Death and dying in Wales

An analysis of inconsistencies in access to specialist palliative care and hospital activity in the last year of life

Marie Curie Cancer Care and the Bevan Foundation

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Contents

1. Introduction

Each year approximately 32,000 people in Wales die – equivalent to 87 every day. The Office for National Statistics predicts that the number of deaths in Wales will have increased to approximately 35,000 per year by 2037[1]. How the NHS in Wales and society as a whole manages and supports terminally ill individuals and their families is one of the major issues facing Wales today.

Care in the last 12 months of life is vitally important to the well-being of a person, their family and friends. It is widely recognised that palliative care and specialist palliative care can help people through their final months, weeks and days of life, and support people to die in the place of their choice.

Wales has made considerable progress since the 2008 Sugar report[2], which looked at palliative care services in Wales and made recommendations on how they should be improved. The Palliative Care Implementation Board (now known as the End of Life Care Implementation Board) has overseen important improvements such as increases in the palliative care workforce, better co-ordination of services across the NHS and third sector providers, 24/7 services, and improved advice. The most recent National Survey of Patient Activity Data for Specialist Palliative Care Services reflects this progress, finding that Wales has a higher level of specialist palliative care services per 1,000 deaths than England or Northern Ireland[3].

Despite this significant improvement, there are clear indications that palliative care services in Wales are not meeting people's needs. Equally, they may be spending more time in hospital than is clinically necessary or desirable. Marie Curie was concerned to explore whether access to palliative care services may be shaped by people's socio-economic status, exacerbating existing inequalities in the incidence of diseases, as well as by factors such as age and diagnosis.

Marie Curie asked the Bevan Foundation, an independent think-tank and research centre, to investigate the association, if any, between socio-economic factors, hospital activity in the final year of life and receipt of palliative care. This report analyses data from the NHS Wales Informatics Service (NWIS) regarding people who are recorded as having received specialist palliative care prior to their death for everyone who died in Wales in 2012. It reveals some striking findings relating to admissions and bed days in the last year of life and access to palliative care according to the cause of death and age, yet a smaller role for deprivation than anticipated.

As is often the case, the research raises more questions than it answers. Finding the answers and developing and implementing solutions is vital to ensuring that the 32,000 people who die in Wales every year have a decent and dignified death.

1.1. What is a palliative approach to care?

A palliative approach to care is often recommended for people with a terminal illness. Someone has a terminal illness when they reach a point where it is understood that their illness is likely to lead to their death. Depending on their condition and treatment, they may live for days, weeks, months or even years after this point.

1.1.1. Generalist palliative care

Palliative or generalist palliative care is the holistic care of patients with advanced progressive illness. It includes management of pain and other symptoms and provision of psychological, social and spiritual support. The goal of palliative care is to achieve the best quality of life for patients and their families, rather than curing the illness. Palliative care is provided by the health and social care professionals who provide day-to-day care to patients and their carers at home and in hospital.

1.1.2. Specialist palliative care

Specialist palliative care is provided by specialist multi-disciplinary palliative care teams with recognised training including consultants and palliative care nurse specialists. It can take place in all settings, including at home or in specialist in-patient facilities such as hospices and in hospitals. Specialist palliative care services may be provided alongside the care provided by a patient's doctor and district nurse.

1.1.3. End of life care

End of life care is care and support for people who are approaching death. Typically it refers to the care given to people who are in their final year of life to help them live as well as possible. End of life care includes palliative care as well as support for families and carers.

1.2. A note on the data

The authors are extremely grateful to NWIS for providing a wealth of data on NHS activity in the final 12 months of life for all people who died in Wales in 2012. The responsibility for interpretation and for any errors remains with the authors.

1.2.1. Diagnostic coding

References to underlying cause of death in respect of this data correspond to the World Health Organisation's International Classification of Disease 10th Revision (ICD-10). It should be noted that references to 'all deaths' in the report correspond to codes A00-R99, therefore omitting deaths caused by accident, suicide or homicide.

1.2.2. Palliative care coding

There are different ways of recording palliative care in patient data. The NWIS data used in this report records specialist palliative care and uses ICD-10 code Z51.5 and Treatment Function Code 315.

Information about all of these coding systems and how they have been used in this report can be found in the Appendix.

2. Hospital activity in the last year of life

People typically make heavy use of hospital services in their last 12 months of life[4].

In the latest ONS survey of bereaved relatives in England[5], hospitals were the care settings least likely to be rated as excellent or good by bereaved relatives. Relatives said this in respect of both overall quality of care and dignity and respect given to patients. Even on the question of pain relief hospitals scored more poorly than care homes and hospices, although better than home settings.

Research shows that a large number of hospital inpatients are in the last year of their lives. A recent study of patients in Scottish hospitals found that 28.8% of those in acute beds on a single ‘snapshot’ day had died within the following year[6]. It is important that inpatients at the end of life are identified and properly accommodated within hospital and health board end of life care strategies so that their end of life care needs can be fully planned for and met.

2.1. Admissions

More than three-quarters of people in their last year of life can expect to be admitted to hospital at least once[7]. In Wales in 2012, NWIS data shows that there were a total of 64,305 admissions of people in their last year of life. This is about 8.5% of all admissions (a total of 761,000 in 2011/12)[8]. On average a person is admitted to hospital 2.13 times in the 12 months before death. This is similar to the number of admissions per person across England (2.1)[9]. NWIS data shows that more than three-quarters of all admissions in the last 12 months of life (76%) were emergencies, compared with 46% of all hospital admissions.

Other evidence shows that the number of admissions, and in particular emergency admissions, increases very substantially during the last 3 months and especially the final month of life[10].

2.1.1. Admissions and cause of death

There are marked differences in the number of hospital admissions according to the underlying cause of death. Looking at the average number of total admissions (i.e. the sum of emergency admissions and elective admissions), people whose underlying cause of death was cancer have a higher average number of admissions per person than people with other causes of death, with an average of 3.15 admissions per person. Of cancers, people with lymphoid, urinary tract and female genital cancers had the highest number of admissions in the last 12 months of life.

Of people with non-cancerous conditions, the average number of admissions per person was substantially lower at 1.7 admissions per person. Those who died from dementia (1.30 admissions per person though see section 2.2 for numbers of bed days in last year of life) and diseases of the circulatory system (1.55 admissions per person) had fewer admissions than those who died from chronic lower respiratory diseases such as chronic obstructive pulmonary disease (COPD).

