

In and out of hospital:

Understanding disparities in emergency admissions in the final year of life



Care and support through terminal illness

Executive Summary

- Our data on emergency admissions in the last year of life show clear differences in the experience of people with different conditions and in different parts of the UK.
- Some disparities are seen throughout the UK, such as a greater frequency of emergency admissions for people with cancer, but a longer duration of emergency admissions for those with non-cancer conditions. Across the UK, people with respiratory conditions also have a far higher rate of admission than average.
- There are sharp disparities between nations. For example, people in England experience almost twice as many emergency admissions as those in the devolved nations.
- The consistency of many of these disparities suggests system issues in how health services manage different conditions towards the end of life.
- Failure to get to grips with the issue threatens the quality of life of people with terminal illnesses.
- Understanding the differences and why they occur will be crucial to the ability of the NHS to plan and allocate resources to effectively tackle over-reliance on emergency services for people in the last year of life.
- Unless something is done soon, our ageing population means that the number of end-of-life emergency admissions will increase significantly. This has negative implications for terminally ill people and the capacity of our health services to meet their needs.

Background

Marie Curie secured data from NHS Wales, NHS Scotland, NHS England and NHS Northern Ireland on the number and duration of emergency admissions people experienced in their last year of life. Our initial analysis of the data focused on the trends over a four-year period (excluding Northern Ireland, where data were only available for two years). The original report, published in March 2018, based on this analysis, looked at how much emergency admissions cost the NHS, in terms of the number of hospital beds occupied and money, and what the implications were of applying the trends to Office for National Statistics projections of the number of deaths in each nation in future years.

Some obvious challenges for the NHS across United Kingdom emerged. For example, establishing whether the pattern of repeated emergency admissions in England is a result of legitimate clinical need and is the best possible care pathway for the individual, or whether it is caused by patients being discharged from hospital too early or a lack of appropriate resources in the community to provide the on-going care and support the individual needs, leading to crisis after crisis. In the devolved nations the problem is one of lengthy duration of these admissions, rather than their frequency. Does this reflect appropriate care pathways that are in the best interests of the individual, or are long hospital stays the result of an inability to discharge because of a lack of resources in the community?

This report looks at the same data in more depth. It provides an analysis of emergency admission frequency and length of stay in the last year of life for specific diseases and groups of diseases. The differences between conditions and nations are, in some instances, stark and alarming.

We see that some people are spending a significant part of their last year of life in hospital after an emergency admission while, for others, there is a pattern of repeat admissions with shorter average stays. In this report we shine a light on variations in the number and duration of emergency admissions that people with different conditions experience in their last year of life; an important aspect of the overall care pathway.

Our analysis will, we hope, help health service planners focus their attention on those areas where the biggest gains can be made in the efficient use of emergency capacity and, most importantly, in the quality of care people receive at the end of their lives.

A note on methodology

In this report we will make frequent reference to non-cancer terminal conditions. This is an extremely broad category, but it allows us to draw wider distinctions between different conditions. While this report examines some individual conditions in more depth, the reader should note that non-cancer terminal conditions include neurological conditions (such as Huntington's disease, multiple sclerosis and motor neurone disease), respiratory conditions, organ failure and all forms of dementia.

It should also be noted that the latest available data provided to us for Northern Ireland were from 2015, whereas data for each of the other nations in this report are taken from 2016.

The cancer/non-cancer divide

One of the clearest differences in emergency admission experience is between the broad categories of cancer and non-cancer deaths. While each of these categories contains a wide range of conditions, our analysis shows the differences between the two categories of disease. See Figures 1, 2 and 3.

People with cancer can expect to experience a higher number of emergency admissions in the final year of life compared with those who die from non-cancer conditions.

