	1946 (6)	1583 (5)
Leinster							
Dublin	408 (5)	486 (6)	607 (8)	537 (7)	638 (8)	693 (8)	562 (7)
Carlow	14 (4)	23 (6)	11 (3)	23 (6)	18 (5)	18 (5)	18 (5)
Kildare	24 (3)	33 (4)	35 (4)	40 (4)	41 (4)	45 (4)	36 (4)
Kilkenny	22 (3)	35 (6)	38 (6)	34 (5)	26 (4)	37 (6)	32 (5)
Laois	19 (4)	20 (5)	23 (5)	23 (5)	35 (7)	30 (7)	25 (5)
Longford	7 (2)	7 (3)	9 (3)	9 (3)	6 (2)	4 (1)	7 (2)
Meath	17 (2)	31 (4)	29 (3)	38 (4)	40 (4)	50 (5)	34 (4)
Louth	28 (4)	32 (4)	38 (5)	28 (4)	32 (4)	48 (6)	34 (4)
Offaly	13 (3)	12 (3)	17 (4)	25 (5)	35 (7)	37 (8)	23 (5)
Wexford	26 (3)	31 (3)	40 (4)	32 (3)	40 (4)	58 (5)	38 (4)
Wicklow	45 (6)	51 (6)	52 (6)	52 (6)	73 (8)	64 (7)	56 (7)
Westmeath	15 (2)	20 (3)	15 (3)	23 (4)	21 (4)	26 (5)	20 (3)
Munster							
Cork	163 (5)	179 (5)	184 (5)	234 (6)	203 (5)	230 (6)	199 (6)
Clare	29 (4)	28 (3)	48 (6)	44 (5)	40 (5)	40 (5)	38 (5)
Kerry	51 (4)	48 (4)	46 (4)	58 (5)	53 (5)	51 (4)	51 (4)
Limerick	48 (4)	44 (3)	50 (4)	61 (4)	86 (6)	83 (6)	62 (4)
Tipperary	45 (4)	39 (3)	58 (5)	58 (4)	53 (4)	72 (6)	54 (4)
Waterford	35 (4)	32 (4)	42 (5)	56 (7)	29 (4)	41 (5)	39 (5)
Connacht							
Leitrim	9 (3)	10 (4)	13 (5)	16 (5)	17 (7)	9 (3)	12 (5)
Sligo	11 (2)	16 (3)	8 (2)	20 (4)	23 (5)	34 (7)	19 (4)
Galway	53 (4)	38 (3)	46 (3)	75 (5)	80 (5)	69 (4)	60 (4)
Mayo	38 (3)	42 (4)	38 (4)	56 (5)	44 (4)	58 (5)	46 (4)
Roscommon	7 (1)	18 (4)	21 (4)	32 (6)	21 (4)	36 (7)	23 (4)
Ulster Rol							
Cavan	25 (5)	19 (4)	29 (6)	24 (5)	21 (4)	30 (6)	25 (5)
Donegal	45 (4)	46 (4)	47 (4)	56 (5)	72 (6)	65 (6)	55 (5)
Monaghan	10 (2)	12 (3)	13 (3)	25 (6)	12 (3)	18 (4)	15 (4)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.

3.5 Diseases of the digestive system

The digestive system comprises the gastrointestinal tract, pancreas, liver and gallbladder. This system is responsible for the breakdown of food that helps to fuel our bodies and promote cell repair. Common diseases of the digestive system include irritable bowel syndrome and Crohn's disease, gastric ulcers, ventral hernias, liver disease, acute pancreatitis and vascular disorders of the intestine⁵. While the deaths caused by diseases of the digestive system as a proportion of all deaths has remained fairly constant over the six-year period, the absolute number of such deaths has increased marginally in recent years from 1,069 deaths (4% of state deaths) in 2013 to 1,105 deaths (4% in state deaths) in 2018 (see Table 3.8). This represents an increase of less than 3% in the absolute number of deaths due to diseases of the digestive system between 2013 and 2018.

Table 3.2 shows that 1,105 deaths in 2018 were caused by diseases of the digestive system, and that, when examined by age, more than 50% of these deaths were aged 65+: <1% of these deaths were at 0–14 years, 14% at 25–54 years, 14% at 55–64 years, 19% at 65–74 years, 26% at 75–84 years, and 26% at 85+. Table 3.3 shows that of the 31,140 deaths in 2018, the proportion of deaths among males and females caused by diseases of digestive system deaths were the same at 2%.

We also present the average proportion of deaths caused by diseases of the digestive system for each county within the six-year period (Table 3.8). On average, 13% of deaths were caused by diseases of the digestive system within the time period. In Table 3.8, seven counties (highlighted orange) experienced a higher death rate than the national average within this setting. Conversely, no counties experienced a lower death rate (blue) and 19 counties matched the national average (green). Including this differential allows us to demonstrate which counties are diverging from national average.

Dublin has the highest average proportion of deaths caused by diseases of the digestive system (4%), followed by Kerry (4%), Louth (4%), Wicklow (4%) and Cork (4%). The counties with the smallest average percentage of digestive system deaths were Laois (3%), Sligo (3%), Meath (3%) and Monaghan (3%) (see Table 3.8).



Table 3.8
Digestive system deaths by county: total, and as a proportion (%) of all county deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths due to digestive illness 2013–2018*
State	1069 (4)	1040 (4)	966 (3)	1055 (3)	1064 (3)	1105 (4)	1050 (3)
Leinster							
Dublin	308 (4)	309 (4)	295 (4)	312 (4)	324 (4)	332 (4)	313 (4)
Carlow	11 (3)	12 (3)	7 (2)	11 (3)	10 (3)	15 (4)	11 (3)
Kildare	29 (3)	36 (4)	32 (3)	35 (4)	26 (3)	26 (3)	31 (3)
Kilkenny	22 (3)	20 (4)	20 (3)	13 (2)	19 (3)	21 (3)	19 (3)
Laois	9 (2)	13 (3)	12 (3)	8 (2)	16 (3)	14 (3)	12 (3)
Longford	5 (2)	9 (3)	6 (2)	6 (2)	14 (5)	15 (5)	9 (3)
Meath	33 (4)	23 (3)	23 (3)	22 (3)	25 (3)	22 (2)	25 (3)
Louth	33 (4)	33 (5)	30 (4)	20 (3)	32 (4)	29 (4)	30 (4)
Offaly	14 (3)	21 (5)	13 (3)	20 (4)	14 (3)	20 (4)	17 (4)
Wexford	36 (4)	28 (3)	34 (3)	34 (3)	30 (3)	30 (3)	32 (3)
Wicklow	24 (3)	24 (3)	30 (4)	26 (3)	50 (6)	36 (4)	32 (4)
Westmeath	25 (4)	12 (2)	20 (4)	21 (3)	16 (3)	21 (4)	19 (3)
Munster							
Cork	128 (4)	127 (4)	114 (3)	127 (3)	143 (4)	144 (4)	131 (4)
Clare	26 (3)	27 (3)	15 (2)	36 (4)	25 (3)	34 (4)	27 (3)
Kerry	45 (4)	45 (4)	44 (4)	55 (5)	40 (4)	41 (3)	45 (4)
Limerick	46 (3)	49 (3)	45 (3)	46 (3)	28 (2)	45 (3)	43 (3)
Tipperary	38 (3)	36 (3)	33 (3)	33 (2)	42 (3)	33 (3)	36 (3)
Waterford	29 (4)	30 (4)	28 (3)	17 (2)	18 (2)	31 (4)	26 (3)
Connacht							
Leitrim	12 (5)	9 (4)	6 (2)	13 (4)	5 (2)	7 (2)	9 (3)
Sligo	14 (3)	10 (2)	13 (3)	15 (3)	12 (2)	16 (3)	13 (3)
Galway	57 (4)	47 (3)	53 (3)	66 (4)	54 (4)	58 (4)	56 (4)
Mayo	40 (3)	40 (4)	31 (3)	33 (3)	34 (3)	41 (4)	37 (3)
Roscommon	15 (3)	20 (4)	10 (2)	18 (4)	15 (3)	15 (3)	16 (3)
Ulster Rol							
Cavan	10 (2)	17 (3)	10 (2)	25 (5)	19 (4)	18 (4)	17 (3)
Donegal	42 (4)	34 (3)	32 (3)	31 (3)	37 (3)	35 (3)	35 (3)
Monaghan	18 (4)	9 (2)	10 (2)	12 (3)	16 (4)	6 (1)	12 (3)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.

3.6 Diseases of the nervous system

Diseases of the nervous system include those that are invisible but still impact on quality of life, and those that are marked by severe and progressive physical or cognitive decline. Common diseases include Huntington's disease, multiple sclerosis, Parkinson's disease, Alzheimer's disease and epilepsy. According to the Neurological Alliance of Ireland (2020), it is estimated that over 800,000 people in the Republic of Ireland are living with a disease of the nervous system⁹. In 2018, 5% of all deaths in the State were caused by diseases of the nervous system. Over the period under review, the number of deaths increased from 1,378 deaths (5% of state deaths) in 2013 to 1,611 deaths (5% of state deaths) in 2018. This represents an increase of less than 17% in the absolute number of nervous system deaths between 2013 and 2018 (Table 3.9).

Table 3.2 shows that, when the 1,611 deaths in 2018 caused by diseases of the nervous system are examined by age, the majority (70%) were aged 75+: 2% of deaths were at 0–24 years, 5% at 25–54 years, 5% at 55–64 years, 18% at 65–74 years, 34% at 75–84 years, and 36% at 85+. Table 3.3 shows that, of the 31,140 deaths in 2018, the proportion of deaths among males and females caused by diseases of the nervous system deaths were the same at 3%.

We also present the average proportion of deaths due to diseases of the nervous system for each county within the six-year period (Table 3.9). On average, 5% of deaths were caused by diseases of the nervous system within the time period. In Table 3.9, five counties (highlighted orange) experienced a higher death rate than the national average within this setting. Conversely, seven counties (blue) experienced a lower death rate and 14 counties matched the national average (green). Including this differential allows us to demonstrate which counties are diverging from national average.

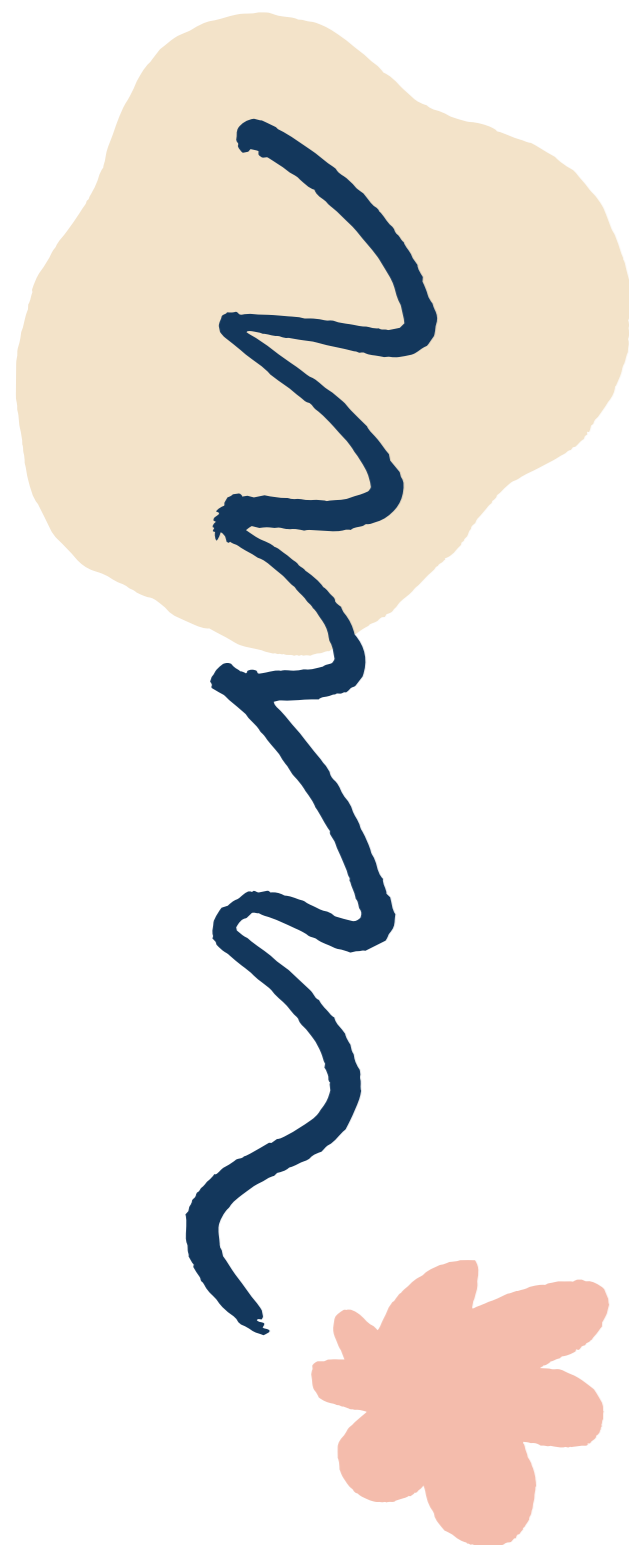
Louth has the highest average proportion of deaths occurring due to nervous system illness (6%), followed by Galway (6%), Donegal (6%), Laois (6%) and Monaghan (6%). The counties with the smallest average percentage of nervous system deaths were Carlow (4%), Clare (4%), Longford (4%), Roscommon (4%) and Offaly (4%) (see Table 3.9).

Table 3.9

Nervous system deaths by county: total, and as a proportion (%) of all county deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths due to nervous system 2013–2018*
State	1378 (5)	1420 (5)	1555 (5)	1603 (5)	1564 (5)	1611 (5)	1522 (5)
Leinster							
Dublin	383 (5)	388 (5)	417 (5)	438 (6)	402 (5)	415 (5)	407 (5)
Carlow	10 (3)	11 (3)	17 (4)	12 (3)	17 (4)	15 (4)	14 (4)
Kildare	44 (5)	42 (5)	28 (3)	34 (3)	52 (5)	52 (5)	42 (4)
Kilkenny	20 (3)	27 (5)	21 (3)	38 (6)	29 (5)	30 (4)	28 (4)
Laois	18 (4)	26 (6)	29 (6)	24 (5)	33 (7)	23 (5)	26 (6)
Longford	9 (3)	9 (3)	12 (4)	10 (4)	14 (5)	8 (3)	10 (4)
Meath	39 (5)	43 (5)	37 (4)	36 (4)	49 (5)	58 (6)	44 (5)
Louth	29 (5)	40 (6)	52 (6)	45 (6)	48 (6)	50 (6)	46 (6)
Offaly	17 (4)	22 (5)	26 (5)	21 (4)	18 (4)	15 (3)	20 (4)
Wexford	45 (5)	51 (5)	38 (4)	54 (5)	46 (4)	54 (5)	48 (5)
Wicklow	44 (6)	30 (4)	59 (7)	36 (4)	27 (3)	42 (5)	40 (5)
Westmeath	31 (5)	27 (4)	32 (6)	31 (5)	28 (5)	32 (6)	30 (5)
Munster							
Cork	197 (6)	186 (6)	185 (5)	208 (6)	193 (5)	197 (5)	194 (5)
Clare	22 (3)	38 (5)	35 (4)	33 (4)	36 (5)	20 (2)	31 (4)
Kerry	44 (4)	64 (5)	80 (7)	73 (6)	64 (6)	56 (5)	64 (5)
Limerick	54 (4)	66 (5)	64 (5)	80 (6)	69 (5)	77 (5)	68 (5)
Tipperary	51 (4)	51 (4)	71 (6)	58 (4)	60 (5)	59 (5)	58 (5)
Waterford	33 (4)	25 (3)	43 (5)	43 (5)	38 (5)	48 (6)	38 (5)
Connacht							
Leitrim	6 (2)	11 (4)	16 (6)	17 (6)	12 (5)	12 (4)	12 (5)
Sligo	19 (4)	22 (5)	20 (4)	30 (6)	24 (5)	43 (8)	26 (5)
Galway	81 (5)	76 (5)	73 (5)	92 (6)	99 (6)	107 (7)	88 (6)
Mayo	48 (4)	48 (5)	64 (6)	55 (5)	62 (6)	51 (5)	55 (5)
Roscommon	21 (4)	21 (4)	27 (5)	17 (3)	22 (5)	17 (3)	21 (4)
Ulster Rol							
Cavan	26 (5)	29 (6)	22 (4)	20 (4)	21 (4)	24 (5)	24 (5)
Donegal	56 (5)	43 (4)	68 (6)	72 (6)	78 (7)	77 (7)	66 (6)
Monaghan	21 (5)	24 (6)	19 (5)	26 (6)	23 (5)	29 (7)	24 (6)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.



3.7 External causes of injury and poisoning

External causes of injury and poisoning codes are used for classifying environmental events and circumstances that cause injury, poisoning and other adverse effects resulting in death⁵. Common examples include road traffic accidents; falls; drowning; choking; burns; and poisoning by, adverse effect of, and overdosing of drugs, medicaments and biological substances. In 2018, 4% of all deaths in the State were caused by external causes of injury and poisoning. Over the period under review, the number of deaths decreased from 1,491 deaths (5% of state deaths) in 2013 to 1,398 deaths (4% of state deaths) in 2018. This represents a decrease of 6% in the absolute number of external causes of injury and poisoning deaths between 2013 and 2018 (Table 3.10).

Table 3.2 shows that there were 1,398 deaths caused by external injury and poisoning in 2018 and that, when examined by age, most of these deaths are aged 25–54 years. Overall, 8% of deaths were at 0–24 years, 43% at 25–54 years, 15% at 55–64 years, 10% at 65–74 years, 10% at 75–84 years, and 14% at 85+. The number of deaths caused by external injury and poisoning for males was more than twice the number for females in 2018.

We also present the average proportion of deaths caused by external causes of injury and poisoning for each county within the six-year period (Table 3.10). On average, 5% of deaths were caused by external causes of injury and poisoning within the time period. In Table 10, five counties (highlighted orange) experienced a higher death rate than the national average within this setting. Conversely, 9 counties (blue) experienced a lower death rate and 12 counties matched the national average (green). Including this differential allows us to demonstrate which counties are diverging from the national average.

Cavan has the highest average proportion of deaths occurring due to external causes of injury and poisoning (6%), followed by Monaghan (6%), Kildare (6%), Galway (6%) and Louth (6%). The counties with the smallest average percentage of external causes of injury and poisoning deaths were Dublin (4%), Sligo (4%), Wicklow (4%), Donegal (4%) and Laois (4%) (see Table 3.10).