Table 1. Total and emergency admissions in the final year of life by cause of death
Source: NWIS data provided to Marie Curie

Underlying cause of death	Total deaths	Total admissions (*emergency admissions*)	Total admissions per person (*emergency admissions per person*)
All deaths	30,219	64,305 *(48,909)*	2.13 *(1.62)*
All cancers	**8,892**	**27,979 *(18,002)***	**3.15 *(2.02)***
Digestive organs	2,514	8,139 *(4,919)*	3.2 *(2.0)*
Respiratory	1,935	5,265 *(3,770)*	2.7 *(1.9)*
Lymphoid	656	3,394 *(1,307)*	5.2 *(2.6)*
Female genital organs	450	1,474 *(997)*	3.3 *(2.2)*
Urinary	505	1,720 *(1,110)*	3.4 *(2.2)*
Non-cancer	**21,327**	**37,326 *(30,907)***	**1.70 *(1.45)***
Diseases of circulatory system	9,313	14,431 *(11,980)*	1.55 *(1.29)*
Chronic lower respiratory diseases	1,721	4,034 *(3,585)*	2.34 *(2.08)*
Dementia	2,210	2,877 *(2,559)*	1.30 *(1.16)*

People with cancer have a higher number of emergency admissions per person in the last 12 months of life than people with other causes of death, at an average of 2.02 admissions per person compared with 1.45 per person for non-cancer causes. People with cancer of the lymphoid system, urinary tract and female genital organs had a slightly above average number of admissions per person.

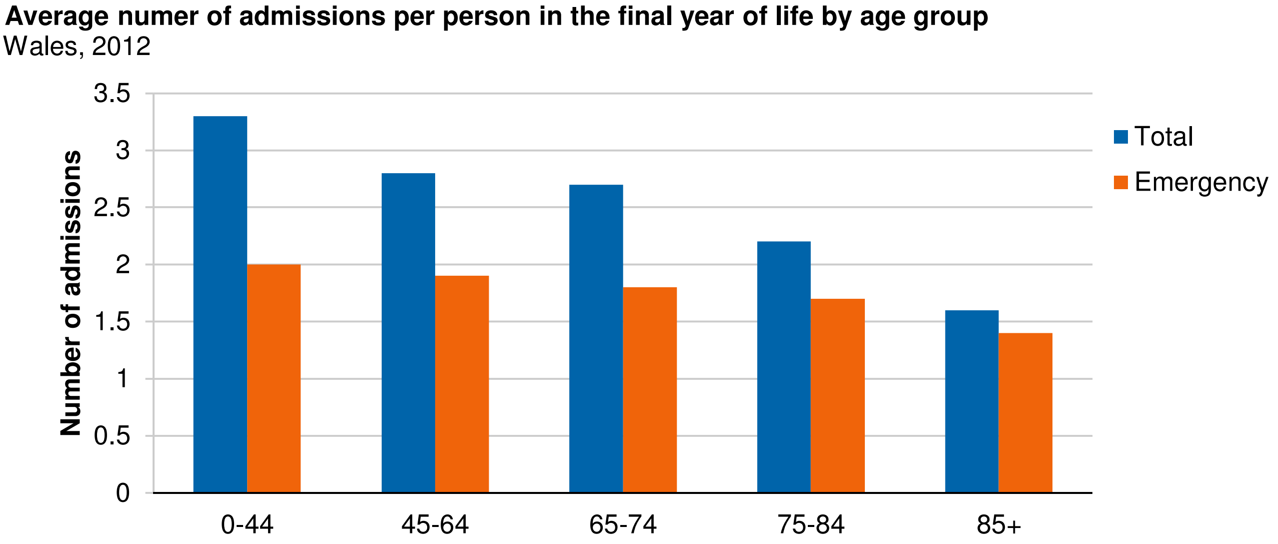
However, those who died of non-cancerous conditions were more likely to have a higher proportion of emergency admissions compared to elective admissions in the final year. On average, 64% of the admissions in the final year of life for a person who died from cancer were as an emergency. The average for someone dying from a cause other than cancer is 85%, rising to 89% for those who died of chronic lower respiratory diseases and dementia.

2.1.2. Admissions and age

There is a very close relationship between the number of hospital admissions in the last year of life and age, reflecting the much greater mortality of older people. People aged over 65 accounted for 82% of all hospital admissions in the last year of life and 84% of emergency admissions. This finding is supported by research carried out in Scotland which found that hospital inpatients on a certain day aged over 85 were three times more likely to have died within the following year than patients under 60 years of age[11].

In terms of the number of admissions, the average number decreases as age increases. The average number of admissions per person was twice as high amongst people aged 0-44 than amongst those aged 85 and over. The average number of emergency admissions per person was also higher amongst people aged 0-44 than older people, although much less markedly so.