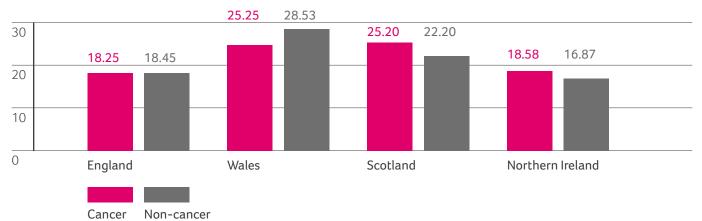


Figure 1: Average time spent in an emergency bed in the last year of life (days)

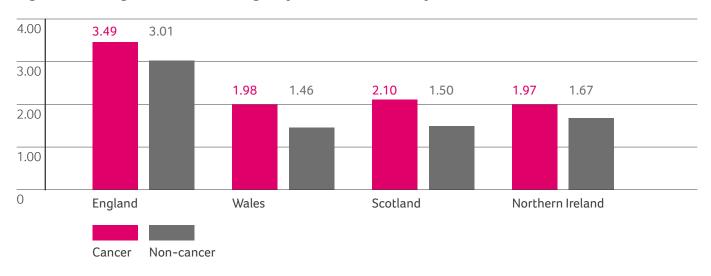


Figure 2: Average number of emergency admissions in last year of life

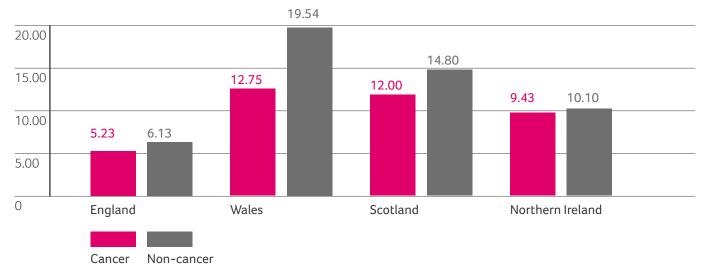
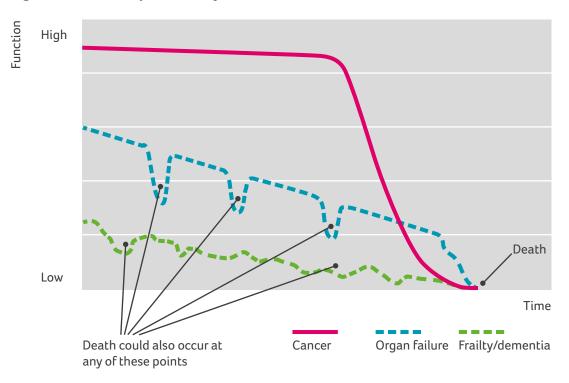


Figure 3: Average emergency admission duration (days)

However, this is offset by the fact that people with cancer will typically spend less time in hospital following an unplanned admission than those who die from noncancer conditions. This is particularly the case in Scotland and Wales. In Scotland, people with non-cancer conditions can expect to spend more than double the number of days in hospital per admission as those in England and half as much again as people in Northern Ireland. In Wales, people who die from a non-cancer condition can expect to spend over three times as many days in a hospital bed as they would in England and nearly twice as many as they would in Northern Ireland.

What is the reason for this disparity and what does it mean?

Although people with a cancer diagnosis have greater numbers of emergency admissions, they have shorter lengths of stay per admission than those with a noncancer diagnosis. This may reflect the need for urgent care in people with cancer, for example pain relief, which leads to their symptoms being better managed and them being able to return to their usual place of care relatively quickly. It may also be an indicator that the health and social care system is not as well-equipped to facilitate the discharge of patients in the last year of their lives with non-cancer diagnoses where death trajectories and accurate prognosis tends to be less predictable (see Figure 4).





Treating cancer at the end life

There has been considerable research showing that people with cancer have better access to specialist palliative care than those with a non-cancer diagnosis. This is partly because patients with cancer tend to have a more predictable end-of-life trajectory and prognosis than those with other terminal conditions.^{*i*} Health professionals often have a clearer idea of when an individual with cancer is rapidly deteriorating and entering a terminal phase of their illness and are therefore better able to refer to specialist palliative care. This is demonstrated particularly clearly

in hospice care. In 2016, around 80% of people supported by hospices had cancer diagnoses despite only 23% of deaths being caused by cancer.

We know that having a clear referral pathway to specialist end of life or palliative care supports quicker discharge from hospital following an emergency admission.^{*ii*} This could be an important factor in the shorter duration of emergency admissions for people with cancer compared with those who have a non-cancer diagnosis.