Table 3.10
External causes of injury and poisoning deaths by county: total, and as a proportion [%] of all county deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths due to external causes of injury & poisoning 2013–2018*
State	1491 (5)	1530 (5)	1316 (4)	1323 (4)	1299 (4)	1398 (4)	1393 (5)
Leinster							
Dublin	385 (5)	356 (5)	247 (3)	270 (4)	251 (3)	257 (3)	294 (4)
Carlow	28 (7)	19 (5)	23 (6)	16 (4)	19 (5)	11 (3)	19 (5)
Kildare	59 (6)	52 (6)	53 (6)	57 (6)	44 (4)	70 (7)	56 (6)
Kilkenny	23 (4)	27 (5)	29 (5)	30 (5)	23 (4)	32 (5)	27 (4)
Laois	16 (4)	13 (3)	22 (5)	18 (4)	17 (4)	24 (5)	18 (4)
Longford	19 (7)	15 (6)	12 (4)	12 (4)	14 (5)	12 (4)	14 (5)
Meath	56 (6)	47 (5)	53 (6)	40 (5)	53 (6)	47 (5)	48 (5)
Louth	48 (6)	44 (6)	35 (4)	29 (4)	44 (5)	55 (7)	43 (6)
Offaly	22 (5)	20 (4)	23 (5)	26 (5)	19 (4)	26 (5)	23 (5)
Wexford	44 (4)	56 (5)	47 (5)	39 (4)	35 (3)	54 (5)	46 (4)
Wicklow	26 (3)	42 (5)	35 (4)	20 (2)	39 (4)	35 (4)	33 (4)
Westmeath	31 (5)	28 (5)	17 (3)	31 (5)	22 (4)	30 (5)	27 (5)
Munster							
Cork	185 (5)	208 (6)	194 (6)	212 (6)	175 (5)	174 (5)	191 (5)
Clare	47 (6)	34 (4)	47 (5)	37 (4)	48 (6)	51 (6)	44 (5)
Kerry	55 (5)	62 (5)	52 (4)	56 (5)	32 (3)	61 (5)	53 (5)
Limerick	68 (5)	81 (6)	52 (4)	62 (4)	69 (5)	79 (5)	69 (5)
Tipperary	66 (5)	64 (5)	65 (5)	58 (4)	55 (4)	57 (4)	61 (5)
Waterford	30 (4)	32 (4)	37 (5)	39 (5)	44 (6)	50 (6)	39 (5)
Connacht							
Leitrim	14 (5)	8 (3)	11 (4)	11 (4)	11 (4)	10 (4)	11 (4)
Sligo	21 (4)	25 (5)	11 (2)	14 (3)	24 (5)	19 (4)	19 (4)
Galway	83 (6)	96 (6)	89 (6)	83 (5)	89 (6)	72 (5)	85 (6)
Mayo	49 (4)	57 (5)	46 (4)	43 (4)	42 (4)	45 (4)	47 (4)
Roscommon	25 (5)	28 (5)	20 (4)	24 (5)	23 (5)	30 (6)	25 (5)
Ulster Rol							
Cavan	31 (6)	36 (7)	21 (4)	34 (7)	30 (6)	35 (7)	31 (6)
Donegal	45 (4)	55 (5)	52 (5)	39 (3)	54 (5)	30 (3)	46 (4)
Monaghan	25 (6)	25 (6)	23 (6)	23 (5)	23 (5)	32 (8)	25 (6)

* Counties highlighted in green correspond to the national average, counties highlighted in orange are higher than the national average and counties highlighted in blue are below the national average.



3.8 Deaths caused by 'other' diseases

'Other' refers to all deaths caused by other diseases that are not encompassed in the seven cause of death categories previously presented, i.e. cancer, diseases of the circulatory system, diseases of the respiratory system, mental and

behavioural disorders, external causes of injury and poisoning, diseases of the digestive system and diseases of the nervous system. See Table 3.11 for a list of the diseases and health conditions included in the 'other' cause of death category.

Table 3.11
'Other' illness types and corresponding ICD-10 code

'Other' illnesses	ICD-10 Codes
Infectious and parasitic diseases	A00-B99
Diseases of the blood and blood-forming organs, immunological disorders	D50-D89
Endocrine, nutritional and metabolic diseases	E00-E90
Diseases of the eye and adnexa	H00-H59
Diseases of the ear and mastoid process	H60-H95
Diseases of the skin and subcutaneous tissue	L00-L99
Diseases of the musculoskeletal system/connective tissue	M00-M99
Diseases of the genitourinary system	N00-N99
Complications of pregnancy, childbirth and puerperium	O00-O99
Certain conditions originating in the perinatal period	P00-P96
Congenital malformations and chromosomal abnormalities	Q00-Q99
Symptoms, signs, abnormal findings, ill-defined causes	R00-R99

In 2018, 8% of all deaths in the State were caused by 'other' diseases and health conditions, and this remained constant between 2013 and 2018. However, over this period, the number of deaths increased marginally from 2,421 deaths in 2013 to 2,445 deaths in 2018. This represents an increase of 1% in the absolute number of deaths caused by 'other' diseases and health conditions between 2013 and 2018. We also present the average proportion of deaths caused by 'other' diseases for each province over the six-year period (Table 3.12).

Table 3.12
'Other' deaths by province: total, and as a proportion (%) of all county deaths, 2013-2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)
State	2421 (8)	2348 (8)	2425 (8)	2427 (8)	2423 (8)	2445 (8)
Leinster	1184 (4)	1124 (4)	1206 (4)	1222 (4)	1187 (4)	1188 (4)
Munster	750 (3)	689 (2)	696 (2)	741 (2)	746 (2)	763 (2)
Connacht	313 (1)	347 (1)	309 (1)	305 (1)	316 (1)	314 (1)
Ulster ROI	174 (1)	188 (1)	214 (1)	159 (1)	174 (1)	180 (1)

Table 3.2 shows that when the 2,445 deaths caused by 'other' disease or health conditions in 2018 are examined by age, 9% of these deaths were at 0-24 years, 7% at 25-54 years, 7% at 55-64 years, 13% at 65-74 years, 27% at 75-84 years, and 39% at 85+. Table 3.3 shows that, of the 31,140 deaths in 2018, the proportion of male and female deaths caused by 'other' diseases and health conditions was the same at 4%.

3.9 Place of death for different causes of death

The most recently available data on place of death for different causes of death are from 2017. The data are available for six different cause of death categories: cancer, diseases of the circulatory system, diseases of the respiratory system, diseases of the digestive system, diseases of the nervous system, and 'other', and five places of death: hospital, LSRCF, hospice, home, other. These data are presented in Table 3.13.

For cancer, hospital was the most common place of death (38%) although this was lower than the national incidence rate (43%). Home deaths from cancer were in line with national trends for this place of occurrence (24%). LSRCF deaths from cancer were relatively low – 13% of cancer deaths versus 23% for all conditions. Hospice deaths accounted for 22% of deaths from cancer, a much higher proportion than for any other condition. Indeed, deaths from cancer accounted for 85% of deaths in this setting nationally.

For diseases of the circulatory system, places of death were broadly in line with national figures. Hospital was the most common place of death (43%). LSRCF (25%) and home (28%) deaths were slightly more common than the national average, offset by relatively few deaths in hospice.

For diseases of the respiratory system, a majority of deaths occurred in hospital (55%). This was offset by lower rates of death at home (15%) and in hospice (2%), while LSRCF deaths (26%) were slightly above the national average.

Diseases of the nervous system was the only cause of death for which hospital (30%) was not the most common place. LSRCFs accounted for 45% of deaths for this cause, double the national average, while deaths at home (17%) and in hospice (5%) were less common.

For diseases of the digestive system, death in hospital was notably high (73%). All other places of occurrence were markedly lower than the national average.

Table 3.13
Place of death for each cause of death category, and as a proportion (%) of each cause of death category, 2017

	Cancer	Diseases of the Circulatory System	Diseases of the Respiratory System	Diseases of the Nervous System	Diseases of the Digestive System	Other	Total
Hospital	3578 (38)	3797 (43)	2251 (55)	467 (30)	776 (73)	2318 (42)	13187 (43)
LSRCF	1215 (13)	2246 (25)	1065 (26)	711 (45)	96 (9)	1650 (30)	6983 (23)
Hospice	2096 (22)	100 (1)	92 (2)	84 (5)	16 (2)	67 (1)	2455 (8)
Domiciliary	2281 (24)	2498 (28)	609 (15)	273 (17)	157 (15)	1080 (20)	6898 (23)
Elsewhere	191 (2)	248 (3)	42 (1)	29 (2)	19 (2)	366 (7)	895 (3)
Total	9361	8889	4059	1564	1064	5481	30418

4 Summary and policy implications

This chapter has used the CSO data on death to summarise data available at the time of writing on the leading causes of death in the State for the period 2013–2018 inclusive. In this section we consider and interpret the key findings.

4.1 Ireland's leading causes of death

The CSO data show that cancer was the leading cause of death in Ireland in 2018, accounting for 31% of all deaths in that year, closely followed by diseases of the circulatory system (29%). This is in contrast to 2013, when diseases of the circulatory system accounted for the highest proportion of all deaths (32%). Over the six-year period 2013–2018, there has been a small increase in deaths caused by cancer, and a slight decrease in deaths caused by diseases of the circulatory system. This partly reflects a long-term trend of declining heart-related mortality in Ireland¹⁰.

Diseases of the respiratory system were the third most common cause of death in 2018 (13%) and there was a small increase in these deaths over the six-year period. Deaths caused by mental and behavioural disorders, diseases of the nervous system and diseases of the digestive system accounted for smaller proportions of all deaths in 2018, at 6%, 5% and 4% respectively.

In the period 2013–2018 there has been a 61% increase in the number of people recorded as dying from mental and behavioural disorders. A more in-depth analysis of deaths due to dementia is provided separately in Chapter 5, where we will discuss factors that could be driving this increase including population ageing, better understanding of dementia, improvements in dementia diagnosis and better reporting of dementia on death certificates.

4.2 Cause of death categories and age

Most deaths in Ireland occur among older people, with aged 65+ accounting for 82% of all deaths in 2018. Approximately three-quarters (77%) of the 9,500 deaths caused by cancer were in individuals aged 65+. As cancer was leading cause of death in Ireland in 2018, a more in-depth analysis of this category by cancer type is undertaken in Chapter 4. Deaths due to diseases of the circulatory system and respiratory system also occurred predominantly in individuals aged 65+ (88% of deaths caused by diseases of the circulatory system and 93% of deaths caused by diseases of the respiratory system). Whereas the cancer category showed a decrease in the number of deaths of individuals aged 85+ (19% of cancer deaths) compared to individuals aged 65–84, diseases of the circulatory and respiratory system experienced a steady increase in number of deaths as age increased (44% of circulatory and 46% of respiratory deaths).

Mental and behavioural disorders (6% of state deaths), diseases of the nervous system (5%), diseases of the digestive system (4%), external causes of injury and poisoning (4%), and 'other' diseases (8%) made up the remaining 27% of state deaths. The distribution of deaths across age categories within these cause of death categories was more varied compared to diseases of the circulatory and respiratory systems. The majority of deaths caused by mental and behavioural disorders are attributable to dementia, and almost all of these deaths occurred in individuals aged 65+ (99%).

Diseases of the digestive system and diseases of the nervous system are two cause of death categories with a similar distribution of deaths across age groups. Ages 0–54 accounted for 15% of disease of the digestive system deaths and 6% of disease of the nervous system deaths. Ages 55–64 accounted for 14% and ages 65+ made up the remaining two-thirds (71%) of diseases of the digestive system deaths. Similarly, ages 55–64 accounted for 5% and ages 65+ made up the remaining 88% of diseases of the nervous system deaths. Diverging from these cause of death categories, 'external causes of injury and poisoning' and 'other' diseases have a broader scope of included illnesses within their classifications, and therefore have a broader age distribution when examining death.

4.3 Cause of death categories disaggregated by sex

Males experienced a higher proportion of deaths in two out of the three leading causes of deaths in Ireland in 2018: cancer and diseases of the circulatory system. This supports previous research demonstrating that sex, in particular being male, plays an important role in cancer incidence, progression and mortality^{11,12}. Males experienced three times the deaths from 'external injury and poisoning' (3%) compared to females (1%). Females experienced a higher proportion of deaths in the third leading cause of death in the State: diseases of the respiratory system. Interestingly, females experienced nearly double (4%) the proportion of mental and behavioural disorder deaths compared to males (2%). This reflects evidence of a higher incidence and prevalence of dementia among females than men, especially in the oldest age groups^{13,14}. Three categories experienced an equal proportion of deaths between males and females: diseases of the digestive system, diseases of the nervous system, and 'other' diseases.

4.4 Cause of death and place of death

Place of death varies greatly for different cause of death categories. This highlights that where a person dies is likely to be influenced by the type of disease and end-of-life trajectory¹⁵. This is consistent with evidence from other countries^{16,17}. For example, prognosis is more accurate in cancer than other major terminal diseases, so people with cancer and their families, and those providing care, are better able to arrange hospice or home care at the right time and to reduce hospital visits near end of life where appropriate. In major organ failure, a person's death is not typically foreseeable long in advance and occurs after a longer period of physical debilitation, and unplanned hospital visits are more common. In dementia, people often live with the disease for many years and are in the oldest age groups when they die. The wide variation in place of death by cause has implications for palliative care in all settings.



04 Deaths Caused by Cancer

1 Introduction

This chapter focuses on deaths caused by cancer in Ireland during the years 2013–2018 using mortality data from the Central Statistics Office (CSO) dataset. Within the CSO dataset, cancer deaths are categorised according to ICD-10 (International Classification of Disease 10th Revision)¹ codes C00-D48 indicating malignant neoplasms.

These ICD-10 codes can be broken down into 18 categories. For this report, we enlisted guidance from a palliative medicine consultant to further condense these categories for discussion purposes, resulting in nine established cancer categories (Table 4.1).

Table 4.1
Cancer types and corresponding ICD-10 codes

Cancer Category	ICD-10 Codes
Head and neck	Malignant neoplasms of lip, oral cavity and pharynx (C00-C14) In situ neoplasms (D00)
Gastrointestinal	Malignant neoplasms of digestive organs (C15-C26, D01) In situ neoplasms (D01)
Respiratory and thoracic	Malignant neoplasms of respiratory and intrathoracic organs (C30-C39) In situ neoplasms (D02)
Skin and musculoskeletal	Malignant neoplasms of bone and articular cartilage (C40-C41) Melanoma and other malignant neoplasms of skin (C43-C44) Malignant neoplasms of mesothelial and soft tissue (C45-C49) In situ neoplasms (D03-D04)
Breast and gynaecological	Malignant neoplasm of breast (C50-C50) Malignant neoplasms of female genital organs (C51-C58) In situ neoplasms (D05-D06)
Genitourinary cancers and testicular	Malignant neoplasms of male genital organs (C60-C63) Malignant neoplasms of urinary tract (C64-C68)
Neurological	Malignant neoplasms of eye, brain and other parts of central nervous system (C69-C72) Malignant neoplasms of thyroid and other endocrine glands (C73-C75)
Cancer of unknown primary sites	Malignant neoplasms of ill-defined, secondary and unspecified sites (C76-C80) Malignant neoplasms of independent (primary) multiple sites (C97-C97) In situ neoplasms (D07 & D09)
Haematological	Malignant neoplasms, stated or presumed to be primary, of lymphoid, haematopoietic and related tissue (C81-C96) Neoplasms of uncertain behaviour, polycythaemia vera and myelodysplastic syndromes (D37-D48)

The category ‘in situ neoplasms (D00-D09)’ was split and re-assigned to the category that corresponded to the site specified. The category ‘benign neoplasms, except benign neuroendocrine tumours (D10-D36)’ was excluded on the consultant’s recommendation, as benign neoplasms are generally not considered to be cancer and normally would

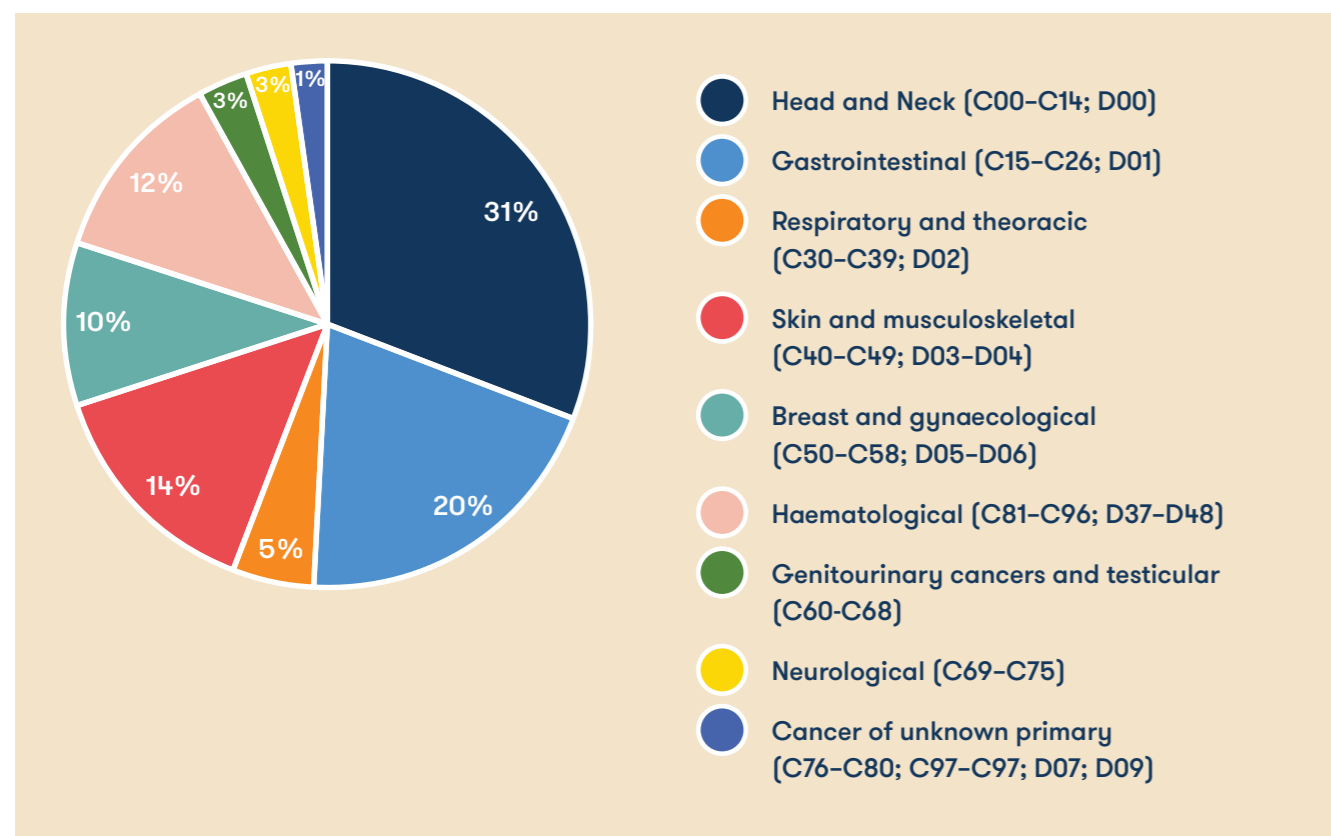
not account for the death. Cancer is considered separate from these. Cancer is a leading cause of death in the State, and this breakdown allows for an overview of death rates for different types of cancer and how these differ by age and sex. The remaining 17 ICD-10 categories are split between our predefined nine cancer categories as shown in Table 4.1.

2 National overview of cancer deaths (2013–2018)

Of the 31,140 deaths that occurred in the State in 2018, approximately one-third were caused by cancer (30%). Of these 9,466 deaths, 30% were caused by gastrointestinal

cancer and 20% by respiratory and thoracic cancer. The remaining 50% of deaths were spread across the remaining seven categories (each accounting for less than 15%).

Figure 4.1
All cancer deaths in Ireland by cancer type, 2018 (%)



Over the six-year period, 2013–2018 inclusive, there has been little change in the proportion of deaths caused by each of the cancer type categories. There were small increases in the proportion of cancer deaths in the following categories: skin and musculoskeletal cancer, and breast and gynaecological cancer. There were small decreases in the proportion of cancer deaths across two categories (respiratory and thoracic cancer, and cancer of unknown primary sites). The remaining five categories accounted for the same percentage of deaths in both 2013 and 2018.

Analyses of these data for the period 2013–2018 showed negligible change across groups (data not shown).

Deaths in 2018 by age group and cancer type are presented in Table 4.2. Of the 9,466 deaths due to cancer, 7,245 (77%) are people aged 65+. This age group accounts for a minimum of half of deaths in each cancer type category (56%–89%).

Table 4.2
State cancer deaths by age, totals and as a proportion (%) of cancer type.