Figure 1. Admissions in the final year of life by age group

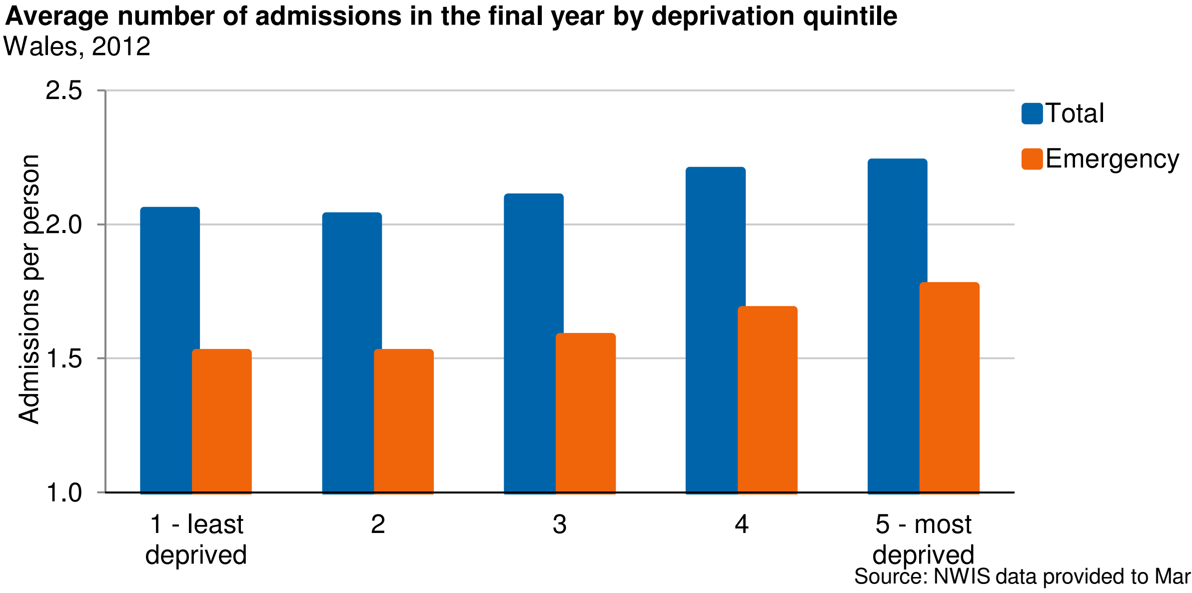


Source: NWIS data provided to Marie Curie

2.1.3. Admissions, deprivation and health boards

People living in the most deprived quintile of neighbourhoods were 10% more likely to experience emergency rather than elective admissions, with an average of 1.77 admissions per person in the most deprived quintile compared with 1.52 per person in the least deprived. For the proportion of admissions that are emergencies, there is again a difference between deprived and less deprived areas. 79.4% of admissions in the last year of life of people from deprived areas were emergencies compared with 74.2% of admissions in the least deprived.

Figure 2. Admissions in the final year of life by deprivation

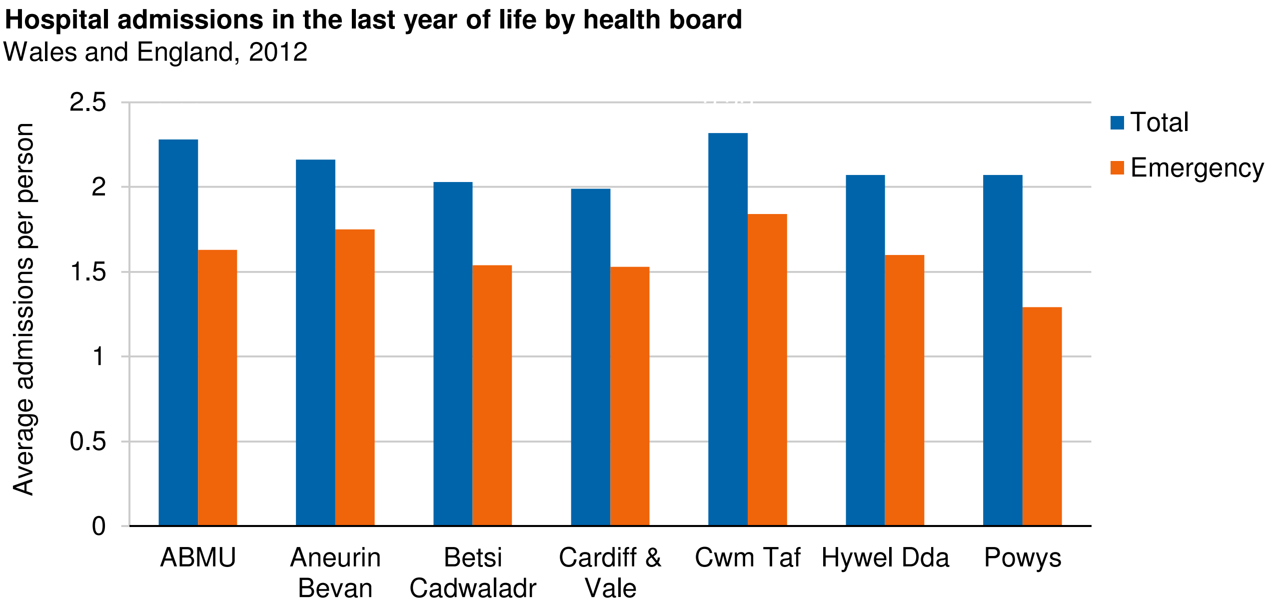


Source: NWIS data provided to Marie Curie

A ‘deprivation effect’ on emergency admissions is evident for most (but not all) causes of death. The difference in the proportion of admissions that were emergencies in the most and least deprived neighbourhoods is greatest when the cause of death is cancer (6.1 percentage points) than for other causes 2.2 percentage points).

There is relatively little difference between health boards' average admission rates or emergency admission rates. Cardiff and Vale UHB had the lowest average rate of admissions overall, at 1.99 per person, and the second lowest rate of emergency admissions, whilst the highest average total and emergency admissions per person was in Cwm Taf.

Figure 3. Average admissions per person in the final year of life by health board



Source: NWIS data provided to Marie Curie

2.2. Bed days

People in the last year of life typically occupy 33.9 hospital bed days. In Wales in 2012, emergency and elective hospital admissions in the last year of life accounted for more than 1 million bed days – nearly a quarter (23.8%) of all hospital bed days. Of this figure, emergency admissions in the last year of life accounted for just over 685,000 bed days.

2.2.1. Bed days and cause of death

There are considerable variations in number of bed days by cause of death. People in the last year of life who died from cancer accounted for a total of 286,000 bed days. The average number of bed days for people with cancer in the last year of life is 32.2 days. This is slightly lower than the number of bed days for people with other conditions. Almost three-quarters of bed days for people with cancer (72%) resulted from an emergency rather than elective admission. As a result people with cancer had a higher average number of bed days accounted for by emergency admissions than people with other conditions.

Of cancer diagnoses, brain, eye and other central nervous system cancers, lymphoid system cancers and cancer of the urinary tract were associated with a greater average number of bed days than other cancers, both in total and as a result of emergency admissions. People with dementia as their underlying cause of death occupied on average 52.3 hospital bed days in their final year of life; considerably more than for most other conditions. As average number of admissions for this group are relatively low (1.3), this indicates that people with dementia spend very long spells in a hospital bed following a hospital admission.