The shorter average length of emergency admission should not, however, disguise the fact that people with cancer are experiencing more emergency admissions in their last year of life than those who do not have cancer. Importantly, research shows that as many as 50% of emergency admissions for people with cancer could be avoided through simple interventions outside hospital.^{*iii,iv*} While some emergency admissions for acute care needs will be unavoidable, it is clear that there is more that could be done to reduce the frequency of emergency admissions for people with cancer who are in their last year of life.

Non-cancer conditions in the last year of life

People with non-cancer diagnoses have a comparatively lower frequency of emergency admissions, but they do experience longer periods of admission. This could reflect greater complexity of care for people with a non-cancer diagnosis, for example those with conditions such as chronic obstructive pulmonary disease (COPD) and heart disease. Combined with the unpredictable disease trajectories of non-cancer conditions, this can make hospital discharge a riskier decision for clinicians to take.^v It is also likely that more complex care arrangements would need to be in place to support an individual in the community.



Case study: Chronic heart failure

Claire Kingston's Mum, Joan Morgans, went to hospital as an emergency admission five times between September 2017 and March 2018 as a result of chronic heart failure. On one occasion Joan was discharged home in a taxi alone, following an emergency admission because of a fall.

"Every time she went in it was an emergency, because they would discharge her, she would come home then become desperately, desperately breathless, and we'd have to get an ambulance and in she would go", said Claire.

After her fifth emergency admission, Joan was referred to the Marie Curie Cardiff and the Vale Hospice, where she was an inpatient for four months. Since being discharged to her home in Penarth, she has had no emergency admissions to hospital. During that time, Joan has been receiving support from the Charity's community nurse specialist team at home with symptom control and pain management.

Talking about the care her Mum received at the hospice, Claire added: "She was safe, she was cared for, people really cared about her. The improvement in her health was amazing. There was lots of balancing meds and that kind of thing and they just seemed to take time to do that. I know it's easier here to do it than in a hospital, but it's just made such an enormous difference to us."

The duration of emergency admissions for people with non-cancer conditions may also be an indicator that discharge pathways are not functioning as effectively for these patients as they are for those with cancer. Research has shown that complex care needs can present considerable challenges if care is not integrated effectively between different teams and specialists across health and social care, which is essential for timely discharge from hospital to the community. ^{vi}

Individual conditions

Examining these issues under umbrellas as wide as 'cancer' and 'non-cancer' only gives us a broad sense of the challenges faced in end of life care for people with different diseases. We will now look at emergency admission experiences for people with specific conditions (or grouped conditions such as dementia, which includes a range of specific diseases). See Figures 5 and 6.

Note: The data for Scotland are based on slightly different International Classification of Diseases (ICD) code groupings to the other nation's datasets. For more information see Annex 1: ICD groupings by nation.

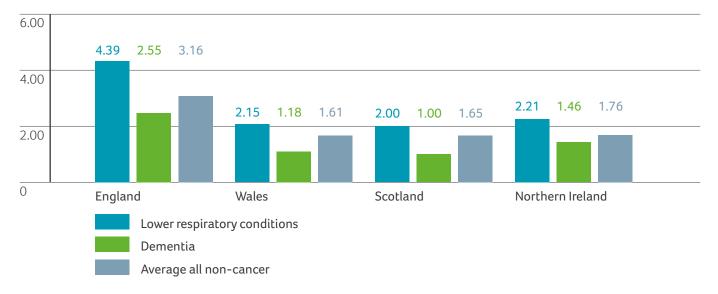


Figure 5: Average emergency admissions in final year by condition

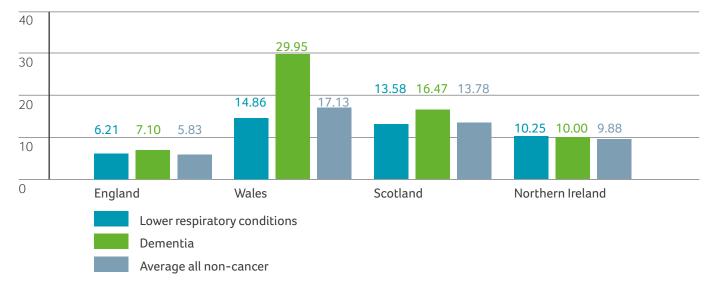


Figure 6: Average emergency admission duration by condition (days)