	0-4yr N (%)	5-14yr N (%)	15-24yr N (%)	25-34yr N (%)	35-44yr N (%)	45-54yr N (%)	55-64yr N (%)	65-74yr N (%)	75-84yr N (%)	84+yr N (%)	All Ages
Head and neck (C00-14)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (1)	<10 (3)	14 (7)	48 (24)	75 (38)	31 (16)	22 (11)	197
Gastrointestinal (C15-C26)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	49 (2)	166 (6)	427 (15)	822 (29)	894 (31)	507 (18)	2879
Respiratory and thoracic (C30-C39)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	26 (1)	79 (4)	333 (17)	655 (34)	588 (31)	233 (12)	1918
Skin and musculoskeletal (C40-C49)	<10 (<1)	<10 (1)	<10 (1)	15 (3)	12 (3)	28 (6)	36 (8)	103 (24)	128 (29)	102 (23)	435
Breast and gynaecological (C50-C58)	<10 (<1)	<10 (<1)	<10 (<1)	16 (1)	67 (5)	173 (13)	232 (17)	319 (24)	320 (24)	212 (16)	1339
Genitourinary cancers and testicular (C60-C68)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	11 (1)	32 (3)	75 (7)	233 (21)	399 (37)	335 (31)	1086
Neurological (C69-C75)	<10 (1)	<10 (1)	<10 (1)	<10 (2)	23 (7)	25 (8)	74 (23)	94 (29)	61 (19)	25 (8)	320
Cancer of unknown primary (C76-C80, C97-C97)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (<1)	<10 (1)	14 (4)	33 (10)	67 (21)	105 (33)	91 (29)	315
Haematological (C81-C96, D37-D48)	<10 (<1)	<10 (<1)	<10 (1)	<10 (<1)	11 (1)	35 (4)	94 (10)	213 (22)	371 (38)	240 (25)	977

3 Deaths by cancer type, 2013–2018

3.1 Deaths at state level

In 2018, 30% of all deaths in the State occurred due to cancer (C00-D09, D37-D48). There was a small increase over the time period under review in the number of cancer deaths from 8,938 in 2013 (30% of state deaths) to 9,466 in 2018 (30% of state deaths). While the absolute number of deaths due to cancer increased by 6% when 2018 is compared to 2013, cancer deaths as a proportion of all deaths remained the same at 30% (see Table 4.3). However, these overall figures conceal the large variation that exists between different cancer types, as shown in Table 4.3.

We also present the average proportion of deaths due to each cancer type nationally within the six-year period (Table 3). This is calculated using the average number of deaths for each cancer type (2013–2018) as a proportion of the average number of total deaths within the State (2013–2018). ‘Gastrointestinal (C15-C26, D01)’ accounted for the highest average proportion of deaths occurring due to cancer (9%), followed by ‘respiratory and thoracic (C30-C39, D02)’ (6%) and ‘breast and gynaecological (C50-C58, D05-D06)’ (4%). The cancer types causing the smallest average percentage of cancer deaths were: ‘head and neck (C00-14, D00)’ (1%), ‘cancer of unknown primary (C76-C80, C97-C97, D07, D09)’ (1%), and ‘neurological (C69-C75)’ (1%) (Table 4.3).

Table 4.3

Cancer deaths by cancer type: total, and as a proportion [%] of all cancer deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths 2013–2018
Total (C00-D09, D37-D48)	8938 (30)	9180 (31)	9017 (30)	9363 (31)	9337 (31)	9466 (30)	9217 (31)
Head and neck (C00-14, D00)	163 (2)	168 (2)	187 (2)	188 (2)	190 (2)	197 (2)	182 (1)
Gastrointestinal (C15-C26, D01)	2710 (30)	2793 (30)	2793 (31)	2856 (30)	2845 (30)	2879 (30)	2813 (9)
Respiratory and thoracic (C30-C39, D02)	1896 (21)	2023 (22)	1903 (21)	1985 (21)	1999 (21)	1918 (20)	1954 (6)
Skin and musculoskeletal (C40-C49, D03-D04)	386 (4)	357 (4)	340 (4)	416 (4)	386 (4)	435 (5)	387 (1)
Breast and gynaecological (C50-C58, D05-D06)	1195 (13)	1272 (14)	1211 (13)	1300 (14)	1287 (14)	1339 (14)	1267 (4)
Haematological (C81-C96, D37-D48)	934 (10)	879 (10)	868 (10)	923 (10)	947 (10)	977 (10)	921 (3)
Genitourinary cancers and testicular (C60-C68)	994 (11)	1051 (11)	1023 (11)	989 (11)	1029 (11)	1086 (11)	1029 (3)
Neurological (C69-C75)	298 (3)	348 (4)	382 (4)	390 (4)	327 (4)	320 (3)	344 (1)
Cancer of unknown primary (C76-C80, C97-C97, D07, D09)	362 (4)	289 (3)	310 (3)	316 (3)	327 (4)	315 (3)	320 (1)

3.2 Deaths at state level – males

In 2018, 16% of all deaths in the State occurred due to cancer in males (C00-D09, D37-D48). There was a small increase over the time period under review in the number of these deaths from 4,732 in 2013 (16% of all deaths) to 5,036 in 2018 (16% of state deaths). The absolute number of deaths due to cancer in males increased by 6% when 2018 is compared to 2013, although as a proportion of all state deaths, the percentage remained the same (see Table 4.4). Mirroring the figures for the whole population, these overall figures conceal the large variation that exists between different cancer types in males, as shown in Table 4.4.

We also present the average proportion of deaths due to each cancer type in males nationally within the six-year period (Table 4.4). This is calculated using the average number of deaths for each cancer type in males (2013–2018) and the average number of total deaths within the State (2013–2018). ‘Gastrointestinal (C15-C26, D01)’ accounted for the highest average proportion of deaths occurring due to cancer (5%), followed by ‘respiratory and thoracic (C30-C39, D02)’ (4%), and ‘genitourinary cancers and testicular (C60-C68)’ (3%). The cancer types with the smallest average percentage of cancer deaths were: ‘breast and gynaecological (C50-C58, D05-D06)’ (<1%), ‘head and neck (C00-14, D00)’ (<1%), and ‘cancer of unknown primary (C76-C80, C97-C97, D07, D09)’ (1%) (Table 4.4).

Table 4.

Male cancer deaths by cancer type: total, and as a proportion [%] of all cancer deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths 2013–2018
Total (C00-D09, D37-D48)	4732 (16)	4815 (16)	4814 (16)	4920 (16)	4966 (16)	5053 (16)	4883 (16)
Head and neck (C00-14, D00)	117 (2)	116 (2)	141 (3)	125 (3)	138 (3)	147 (3)	131 (<1)
Gastrointestinal (C15-C26, D01)	1554 (33)	1620 (34)	1659 (34)	1650 (34)	1677 (34)	1689 (33)	1642 (5)
Respiratory and thoracic (C30-C39, D02)	1132 (24)	1138 (24)	1103 (23)	1106 (22)	1103 (22)	1105 (22)	1115 (4)
Skin and musculoskeletal (C40-C49, D03-D04)	229 (5)	205 (4)	209 (4)	252 (5)	244 (5)	279 (6)	236 (1)
Breast and gynaecological (C50-C58, D05-D06)	9 (<1)	5 (<1)	2 (<1)	8 (<1)	5 (<1)	8 (<1)	6 (<1)
Haematological (C81-C96, D37-D48)	507 (11)	521 (11)	476 (10)	556 (11)	543 (11)	564 (11)	528 (2)
Genitourinary cancers and testicular (C60-C68)	836 (18)	869 (18)	863 (18)	841 (17)	896 (18)	915 (18)	870 (3)
Neurological (C69-C75)	168 (4)	197 (4)	211 (4)	235 (5)	198 (4)	190 (4)	200 (1)
Cancer of unknown primary (C76-C80, C97-C97, D07, D09)	180 (4)	144 (3)	150 (3)	147 (3)	162 (3)	156 (3)	157 (1)

3.3 Deaths at state level – females

In 2018, 14% of all deaths in the State occurred due to cancer in females (C00-D09, D37-D48). There was a small increase over the time period under review in the number of these deaths from 4,206 in 2013 (14% of state deaths) to 4,413 in 2018 (14% of state deaths). The absolute number of deaths due to cancer in females increased by 5% when 2018 is compared to 2013 (see Table 4.5). Like males, these overall figures conceal the large variation that exists between different cancer types in females, as shown in Table 4.5.

We also present the average proportion of deaths due to each cancer type in females nationally within the six-year period (Table 4.5). This is calculated using the average number of deaths for each cancer type in females (2013–2018) and the average number of total deaths within the State (2013–2018). ‘Breast and gynaecological (C50–C58, D05–D06)’ (4%), followed by ‘gastrointestinal (C15–C26, D01)’ (4%), and ‘respiratory and thoracic (C30–C39, D02)’ (3%) accounted for the highest average proportion of deaths due to cancer in females. The cancer types with the smallest average percentage of cancer deaths were: ‘head and neck (C00–14, D00)’ (<1%), ‘neurological (C69–C75)’ (<1%), and ‘skin and musculoskeletal (C40–C49)’ (<1) (Table 4.5).

Table 4.5

Female cancer deaths by cancer type: total, and as a proportion [%] of all cancer deaths, 2013–2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of deaths 2013–2018
Total (C00–D09, D37–D48)	4206 (14)	4365 (15)	4203 (14)	4443 (14)	4371 (14)	4413 (14)	4334 (14)
Head and neck (C00–14, D00)	46 (1)	52 (1)	46 (1)	63 (1)	52 (1)	50 (1)	52 (<1)
Gastrointestinal (C15–C26, D01)	1156 (27)	1173 (27)	1134 (27)	1206 (27)	1168 (27)	1190 (27)	1171 (4)
Respiratory and thoracic (C30–C39, D02)	764 (18)	885 (20)	800 (19)	879 (20)	896 (20)	813 (18)	840 (3)
Skin and musculoskeletal (C40–C49, D03–D04)	157 (4)	152 (3)	131 (3)	164 (4)	142 (3)	156 (4)	150 (<1)
Breast and gynaecological (C50–C58, D05–D06)	1186 (28)	1267 (29)	1209 (29)	1292 (29)	1282 (29)	1331 (30)	1261 (4)
Haematological (C81–C96, D37–D48)	427 (10)	358 (8)	392 (9)	367 (8)	404 (9)	413 (9)	394 (1)
Genitourinary cancers and testicular (C60–C68)	158 (4)	182 (4)	160 (4)	148 (3)	133 (3)	171 (4)	159 (1)
Neurological (C69–C75)	130(3)	151 (3)	171 (4)	155 (3)	129 (3)	130 (3)	144 (<1)
Cancer of unknown primary (C76–C80, C97–C97, D07, D09)	182 (4)	145 (3)	160 (4)	169 (4)	165 (4)	159 (4)	163 (1)

3.4 Trends across male and female populations

3.4.1 Similarities

When comparing 2013 and 2018, there were increases for both males and females in the number of deaths across the following categories: ‘head and neck (C00–C14, D00)’, ‘gastrointestinal (C15–C26, D01)’, ‘genitourinary cancers and testicular (C60–C68)’, and ‘neurological (C69–C75)’ (Table 4.6).

Table 4.6

Male and female cancer deaths by cancer type: increases in both categories between 2013 and 2018

		2013	2014	2015	2016	2017	2018
Head and neck (C00–14, D00)	Male	117	116	141	125	138	147
	Female	46	51	46	63	52	50
Gastrointestinal (C15–C26, D01)	Male	1554	1620	1659	1650	1677	1689
	Female	1156	1173	1134	1206	1168	1190
Genitourinary cancers and testicular (C60–C68)	Male	836	869	863	841	896	915
	Female	158	182	160	148	133	171
Neurological (C69–C75)	Male	168	197	211	235	198	190
	Female	130	151	171	155	129	130

Similarly, both males and females showed decreases across the following category: ‘cancer of unknown primary (C76–C80, C97–C97, D07, D09)’ (Table 4.7).

Table 4.7

Male and female cancer deaths by cancer type: decreases in both categories between 2013 and 2018

		2013	2014	2015	2016	2017	2018
Cancer of unknown primary (C76–C80, C97–C97)	Male	180	144	150	147	162	156
	Female	182	145	160	169	165	159

3.4.2 Differences

When comparing 2013 and 2018, there were some differences between males and females. It was found that where males showed increases in the following categories, females showed decreases: 'skin and musculoskeletal (C40-C49, D03-D04)' and 'haematological (C81-C96, D37-D48)' (Table 4.8).

Table 4.8
Male and female cancer deaths by cancer type: increases in male category and decreases in female category between 2013 and 2018

		2013	2014	2015	2016	2017	2018
Skin and musculoskeletal (C40-C49, D03-D04)	Male	229	205	209	252	244	279
	Female	157	152	131	164	142	156
Haematological (C81-C96, D37-D48)	Male	507	521	476	556	543	564
	Female	427	358	392	367	404	413

Contrasting this, where females exhibited increases in the following categories, males exhibited decreases: 'respiratory and thoracic (C30-C39, D02)' and 'breast and gynaecological (C50-C58, D05-D06)' (Table 4.9).

Table 4.9
Male and female cancer deaths by cancer type: increases in female category and decreases in male category between 2013 and 2018

		2013	2014	2015	2016	2017	2018
Respiratory and thoracic (C30-C39, D02)	Male	1132	1138	1103	1106	1103	1105
	Female	764	885	800	879	896	813
Breast and gynaecological (C50-C58, D05-D06)	Male	9	5	2	8	5	8
	Female	1186	1267	1209	1292	1282	1331

4 Summary and policy implications

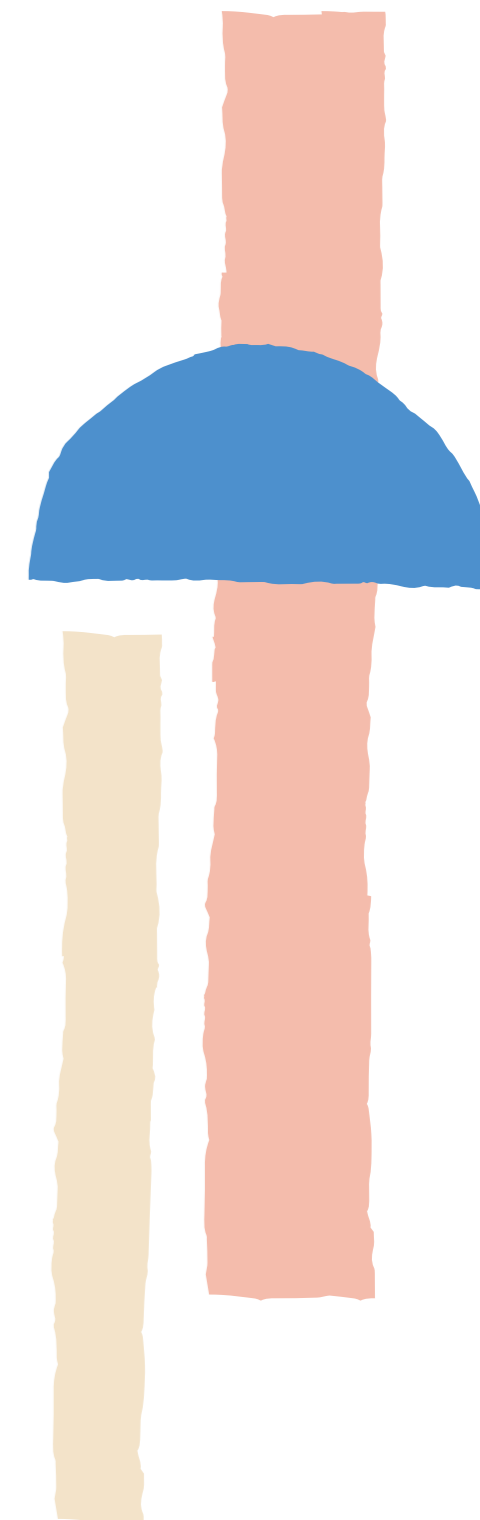
This chapter has used the CSO data on death to summarise data currently available on deaths caused by cancer in the State for the period 2013–2018 inclusive. In this section we consider and interpret the key findings.

4.1 Cancer as a leading cause of death and the importance of type of cancer

The CSO data show that the number of deaths caused by cancer has increased over the six-year period, although, as a proportion of all deaths, it has remained the same. There were four leading cancer categories causing death in 2018: gastrointestinal (31% of cancer deaths), respiratory and thoracic (20%), breast and gynaecological (14%), and genitourinary and testicular (12%). Individuals aged 65+ accounted for a minimum of two-thirds of deaths in each of these four cancer categories (64%–89%). The remaining five cancer categories accounted for the remaining 23% of cancer deaths in 2018: head and neck (2% of cancer deaths), skin and musculoskeletal (5%), neurological (3%), haematological (10%) and cancer of unknown primary (3%).

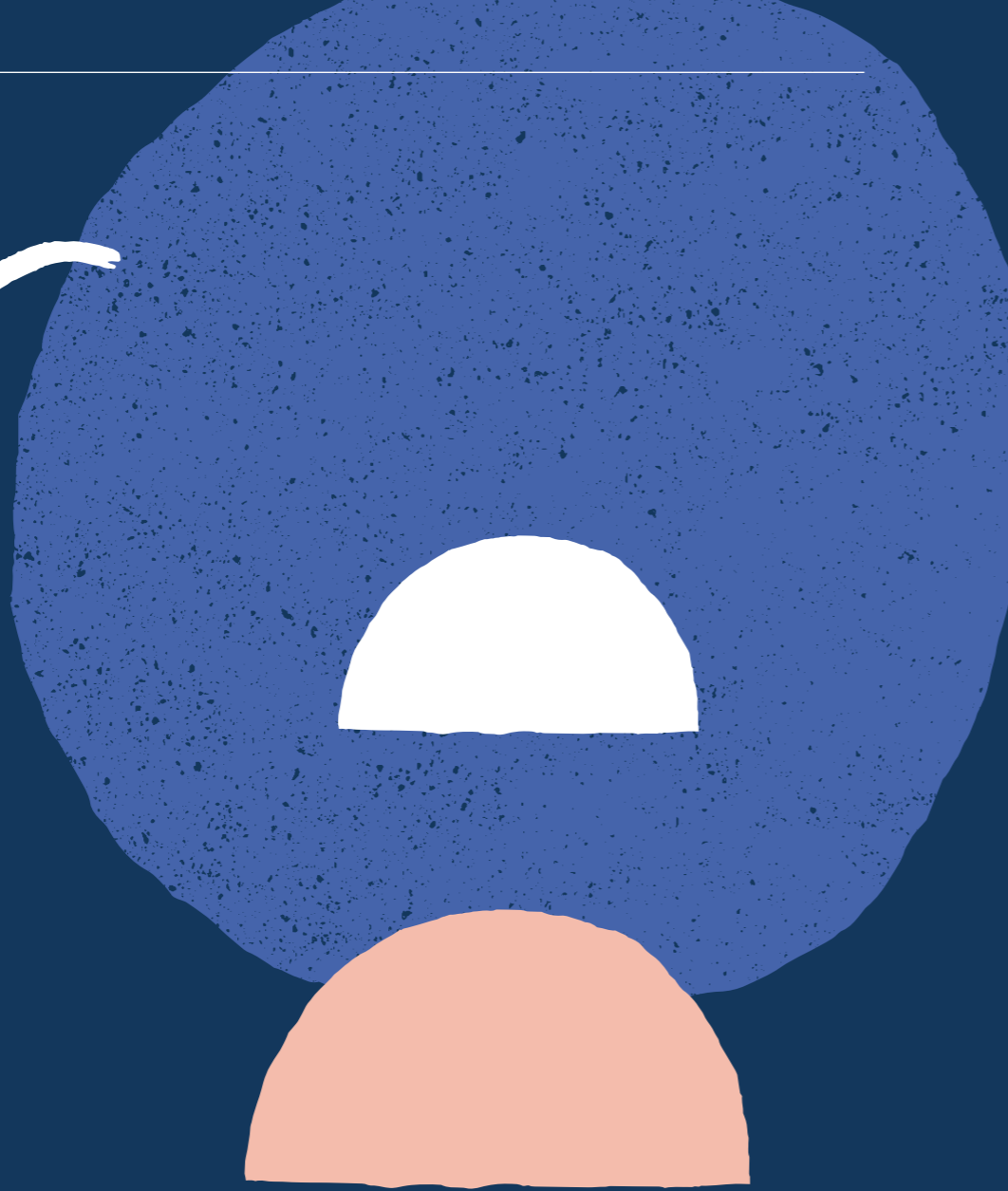
4.2 Cancer disaggregated by sex

Out of the 9,466 deaths caused by cancer reported in 2018, males accounted for a greater percentage of deaths (53% of cancer deaths) compared to females (47%). This is broadly in line with the national average for 2018, when males accounted for 52% of deaths. Males accounted for a higher proportion of deaths in each of the following categories: head and neck, gastrointestinal, respiratory and thoracic, skin and musculoskeletal, haematological, genitourinary and testicular, and neurological. Conversely, females accounted for a higher proportion of deaths in two categories: breast and gynaecological, and cancer of unknown primary.