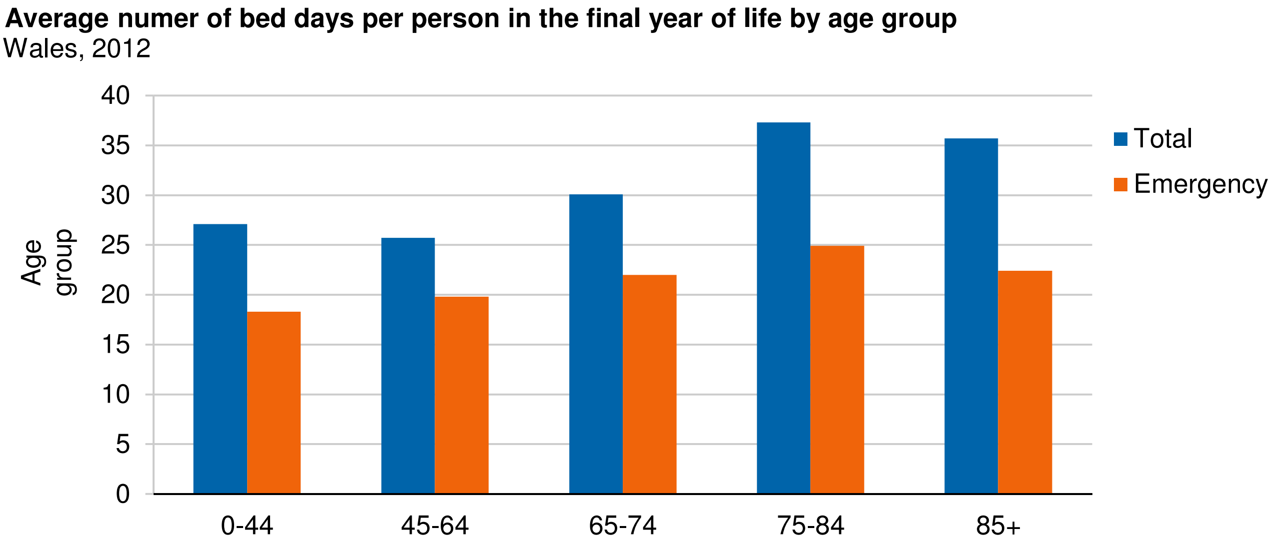
Table 2. **Total and emergency bed days in the final year of life by cause of death**
Source: NWIS data provided to Marie Curie

Underlying cause of death	Total deaths	Total bed days (*emergency bed days*)	Total bed days per person (*emergency bed days per person*)
All deaths	30,219	1,024,837 *(685,018)*	33.9 *(22.7)*
All cancers	**8,892**	**285,962 *(205,523)***	**32.2 *(23.1)***
Digestive organs	2,514	75,367 *(54,169)*	30.0 *(21.5)*
Respiratory	1,935	49,420 *(38,457)*	25.5 *(19.9)*
Urinary	505	20,356 *(14,029)*	40.3 *(27.8)*
Lymphoid	656	27,443 *(19,555)*	41.8 *(29.8)*
Non-cancer	**21,327**	**738,875 *(479,495)***	**34.6 *(22.5)***
Diseases of circulatory system	9,313	268,699 *(174,702)*	28.9 *(18.8)*
Chronic lower respiratory diseases	1,721	60,358 *(45,053)*	35.1 *(26.2)*
Dementia	2,210	115,585 *(61,802)*	52.3 *(28.0)*

2.2.2. Bed days and age

In terms of age, older people account for more bed days per person in the last year of life – an average of 37.3 total bed days days for someone aged 75-84 compared with less than 27 days for people aged under 65. The combination of a greater proportion of emergency admissions and more use of beds amongst older people means that emergency admissions of people aged 65 and over in the last year of life accounted for nearly half a million bed days (492,735) which is nearly two thirds (64.4%) of all emergency bed days occupied in the last year of life.

Figure 4. **Bed days in the final year of life by age group**



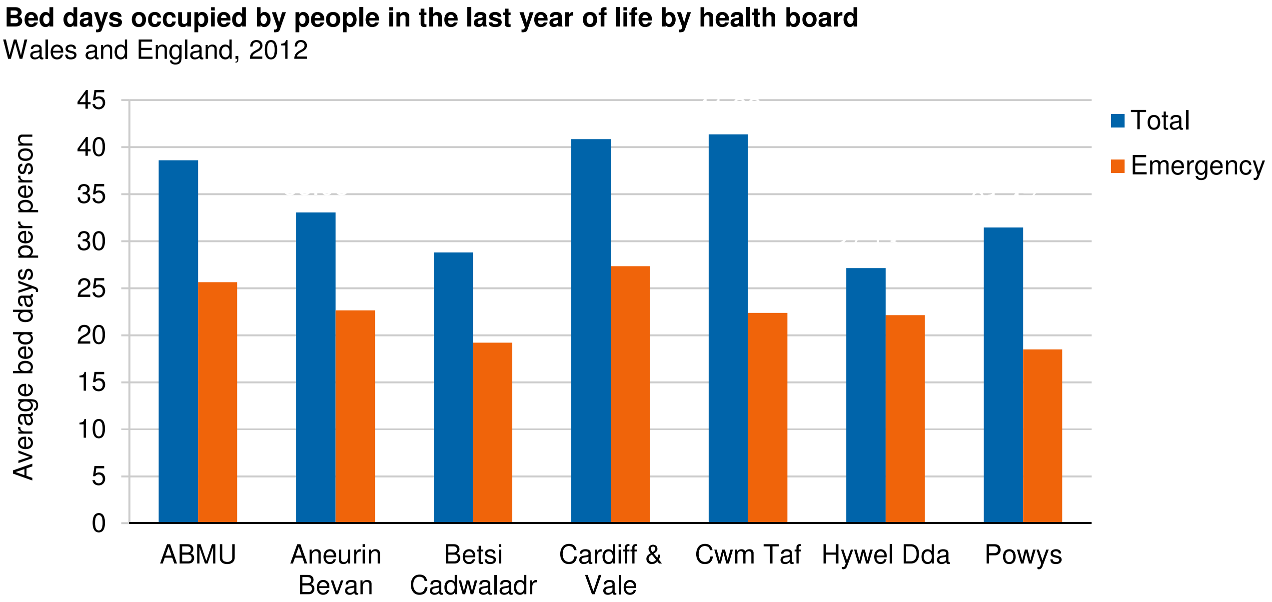
Source: NWIS data provided to Marie Curie

2.2.3. Bed days, deprivation and health boards

The data shows that deprivation has very little effect on the number of days spent as an in-patient in the last year of life. Looking at all deaths, the average number of bed days is the same for the most and least deprived quintiles. For people with cancer, those from the most deprived quintile have a slightly higher number of bed days (2.4 days more) than those from the least deprived. For people with other conditions, those in the most and the least deprived quintiles have the highest number of bed days – those in the middle quintiles have the lowest.

There is much more variation in the average number of bed days as an in-patient in the last year of life between health boards. Cardiff and Vale University Health Board and Cwm Taf Health Board both had an average of over 40 bed days per person, compared with 27.1 in Hywel Dda and 28.8 in Betsi Cadwaladr University Health Boards – a difference of more than 11 days. The variation in the average number of bed days as an emergency admission was just under 9 days – with that for Powys residents being 18.5 and Cardiff and Vale being 27.4 days.