Lower respiratory conditions

Patients with lower respiratory conditions (such as chronic bronchitis, emphysema, COPD and asthma) have a considerably higher-than-average frequency of emergency admissions in the final year of life. This is particularly the case in England, where a person with COPD can expect to experience an average of 4.39 emergency admissions in their final year, around twice as many as in Scotland, Wales and Northern Ireland. With each emergency admission in England lasting almost a week, someone with COPD is spending just under a month in an emergency hospital bed in their last year of life in England. In each of the other nations, people with COPD are spending a similar number of days in an emergency hospital bed in their last those in England (an average of 32, 27 and 23 days in Wales, Scotland and Northern Ireland, respectively) because, while the number of admissions is fewer, the average length of stay per admission is far longer than in England.

These data suggest that people with lower respiratory conditions are reaching crisis points and there is then a reliance on emergency admissions to address these crises; yet research has shown that the right community care being available can have a significant impact on reliance on hospital services for people with COPD.^{vii} Similarly, a study in Barnsley found that a multi-disciplinary team approach had a demonstrable impact on ensuring that COPD patients could be cared for at home at the end of their lives.^{viii}

"Mum was in and out of hospital when she was ill, which was a very traumatic time for the whole family. She had a heart attack in September 2015, and was admitted for about a month after that. It was heartbreaking, she was rushed into hospital in an ambulance and we were told there was fluid on her lungs.

Mum had a DNR, but this isn't something we discussed with her as I knew she would find it quite distressing - we never told her how bad she was, as I know this would have really brought her down.

It was very hard to try to get her home, the doctors in the hospital said there was a chance that she could die in the ambulance. We didn't want her told about the DNR, and had been quite specific about this. One of the doctors ended up telling her - we were furious, and wanted to complain."

Daughter of a woman with COPD, England

Although COPD is often a highly complex condition to care for, it is clear that, with the right approach, people living with this and other lower respiratory conditions, can experience fewer and shorter emergency admissions in their last year of life. The impact on the quality of their lives would be considerable, as would the impact on emergency bed use across all four nations.

Dementia and Alzheimer's disease

Dementia and Alzheimer's are now the leading cause of death in the UK, responsible for 12% of all deaths.^{ix} There has been a marked rise in the number of recorded deaths caused by some form of dementia in recent years. This can be attributed to rising life expectancy increasing the likelihood of people presenting with dementia, however some caution is needed because identification of dementia and Alzheimer's as a cause of death has also improved significantly in recent years.^x We know that the number of people diagnosed with some form of dementia is going to continue to grow.^{xi} The extent to which the last year of life is characterised by emergency admissions, therefore, has important implications for a growing number of people as well as the health and social care system as a whole.

People with a dementia diagnosis experience fewer emergency admissions in their final year of life than the average across all diseases in each of the four nations but the duration of each emergency admission (a week in England and almost a fortnight in Scotland) is longer than the average.

"Our ageing population, and the projected increase in the number of people dying with dementia, mean that there is an urgent need to understand how we can improve care for people dying with dementia, including enabling people with dementia to be cared for in their own home or in a care home in the weeks and months before they die.

Many people with dementia experience a number of problems and conditions, in addition to the dementia itself. While emergency admissions and hospital care are sometimes needed, they can be distressing for patients and carers, and some hospital admissions could be avoided with better community support. While it is reassuring that people with dementia have fewer emergency admissions than those with other non-cancer conditions, the high lengths of hospital stay (particularly in Wales) are concerning and should prompt research to understand the factors that contribute to longer lengths of stay, and how to mitigate against them."

Dr Katherine Sleeman, PhD, NIHR Clinician Scientist in palliative medicine at the Cicely Saunders Institute, King's College London

Case study: Palliative care working alongside other specialities

Peter Moon's wife Diane was aged 67 when she died at the Marie Curie Cardiff and the Vale Hospice. But thanks to intervention from palliative care teams, including Marie Curie, she was able to spend her final year without enduring the emergency hospital admissions she had in the two previous years.