05 Dementia as a cause of death



1 Introduction

This chapter focuses on deaths caused by dementia in Ireland during the years 2013–2018 using mortality data from the Central Statistics Office (CSO) dataset. Dementia is not a specific disease but an umbrella term for the impaired ability to remember, think, or make decisions that is sufficiently severe to interfere with a person's ability to do everyday activities. The most common type of dementia is Alzheimer's disease, followed by Vascular Dementia. Other common types of dementias are Lewy body dementia, frontotemporal degeneration, and mixed dementias. It is estimated that there are between approximately 39,000 and 55,000 people with dementia in Ireland¹. Dementia has been identified as a public health priority².

In recent years, dementia increasingly features in discussions surrounding the leading causes of death in the State and the wider world. In Ireland, until 2016, the CSO Vital Statistics Report³ did not specifically mention dementia as a leading cause of death, but focused on deaths attributed predominantly to three ICD-10 categories: neoplasms (cancer); diseases of the circulatory system; and diseases of the respiratory system. In 2016, these three categories accounted for almost three-quarters (73.6%) of all State deaths. Since 2017, the Vital Statistics Annual Reports⁵ have included a short section reporting on dementia as a cause of death. Although neoplasms, circulatory illness and respiratory illness continue to account for three-quarters (73.3%) of all State deaths, there has been a steady increase in the proportion of deaths caused by dementia over recent years (6% of deaths in 2013 and 8% in 2018).

Dementia death figures can become concealed under ICD-10 code categories, as is evident within 'Mental and Behavioural Disorder' (F00-F99) deaths, a category that includes Vascular Dementia (F01) and Unspecified Dementia (F03). The steady increase in mental and behavioural disorder deaths between 2013 (1,207 deaths; 4% of State deaths) and 2018 (1,946 deaths; 6% of State deaths) is largely attributed to dementia. Of the 1,946

deaths in 2018, dementia was the cause of death in the vast majority (96.6%) of cases. The absolute number of deaths due to mental and behavioural disorders increased by 61% when 2018 is compared to 2013, demonstrating a growing increase in deaths caused by dementia over the six-year period. In the UK, deaths due to dementia and Alzheimer's disease ranked as the leading cause of death in 2018⁶. In Australia, dementia was the second leading cause of deaths after heart disease in 2018, and the leading cause of death for women⁷. These trends have meant that more attention has become focused on dementia as a cause of death.

In this chapter, we used the same ICD-10 (International Classification of Disease 10th Revision) codes for dementia type that were employed in a previous study utilising CSO data to examine population health and palliative care planning⁸. Dementia deaths are categorized according to three ICD-10 codes: F01 (Vascular Dementia), F03 (unspecified dementia), and G30 (Alzheimer's disease) (Table 5.1). These ICD-10 codes for dementia fall under two different cause of death categories discussed in Chapter 3 on leading causes of death. Deaths caused by Vascular Dementia (F01) and unspecified dementia (F03) are classified under 'mental & behavioural disorders' (F00-F99), whereas deaths caused by Alzheimer's disease (G30) are classified under deaths caused by diseases of the nervous system (G00-G99). Unspecified dementia is usually classified where the dementia sub-type is unknown, where symptoms include those that are found in more than one type of dementia, making it hard to distinguish between different dementia sub-types, or where different types of dementia coexist, e.g., mixed dementia. In this chapter, we examine dementia as cause of death in comparison to other cause of death categories, i.e. 'Cancer', 'Diseases of the circulatory system', 'Diseases of the respiratory system', 'Diseases of the digestive system', 'External causes of injury and poisoning', and 'Other' categories. For the purposes of this chapter, the categories 'Diseases of the nervous system' and 'Mental & behavioural disorder' exclude deaths due to dementia.

Table 5.1
Dementia types and corresponding ICD-10 codes

Dementia Category	ICD-10 Codes
Vascular Dementia	F01 — Classified under 'Mental & behavioural disorder' category
Unspecified Dementia	F03 — Classified under 'Mental & behavioural disorder' category
Alzheimer's Disease	G30 — Classified under 'diseases of the nervous system' category
Total Dementia	F01; F03; G30

1.1 National Overview of dementia deaths (2013-2018)

Of the 31,140 deaths that occurred in Ireland in 2018, 2,446 (8%) of deaths were caused by dementia. Of these deaths, 64% were attributed to unspecified dementia, 23% to Alzheimer's disease and the remaining 12% attributed to Vascular Dementia (12%) (Figure 5.1)

Over the six-year period 2013-2018 inclusive, there was an increase in the proportion of deaths attributed to unspecified dementia (from 3% in 2013 to 5% in 2018), while deaths attributed to Alzheimer's disease and Vascular Dementia remained constant in proportional terms. Total deaths attributed to dementia increased from 6% of all State deaths in 2013 to 8% in 2018 (Figure 5.2).

Figure 5.1
All dementia deaths in Ireland by dementia type, 2018 (%)

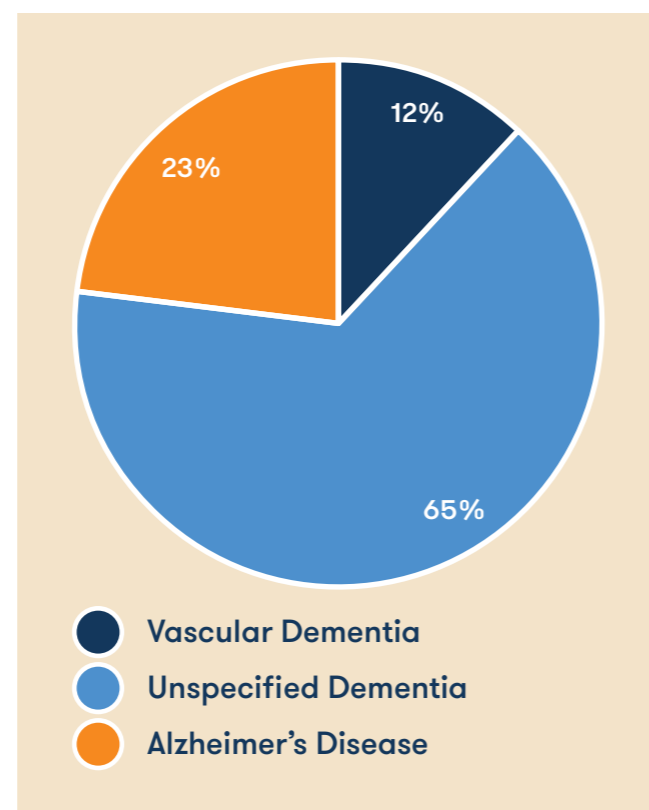
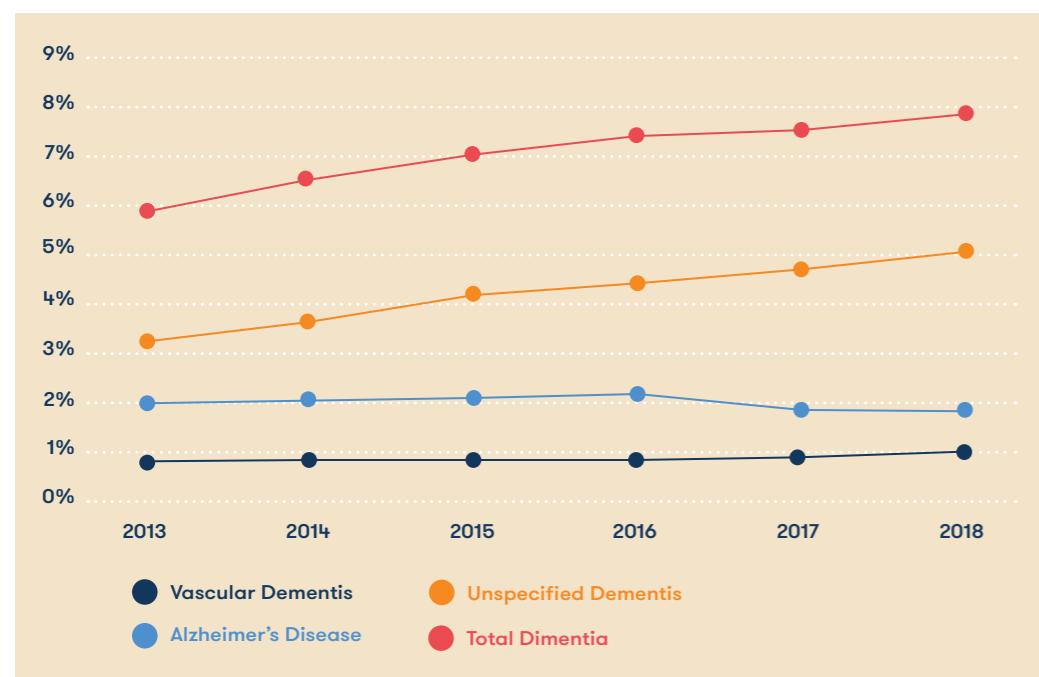


Figure 5.2
Trends in deaths attributable to dementia in Ireland, 2013-2018



Deaths in 2018 by age group and dementia sub-type are presented in Table 5.2. Of the 2,473 deaths due to dementia, nearly all are people aged 65+ (99%-100%). A minority (1%) of deaths attributable to unspecified

dementia and Alzheimer's disease are among individuals aged 55-64. Individuals aged 85+ account for nearly two-thirds of deaths attributed to dementia (58%-66%).

Table 5.2
Dementia death totals by age: total, and as a proportion [%] of all deaths attributed to each dementia sub-type, 2018

	Vascular Dementia N (%)	Unspecified Dementia N (%)	Alzheimer's Disease N (%)
0yr-4	<10 (<1)	<10 (<1)	<10 (<1)
5yr-14	<10 (<1)	<10 (<1)	<10 (<1)
15yr-24	<10 (<1)	<10 (<1)	<10 (<1)
25yr-34	<10 (<1)	<10 (<1)	<10 (<1)
35yr-44	<10 (<1)	<10 (<1)	<10 (<1)
45yr-54	<10 (<1)	<10 (<1)	<10 (<1)
55yr-64	<10 (<1)	10 (1)	<10 (1)
65yr-74	22 (7)	74 (5)	56 (10)
75yr-84	100 (33)	452 (29)	180 (32)
84yr+	179 (59)	1040 (66)	328 (58)
All Age	302	1577	567

2 Deaths by dementia type, 2013-2018

2.1 Deaths at State level

In 2018, 8% of all deaths in the State were attributed to dementia (F01; F03; and G30). There was an increase over the time period under review from 1,742 deaths in 2013 (6% of all deaths) to 2,446 deaths in 2018 (8% of State deaths). The absolute number of deaths due to dementia increased by 40% when 2018 is compared to 2013 (See Table 5.3). However, the overall figure conceals the large variation that exists between different dementia types, as shown in Table 5.3.

We present the average proportions of deaths due to each dementia sub-type nationally within the six-year period (Table 5.3). This is calculated using the average number of deaths for each dementia type (2013-2018) as a proportion of the average number of total deaths within the State (2013-2018). Of the three sub-types, the highest average proportion of deaths were attributed to 'unspecified dementia (F03)' (4%) and the lowest to 'Vascular Dementia (F01)' (1%) (Table 5.3).

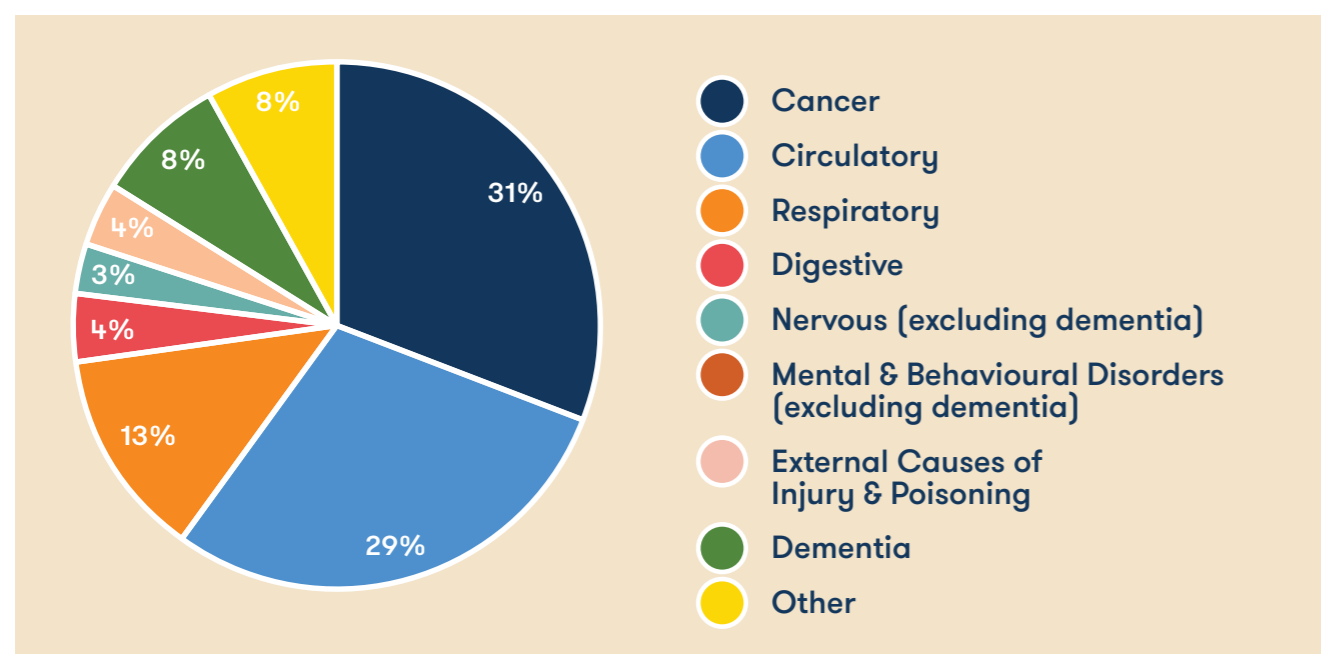
Table 5.3
Dementia deaths by dementia sub-type: total, and as a proportion [%] of all cancer deaths, 2013-2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of all deaths 2013-2018
Total Dementia	1742 (6)	1905 (7)	2127 (7)	2279 (7)	2291 (8)	2446 (8)	2132 (7)
Vascular Dementia	231 (13)	246 (13)	252 (12)	266 (12)	266 (12)	302 (12)	261 (1)
Unspecified Dementia	946 (54)	1066 (56)	1249 (59)	1358 (60)	1439 (63)	1577 (64)	1273 (4)
Alzheimer's Disease	565 (32)	593 (31)	626 (29)	655 (29)	586 (26)	567 (23)	599 (2)

The vast majority of deaths categorised as mental and behavioural disorders are caused by dementia. In 2013, there were 1,207 deaths (4% of State deaths) in this category, falling to 30 deaths (<1%) when deaths due to dementia were excluded. Similarly, in 2018, 1,946 (6% of State deaths) deaths in this category fell to 67 deaths (<1%) when dementia was excluded. The large proportion of deaths caused by diseases of the nervous system are also due to dementia. In 2013, there were 1,378 deaths (5% of

State deaths) in this category and this fell to 813 deaths (3%) when dementia was excluded. In 2018, the number of deaths in this category decreased from 1,611 (5% of State deaths) to 1,044 deaths (3%) when dementia was excluded. See Figure 5.3 for all deaths from 2018 in the State, including dementia as a cause of death, which shows that dementia is the fourth leading cause of death after cancer, diseases of the circulatory system and diseases of the respiratory system.

Figure 5.3
All deaths in Ireland by cause of death, 2018 (%)



2.2 Deaths at State level - males

In 2018, 902 male deaths (3% of all deaths) in the State were attributed to dementia (C00-D48). This was an increase over the time period under review from 549 deaths

in 2013 (2% of all deaths). The absolute number of male deaths due to dementia increased by 64% when 2018 is compared to 2013 (See Table 5.4). Mirroring the figures for the whole population, most of these deaths were attributed to unspecified dementia, as shown in Table 5.4.

Table 5.4
Male dementia deaths by dementia type: total, and as a proportion (%) of all dementia deaths, 2013-2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of all deaths 2013-2018
Total Dementia	549 (2)	639 (2)	705 (2)	796 (3)	774 (3)	902 (3)	728 (2)
Vascular Dementia	91 (17)	102 (16)	107 (15)	115 (14)	107 (14)	140 (16)	110 (15)
Unspecified Dementia	281 (51)	351 (55)	414 (59)	465 (58)	460 (59)	571 (63)	424 (58)
Alzheimer's Disease	177 (32)	186 (29)	184 (26)	216 (27)	207 (27)	191 (21)	194 (27)

2.3 Deaths at State level - females

In 2018, 1,544 female deaths (5% of all deaths) in the State were attributed to dementia (F01; F03; G30). This was an increase over the time period under review from 1,194 deaths in 2013 (4% of all deaths). The absolute number of

female deaths due to dementia increased by 29% when 2018 is compared to 2013 (See Table 5.5). Mirroring the figures for the whole population and for males, most female deaths were attributed to unspecified dementia, as shown in Table 5.5.

Table 5.5
Female dementia deaths by dementia type: total, and as a proportion (%) of all dementia deaths, 2013-2018

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	Average proportion of all deaths 2013-2018
Total Dementia	1193 (4)	1266 (4)	1422 (5)	1483 (5)	1517 (5)	1544 (5)	1401 (5)
Vascular Dementia	140 (12)	144 (11)	145 (10)	151 (10)	159 (10)	162 (10)	150 (11)
Unspecified Dementia	665 (56)	715 (56)	835 (59)	893 (60)	979 (65)	1006 (65)	849 (60)
Alzheimer's Disease	388 (33)	407 (32)	442 (31)	439 (30)	379 (25)	376 (24)	405 (29)

3. Summary and policy implications

This chapter has used the CSO data on death to summarise data currently available on deaths caused by dementia in Ireland for the period 2013-2018 inclusive. In this section we consider and interpret the key findings.

3.1 Dementia is in the top four leading causes of death, but likely to be undercounted

The CSO data show that deaths caused by dementia have increased steadily over the six-year period 2013 to 2018 (F01; F03; and G30), and in 2018 accounted for 8% of all deaths in Ireland. In the 2017 and 2018 Vital Statistics Reports⁵, the inclusion by the CSO of dementia in their cause of death discussions appears to be a signal of the increasing importance of dementia as a cause of death. Based on the data presented in this chapter, dementia figures in the top four main causes of death for 2018 in Ireland, following cancer (31%), diseases of the circulatory system (29%) and diseases of the respiratory system (13%). The proportion of all death attributable to dementia is higher than deaths caused by diseases of the nervous system (excluding dementia) (3%) and diseases of the digestive system (4%).

A number of factors are likely to be contributing to the rise in the proportion of deaths attributed to dementia. These include people living longer and surviving other illnesses, improvements in dementia diagnosis and increased

reporting of dementia on death certificates as a result of better understanding of dementia⁹. However, at 8%, the proportion of deaths attributed to dementia is likely to be an undercount and unlikely to be a 'true' reflection of deaths caused by dementia. It is known that dementia is often omitted from death certificates, and more likely to be recorded if death occurs when dementia is severe or takes place in a long-stay residential care facility¹⁰. In the UK, where doctors are encouraged to report dementia on death certificates, the recording of dementia on death certificates has increased significantly. In 2019, the Office of National Statistics reported that 12.5% of all deaths registered in England and Wales were caused by dementia¹¹. However, under-reporting of dementia on death certificates continues to be a major problem in the UK¹⁰. The extent of undercounting or under-identification of dementia as the main cause of death on death certificates in Ireland is unknown. However, if the UK death rate of 12.5% was applied to total deaths in Ireland in 2018, the number of deaths caused by dementia would be 3,893, substantially higher than 2,446 reported above.

While this chapter has focused on deaths where dementia has been the main cause of death, there will be many more deaths of people with dementia, which is important to note as dementia interacts with other conditions to predispose to early death¹⁰. A study of dementia mentioned anywhere on death certificates would give a more accurate picture of the contribution of dementia to death, both as a primary and contributory cause.