Figure 5. Bed days in the final year of life by health board



Source: NWIS data provided to Marie Curie

2.3. Conclusions

People make heavy use of hospital in-patient services in their last year of life, accounting for more than 1 million bed days in total in 2012. On average, each person is admitted 2.13 times and stays for 33.9 days in total.

People with cancer have a higher average number of admissions and a higher number of emergency admissions per person, although a slightly shorter average length of stay both in total and of emergency admissions. People with some cancers, however, have much higher average numbers of elective and emergency admissions leading to more bed days than the norm. People who die from dementia typically have a lower number of admissions; however, they are likely to spend much longer in a hospital bed once they have been admitted.

Deprivation appears to have a lesser impact on the use of hospital services in the last year of life, as measured by the number of admissions per person and average number of bed days, than might have been expected, although it has slightly more impact on people with cancer than those with other conditions. There is more variation by local health board than deprivation, suggesting that local factors over and above levels of deprivation are important. These might include different policies and practices between acute services providers, variations in local community-based services, and distance from acute services.

There may therefore be scope to reduce the number of emergency admissions through increasing the number and range of interventions available outside hospital settings. Not only might this be more appropriate care for the patient, it also has the potential to reduce the demands on hospital services and therefore expenditure.

3. Access to palliative care

The Welsh Government has recognised the importance of access to good quality end of life care, based on the principle that it should be available to everyone who needs it, when they need it, irrespective of their diagnosis and place of care.

Since the Sugar report in 2008[12], a great deal of progress has been made in improving the quality of and access to care[13]. Steps to deliver more effective and efficient services have been taken through initiatives such as seven-day working for clinical nurse specialists, 24/7 access to Specialist Palliative Care Consultants, better access to medication, investment in specialist staff and staff training, and advance care planning.

Focus on improving the quality and consistency of end of life care services has been further strengthened through the publication of the Welsh Government's end of life care delivery plan and the requirement on health boards to publish their own local plans. An annual report has recently been published which includes progress, or otherwise, against a set of indicators[14].

Although these improvements are very important and welcome, it is critical that we ensure that all those who need and would benefit from specialist palliative or palliative care get it. We know that need currently outstrips supply. It is estimated that between 69% and 82% of people dying need palliative care[15], of which those with more complex conditions will need specialist palliative care[16].

Other research supports our analysis of the Welsh data which shows that you are far more likely to receive specialist palliative care if you have a cancer diagnosis than if you are terminally ill with a non-cancer diagnosis[17]. Deprivation is also identified as a significant factor in accessing palliative care services[18], along with ethnicity, age and gender[19].

It is worth noting that a Dr Foster report[20] has identified significant issues in the practices around coding of data in respect of palliative care. A report by the NHS Health and Social Care Information Centre in England also found considerable variation in how guidelines about coding palliative care are interpreted: some health professionals may apply a code when a patient has any form of contact with a member of the palliative care team whereas others may reserve it only for when a patient has specifically seen a palliative care consultant[21]. Such issues may have had an effect on the data presented here; however, the impact is unlikely to be so great as to affect the overall conclusions.

It should also be noted that the way the NWIS data is coded allows only an analysis based on numbers of people receiving specialist palliative care and not palliative care in general. It may be that many people's palliative care needs at the end of life are met through generalist care and support. One way of assessing this is to monitor the number of patients recorded on primary care palliative care registers prior to their death, as has been done in the Welsh Government's end of life care annual report. Although the report finds a marked increase in recent years, the number recorded in 2013 (7,152) is still less than a third below the lower limit required by estimates of palliative care need (see Table 3).

3.1. Palliative care need in Wales

The NWIS data shows that just over 1 in 6 people (17.4%) who died in Wales in 2012 received specialist palliative care. The proportion of people who are estimated to need palliative care is very considerably higher than is recorded in Wales. Recent research found that the need for palliative care is likely to be within a range of 69% and 82% of deaths. Taking the mid-point of the intermediate estimates produced by this method would place the need for palliative care at approximately 75% of all deaths.

Applying these benchmarks to Wales, it is clear that current provision falls short (see Table 3). At 17%, provision of specialist palliative care in Wales is less than half of the figure for minimal provision of palliative care, and is dramatically short of the 75% figure. As the data from primary care palliative care registers shows, it is highly unlikely that generalist palliative care provision makes up for this shortfall.

Table 3. Estimated number of people with palliative care need in Wales
Extrapolated from figures in Palliative Care Funding Review (2011) Funding the Right Care and Support for Everyone

All deaths	**(100%)**	**32,000**
Actual proportion receiving palliative care	*17%*	*5,300*
Minimal	37%	11,800
Low	63%	20,200
Intermediate (lower limit)	69%	22,100
Funding Review Benchmark	**75%**	**24,000**
Intermediate (upper limit)	82%	26,200
Maximal	97%	31,000

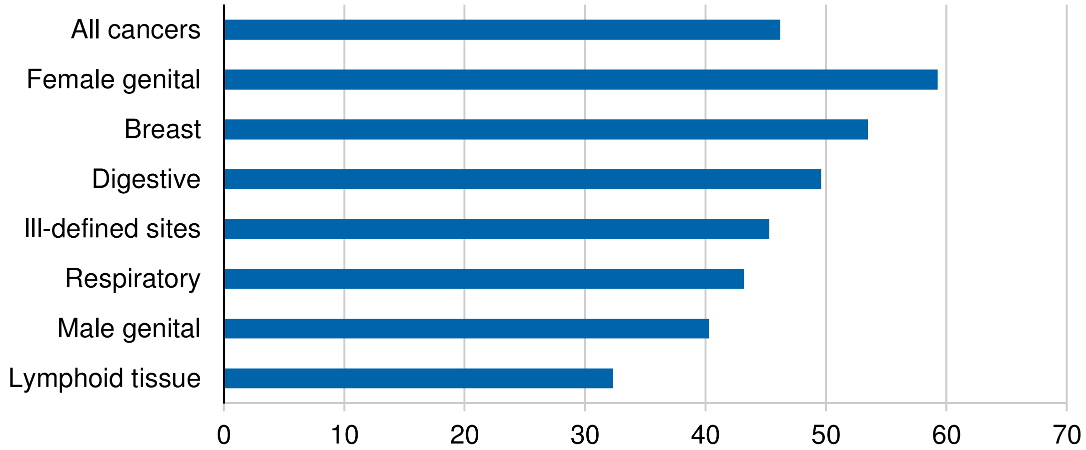
3.2. Specialist palliative care and cause of death

The NWIS data shows that there are striking differences in the receipt of specialist palliative care with the cause of death. People with cancer are much more likely to receive specialist palliative care than people with other terminal conditions: 46.2% of those who died from cancer received specialist palliative care compared with 5.3% of those with other diagnoses.