Diane was under the care of Consultant Victor Sim, at Llandough Hospital, for chronic heart failure. For around two years before 2017, she had been in and out of hospital on an emergency basis every six weeks.

"She would spend about two or three weeks in Llandough, so there would be around seven or eight admissions a year," said Peter.

Diane was introduced to Palliative Medicine Consultant Clea Atkinson, who signed her up to a testing phase of using a subcutaneous infusion of furosemide in the community, instead of intravenous furosemide, which would have required her to be an inpatient.

"This was a 12 month pilot Bevan Commission supported project", said Dr Atkinson. "It was very successful in supporting people with advanced heart failure to be managed at home instead of hospital and greatly increased time spent in preferred place of care and achievement of preferred place of death."

Peter said the opportunity to be involved in this work allowed him to support Diane at home and to spend more time with her in her final year of life.

In England, the number of admissions for people with dementia is more than double that of Wales or Scotland.

Perhaps the figure that stands out most starkly is the average length of admission experienced in Wales, where each emergency admission lasts an average of one month. This suggests that the biggest gains in quality of care and easing the pressure on hospital bed occupancy would be made through a strategic focus on community services that facilitate earlier discharge, as opposed to a focus on reducing admission rates (which are comparatively low).

This situation is concerning given the nature of dementia as a condition. The symptoms of dementia make hospitals uniquely ill suited as a care setting. The busy environment and disruption resulting from an emergency admission can exacerbate confusion and cause serious distress to the individual and their loved ones. Minimising transitions between care settings should be a key priority in the care of people living with dementia.

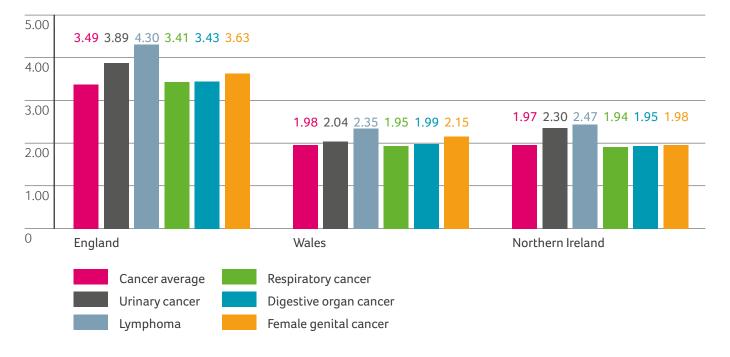


Figure 7: Average emergency admissions in final year by cancer type

Research by the Cicely Saunders Institute found that the number of emergency admissions a person with dementia will experience towards the end of life has risen in recent years. It also found a strong correlation between care home residency and a reduced rate of emergency admissions for people living with dementia towards the end of their lives.^{xii} One way of ensuring reduced emergency admissions for people with dementia, and in doing so improving quality of life at the end of life, would therefore be to invest in care home capacity and, in turn, specialist end of life care support for the care home sector. However, we know that, in terms of care home bed numbers, just the opposite is happening with the number of care home beds decreasing across all four nations.^{xiii}

Cancer disparities: Urinary and lymphoma

As well as inconsistencies between emergency admissions data in non-cancer conditions and cancer, there are also clear disparities between different types of cancer when compared with the average for all cancers. Urinary cancer and lymphomas stand out as having a higher-than-average rate of admission and in some cases a longer length of stay as well.

Examining data from across England, Wales and Northern Ireland, we can see that England has some of the most troubling differences between conditions. See Figure 7. Data on specific types of cancer are not available for Scotland, which means the the data in this section only examine England, Wales and Northern

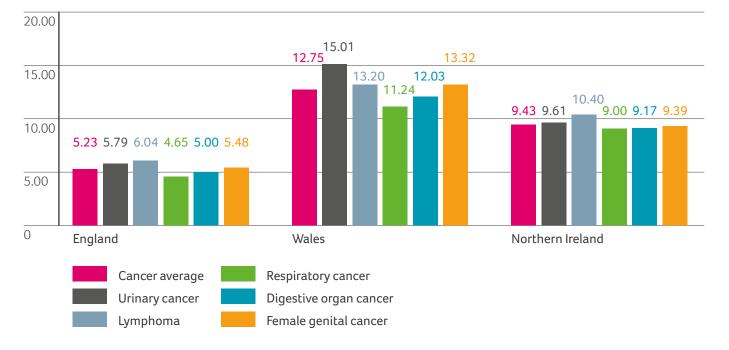


Figure 8: Average emergency admission duration by cancer type (days)

Ireland.