3.2 An overwhelming majority of deaths attributed to dementia are in older age groups

Although younger people are affected by dementia, the vast majority of people living with dementia are aged 65+. The CSO shows that the number of deaths due to dementia in people aged under 65 years was very small, and included close to an equal number of males and females. Accordingly, nearly all deaths caused by dementia were in the older age categories (age 65+). For each dementia sub-type, the proportion of deaths increased as age increased, reflecting that increasing age is the single strongest risk factor for dementia. Most deaths were in the 85+ age category, and this was true for the three dementia sub-types and for males and females.

3.3 Gender differences in deaths caused by dementia

In Ireland, as in other countries, the majority of people living with dementia are women. An explanation often cited for this gender difference is that females tend to live longer¹² and the risk for developing dementia increases with age. Almost two-thirds of people with dementia in Ireland are women^{13,14}. This is reflected in the CSO data reviewed in this chapter, which shows that in 2018 women accounted for 63% of deaths caused by dementia. This is consistent with mortality data globally showing that 65% of deaths from dementia are women¹⁵. With respect to different dementia sub-types, the difference was less pronounced for Vascular Dementia; females accounted for 54% of deaths due to Vascular Dementia. The differences between men and women remind us that dementia is a gendered issue and highlight the importance of paying attention to the gender dimension and promoting gender-sensitive approaches in end of life and palliative care services for people with dementia.

3.4 For deaths caused by dementia, data on place of death is lacking

In Chapter 2 we presented data on place of death for six main cause of death categories. Unfortunately, data on place of death is not available to us for deaths caused by dementia. International studies show that place of death for people with dementia differs substantially between countries, mainly due to organisational differences in end-of-life care provision¹⁶. However, most people with dementia die in residential long-stay facilities and to a lesser extent in hospital. Having evidence about where people with dementia die is important for knowing where the focus needs to be for end-of-life and palliative care services for people with dementia.

3.5 ICD-10 codes for deaths attributable to dementia

For the purposes of this chapter, we included three dementia ICD-10 codes (e.g. F01 (Vascular Dementia); F03 (Unspecified dementia); G30 (Alzheimer's disease)) based on previous research examining mortality prediction of diseases indicating palliative care need^{8,17}. However, unlike other previous research, we excluded the ICD-10 code R54 (Senility). Studies estimating how many people are in need of palliative care^{17,18}, tend to use a category developed by Rosenwax et al. (2005) which includes the code for senility (R54) alongside dementia ICD-10 codes¹⁹. While the term senility was used for many years to refer to people with cognitive decline or memory loss, and used (incorrectly) to refer to dementia, senility is not synonymous with dementia. Senility implies that characteristics of dementia are typical of advancing age, which is not true. For the purposes of this chapter, we are guided by the ICD-10 codes (F01, F03, and G30) used by the Office of National Statistics in the UK for reporting on deaths caused by dementia¹¹.

06 Minimum Data Set – Specialist Palliative Care Services



1 Introduction

This chapter presents an overview of specialist palliative care (SPC) services in Ireland for the period 2013–2019 inclusive using data from the Health Service Executive's (HSE) Minimum Data Set for Specialist Palliative Care (MDS SPC). It aims to expand and update the previously published report: National Summary of Patient Activity Data for Adult Specialist Palliative Care Services in the Republic of Ireland, 2012–2015¹.

Data are presented by community healthcare organisation (CHO) regions 1–9 (Table 6.1) and by setting: in-patient, community and day care. In-patient SPC refers to care received by those admitted to SPC services as an in-patient in a hospice or in an acute hospital that provides specialist palliative care beds. At the end of 2017, there were 11 hospices providing In-patient SPC services and one acute hospital with two dedicated SPC beds. Community SPC is provided to people in their normal place of residence by members of an SPC team, and is also known as 'homecare'. Finally, Day SPC is defined as a short-term (day) admission to a service that provides care and support to patients with a serious illness. 'Day hospice care' allows a patient to continue living at home while having access to SPC facilities.

2 New patients in receipt of in-patient services

As shown in Table 6.2, Community SPC has the highest volume of new patients annually, followed by In-patient SPC and Day SPC. An increase in the number of new patients in receipt of both In-patient SPC (from 2,283 to 3,225) and SPC in the community (from 8,822 to 10,301) occurred between 2013 and 2019 (Table 6.2), representing a 33% and 17% increase respectively. While In-patient and

Table 6.1
CHO regions for specialist palliative care

CHO	Region
1	Cavan, Monaghan, Donegal, Sligo, Leitrim
2	Galway, Mayo, Roscommon
3	Clare, Limerick, North Tipperary
4	Kerry, Cork (North Lee, South Lee, North, West)
5	Carlow, Kilkenny, South Tipperary, Waterford, Wexford
6	Dublin South East, Dun Laoghaire, Wicklow
7	Dublin (South, South West, West), Kildare, West Wicklow
8	Laois, Offaly, Longford, Westmeath, Louth, Meath
9	Dublin (North, North Central, North West)

Community SPC showed a steady upward trend over the seven-year period, there was a different pattern for day care, reflecting varying patterns of change in Day SPC services at local level. Between 2013 and 2016, the number of new patients in receipt of Day SPC fluctuated around 950 but dropped to well below 900 in 2018 and 2019.

Table 6.2
Number of new patients* in receipt of In-patient SPC, Community SPC and Day SPC, 2013–2019

New Patients	2013	2014	2015	2016	2017	2018	2019
In-patient SPC	2283	2433	2,628	3019	2963	3230	3225
Community SPC	8822	8889	8968	9660	9344	9977	10301
Day SPC	946	945	934	961	966	821	862

*New patients' are people who have been admitted to an In-patient SPC unit or received SPC community or day care for the first time ever. The totals for the individual services cannot be added as many patients access more than one service.

3 Summary of In-patient SPC data

3.1 In-patient SPC: Ratio and number of beds

In 2019, there were 223 In-patient SPC beds available nationally, equating to 4.7 beds per 100,000 people. The number of beds is up from 156 in 2013, representing an increase of 1.3 beds per 100,000 people nationally (Table 6.3). While nationally there is an upward trend, SPC in-patient bed availability varies widely across CHO areas and trends vary remarkably from one CHO area to another. The number of beds available per 100,000 people in CHO 1 remained unchanged at 4.1, which was slightly above

the national average in 2103 but slightly below in 2019. Increases were seen in CHOs 2, 3, 4 and 9, most notably in CHO 4, which in 2019 had the highest number of SPC in-patient beds per 100,000 population. Rising population figures and static bed numbers have meant that in CHO 6 and CHO 7 the number of beds per 100,000 population was lower in 2019 than 2013. There were no In-patient SPC beds in CHO 8 in 2013 and this has remained unchanged. There was a large increase in the number of beds per 100,000 population in CHO 9 from 3.3 in 2013 to 7.4 in 2014, but this fell to 6.9 in 2017 and remained unchanged in 2018 and 2019.

Table 6.3
Ratio and number of SPC in-patient beds per 100,000 population, 2013–2019*

IPU Beds / 100K Pop	2013	2014	2015	2016	2017	2018	2019
	Beds / 100,000 (Number of beds)	Beds / 100,000 (Number of beds)	Beds / 100,000 (Number of beds)	Beds / 100,000 (Number of beds)	Beds / 100,000 (Number of beds)	Beds / 100,000 (Number of beds)	Beds / 100,000 (Number of beds)
National	3.4 (156 beds)	4.3 (196 beds)	4.4 (200 beds)	4.6 (208 beds)	4.6 (221 beds)	4.6 (221 beds)	4.7 (223 beds)
CHO1	4.1	4.1	4.1	4.1	4.1	4.1	4.1
CHO2	2.7	2.7	2.7	4.0	4.0	4.0	4.0
CHO3	7.4	7.4	7.4	7.9	7.8	7.8	7.8
CHO4	3.6	6.0	6.0	6.6	8.5	8.5	8.5
CHO5**	N/A	N/A	N/A	N/A	N/A	N/A	N/A
CHO6	3.3	3.3	3.3	3.3	3.1	3.1	3.1
CHO7	6.4	6.4	6.4	6.5	5.8	5.8	5.8
CHO8***	0.0	0.0	0.0	0.0	0.0	0.0	0.0
CHO9	3.3	7.4	7.4	7.4	6.9	6.9	6.9

* Bed total by year-end.

** CHO 5: No hospice and only two specialist palliative care beds located in University Hospital Waterford; for this reason figures are not included.

*** CHO 8: No SPC in-patient service.

3.2 In-patient SPC: New patients by age

There was a 41% increase in the number of patients accessing the in-patient service nationally between 2013 and 2019 (Table 6.4). The use of In-patient SPC varies dramatically by age. Patients within the 65+ age group account for the highest proportion of new patients, and

this has increased by 6% from just over two-thirds (68%) in 2013 to almost three-quarters (74%) in 2019. In contrast, patients within the 18- to 64-year-old age group decreased by 6% and in 2019 accounted for just over one-quarter (26%) of new patients as compared to almost one-third (32%) in 2013. Consistently, 0–17 year olds accounted for less than 1% of new patients.

Table 6.4
New patients in receipt of In-patient SPC by age, 2013-2019

New Patients IPU Ages Profile	2013	2014	2015	2016	2017	2018	2019
National	2,283	2,433	2,628	3019	2963	3230	3225
0–17	<1%	<1%	<1%	<1%	<1%	<1%	<1%
18–64	32%	31%	31%	29%	31%	27%	26%
65+	68%	69%	69%	71%	69%	73%	74%

3.3 In-patient SPC: New patients per 10,000 population

In 2013, the number of new patients per 10,000 population admitted to an SPC unit nationally was 4.98 (Table 6.5). This rose to 6.36 in 2019, representing a 22% (1.38) increase. This is likely to reflect the overall increase in the number of hospice beds across the country from a total of 190 beds in 10 hospices in 2013 to 221 beds in 11 hospices by the end of 2017.

When comparing 2013 and 2019, six CHO regions showed an increase in new patients receiving specialist in-patient care per 10,000 population (CHO 2, CHO 3, CHO 4, CHO 6, CHO 7 and CHO 9), with the biggest increases in CHO 4 and CHO 9. There was a decrease in one CHO region (CHO 1).

Table 6.5
New patients in receipt of specialist palliative in-patient care, per 10,000 population by CHO, 2013–2019

IPU New Patients / 10K Pop	2013	2014	2015	2016	2017	2018	2019
National	4.98	5.30	5.75	5.93	5.81	6.41	6.36
CHO1	8.80	7.50	6.53	7.33	6.75	6.75	4.73
CHO2	4.10	5.46	4.54	5.34	4.55	4.94	4.94
CHO3	9.03	10.26	10.60	9.95	9.64	11.38	11.12
CHO4	6.53	6.96	9.04	8.95	7.63	11.48	11.60
CHO5*	N/a	N/a	N/a	N/a	N/a	N/a	N/a
CHO6	5.01	5.34	5.27	5.40	6.03	5.72	7.12
CHO7	6.77	7.22	7.14	6.71	7.25	7.14	7.35
CHO8**	0.00	0.00	0.00	0.00	0.00	0.00	0.00
CHO9	4.71	4.60	7.67	9.03	9.46	9.27	9.49

* CHO 5 has no hospice and only two specialist palliative care in-patient beds, located in University Hospital Waterford; for this reason figures are not included.

** No In-patient SPC service in CHO 8; however, some patients access services in other CHOs.

3.4 In-patient SPC: New patients by primary diagnosis

As Chapter 3 has shown, cancer is one of the leading causes of death within Ireland, and while there has been a small increase in the absolute number of deaths due to cancer, cancer deaths as a proportion of all deaths has remained much the same^{2,3}.

The MDS SPC data show that nationally, the vast majority of new patients admitted to SPC in-patient units are patients with a primary diagnosis of cancer. There has been a small but steady decrease in the proportion of new patients with cancer as a primary diagnosis being admitted to In-patient SPC units, representing a drop of 5 percentage points when comparing 2013 to 2019 (conversely non-cancer increased by 5 percentage points) (Table 3.6). The national trend is mirrored at regional level; all CHO regions with SPC services showed a decrease in new patients having cancer as their primary diagnosis between 2013 and 2019.

Table 6.6
SPC in-patient units, new patients by primary diagnosis and CHO, 2013–2019

New Patients IPU C/NC	2013		2014		2015		2016		2017		2018		2019	
	Cancer	Non-Cancer	Cancer	Non-Cancer	Cancer	Non-Cancer	Cancer	Non-Cancer	Cancer	Non-Cancer	Cancer	Non-Cancer	Cancer	Non-Cancer
National	89%	11%	88%	12%	86%	14%	86%	14%	86%	14%	86%	14%	84%	16%
CHO1	87%	13%	86%	14%	82%	18%	79%	21%	80%	20%	75%	25%	71%	29%
CHO2	85%	15%	83%	17%	88%	12%	85%	15%	85%	15%	86%	14%	84%	16%
CHO3	90%	10%	89%	11%	87%	13%	88%	12%	88%	12%	84%	16%	85%	15%
CHO4	91%	9%	89%	11%	87%	13%	88%	12%	92%	8%	94%	6%	86%	14%
CHO5*	96%	4%	97%	3%	85%	15%	94%	6%	87%	13%	76%	24%	75%	25%
CHO6	84%	16%	86%	14%	77%	23%	83%	17%	82%	18%	82%	18%	79%	21%
CHO7	87%	13%	91%	9%	90%	10%	89%	11%	88%	12%	87%	13%	86%	14%
CHO8**	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
CHO9	92%	8%	86%	14%	87%	13%	87%	13%	83%	17%	86%	14%	86%	14%

* CHO 5 had only two specialist beds, located in University Hospital Waterford.

** No in-patient service in CHO 8.

3.5 In-patient SPC: Normal place of residence of new patients prior to admission

In 2013, slightly more than half (51%) of new patients were living in their own or their carer's home prior to admission to an In-patient SPC unit, and slightly less than a half

(46%) were admitted from an acute hospital (Table 6.7). This trend has reversed over time, and in 2019 slightly less than a half (47%) of new patients were admitted from their own or their carer's home and slightly more than a half of new patients were admitted from an acute hospital (52%). The remaining new patients (<1%) were admitted from a range of other locations, which were categorised differently before and after 2019.

Table 6.7

Location (normal place of residence) of new patients prior to admission to Specialist Palliative Care In-patient Units, 2013–2019

	2013	2014	2015	2016	2017	2018	2019
Total new patients	2,283	2,433	2,637	2,821	2,768	3,063	3029
Patient's home/Carer's home	51%	51%	51%	52%	49%	46%	47%
Acute hospital	46%	47%	47%	47%	50%	52%	52%
Intermediate/Support bed*	1%	1%	1%	0%	0%	<1%	
Non-acute bed*	<1%	<1%	<1%	0%	0%	<1%	
Other*	2%	<1%	<1%	1%	1%	N/a	
Residential care (nursing home community nursing unit district hospital)†							<1%
Designated non-specialist intermediate care bed in community setting†							<1%

* Categories that existed before 2019.

† Categories that were updated from 2019.

3.6 In-patient SPC: Number of discharges/transfers and deaths

The data indicates that in the years 2013 to 2019, approximately two-thirds of patients admitted to an In-patient SPC unit died there and one-third were

discharged or transferred. Compared to 2013, the proportion of patients who died in an In-patient SPC unit in 2019 (69%) increased by 5% and the proportion of patients who were discharged or transferred (31%) decreased by 5%.

Table 6.8

Number of discharges/transfers and deaths in In-patient SPC Units, 2013–2019

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)
Total number of patients	2909	3086	3387	3541	3436	3782	3708
Discharged/transferred	1045 (36)	1075 (35)	1156 (34)	1199(34)	1044 (30)	1180 (31)	1131 (31)
Deaths	1864 (64)	2011 (65)	2231 (66)	2342 (66)	2392 (70)	2602 (69)	2577 (69)

3.7 In-patient SPC: Normal place of residence of patients after discharge

In 2013, while nearly two-thirds (64%) of patients died in an In-patient SPC unit, close to one-third (31%) were discharged to their own home (Table 6.9). The proportion of patients who died in an In-patient SPC unit (69%) increased in 2019, compared to a decrease in the

proportion of patients discharged to their own home (28%), representing a 5% increase and a 3% decrease respectively. The proportion of patients discharged/transferred to other settings was very small. These locations were categorised differently before and after 2019. In 2019, residential care (nursing home, community nursing unit district hospital) accounted for <1% of discharges/transfers from In-patient SPC units.

Table 6.9

Location of patients after discharge from In-patient SPC, 2013–2019

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)
Total patients	2909	3086	3387	3541	3436	3782	3708
Died in In-patient SPC	1864 (64)	2011 (65)	2231 (66)	2342 (66)	2392 (70)	2602 (69)	2577 (69)
Patient's permanent home	904 (31)	943 (30)	1046 (31)	1069 (30)	910 (26)	1052 (28)	1025 (28)
Carer's home	2 (<1)	7 (<1)	5 (<1)	7 (<1)	11 (<1)	0 (<1)	0 (<1)
Acute hospital	39 (1)	51 (2)	51 (2)	69 (2)	53 (2)	60 (2)	68 (2)
Intermediate care bed in community setting (including designated bed in nursing home)	28 (1)	20 (1)	17 (1)	10 (<1)	34 (1)	54 (1)	31 (1)
Non-acute hospital*	15 (<1)	11 (<1)	9 (<1)	10 (<1)	8 (<1)	13 (<1)	
Private nursing home*	32 (1)	21 (1)	26 (1)	34 (1)	28 (1)	1 (<1)	
Other	25 (1)	22 (1)	2 (<1)	0 (<1)	0 (<1)	0 (<1)	0 (<1)
Residential care (nursing home, community nursing unit, district hospital)†							7 (<1)

* Categories that existed before 2019.

† Categories that were updated from 2019.

3.8 In-patient SPC: Bed days – availability and occupancy

Table 6.10 shows that the number of In-patient SPC bed days available was 56,058 in 2013 and that this rose to

78,991 in 2019, an increase of 40%. It shows that in each year more than three-quarters of available In-patient SPC unit beds were occupied. However, the percentage of bed days used (occupancy) fell from 86.6% in 2013, to 80.5% in 2019, a decrease of 6.1%.

Table 6.10.

In-patient SPC bed days - availability and occupancy, 2013-2019

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)
Bed days available	56058	61395	69450	74388	74874	79868	78991
Bed days available (bed days used)	56058	61395	69450	74388	74874	79868	78991
% occupancy	86.6%	84.8%	80.4%	82.6%	78.5%	79.5%	80.5%

3.9 In-patient SPC: Length of stay

Between 2013 and 2017, there was no notable change in the length of stay for patients in any length-of-stay category. In 2019, an equal proportion of patients stayed for a week

or less (44%) and for 8–28 days (44%). The length-of-stay categories altered from 2018. Data show that in 2019, 14% of patients stayed for one to three months and a very small proportion (<1%) stayed more than three months.

Table 6.11

Length of stay in In-patient SPC beds, 2013-2019

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)
1–7 days	1240 (43)	1257 (41)	1417 (42)	1412 (40)	1361 (40)	1670 (43)	1624 (44)
8–28 days	1293 (44)	1367 (45)	1487 (44)	1556 (44)	1549 (45)	1673 (43)	1567 (44)
29–84 days*/1–3 months†	325 (11)	373 (12)	432 (13)	492 (14)	458 (13)	551 (14)	505 (14)
84+ days*/3+ months†	54 (2)	53 (2)	57 (2)	86 (2)	74 (2)	19 (<1)	17 (<1)

* Categories that existed before 2018.

† Categories that were updated from 2018.

4 Summary of Community SPC data

4.1 Community SPC: New patients by age

Similar to In-patient SPC, the majority of new patients in receipt of SPC in the community (homecare) are people in the 65+ age group. For 2018 and 2019, the age categories were expanded and show that patients in the 65–84 age group make up the majority of new patients in receipt

of SPC in the community. Patients in the 51–64-years age group also account for a sizeable proportion of new patients, around one-fifth, followed by people in the 85+ age group. People in younger age groups account for smaller proportions of new patients. In 2019, 7% were aged 18–50 years. In 2019, <1% of patients in receipt of SPC in the community were aged 0–17 years, a decrease from 1% in the years 2013 to 2015.