There is also considerable variation in receipt of specialist palliative care between different cancer diagnoses (Figure 6). For example, almost 60 per cent of women who die from malignant cancer of the genital organs received specialist palliative care in their final year; however, for men who die from malignant cancer of the genital organs this figure is closer to 40 per cent. From the data available it is not possible to tell whether it is gender or nature of the cancer that is leading to this disparity.

Figure 6. Variations in receipt of specialist palliative care by cancer diagnosis

Percentage receiving specialist palliative for people dying from different cancers
Wales, 2012



Source: NWIS data provided to Marie Curie

Cancer is one of the conditions for which there is a clear need for specialist palliative care, for example in providing pain relief, nutrition and hydration. Yet less than half of people in Wales who die from cancer receive specialist palliative care. In 2012, some 4,700 people did not receive this support prior to their death.

Palliative care is even less common for conditions other than cancer (see Table 4). Not all people towards the end of their lives will require specialist palliative care. Even having taken this factor into account the numbers recorded as having received it appear very low.

For example, only 7.1% of people whose underlying cause of death was a chronic lower respiratory disease - which includes chronic obstructive pulmonary disease (COPD), a condition with symptoms that again are highly appropriate for palliative care - are recorded as having received specialist palliative care.

As dementia is a progressive and complex condition which currently has no cure, specialist palliative care can similarly help to promote the quality of life and comfort of someone with dementia as they approach the end of life. Yet only 3.8% of people whose death was attributed to dementia received this specialist care.

Table 4. Specialist palliative care (SPC) receipt for non-cancer deaths, Wales 2012

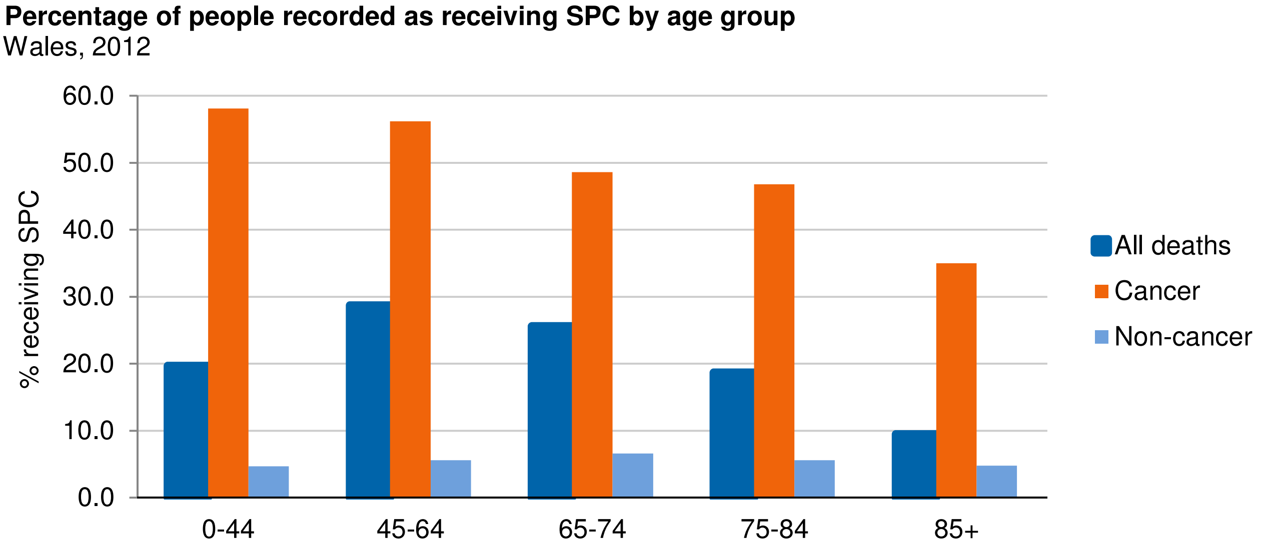
Source: NWIS data provided to Marie Curie

Underlying cause of death	Total deaths	Number recorded as receiving SPC	% recorded as receiving SPC
All non-cancerous conditions	21,327	1,135	5.3
Diseases of circulatory system	9,313	414	4.4
Chronic lower respiratory diseases	1,721	122	7.1
Dementia	2,210	83	3.8
All deaths	**30,219**	**5,423**	**17.4**

3.3. Specialist palliative care and age

There are clear differences in the proportion of people in the last year of life who receive specialist palliative care according to age (Figure 7). Both the youngest age group, i.e. 0-44 years, and the oldest age group, those 85 years and over, are least likely to receive specialist palliative care at 19.7% and 9.5% of people in the last year of life respectively, compared with 28.7% of 45-64 year olds and 25.6% of 65-74 year olds.

Figure 7. Receipt of specialist palliative care by age group



Source: NWIS data provided to Marie Curie

The decline in receipt of palliative care for older age groups is particularly true for people with cancer diagnoses. Only 35% of people aged 85 and over received specialist palliative care in the last year of life compared with 58% of those aged 0-44. This difference is also evident amongst those with respiratory or digestive cancers, as Table 5 shows. For people with different non-cancer diagnoses, such as chronic lower respiratory diseases, receipt of specialist palliative care does again seem to vary by age group. However, due to the low numbers receiving palliative care, it is difficult to detect any clear trends.

Table 5. Specialist palliative care receipt by age and cause of death, Wales 2012
Source: NWIS data provided to Marie Curie

	Percentage of deaths recorded as having received specialist palliative care					
	Cancer			Non-cancer		
Age group	All	Respiratory	Digestive	Circulatory[i]	Lower resp[ii]	Dementia
0-44	58.1	87.5	65.6	1.0	0	n/a
45-64	56.2	46.2	60.8	3.1	8.1	0
65-74	48.6	42.9	51.4	3.8	10.4	12.1
75-84	46.8	44.7	49.0	4.7	7.9	2.6
85+	35.0	35.1	37.5	4.9	4.1	3.7
Average	**46.7**	**43.2**	**49.6**	**4.4**	**7.1**	**3.8**

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[i] Diseases of the circulatory system
[ii] Chronic lower respiratory diseases

3.4. Specialist palliative care and deprivation

Literature from elsewhere in the UK[22] suggests that people from lower socio-economic groups are less likely to receive palliative care than those from higher socio-economic groups. Yet in Wales, using the deprivation of area of residence as a measure of socio-economic status, deprivation seems to have little effect (Table 6). Nearly the same proportion of people living in the most deprived quintile (i.e. fifth) of neighbourhoods received specialist palliative care as those from other neighbourhoods (18.3% in the most deprived quintile of deaths received it compared with 18.1% in the least deprived).