In England there is an average of 4.3 emergency admissions for people with lymphoma and 3.9 for people with urinary cancer in the last year of life. This means that people with these conditions can expect an emergency hospital admission every three months in their final year, resulting in almost four weeks in hospital. Similar, although less marked, differences also occur in Wales and Northern Ireland.

People with lymphoma or urinary cancer can also expect slightly longer-thanaverage stays in hospital following an emergency admission in their last year of life. Again, England has a lower average number of days per admission but a significantly greater number of admissions in the last year of life than the other nations.

Comparing these figures with those for other types cancer, for example respiratory cancer, demonstrates how different the experience is for patients with different types of cancer. This may be partly because of the complexity of care required for different symptoms, but this complexity should not detract from the importance of giving everyone the opportunity to be cared for in the community at the end of their lives, if that is where they want to be and could be with appropriate care and support.



"Variation found in data such as these raises some very interesting questions, which merit further research and analysis, especially where individual diagnoses appear to sit outside the norm.

It would be prudent to understand why some groups have fewer admissions as well as those who stand out by having more than expected. Admission to hospital can be an appropriate and acceptable part of an individual patient's experience, however, unnecessary or avoidable admissions can cause distress and harm. The more we know about the reasons for these events, the better we can tailor our services to support our patients and their families to enhance their experience in the latter phase of their lives.

This is particularly poignant when considering the difference between people with cancer and dementia. People with cancer, and some other diagnoses such as COPD, may see hospital admission as a necessary and valued part of their care, whereas those with dementia may find the whole experience disorienting, unpleasant and adding to their decline. The more we harness the information we have at our fingertips and ask ourselves the difficult questions, the better our care can be."

Dr Grahame Tosh, Executive Medical Director, Marie Curie

The broader picture

Above, we have provided an analysis that looks at specific and grouped conditions. A clear picture has emerged that shows differences between diseases and between the four nations of the UK. To understand the sheer scale of the challenge it is informative to look at the number of emergency bed days in the last year of life per thousand deaths throughout the UK (see Figure 9)

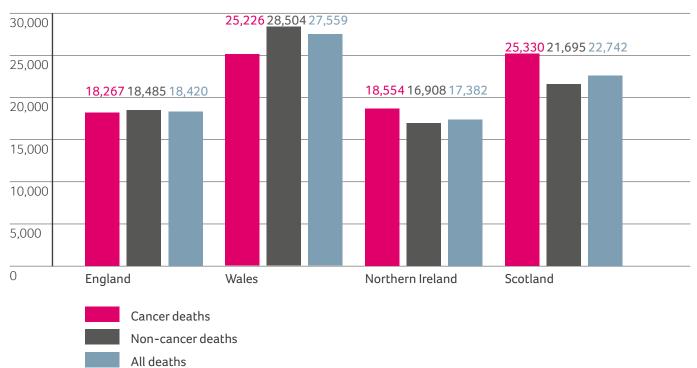


Figure 9: Emergency bed days per 1,000 deaths

At this population level we can see the impact of emergency admissions on NHS resources and how this differs across the nations. The analysis provides health service planners the opportunity to see the impact that measures to reduce either the number of admissions or their length would have on hospital resources. For example, investment in community resources in Wales that reduced the length of emergency admission stays for all deaths in the last year of life by 10% would release 239 beds and just over £19 million each year.

Finding solutions

As these findings show, issues with emergency admissions are present throughout the UK, although their precise nature varies between the nations. Marie Curie works with the NHS to tackle these issues in each of the four nations, reducing our reliance on emergency care at the end of life and ensuring that people have the support they need to be cared for in a place of their choosing.

As part of this drive, Marie Curie has developed services that help to smooth the discharge process from hospital and make sure that the right care is available in the community to reduce the need for emergency admissions. The following section highlights examples of these services.