Table 6.12

New patients in receipt of Community SPC by age, 2013-2019

	2013	2014	2015	2016	2017	2018	2019
0–17 years	1%	1%	1%	<1%	<1%	<1%	<1%
18–64 years*	22%	23%	21%	29%	31%	27%	26%
18–50 years†						6%	7%
51–64 years†						21%	19%
65 years or over*	77%	76%	78%	71%	69%	73%	74%
65–84 years†						60%	57%
85 years and over†						13%	17%
Total	8822	8889	8967	2825	2769	3033	3029

* Categories that existed before 2018.

† Categories that were updated from 2018.

4.2 Community SPC: Zero-to seven-day wait times by CHO

In 2014 the 0–7 day admission access target for all services was set at 95%. In 2019, this target was not reached in any

Table 6.13
0–7 day wait times for Community SPC by CHO, 2013–2019

	2013	2014	2015	2016	2017	208	2019
National	87%	88%	89%	92%	92%	87%	86%
CHO1	91%	92%	92%	95%	96%	93%	94%
CHO2	90%	92%	91%	92%	95%	90%	90%
CHO3	100%	79%	96%	93%	93%	77%	85%
CHO4	78%	94%	91%	89%	86%	77%	72%
CHO5	95%	94%	98%	97%	96%	92%	86%
CHO6	78%	83%	77%	90%	83%	89%	88%
CHO7	78%	78%	77%	83%	86%	82%	86%
CHO8	91%	92%	91%	93%	95%	88%	88%
CHO9	76%	76%	79%	94%	94%	93%	91%

CHO area, although CHO 1 came close at 94%. Over the seven years from 2013–2019, CHO 5 stands out as the area to most frequently reach the target (four out of seven years). CHO 1 reached the target twice, CHOs 2, 3, 8 and 9 once, and the target was never achieved in CHOs 4, 6 and 7.

4.3 Community SPC: Rate of new patients per 10,000 population by CHO

In 2013, 19.2 new patients per 10,000 population received SPC in the community nationally (Table 6.5). This increased to 21.6 in 2019. However, there is wide variation across CHO areas, ranging in 2019 from 14.0 new patients

per 10,000 population in CHO 7 to 28.8 in CHO 2. In six CHO areas, the rate was higher than the national average of 21.6. When 2013 and 2019 are compared, eight CHO regions showed an increase in new patients receiving SPC in the community per 10,000 population (CHOs 1, 2, 3, 4, 5, 6, 7, 9), although the rate of increase varied substantially between these regions. CHO 8 was the only region to experience a decrease over the seven-year period.

Table 6.14
New patients in receipt of Community SPC per 10,000 population by CHO, 2013–2019

	2013	2014	2015	2016	2017	208	2019
National	19.2	19.4	19.6	20.3	20.2	21.0	21.6
CHO1	20.4	20.6	21.7	23.1	23.3	23.6	25.5
CHO2	21.8	22.0	24.1	24.6	26.5	26.5	28.9
CHO3	23.3	23.4	21.9	21.7	18.8	23.1	23.9
CHO4	21.2	22.7	21.8	24.7	22.2	21.7	22.7
CHO5	21.3	19.7	20.7	22.8	22.2	25.3	24.7
CHO6	16.9	19.5	21.9	21.6	22.0	20.7	23.5
CHO7	11.8	11.9	12.6	12.9	13.0	14.2	14.0
CHO8	25.3	24.0	21.2	20.6	21.6	21.8	20.4
CHO9	13.7	13.8	14.5	14.8	16.4	16.5	17.4

4.4 Community SPC: New patients by primary diagnosis and CHO area

Overall, between 2013 and 2019, the proportion of new patients with cancer as a primary diagnosis receiving SPC in the community decreased by 9 percentage points from 74% to 65% (conversely non-cancer increased by 9 percentage points) (Table 6.15). This pattern was observed

across the nine CHO regions, all of which showed a decrease in the proportion of new patients with cancer as their primary diagnosis between 2013 and 2019. However, there are differences between different CHO regions in the proportion of new patients living with cancer. For example, the lowest proportion in 2019 of new patients with a non-cancer primary diagnosis was in CHO 5 (26%) and the highest proportion was in CHO 2 and CHO 6 (both 42%).

Table 6.15
Community SPC New Patients by Primary Diagnosis and CHO, 2013–2019

New Patients	2013		2014		2015		2016		2017		208		2019	
	Cancer	Non-Cancer	Cancer	Non-Cancer	Cancer	Non-Cancer	Cancer	Non-Cancer	Cancer	Non-Cancer	Cancer	Non-Cancer	Cancer	Non-Cancer
National	74%	26%	72%	28%	71%	29%	70%	30%	68%	32%	70%	30%	65%	35%
CHO1	70%	30%	67%	33%	67%	33%	66%	34%	65%	35%	64%	36%	62%	38%
CHO2	70%	30%	67%	33%	65%	35%	62%	38%	58%	42%	64%	36%	58%	42%
CHO3	71%	29%	71%	29%	68%	32%	69%	31%	72%	28%	73%	27%	66%	34%
CHO4	74%	26%	71%	29%	70%	30%	69%	31%	73%	27%	68%	32%	67%	33%
CHO5	89%	11%	85%	15%	83%	17%	79%	21%	75%	25%	83%	17%	74%	26%
CHO6	70%	30%	65%	35%	64%	36%	65%	35%	61%	39%	67%	33%	58%	42%
CHO7	81%	19%	78%	22%	75%	25%	76%	24%	75%	25%	69%	31%	70%	30%
CHO8	64%	36%	66%	34%	67%	33%	66%	34%	66%	34%	71%	29%	63%	37%
CHO9	83%	17%	84%	16%	76%	24%	74%	26%	70%	30%	69%	31%	68%	32%

4.5 Community SPC: Patient deaths by place of death

In 2013, over two-fifths (42%) of patients receiving Community SPC died at home, compared with 14% who died in an In-patient SPC unit (Table 6.16).

Table 6.16.

Community SPC patient deaths by place of death, 2013-2019.

	2013 N (%)	2014 N (%)	2015 N (%)	2016 N (%)	2017 N (%)	2018 N (%)	2019 N (%)
Total Community SPC patient deaths	7,382	7,676	7,828	8362	7999	8268	8889
Patient's home*	42%	42%	41%	41%	41%		
Specialist palliative care in-patient unit	14%	15%	17%	17%	17%	19%	18%
Acute hospital	20%	19%	16%	16%	15%	16%	15%
Intermediate care beds in community setting*	6%	6%	5%	5%	5%		
Non-acute hospital bed*	4%	5%	5%	5%	5%		
Private nursing home	14%	13%	14%	14%	15%	20%	18%
Other*	1%	1%	2%	2%	3%		
Patient's home/carer's home†						39%	40%
Residential care (community nursing unit, district hospital)†						7%	9%

* Categories that existed before 2018.

† Categories that were updated from 2018.

For 2018 and 2019, place of death categories changed somewhat, making it a little difficult to make comparisons with earlier years. Nevertheless, in 2019, patient's home/carer's home continued to account for the majority (40%) of deaths, although the proportion who died in an In-patient SPC unit rose to 18%. There was a decrease in the proportion of Community SPC patients who died in acute hospitals, from 20% in 2013 to 15% by 2019. Conversely, the proportion of patients who died in private nursing homes increased from 14% in 2013 to 18% in 2019. Residential care (community nursing unit district hospital) accounted for 9% of deaths in 2019.

5 Summary of Day SPC data

5.1 Day SPC: New patients by age

The overall number of new patients in receipt of Day SPC was 946 in 2013 and 862 in 2019, representing a 9% decrease in the number of patients between these years (Table 6.17). Whereas people aged 18–64 years accounted for approximately one-third of patients in receipt of Day SPC in 2013, in 2019 they accounted for one-quarter

of patients. There was a corresponding increase in the proportion of patients aged 65 years and over from two-thirds in 2013 to three-quarters in 2019. A small proportion of patients are aged 0–17 years. For 2018 and 2019, the age categories were expanded showing that the majority of patients were aged 65–84 years in both 2018 and 2019, followed by people aged 51–64 years.

Table 6.17

New patients in receipt of Day SPC by age, 2013–2019

	2013	2014	2015	2016	2017	2018	2019
0–17 years	N/A	N/A	N/A	<1%	<1%	<1%	<1%
18–64 years*	34%	33%	29%	30%	29%	25%	25%
18–50 years†						7%	5%
51–64 years†						18%	20%
65 years or over*	66%	67%	71%	70%	68%	68%	75%
65–84 years†						55%	62%
85 years and over†						13%	13%
Total	946	945	934	961	966	821	862

* Categories that existed before 2018.

† Categories that were updated from 2018.

5.2 Day SPC: New patients by primary diagnosis

Patients with a primary diagnosis of cancer accounted for the majority of new Day SPC patients between 2013 and 2019. However, the proportion of patients with a primary diagnosis of cancer decreased from 87% in 2013 to 77% in 2019, and there was a corresponding increase in the proportion of new patients with a non-cancer diagnosis.

Table 6.18

Day SPC – new patients by primary diagnosis, 2013–2019

	2013	2014	2015	2016	2017	2018	2019
Total	946	945	928	961	966	821	862
Cancer	87%	83%	83%	83%	82%	82%	77%
Non-cancer	13%	17%	17%	17%	18%	18%	23%

6 Discussion

6.1 New patients receiving SPC

The number of new patients receiving SPC varies by SPC type. Changes over time also vary by SPC type. Of the three types of SPC services, the greatest number of new patients are accessing Community SPC followed by In-patient SPC and Day SPC (Table 6.17). In 2019, there were 10,301 new patients accessing Community SPC, which is an increase of 17% when compared with 2013. There were 3,029 new patients accessing In-patient SPC in 2019, representing a bigger increase of 33% when compared with 2013. There were 862 patients in receipt of Day SPC in 2019, up from the previous year, but a decrease from over 900 new patients in the years 2013 to 2018. In 2019, individuals aged 65+ years accounted for at approximately three-quarters of the total number of new patients in receipt of SPC across each setting (in-patient, Table 6.4; community, Table 6.12; and day care, Table 6.17).

6.2 Access to SPC services – in-patient and community

There was an overall upward trend in the number of SPC in-patient beds available per 100,000 population over the period under review, rising at national level to 4.7 beds per 100,000 population in 2019. However, this still falls far short of the recommendation made in 2001 by the National Advisory Committee on Palliative Care (NACPC) that ‘there should be at least 8 to 10 SPC beds available per 100,000 population to meet the increasing needs for specialist palliative care services in Ireland’⁴. Moreover, there was wide variation across CHO areas, with only CHO 4 reaching the recommended eight to ten SPC beds per 100,000 population. Despite a recommendation by the NACPC in 2001 that ‘there should be at least one SPC unit in each health board area’, there were no In-patient SPC beds available in CHO 5 or CHO 8 in 2019 (Table 6.3)⁴.

Nationally, there was also an increase in the number of new patients per 10,000 population admitted to an In-patient SPC unit from 4.98 in 2013 to 6.36 in 2019, a 22% (1.38) increase. Regionally, increases occurred in six of the nine CHO regions over the seven-year period (Table 6.5).

Between 2013 and 2019, there was an increase in the number of In-patient SPC unit bed days available (40% increase). On average, approximately three-quarters of available In-patient SPC unit beds were occupied, but occupancy fell by 6% between 2013 and 2019 (Table 6.10). There was no notable change in length of stay for patients between 2013 and 2017. In 2019, 44% of patients stayed for less than a week, 44% for 8–28 days, 14% for 1–3 months and <1% for 3+ months (Table 6.11).

The number of new patients per 10,000 population accessing Community SPC increased from 19.2 in 2013 to 21.6 in 2019, an increase of 13% (2.4). While access varied widely across CHO areas, access increased in eight CHO regions over the seven-year period, but decreased in CHO 8 (Table 6.14).

6.3 Access to SPC services – primary diagnoses

Data were available on the primary diagnosis type (cancer vs non-cancer diagnoses) of new patients in the three types of SPC service – In-Patient, Community and Day SPC. It shows that in 2019 the vast majority of new patients admitted to SPC in-patient units at national (84%) and CHO level (71% to 86%) were patients with cancer and that there has been a small but steady decrease since 2013 at both national (89%) and CHO level (84% to 96%) (Table 6.6).

While the majority of patients receiving Community SPC at both national (65%) and CHO level (58% to 74%) in 2019 had cancer as a primary diagnosis, the proportion is lower than for SPC in-patient units. Similar to In-patient SPC units, the proportion of patients receiving Community SPC with a primary diagnosis of cancer has fallen since 2013 at both national (74%) and CHO level (64% to 89%) (Table 6.15). Likewise, in 2019 the majority (77%) of new patients accessing Day SPC in 2019 had cancer as a primary diagnosis, a reduction from 87% in 2013 (Table 6.18).

The data indicate that patients with life-limiting illness other than cancer are making up a greater proportion of new patients using SPC services. This is in keeping with the principle underpinning the NACPC that palliative care should be available to all, irrespective of diagnosis⁴. Nationally, in 2019, they make up 16% of new patients using In-patient SPC units, 35% of Community SPC patients and 23% of Day SPC patients. The desired level of activity for these patients within SPC services is 25%⁵. Therefore, within Community SPC the desired level of activity for these patients was not only achieved but exceeded and this level is also close to being achieved in Day SPC.

6.4 Normal place of residence of patients on admission and discharge

Data available on place of residence before admission to an In-patient SPC unit shows that in 2019 slightly more than a half of new patients were admitted from an acute hospital (52%) and slightly less than half (47%) from their own/carer's home, a reversal of trends in 2013 (Table 6.7).

Around two-thirds (66%) of patients admitted to an In-patient SPC unit in 2019 died there, but around a quarter (28%) were discharged to their own home, a smaller proportion than in 2013. Discharges or transfers to other settings are very low (Table 6.9).

Data on place of death for new patients availing of Community SPC data show that in 2019 around two-fifths die at home (similar to 2013), around one-fifth die in an In-patient SPC unit (up from 2013), one-fifth in an acute hospital (down from 2013), and one-fifth in private nursing homes (up from 2013) (Table 6.16).

07 Acute hospital admissions

1 Introduction

This chapter presents an overview of emergency admissions to acute public hospitals in Ireland for the period 2013–2017 inclusive, using data from the Hospital Inpatient Experience (HIPE) database.

In Ireland throughout this period there were 34 acute public hospitals with an emergency department. Every admission is recorded in HIPE, which is operated by the Health Service Executive and Healthcare Pricing Office. Recorded categories of data are:

- Dates of Admission and Discharge
- Admission Type: booked or emergency
- Sex
- Marital / Civil Status
- Area of Residence by county
- Medical Card status
- Diagnoses: Principal and up to 29 additional secondary diagnoses, recorded using International Statistical Classification of Diseases and Related Health Problems (ICD) codes
- Procedures: Principal and up to 19 additional secondary procedures, recorded using ICD codes
- Discharge Destination

Due to the lack of a unique patient identifier, there is no way to quantify how many individuals are reflected in the data.

In this chapter we present HIPE data with a particular focus on emergency admissions indicating palliative and end-of-life care needs.

2 National overview

2.1 All admissions, by discharge status and serious illness

HIPE specifies 15 discharge destinations. We group these into six categories to ease interpretation.

Table 7.1
HIPE discharge destinations

HIPE discharge destination	Grouped in this chapter
Died no post mortem	Death
Died with post mortem	
Home	Home
Hospice	Hospice
Hospital/acute hospital – emergency	Other hospital
Hospital/acute hospital – non-emergency	
Hospital non-acute – emergency	Long-stay residential care facility (LSRCF)
Hospital non-acute – non-emergency	
Nursing/convalescent home	
Other	
Prison	
Psychiatric hospital/unit	Other place
Rehabilitation facility – non-HIPE	
Self discharge	
Absconded	

In Table 7.2 we present emergency admissions of adults to acute hospitals in Ireland in 2017, resulting in overnight stay, by discharge status. There were 273,244 such admissions recorded. The majority of patients went home upon discharge (79%). Next most common destinations were LSRCF (11%) followed by transfer to another acute hospital (4%). Most relevant for this report are those who died in acute hospitals (4%) and those discharged to a hospice (<0.5%).

Table 7.2 separates out the 143,383 emergency admissions where the patient had a recorded diagnosis of serious life-limiting illness. We identify these diagnoses in the same way as in Chapter 3 ICD codes for cancer, major organ failure or dementia. Compared to all emergency admissions, these admissions are more likely to end in death (6%), discharge to LSRCF (15%) or discharge to hospice (0.7%), and less likely to result in discharge home or to other place.

Admissions with a serious illness were 52% of all admissions. These admissions accounted overwhelmingly for deaths (94%) and hospice discharges (94%) as well as for the majority of discharges to other hospitals (71%) and LSRCFs (57%).

Table 7.2
Emergency admissions of adults to acute hospitals in the Republic of Ireland, 2017

	All admissions (%)	With a serious illness (%)	Admissions with a serious illness as a percentage of all admissions (%)
Died in hospital	9,697 (4%)	9,134 (6%)	94%
Home	215,582 (79%)	102,313 (71%)	47%
Hospice	1,074 (<0.5%)	1,006 (0.7%)	94%
LSRCF	31,386 (11%)	21,517 (15%)	57%
Other hospital	10,758 (4%)	7,612 (5%)	71%
Other place	4,747 (2%)	1,801 (1%)	38%
Total	273,244	143,383	52%

2.2 Length of stay, by discharge status and serious illness

In Table 7.3 we present mean and median length of stay in days, by discharge status and serious illness. Mean length of stay for all 273,244 admissions was 8.7 days and median length of stay was four days. This indicates that a small number of patients had unusually high length of stay. It is a near-universal characteristic of health care data that a minority of people account for a majority of use, and this is the case for all admissions and admission with a serious illness as well as for all discharge destinations in Table 7.3.

With respect to discharge status, admissions ending in discharge to hospice (average stay 20.5 days), discharge to LSRCF (18.8 days) and death (17.8 days) account for the majority of hospital days. A similar pattern is observed when looking only at those admissions with a serious illness, and average length of stay (LOS) is longer overall (11.6 days) and for each discharge destination.

Table 7.3
Mean and median length of stay in days, by discharge status and serious illness, 2017

	All admissions (N=273,244) Mean LOS (Median)	With a serious illness (N=143,383) Mean LOS (Median)
Died in hospital	17.8 (10)	18.0 (10)
Home	6.8 (4)	9.1 (6)
Hospice	20.5 (14)	21.0 (14)
LSRCF	18.8 (10)	21.4 (11)
Other hospital	9.0 (5)	9.6 (5)
Other place	8.4 (3)	13.1 (5)
Total	8.7 (4)	11.6 (6)

3 Hospital groups

HIPE data restrictions preclude reporting at the individual hospital level. Each hospital is part of one regional group:

- Ireland East Hospital Group
- Dublin Midlands Hospital Group
- RCSI Hospital Group
- South/Southwest Hospital Group
- UL Hospitals
- Saolta Hospital Group

In this section we report admission numbers, discharge status and LOS by hospital group. We restrict the sample to the 143,383 admissions with diagnosis of serious illness, since these account for the large majority of episodes that end in discharge to hospice, discharge to LSRCF and patient death.

Table 7.4.
Total number of admissions with a serious illness, by discharge status and hospital group, 2017

	Ireland East Hospital Group	Dublin Midlands Hospital Group	RCSI Hospital Group	South/Southwest Hospital Group	UL Hospitals	Saolta Hospital Group	All admissions with a serious illness
Died in hospital	2,069 (7%)	1,592 (7%)	1,563 (7%)	1,926 (8%)	524 (5%)	1,460 (5%)	9,134 (6%)
Home	19,622 (69%)	21,527 (72%)	16,262 (72%)	17,943 (70%)	7,772 (70%)	19,187 (72%)	102,313 (71%)
Hospice	128 (<0.5%)	195 (1%)	174 (1%)	205 (1%)	81 (1%)	223 (1%)	1,006 (0.7%)
LSRCF	4,675 (16%)	3,355 (16%)	3,615 (16%)	4,146 (16%)	1,737 (16%)	3,989 (15%)	21,517 (15%)
Other hospital	1,484 (5%)	1,553 (4%)	942 (4%)	1,066 (4%)	896 (8%)	1,671 (6%)	7,612 (5%)
Other place	569 (2%)	419 (1%)	182 (1%)	273 (1%)	107 (1%)	251 (1%)	1,801 (1%)
All Age	28,547	28,641	22,738	25,559	11,117	26,781	143,383

3.1 Admissions, by discharge status and hospital group

Total number of admissions with a serious illness, by discharge status and hospital group, are presented in Table 7.4.