For deaths from cancer, the proportion of people receiving specialist palliative care is slightly higher in the most deprived quintile than in the least deprived quintile. This is also the case for some specific cancer diagnoses and is most significant when cancer of the female genital organs is the underlying cause of death.

Table 6. Specialist palliative care receipt by deprivation quintile and cause of death, Wales 2012

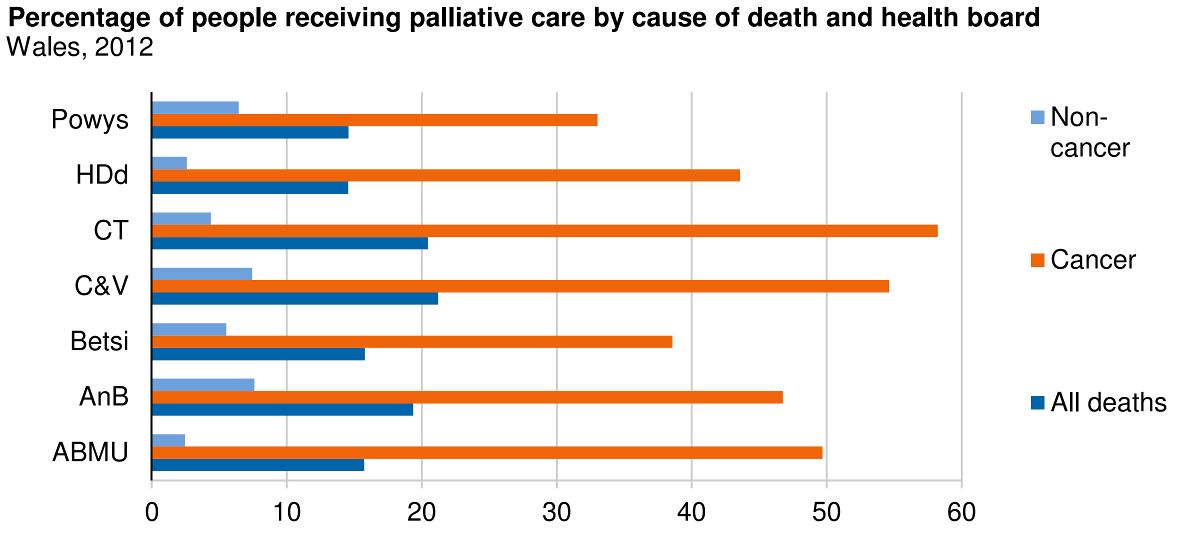
Source: NWIS data provided to Marie Curie

Deprivation quintile	All deaths (%)	All cancer (%)	Respiratory cancers (%)	Digestive cancers (%)	Fem genital cancers (%)	Non-cancer (%)
1 (least)	18.1	46.7	48.4	48.5	55.9	5.5
2	16.4	42.9	38.4	45.9	48.5	5.2
3	16.7	44.4	37.1	48.3	60	5.1
4	17.2	47.2	45.7	50.2	64.0	5.2
5 (most)	18.3	49.8	45.9	55.2	70.1	5.7
Average	**17.4**	**46.2**	**43.2**	**49.5**	**59.3**	**5.3**

For all causes of death, there is much more variation in palliative care receipt between health board areas than between areas categorised by different levels of deprivation. A higher proportion of people were flagged as receiving specialist palliative care in Cardiff and the Vale University area and in Cwm Taf Health Board areas (21.2% and 20.5% respectively) than in Hywel Dda and Powys (each 14.6%).

The variation in respect of people with cancer is even greater, ranging from a high of 58.2% in Cwm Taf to 33.0% in Powys Health Board areas. The proportion of people with other conditions receiving palliative care is very small in some areas – less than 3% in Abertawe Bro Morgannwg University and Hywel Dda Health Boards.

Figure 8. Specialist palliative care receipt by health board and cause of death, Wales 2012



NWIS data provided to Marie Curie

The findings in respect of deprivation might be viewed as surprising as they run counter to most trends identified in the literature on the topic. This could be seen as a significant success in Wales as it appears from the data that the Welsh NHS is succeeding in delivering palliative care equitably as far as deprivation is concerned. If so then Wales has an important story to tell.

Tempering this conclusion are the clear differences between health boards, particularly in respect of people with cancer, which suggest that access to specialist palliative care is far from equitable in other respects. Indeed, the very low proportions of dying people receiving specialist palliative care in some health board areas suggests either that substantial numbers of people are not receiving the care they need, that there are serious issues with the coding of care or there are clinical practices that deliver the care needed that the methods of coding do not capture.

What is certain is that further research and analysis is needed to establish accurately the levels of palliative care that terminally ill people are getting in Wales and what barriers to access exist. It is also important to further explore the relationship between deprivation and access to specialist palliative care in Wales. The outcome of this work could well be an important example of good practice in Wales.

4. Conclusions

People make heavy use of hospital services in their last year of life, averaging 2.13 admissions and 33.9 bed days. In total people in the last 12 months of life accounted for more than 1 million NHS bed days in 2012, nearly a quarter of all NHS bed days.

While some hospital interventions may be an attempt to save a life or relieve symptoms, by no means are all admissions likely to be essential. Clearly the Welsh government's prudent healthcare policy could provide an important focus on these admissions. Indeed, many relatives rate the care received in other settings more highly than hospital care, though regrettably data is not available for Wales.

People with cancer on average experience more admissions, both in total and emergency admissions, but use fewer bed days in hospital in the last year of life than people with other conditions. Some cancers, notably lymphoid, brain and central nervous system and urinary tract cancers, are associated with very high admission rates and bed days. People who died from dementia had relatively low numbers of admissions but occupied on average 52.3 hospital bed days in their final year of life; considerably more than for most other conditions.

Age is a significant factor in the use made of hospital services in the last year of life, with the average number of admissions per person falling with age while the average number of bed days rises. Because the number of admissions of older people in the last year of life is very much higher than the number of younger people, people aged 65 and over in the last year of life accounted for nearly half a million bed days.

Palliative care can be an important contributor to the quality of an individual's life before death. The Welsh Government and NHS Wales have made great strides in improving the quality and quantity of palliative care provided.