Marie Curie 🔊 Northumbria, England

Marie Curie (a) Northumbria is a partnership between Marie Curie and Northumbria Healthcare NHS Foundation Trust. The partnership aims to provide high-quality palliative and end of life care, increasing capacity to care for more patients at the end of life and reaching more people through a combination of a hospital-based palliative end of life care liaison team and a rapid response service in the community to ensure expert care in any setting.

The Hospital Palliative and End of Life Care Liaison Team works in three hospitals across Northumberland and North Tyneside. The team provides expert clinical care and supports ward staff in arranging patient discharge with community nursing teams. Nurses often accompany patients home to provide a face-to-face handover to community nursing teams, easing the transition from hospital to home and ensuring a good communication flow.

In the community, a rapid response service works to ensure that people can receive care at home responsively. From January to June 2017 alone, the service received 1,337 patient referrals, 97% of whom could stay at home, sparing them and their families the stress and disruption of an avoidable emergency admission.

Glasgow City Fast Track Discharge Service

The Marie Curie Glasgow City Fast Track Discharge Service provides short-term, hands-on care for any adult with a terminal diagnosis, along with care and support for their families and carers. Care is provided through multiple short visits, usually two or three visits over the course of a day.

People cared for through the service typically receive care for about six days before being transferred on to other caring services. This is extended for patients approaching the end of life to allow appropriate, high-quality care for the individual and for their family. Referral is quick and simple, usually requiring only one phone call.

There are two main groups of people who use the service: Those being discharged from secondary care (usually from an acute hospital) and people at home who experience a change or deterioration in their condition. In the latter case, the fast track discharge service is on hand to prevent avoidable emergency admissions and keep people at home. In total, the service carried out 3,651 visits between 2017 and 2018.

Marie Curie Rapid Response Service, Northern Ireland

The Marie Curie Rapid Response Service (RRS) delivers flexible access to out-of-hours palliative nursing care for patients with unscheduled and urgent care needs in their own home. The service operates in three of the five Health and Social Care Trusts in Northern Ireland (Northern, Southern and Western) and is delivered in partnership with GP out of hours – running from 6pm to 8am seven days a week, 24/7 (including weekends and bank holidays).

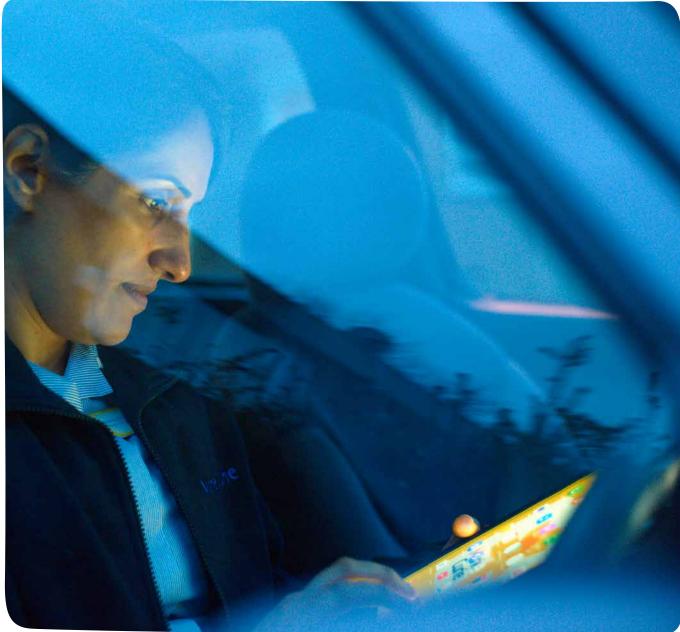
Between January and October 2015, over 1,500 patients were supported by the RRS. Nurse visit logs show that just 1% of visits during this period ended with the patient being admitted to hospital, whereas 43% of patients received at least one visit which prevented an admission. Patient, carer and family feedback demonstrates the value of the service – with nearly 60% of respondents to a user survey saying that they would have either phoned an ambulance (50%) or gone directly to A&E (9%) if the service had not been available.