Five of the six hospital groups each account for 16%–20% of total admissions. The exception is UL Hospitals, which account for 8% of episodes.

There is high consistency of discharge destination across groups. Home is the majority destination in all cases (69%–72%) and LSRCF is the second most common (15%–16%). Between 5% and 8% of admissions end in the patient's death in hospital. Approximately 1% of patients are discharged to hospice.

3.2 Length of stay, by discharge status and hospital group

Length of stay for admissions with a serious illness, by discharge status and hospital group, are presented in Table 7.5.

UL Hospitals had the lowest average LOS (mean=9.8 days) and Ireland East Hospital Group the highest (12.7

days). Both groups had a median stay of six days, and all groups had a median stay of six or seven days, suggesting that higher means are driven by a relatively small number of longer-stay admissions. Longer stays in the Ireland East Hospital Group, which includes two large university hospitals and cancer centres, may reflect visits for specialist care from all parts of the country.

Table 7.5 Length of stay for admissions with a serious illness, by discharge status and hospital group, 2017

Mean LOS (Median)	All admissions with a serious illness	Ireland East Hospital Group	Dublin Midlands Hospital Group	RCSI Hospital Group	South/Southwest Hospital Group	UL Hospitals	Saolta Hospital Group
Died in hospital	18.0 (10)	20.1 (10)	21.0 (12)	18.2 (10)	16.0 (10)	14.3 (8)	15.6 (9)
Home	9.1 (6)	9.1 (5)	9.6 (6)	9.5 (6)	8.8 (6)	8.3 (6)	8.5 (5)
Hospice	21.0 (14)	27.5 (18.5)	27.8 (20)	26.9 (19)	14.1 (10)	12.3 (9)	16.3 (12)
LSRCF	21.4 (11)	23.7 (12)	27.4 (13)	22.2 (11)	20.3 (11)	15.6 (11)	16.5 (10)
Other hospital	9.6 (5)	9.6 (5)	8.4 (3)	11.8 (8)	8.6 (4)	9.0 (5)	10.2 (6)
Other place	13.1 (5)	22.3 (6)	10.3 (5)	8.1 (4)	8.1 (4)	7.0 (4)	8.8 (4)
All Age	11.6 (6)	12.7 (6)	12.4 (6)	12.3 (7)	11.3 (6)	9.8 (6)	10.3 (6)

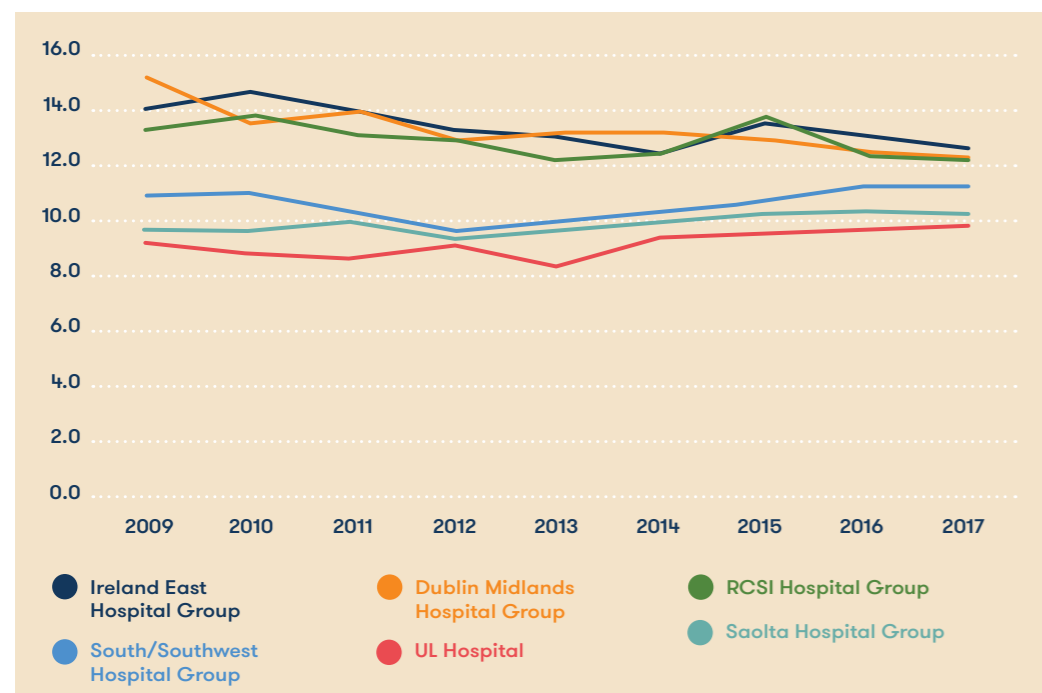
3.3 Length of stay, over time

Mean length of stay (days) for admissions by hospital group between 2009 and 2017 are presented in Figure 7.1.

At the start of this period, in 2009, there were notable differences in mean length of stay between hospital groups:

from 15.1 days (Dublin Midlands) to 9.2 (UL). Some convergence over time, with a drop in mean LOS among high-LOS hospital groups and an increase in LOS among low-LOS hospital groups, meant that this difference was smaller in 2017: from 12.7 days (Ireland East) to 9.8 days (UL).

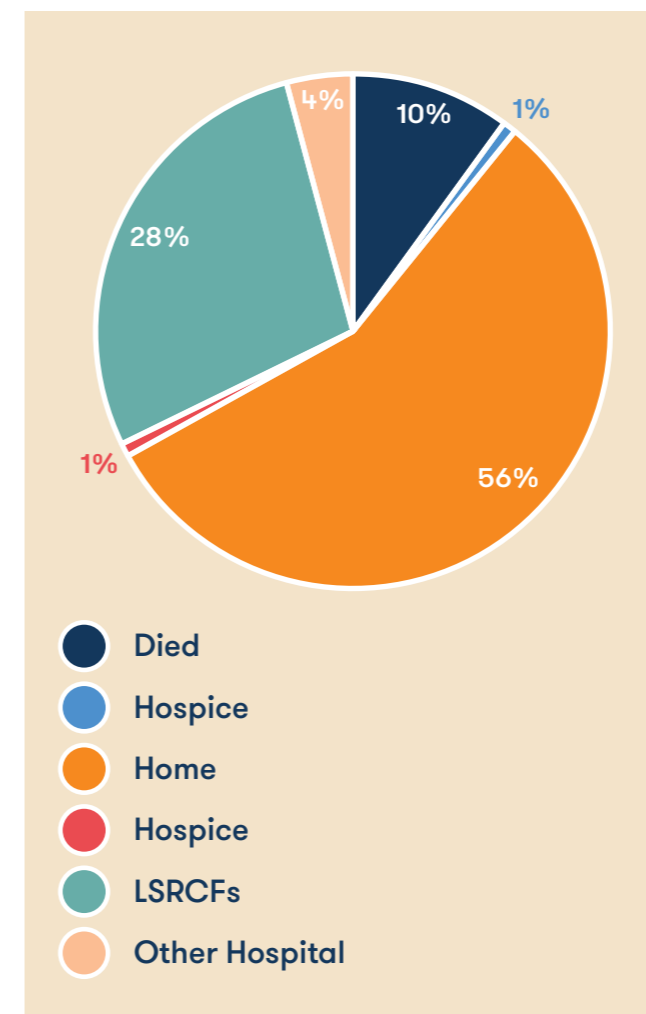
Figure 7.1 Mean length of stay (days) for admissions by hospital group, 2013-2019



4 End-of-life care as a core activity in acute hospitals

Summary data on admission numbers, length of stay and discharge status emphasise that death and dying are a central issue for all acute hospital services. If we combine the data provided in Tables 7.2 and 7.3 then we can calculate the total number of bed days in Irish public hospitals in 2017 – and the proportion accounted for by each discharge status. These data are presented for patients with a serious illness in Figure 7.2. The 6% of patients who die during admission account for 10% of days. Those discharged to long-stay residential care facilities (28%) and hospice (1%) also account for significant numbers of days.

Figure 7.2 Total bed days in 2017, by discharge status, among admissions with a serious illness



Another useful perspective is to consider expected survival of hospital in-patients beyond their admission. A large majority of people with serious illness in Irish hospitals are discharged alive, but within this group exists a significant number who would benefit from palliative and end-of-life care. In their landmark paper, Clark et al. tracked 10,743 in-patients in 25 Scottish teaching and general hospitals on 31 March 2010 for one year¹. They found that 3,098 (28.8%) patients died during the year following, and concluded, ‘Large numbers of hospital in-patients have entered the last year of their lives. Such data could assist in advocacy for these patients and should influence end-of-life care strategies in hospital.’

A replication study is not possible in Ireland because the lack of a unique identifier prevents us following patients for the year following admission. Nevertheless, we can compare the data reported by Clark et al. with the data available via HIPE and make some inferences about the role of death and dying in Irish hospitals.

In Table 7.6 we replicate the data from Clark et al., alongside data on people in HIPE as Irish in-patients admitted as an emergency on 29 March 2017. We chose this date as (1) the most recent year in our data, (2) the date in 2017 that was as close as possible to Clark et al.’s census date of 31 March 2010 while still being the same day of the week (Wednesday). We adopted this strategy to minimise temporal effects in comparison: hospital admissions vary by day of the week and time of year.

The age distribution of patients in the two studies was extremely similar: 28% aged under 60 in Scotland compared to 27% in Ireland, 8% versus 7% aged 60–64, 10% in both places aged 65–69, 11% versus 12% aged 70–74, 14% versus 13% aged 75–79, 13% versus 14% aged 80–84, and 16% versus 17% aged over 85.

An important difference immediately observable is the hospital mortality rate: of the Scottish cohort, 1001 (9%) died during the index admission. For the Irish cohort, the equivalent figure is 460 (6%). This is consistent with evidence cited elsewhere in this report that the Irish health care system is unusually reliant on hospital in-patient admissions, and so has shorter length of stay and lower hospital mortality rates than similar countries².

A direct comparison of age distributions and mortality rates is not possible because HIPE provides only death data for the admission under study, while Clark et al. do not provide mortality rates by age and location but instead by age and survival at 30 days. The 30-day mortality rate in Scotland was also 9%, suggesting a good level of comparability with index admission mortality rate even if the two are not

identical. An indirect comparison of HIPE mortality rates for the admission against Scottish mortality rates after 30 days suggests that Irish hospital mortality rates are lower across the age distribution: 11% of admissions for over 85 year olds end in death, whereas in Scotland 15% of patients over 85 years died within a month, and proportions are lower in Ireland than Scotland for every other age bracket also.

Table 7.6
Mortality among hospital in-patients in Scotland and Ireland

Age	Scottish hospitals, 31/3/2010				Irish hospitals, 29/3/2017							
	At Census		Died during admission		Died 1 month		Died 12 mths		At Census		Died during admission	
<60	3008	28%	.	.	110	4%	394	13%	1962	27%	55	3%
60–64	845	8%	.	.	60	7%	191	23%	517	7%	20	4%
65–69	1021	10%	.	.	87	9%	299	29%	758	10%	42	6%
70–74	1185	11%	.	.	105	9%	355	30%	895	12%	54	6%
75–79	1487	14%	.	.	148	10%	491	33%	954	13%	66	7%
80–84	1430	13%	.	.	180	13%	562	39%	997	14%	80	8%
85+	1767	16%	.	.	261	15%	806	46%	1279	17%	143	11%
All	10743		1001	9%	951	9%	3098	29%	7362		460	6%

. = data not provided. Data for 'Scottish Hospitals' are replicated without change from Clark et al. (2014) under licence from Creative Commons BY 3.0.

Hospital in-patients in Scotland have approximately 1.5 times the odds of dying compared to in-patients in Ireland (a 9% mortality rate versus 6%). If this differential is consistent across a 12-month period then approximately 20% of adult in-patients in Irish public hospitals on a given day will die within the year. While not as high as trends in Scotland, this is still a large number of adults approaching end of life who would benefit from acute hospital care that is tailored to their needs.

5 Use of Z51.5

Palliative care engagement is not routinely recorded in HIPE data. In the ICD-10 handbook, the ICD-10 code Z51.5 denotes 'encounter for palliative care'. However, there is no requirement for a palliative care team to have been involved in in-patient care in order for an in-patient to receive this code. Often it is added to a patient record when the attending clinical team (e.g. oncology, cardiology) deems that the emphasis of care has shifted from mainly curative to mainly supportive. Ultimately, patients who do not receive specialist palliative care may nevertheless have a Z code recorded; those who do receive specialist palliative care may not. Consequently, this Z code is not deemed a reliable indicator of specialist palliative care involvement. Studies in the US have shown that, on the one hand, the Z code has a high true negative rate, that is, it is rare for someone to have Z51.5 recorded in their file without having received specialist palliative care – for example, because their attending physician does not involve the palliative care team but shifts the emphasis to supportive rather than curative care in their own approach to the patient. On the other hand, these studies have shown that the Z code does not have a particularly strong true positive rate for identifying palliative care involvement³, since a third of people who do receive palliative care do not have Z51.5 recorded in their file, mainly because there is no systematic requirement for any clinical team to do so.

Despite its limitations, Z51.5 has some uses for understanding patterns of practice for seriously ill people in acute hospitals. First, while it is not perfectly aligned with specialist palliative care receipt it is nevertheless strongly correlated. Therefore, if we observe changing patterns of use of Z51.5 over time we can reasonably infer changing patterns of palliative care use. Second, where use of the Z51.5 code is not indicating specialist palliative care involvement it is nevertheless indicative of changing mindset among non-palliative clinicians; for example, increased use of the Z51.5 code for people not receiving palliative care would suggest that other specialisms are themselves more frequently changing emphasis from curative to supportive intent in their care of seriously ill patients.

5.1 Diagnoses of people receiving Z51.5 code

Table 7.7 includes data on the primary diagnoses (i.e. reason for hospital episode) of the 16,755 episodes (either in-patient or day case) which had a coding for Z51.5 in 2017. To correspond with 'Chapter 3: Cause of Death', we have grouped the primary diagnoses into seven overarching conditions. The majority of hospital episodes had a primary diagnosis of cancer (29.9%), a disease of the respiratory system (20%) or a disease of the circulatory system (8.7%). Diseases of the digestive and nervous systems, and mental and behavioural disorders, accounted for a combined total of 8.4% of hospital episodes. The remaining 33.5% of hospital cases were due to 'other' conditions.

Table 7.7
Hospital episodes that used Z51.5 coding by primary diagnoses, 2017

Condition	Hospital Episodes N	Percent %
Cancer	5004	29.9
Disease of the circulatory system	1448	8.7
Disease of the respiratory system	3350	20.0
Disease of the digestive system	1066	6.4
Disease of the nervous system	234	1.4
Mental & behavioural disorders	87	0.6
Other	5566	33.5
Total	16755	100

* The true negative rate (also known as specificity) is the probability that an actual negative (in this case: did not receive SPC) will test negative (in this case: did not receive a Z51.5 code in their file).

† The true positive rate (also called specificity) is the probability that an actual positive (received SPC) will test positive (receive a Z51.5 code).

5.2 Use of Z51.5 code over time

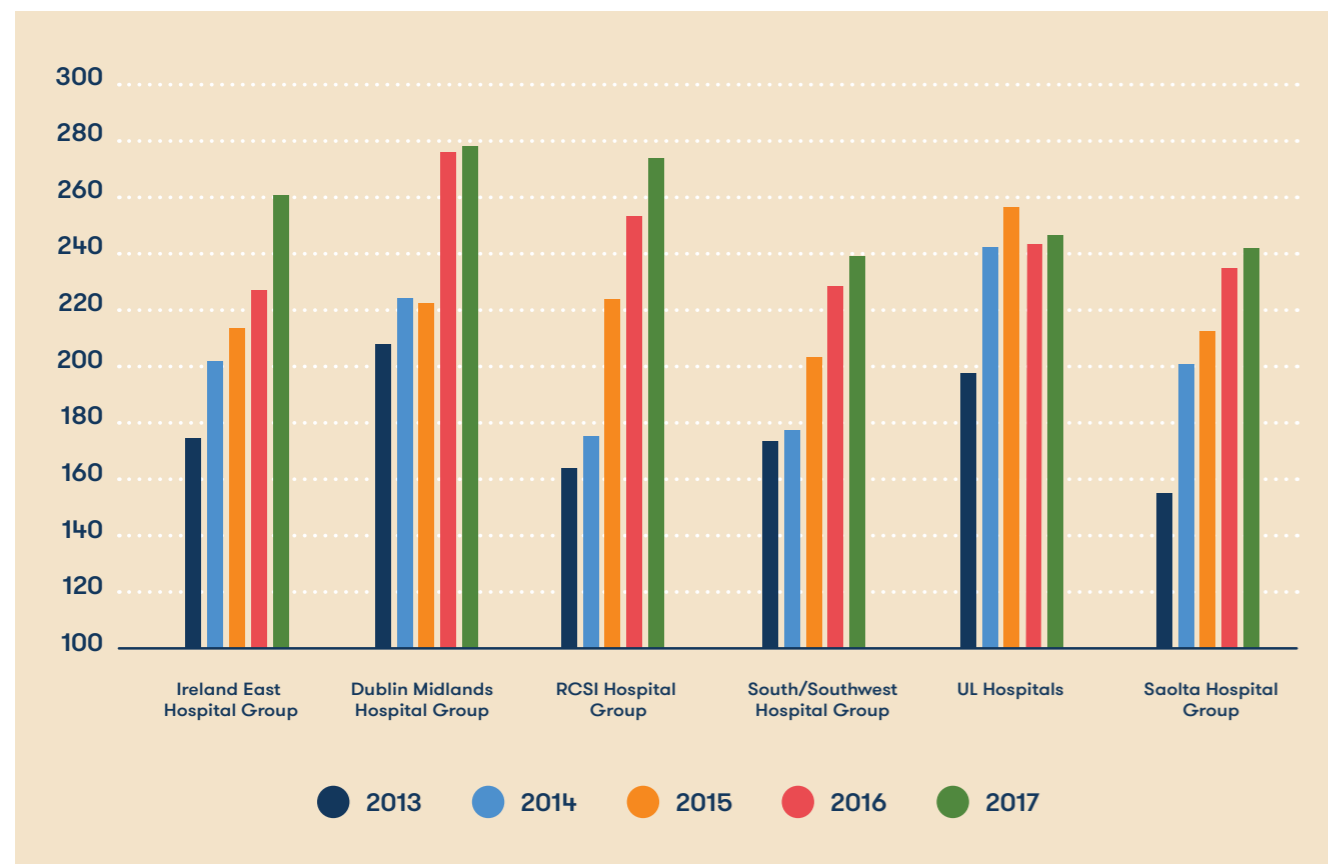
The number of Z51.5 episodes per 10,000 in-patient episodes by hospital group between 2013 and 2017 is presented in Figure 7.2.

Between 2013 and 2017, each hospital group experienced an increase in the number of Z51.5 episodes per 10,000 in-

patient episodes. The RCSI Hospital Group experienced the greatest increase over the five-year period (67% increase) and UL Hospitals experienced the smallest increase (24%). In 2017, the Dublin Midlands Hospital Group accounted for the highest number of Z51.5 episodes per 10,000 in-patient episodes (279 episodes) and the South/Southwest Hospital Groups accounted for the lowest (240 episodes).

Figure 7.3

Number of Z51.5 episodes per 10,000 in-patient episodes by hospital group, 2013–2017



6 Discussion

Emergency in-patient hospital admissions are an important aspect of health care use for people living and dying with serious illness. This group inevitably faces a relatively high number of episodes requiring emergency care⁴. At the same time, most people prefer to keep hospital stays as short as possible provided they can access suitable supports at home⁵. Furthermore, hospital in-patient stays account for over half of health care costs in the last year of life⁶. Ireland's hospital system has much lower spare capacity than many similar EU countries⁷. Therefore it is essential that hospital stays for people with serious illness are responsive to needs from the point of emergency admission, including early involvement of palliative care where appropriate, while maintaining the length of admission at no longer than necessary to maximise patient experience and minimise inefficient expenditures.