The evidence from the NWIS data is mixed and can only tell part of the story. The data suggests that the proportion of people receiving specialist palliative care is about half the estimated minimum need for palliative care, and only a quarter of the optimum level of provision. While people with cancer are much more likely to receive palliative care than others, overall less than half of cancer patients receive specialist palliative care prior to their death. The provision of specialist palliative care to people with other conditions is extremely low. This leads us to the conclusion that though there has been significant progress in the development and delivery of specialist palliative care services in Wales, there is much more to be done.

The data highlights two further issues. The first is that the proportion of people receiving specialist palliative care decreases with age, with the decrease being particularly marked for people with cancer[23]. The low proportion of older people with cancer receiving specialist palliative care coupled with the relatively large numbers of older people in their last 12 months of life suggests that there are substantial unmet needs amongst this age group. The extent of this unmet need is unclear as again there may well be issues affecting the coding of data.

The second is that there are considerable variations across health boards in palliative care. However, the deprivation effect appears to be less than anticipated. As has been reported elsewhere, coding issues may be impacting on the accuracy of the data and therefore a degree of caution should be applied when interpreting these results. This potential limitation of the data reinforces the need to develop robust and uniform patient data collection and recording practices throughout Wales. Without this, there is the risk that that the level of people's needs for palliative care will be underestimated and needs will go under-fulfilled.

4.1. Recommendations

- We call on the Welsh Government and NHS Wales to focus effort on reducing the number of emergency bed days spent by people in their last year of life. We feel that a 10% reduction over a three year period is a reasonable target. This is the equivalent of 188 hospital beds.

- On the basis of the data available we have been able to draw some important conclusions. Some of these conclusions point to real achievements in the equity of access to palliative care in Wales across socio-economic groups. We would urge the Welsh Government and NHS Wales to commission a study to establish whether this is the case or whether the current data is hiding the reality.

- We call on Public Health Wales to work with NHS Wales and independent sector providers to explore the feasibility of bringing individual level palliative care data into one national data set that captures activity and outcomes from hospices and specialist palliative care services, including information on demographic details, activity information and patient outcomes.

- We urge the Welsh Government and NHS Wales to focus on those areas where there appears to be insufficient access to specialist palliative care services:
    1. For those with a non-cancer diagnosis
    2. For older people, in particular those with terminal cancer

- We think that work is needed to establish what is behind the apparent inconsistencies of provision across health boards. It is important to establish whether this is an issue of how services are being coded, whether there are specific barriers to access, variations of provision or some other factors.

5. References

1 ONS (2013) 2012-based National Population Projections.

2 Palliative Care Planning Group Wales (2008) Report to the Minister for Health and Social Services, Welsh Government.

3 NCPC (2014) National Survey of Patient Activity Data: MDS Report for 2012-2013.

4 Bardsley M, Georghiou T, Dixon J (2010) Social care and hospital use at the end of life. The Nuffield Trust.

5 ONS (2014) National Survey of the Bereaved (VOICES), 2013.

6 Clark D et al. (2014) Imminence of death among hospital inpatients: Prevalent cohort study. Palliative Medicine 28(6): 474-479.

7 National End of Life Care Intelligence Network (2012) What do we know now that we didn’t know a year ago?

8 NHS Wales, New Hospital Admission Information published, February 2013.

9 Op. cit. NEoLCIN, What do we know now…?

10 Nuffield Trust (2012) Understanding Patterns of Health and Social Care at the End of Life.

11 Clark D et al. (2014) Imminence of death among hospital inpatients.

12 Palliative Care Planning Group Wales (2008) Report to the Minister for Health and Social Services.

13 Palliative Care Cymru Implementation Board (2011) Dying Well Matters – One Wales: 3 Years On.

14 Welsh Government (2014) Together for Health End of Life Care Delivery Plan: Annual Report 2014.

15 Murtagh FM et al. (2014) “How many people need palliative care? A study developing and comparing methods for population-based estimates.” Palliative Medicine 28(1):49-58.

16 NCPC et al. (2012) Commissioning Guidance for Specialist Palliative Care: Helping to Deliver Commissioning Objectives, p. 15.

17 Zheng L et al. (2013) “How good is primary care at identifying patients who need palliative care? A mixed-methods study”. European Journal of Palliative Care; 20: 216–222.

18 Campbell M et al. (2010) “Exploring differences in referrals to a hospice at home service in two socio-economically distinct areas of Manchester, UK.” Palliative Medicine 24(4): 403-409.

19 Ahmed N, Bestell JC, Ahmedzai SH, et al. (2004) “Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals.” Palliative Medicine 18: 525-542.

20 Dr Foster Intelligence (2014) Palliative Care.

21 The Health and Social Care Information Centre (2013) The Use of Palliative Care Coding in the Summary Hospital-level Mortality Indicator (SHMI).

22 Lewis JM1, DiGiacomo M, Currow DC, Davidson PM (2011) Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world. Journal of Pain and Symptom Management 42.1 (July): 105-119.

23 See also NCPC (2014) National Survey of Patient Activity Data: MDS Report for 2012-2013.

6. Appendix

6.1. Palliative care coding in hospital datasets

There are different ways to record palliative care in patient data. The NWIS data referred to in this report uses the following two methods which record specialist palliative care:

6.1.1. ICD-10 code Z51.5

ICD-10 code Z51.5 indicates that a person's records show a diagnosis of or encounter with palliative care. There are reported issues with this relating to scope for interpretation and application as some may apply it when a patient has any form of contact with a member of the palliative care team whereas others may reserve it for when a patient has specifically seen a palliative care consultant. See the NHS HSCIC's The Use of Palliative Care Coding in the Summary Hospital-level Mortality Indicator for more information.

6.1.2. Treatment Speciality Coding

Treatment Function Code 315 records specialist palliative care and indicates that a person is or will be treated under the specialty of palliative medicine, i.e. palliative medicine is the consultant's main specialty or an interest specialty.

6.2. ICD-10 'underlying cause of death' diagnosis codes

The NWIS data used in this report uses ICD-10 coding to record underlying cause of death. For brevity and ease of reading, the report adopts familiar disease categories when discussing some underlying causes of death. The relevant ICD-10 codes are as follows:

Underlying cause of death (report)	ICD-10 codes referred to
All deaths	A00-R99
All cancers/neoplasms	C00-D48
Respiratory cancers	C30-C39
Cancer of lymphoid tissue	C81-C96
Non-cancer deaths	A00-R99 excluding C00-D48
Diseases of the circulatory system	I05-I99
Chronic lower respiratory diseases	J40-J47
Dementia	F00-F09

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Disclaimer

The responsibility for interpretation of the data and for any errors remains with the authors.

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