"People often express how much it means to them when we visit and that they couldn't manage without the service. I was recently involved with one family – the father had a very complex condition and acute pain at times, but it was his wish to remain at home and through the Rapid Response Service we made this happen. He never had to visit hospital and died at home surrounded by his family." – Marie Curie Rapid Response Service Nurse

The service has been commissioned to commence in the remaining Health and Social Care Trusts in Northern Ireland (Belfast and South Eastern) in 2019.

It is important to understand that these examples are only a small part of the solution to reducing the rate and duration of emergency admissions for people at the end of their lives across the UK. Nonetheless, these cases stand as a useful example of the kind of services that can make a difference locally.

Ultimately, these services are about prioritising community care capacity and discharge processes, which will be key to comprehensively tackling our over-reliance on emergency care for people approaching the end of life and ensuring a high-quality experience for everyone.



Conclusion

These figures demonstrate significant disparities between the number and length of emergency admissions that people experience depending on their condition and where they live in the UK. Without doubt, there are valid clinical reasons and disease characteristics that lead to some differences in emergency admissions, but this does not explain or excuse differences between nations. Equally, it does not explain the pattern that exists across the full range of disease conditions, in which Scotland, Wales and Northern Ireland have higher average lengths of stay and England has a considerably higher rate of admission.

Pinpointing why this pattern exists is difficult, although its consistency across different conditions does suggest a systemic cause. Undoubtedly the cause will be inextricably linked to the way that health and social care services are working together – or not working together – to provide the care and support needed to either avoid an admission (in England) or to facilitate an earlier discharge (in the devolved nations).

The inconsistencies that stand out from this pattern include the high rate of admission for COPD patients in England and extraordinarily long lengths of stay for people living with dementia in Wales. Time would be well spent by the health and social care system looking at ways of addressing these specific outliers where people's needs are clearly not being met.

Similarly, the frequency of admission and lengths of stay for patients with urinary cancer or lymphoma is another outlier, considerably exceeding the average. Is this for a clinical or disease characteristic reason, or is it to do with the care pathways that people with these diseases experience?

We believe that emergency admissions in the last year of life can act as a good indicator of how well the health and social care system is serving people at the end of their lives. It is simply unacceptable that someone with a year or less to live is faced with the prospect of repeated admissions or inordinately long lengths of hospital stay. This is particularly urgent given recent research suggesting that the rate at which people are admitted as emergencies to hospital rises the closer someone gets to the end of their lives.^{xii} In a future report we will look at how the pattern of emergency admissions changes throughout the last year of life.

Finding the answers to these issues, developing and implementing systems and processes to manage them and, perhaps above all else, recognising that this is a whole-system issue both in terms of planning and, importantly, resourcing will have a significant impact on the quality of people's lives and the efficient and effective use of NHS resources.

Annex 1: ICD groupings by nation

England, Wales and Northern Ireland	ICD code group
Cancer	C00-D48
Non-cancer deaths	A00-B99
Cancer Digestive Organs	C15-C26
Cancer Respiratory	С30-С39
Cancer Lymphoid	C81-C96
Cancer Female Genital Organs	C51-C58
Cancer Urinary	C64-C68
Circulatory	105-199
Lower Respiratory	J40-J47
Dementia	F00-F09

Scotland	ICD code group
Certain infectious and parasitic diseases	А00-В99
Neoplasms	C00-D48
Diseases of the blood and bloodforming organs and certain disorders	
involving the immune mechanism	D50-D89
Endocrine, nutritional and metabolic diseases	E00-E90
Mental and behavioural disorders	F00-F99
Diseases of the nervous system and the sense organs	G00-H95
Diseases of the circulatory system	100-199
Diseases of the respiratory system	J00-J99
Diseases of the digestive system	КОО-К93
Diseases of the skin and subcutaneous tissue	L00-L99
Diseases of the musculoskeletal system and connective tissue	M00-M99
Diseases of the genitourinary system	N00-N99
Pregnancy, childbirth and the puerperium	000-099
Certain conditions originating in the perinatal period	P00-P96
Congenital malformations, deformations and chromosomal abnormalities	Q00-Q99
Symptoms, signs and ill defined conditions, not elsewhere classified	R00-R99
External causes of morbidity and mortality	V01-Y98

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