The data in this chapter show that approximately half of adult emergency admissions to acute hospitals in Ireland occur for people with a diagnosis of cancer, major organ failure or dementia. These admissions account disproportionately for both length of stay and discharges ending in death. Patterns of length of stay and discharge locations have been broadly consistent across hospital groups and over time.

It is therefore clear that care for dying patients is a core function of acute public hospitals, though this fact is not always clearly acknowledged. People dying with a serious illness accounted for 10% of all bed days in 2017 and additional large numbers were accounted for by those discharged to hospice and long-term residential care. Combining data from HIPE with a prior study in Scotland, we estimate that on a given day 20% of people in Irish public hospitals following an emergency admission will die within 12 months.

Research efforts by policymakers and academics to tackle the Irish system's high reliance on hospital care face data challenges. First, the lack of a unique patient identifier means that investigators cannot track people before or following a given admission, which profoundly limits our understanding of how they came to be admitted and how they fared after discharge. Indeed, in this chapter we cannot quantify how many individuals were admitted to Irish hospitals – only the total number of admissions. Second, the lack of a reliable indicator of specialist palliative care receipt is an important barrier to measuring access, and to evaluating the effectiveness and cost-effectiveness of services. Third, the volume of admissions with a serious illness far exceeds the capacity of specialist palliative care in acute hospitals. Diffusing palliative care approaches across hospital staff is essential to meet this large and growing need, and data collection is essential to monitor and evaluate those approaches.

It is also important to consider dynamics outside the hospital silo. A recent study in Dublin found that better community services are associated with a reduction in length of hospital stay⁸. Reducing length of stay can improve experiences for patients and costs for the system, but better still might be eliminating an admission altogether. Up to a quarter of emergency admissions in Ireland are potentially avoidable⁹, and international evidence suggests that Ireland has unusually high reliance on in-patient stay⁷.

08 Discussion

The aim of this report was to present and appraise routine data collection on death and dying in the Republic of Ireland. The report drew on three main sources: CSO data generated from death certificates, the HSE's specialist palliative care service's Specialist Palliative Care Minimum Data Set (SPC MDS), and the Hospital In-Patient Experience (HIPE) database on admissions to public hospitals.

We used the CSO data on mortality covering the years 2013 to 2018 inclusive in two main ways: (1) to examine place of death, and (2) to examine leading causes of death in Ireland. For the latter, we first examined the main cause of death categories and then examined cancer

and dementia separately as leading causes of death. The SPC MDS provides summary data on activity and utilisation of SPC services for the period 2013–2019 inclusive. We used HIPE data to present an overview of emergency admissions to acute public hospitals in Ireland for the period 2013–2017 inclusive, with a focus on those with serious life-limiting illnesses such as cancer, advanced organ disease and dementia.

This chapter presents the main findings from our analysis and discusses the most important implications with respect to data access, classification and coding practices, and data gaps and limitations.

1 Summary of main results

1.1 Place of death

In Chapter 2 we grouped CSO data on place of death into five main categories: hospital, home, long-stay residential care facility (LSRCF), hospice and elsewhere. For each of these categories we examined trends over time, regional variations and age-related variations.

Data showed that hospitals are the most common place of death in Ireland and hospital death rates remained steady over the period under review. Hospitals are the most common place of death for all age groups apart from people aged 85+ years. A greater proportion of people aged 85+ die in LSRCFs than in hospitals. Accordingly, LSRCFs are a significant place of death for older people. This is important given the ageing of the population and highlights the need for end-of-life and palliative care services to respond to changing demographics. While the proportion of deaths in LSRCFs has increased only slightly over the six-year period under review, different trends were observed when nursing homes and community hospitals were examined separately. Deaths in nursing homes have increased while deaths in community hospitals have decreased. The reasons for these diverging trends warrant further investigation.

There was a small increase in the number of in-patient hospice beds between 2013 and 2018, and this is likely to be responsible for the increase in the proportion of deaths in hospices from 6% to 8%. The proportion of deaths that take place at home has remained steady at 23%. Given that the expressed preference of most people is for a home death and the least preferred place of death is hospital, there is a marked mismatch between preferred and actual place of death. While the reasons for this are multiple, and place of death is determined by a complex interplay of factors, more attention needs to be focused on enabling people who wish to die at home to do so, where this is possible and appropriate.

With respect to regional variations in place of death, the most marked variation was for hospices. Not all regions have a hospice, so while people do move across regional borders for a hospice admission, this inevitably impacts patterns of care: access to a hospice relies heavily on whether you live near to one. This highlights the need for greater access to in-patient hospice care across the country to reduce the geographical inequity that currently exists. It is expected that the recent or planned opening of new hospices will go some way to addressing this inequity. While home death rates have remained stable at 23% since 2013, there is marked regional variation across the country. Whereas in Dublin 17% of deaths occurred at home, most counties had home death rates above the national average

of 23%, reaching a high of 30% or more in Carlow and Longford. The CSO data do not allow us to quantify how many such deaths occur in places consistent with preference. For example, low home deaths in Dublin may be due to low home care capacity and overreliance on hospitals, and/or high home deaths in rural areas may be due to improved accessibility of other services or high reliance on unpaid family carers. Further investigation is needed to understand how regional variation reflects preferences and the extent to which it reflects unmet need.

1.2 Cause of death

In Chapter 3, we grouped 1,780 different causes of death into eight main categories, and used these data to examine trends over time, regional variations in leading causes of death, and age and sex differences.

The CSO data show that between 2013 and 2018 cancer replaced diseases of the circulatory system as the leading cause of death in Ireland. This change partly reflects a long-term trend of declining heart-related mortality in Ireland. Diseases of the respiratory system were the third most common cause of death in 2018. While deaths caused by mental and behavioural disorders was lower, accounting for 6% of all deaths, these deaths increased substantially, by 61%, between 2013 and 2018.

Most deaths in Ireland occur among older people, with people aged 65+ accounting for 82% of all deaths in 2018. However, this varies across different cause of disease categories, ranging from 77% for deaths caused by cancer to 99% for deaths caused by mental and behavioural diseases, the latter being largely attributed to dementia. This highlights the importance that diseases such as dementia are gaining as a cause of death for older people. The data also show that leading causes of death vary among different sexes. Cancer mortality is higher among males, whereas deaths from diseases caused by mental and behavioural disorders are more prevalent among females. These findings highlight the importance of organising specialist palliative care services to be responsive to individuals' needs, such as age, sex, circumstances and preferences for end-of-life care.

Cause of death was also examined with respect to place of death and data show that place of death varies greatly for different cause of death categories, highlighting that where a person dies is likely to be influenced by the type of disease and the disease trajectory.

1.2.1 Cancer as a cause of death

In Chapter 4, we grouped different types of cancer into nine categories to enable us to provide an overview of death rates for different types of cancer and how these differ by age and sex. Data show that there were four leading cancer categories among the 9,466 deaths caused by cancer in 2018: gastrointestinal (31% of cancer deaths), respiratory and thoracic (20%), breast and gynaecological (14%), and genitourinary and testicular cancers (12%). People aged 65+ accounted for at least two-thirds of deaths in each of these four cancer categories. There were important sex differences, with females accounting for a higher proportion of deaths in two categories (breast and gynaecological and cancer of unknown primary), and males accounting the majority in all other cancer categories.

1.2.2 Dementia as a cause of death

In Chapter 5, we analysed deaths caused by dementia. There has been a steady increase in deaths caused by dementia over the period 2013–2018 and of the 31,140 deaths that occurred in Ireland in 2018, 2,446 (8%) were caused by dementia. Of these, 64% were attributed to unspecified dementia, 23% to Alzheimer's disease and 12% to vascular dementia. Factors likely contributing to this rise include longer life expectancy and increasing dementia prevalence, improved dementia diagnosis, and better reporting of dementia on death notification forms. It is highly likely that there is an underreporting of deaths caused by dementia for a variety of reasons, but the extent of underreporting is unknown. Nearly all deaths caused by dementia were among older age groups, and increased as age increased, which is not surprising given that increasing age is the biggest risk factor for dementia. Women accounted for two-thirds of the deaths caused by dementia. This reminds us that dementia is a gendered issue and highlights the importance of paying attention to the gender dimension and promoting gender-sensitive approaches in end-of-life and palliative care services for people with dementia.

1.3 Activity for Specialist Palliative Care services

Chapter 6 summarised data on activity for and utilisation of adult SPC services for the period 2013 to 2019, based on the SPC MDS. It updates a previously published report¹. Data show that while there was an upward trend in the number of new patients admitted to an in-patient SPC unit and receiving SPC community care for the first time, the number of new patients receiving SPC day care decreased from 2018. While nationally the number of SPC in-patient beds per 100,000 population increased to 4.7, this is still below the level recommended in 2001 by the National

Advisory Committee on Palliative Care (NACPC)², and there is wide variation regionally, with only one Community Healthcare Organisation (CHO) achieving the recommended level of beds. There was one CHO with no in-patient SPC beds in 2019. With respect to Community SPC, access also varied regionally.

The primary diagnosis of the vast majority of new patients admitted to in-patient SPC units and receiving Community SPC and specialist palliative day care is cancer. However, patients with life-limiting illness other than cancer make up a greater proportion of new patients using SPC services. This is in keeping with the principle underpinning the NACPC2 and the substantial work by IHF over many years through their Palliative Care for All programme, that palliative care should be available to all, irrespective of diagnosis. The desired level of activity for these patients is being achieved in Community SPC, but not in other SPC services.

In regard to place of death, the SPC MDS showed that two-thirds of new patients admitted to in-patient SPC units die there, with most of the remainder discharged home. The place of death for new patients receiving Community SPC is varied.

1.4 Hospital emergency admissions

Chapter 7 showed that people with a diagnosis of cancer, major organ failure or dementia make up approximately half of all **adult emergency admissions to acute hospitals** in Ireland. These admissions account disproportionately for both length of stay and discharges ending in death. Patterns of length of stay and discharge locations are broadly consistent across hospital groups and over time.

Death and dying are a core activity of acute public hospitals in Ireland. We estimate that among all adults in an acute public hospital in Ireland following emergency admission on a given day, one in five will die within the next 12 months. It is clear that the volume of admissions with a serious illness far exceeds the capacity of SPC services in acute hospitals. Diffusing palliative care approaches across hospital staff is essential to meet this large and growing need. Moreover, better community services could potentially reduce emergency admission of patients with serious illness to acute hospitals in the first place.

2 Challenges, policy implications and next steps

2.1 Reliable indicators and outcome measures

In this report we have used available data to establish what is known in relation to important issues on death and dying in Ireland. In reviewing our findings, it is essential to remember what is not currently measured. This should inform interpretation of the data that we have and prompt consideration of improved data collection practices in future.

Dying at the preferred place is widely held to be a desirable outcome of palliative care. Accordingly, place of death is commonly used as an indicator of a 'good death' and as a proxy for quality of care. However, place of death *on its own* is not necessarily a good indicator or proxy for either. For example, where a person dies is determined by a complex interplay of factors, some of which are not easily modified. Therefore, while population-level indicators of home and hospital deaths may tell us something about how the overall system is performing, they tell us nothing about individual experiences, which will vary very widely. There is a need to broaden the focus beyond place of death, with place of death used as one indicator in a suite of indicators of quality of care at end of life.

Similarly, cause of death is a measure that must be carefully interpreted. We have highlighted, for example, that the proportion of deaths (8%) attributed to dementia is likely to be an undercount, signalling the need for improvements in dementia diagnosis as well as better reporting of dementia on death certificates. Moreover, as populations age and people live and die with multiple serious conditions and limitations, the concept of a single identifiable 'cause of death' is increasingly flawed. What is recorded on the death certificate as the primary cause is often a value judgement by the person filling the certificate in. Improved understanding of the total prevalence of conditions, and the co-occurrence of specific conditions, as people age and die is critical to planning and providing appropriate services.

The SPC MDS is a standardised dataset, with a focus on SPC services activity and utilisation. It does not tell us if there is an essential minimum core of professionally trained staff with recognised post-qualification specialist training and critical expertise in SPC services. Moreover, it does not include standardised outcome measures for use in evaluating and monitoring the quality of SPC services at a national level. Increasingly, person-centred outcome measures are seen as the gold standard for measuring quality of care. The Palliative Care Outcomes Collaboration (PCOC) in Australia (<https://www.uow.edu.au/ahsri/pcoc/>), which provides a useful source of routine palliative

care outcome data in Australia and is being implemented internationally, offers a useful model for consideration for Ireland. There may also be examples from other countries.

Furthermore, not all patients who could benefit from SPC services will receive SPC services. These patients will be excluded from the MDS. Some people will be receiving SPC services provided by voluntary sector organisations such as the Nurses for Night Care Programme operated by the Irish Hospice Foundation and Night Nursing by the Irish Cancer Society, neither of which is captured by the MDS. For this reason, access to a broad range of data is needed to understand end-of-life care of all people with life-limiting illnesses in Ireland.

With respect to in-patients in acute hospitals, the lack of a reliable indicator of SPC receipt is an important barrier to measuring access, and to evaluating the effectiveness and cost-effectiveness of in-patient care in acute hospital services.

2.2 Classification and coding practices

A methodological challenge associated with using secondary data relates to classification and coding practices. Although changes to classifications can affect comparability over time, we regard the new place of death classification introduced by the CSO in 2017 as a positive development. For example, 'hospice' is now included as a separate place of death category. We found that the new 11-category classification introduced by the CSO allows for reasonably accurate data that will inform regional and national trends of place of death and impact future service planning. However, we found interpreting CSO data on place of death to be challenging as definitions are not provided for each category. Two categories in particular, i.e. 'community hospitals' and 'nursing homes', are problematic, as, lacking clear definitions, they make interpretation of the findings more difficult. The provision of clear definitions by the CSO for 'nursing homes' and 'community hospitals' would be helpful for data interpretation. Moreover, we found that each of the datasets that we used classifies long-stay residential care facilities in a different way, and incompatibility across datasets is an issue that needs to be addressed. Classification changes occurred with respect to the MDS, specifically with respect to place of residence both before admission to and after discharge from an in-patient SPC unit, and to length of stay. These changes affected comparability over time. Expansion of age categories in the MDS is to be welcomed.

2.3 Absence of a unique patient identifier

There is no unique patient identifier in Ireland, which presents challenges for secondary data analysis. For example, it means that investigators cannot track people before or following a given hospital admission, which profoundly limits our understanding of how they came to be admitted and how they fared after discharge. Indeed, in this report we could not quantify how many *individuals* were admitted to acute hospital or receiving SPC services, only the total numbers in receipt of these services. Palliative and end-of-life care is complex care: people use a variety of different services in different settings, and optimally they do so from early in the diagnosis of a serious disease until death. Therefore, understanding how the trajectory of disease and need changes, how people use and access services, and how people die requires the linking of multiple data sources over time at the individual level. The Covid-19 crisis has provided a further illustration of the limitations placed upon providers and patients by the lack of a unique identifier. Acting upon existing legislation to implement a unique identifier is a long-standing priority in the Irish health system and a pre-requisite if patients are to receive responsive, efficient, high-quality health care across multiple providers and settings as they approach end of life.

2.4 Data limitations and gaps

We have shown that there are wide regional variations with respect to use of SPC services, highlighting that access to services may be limited by where a person lives. Similarly, we have shown that there are age disparities with respect to place of death.

Concerns about equity often fuel debates regarding the extension of palliative care services. While the datasets we used allowed us to examine some variations between groups, for the purposes of demonstrating inequities, we would also need to show that such variations can be attributed to variations in need. This was not possible with the datasets available to us, highlighting the need for research to examine why the variations identified occur.

We do not have data to show place of death for people with dementia. Having evidence about where people with dementia die is important for knowing where the focus

needs to be for end-of-life and palliative care services for people with dementia. A more general problem with the CSO data is that it does not provide a breakdown of place of death by sex, ethnicity or socio-economic status, thus limiting the usefulness of the data for understanding gendered, ethnic and socio-economic variations in place of death. A specific request could be made for a breakdown by gender and by occupational status. However, ethnicity is not currently recorded on the Death Notification Form.

It is possible to analyse data from the MDS by age, but not by sex, ethnicity or socio-economic group. This is in spite of the fact that the NACPC in 2001 stated that the SPC MDS ‘should include demographic (e.g. age, sex, ethnic) information on all patients of the SPC services’ (p. 120)². The NACPC in 2001 drew particular attention to ethnicity stating that: ‘ethnic and cultural diversity is now a demographic reality within most western societies and cannot be ignored by SPC services’ (p. 45)². It must not be ignored in death registration data either. These data gaps need to be addressed.

2.5 Challenges accessing data

The research team faced challenges in gaining access to data for secondary analysis. The National Cancer Registry Ireland (NCRI) maintains a national cancer register with information on every case of cancer in Ireland. It was intended at the outset to use NCRI data, but access to the national dataset was not achieved due to NCRI capacity issues in processing the data. While access to data from other sources was achieved, capacity issues contributed to delays in accessing data from the MDS and HIPE data, and there were limits to the level of data that the CSO could produce for the research team. Getting access to or clarification on data was further hampered by the Covid-19 pandemic and in 2021 the cybersecurity attack on the HSE. There is increasing recognition of the power of data to inform better care, but our experience is that accessing population data for secondary data analysis is problematic. Better systems need to be put in place to facilitate researchers to gain access to health and social care data, and capacity issues preventing access needs to be addressed.

2.6 Data on impact of Covid-19 pandemic not yet available

Undoubtedly, the Covid-19 pandemic has had a significant impact on dying and death in Ireland. Data for 2020 is not yet available from any of the datasets examined and it remains to be seen how the Covid-19 pandemic has impacted this area, although it is highly likely that when it becomes available the data will show that the Covid-19 pandemic had an impact on place of death, SPC activity and utilisation, and hospital emergency admissions. In the UK, for example, data show that the number of deaths from all causes in private homes for 2020 increased by approximately one-third when compared with previous years and the increase was sustained throughout 2020^{3,4}. Several reasons were identified for this increase⁴. However, in the UK, concerns have been raised that without adequate support and care in the community, dying at home may not have been a positive experience during the pandemic, and many gaps in knowledge were highlighted. In Ireland, even in the absence of data, Covid-19 provides us with an opportunity to generate debate on important issues relating to dying and death.

2.7 Suggested next steps in data infrastructure

The following steps have been identified by the research team for progressing work in the area of secondary data analysis on death and dying in the Republic of Ireland.

- Promote the use of person-centred outcome measures, including people’s preferences, to better evaluate and monitor end-of-life care at national level.
- Address data gaps relating to sex, ethnicity and socio-economic status.
- Address the lack of a unique identifier so that we can understand people’s experiences and health care use across the trajectory of serious illness.
- Increase compatibility between datasets, particularly in relation to data on long-stay residential care and how it is classified.
- Improve access to relevant datasets by researchers.
- Promote collaboration among data-holding bodies and researchers.

Such considerations should be taken alongside other relevant work in this area in recent times⁵.

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List of Abbreviations

CHO	Community Healthcare Organisation
COD	Cause of death
COPD	Chronic obstructive pulmonary disease
CSO	Central Statistics Office
G&O	General and Orthopaedic
GRO	General Register Office
HSE	Health Service Executive
HIPE	Hospital In-Patient Experience
ICD-10	International Classification of Diseases, Version 10
IHF	Irish Hospice Foundation
LOS	Length of Stay
LSRCF	Long-stay residential care facility
NACPC	National Advisory Committee on Palliative Care
NCRI	National Cancer Registry Ireland
PCOC	Palliative Care Outcomes Collaboration
PELCI	Palliative and End-of-Life Care Ireland
POD	Place of Death
RCSI	Royal College of Surgeons in Ireland
SPC	Specialist Palliative Care
SPC MDS	Specialist Palliative Care Minimum Dataset
UK	United Kingdom
UL	University of Limerick

