

Palliative care and the UK nations

An updated assessment on need, policy and strategy

Implications for England



Care and support
through terminal illness

Background

The Economist Intelligence Unit ranked the UK first in the world in its *2015 Quality of Death Index* because of its ‘comprehensive national policies, the extensive integration of palliative care into the National Health Service, a strong hospice movement and deep community engagement on the issue’¹.

However, since the devolution of powers to Scotland, Wales and Northern Ireland in 1999, four divergent health systems have developed in each nation across the UK. While this has not resulted in one nation consistently outperforming the others², it does mean that there are distinct policies, strategies and delivery mechanisms in place.

What is the level of palliative care need?

Estimating the need for palliative care is difficult given the range of diseases that can lead to death and the different trajectories they follow. However, Murtagh et al (2014) undertook to arrive at a population based estimate of palliative care need, based on the number of people dying from particular illnesses³. This estimate used English data only and was based on data between 2006 and 2008. Nevertheless, this is a widely respected and used estimate.

We have updated this estimate, applying the Murtagh methodology to data from across the UK and using more recent data from 2012 to 2014⁴.

In doing this we have sought to establish if or how need has changed between 2006-8 and 2012-14, and whether there are any differences in need between the nations of the UK.

What policies, strategies and delivery plans are in place to address palliative care need?

We also wanted to look at the development of policies, strategies and delivery plans across the UK, and how these meet palliative care needs.

We commissioned the Centre for Health and Social Care Research at Sheffield Hallam University to assess the strategies, policies and delivery mechanisms which underpin care for people living with a terminal illness across the UK.

⁴ Data for Scotland unavailable at time of publication. A further report will be published later in 2016 containing the Scottish figures.

We wanted to take stock of where national approaches to developing and implementing policy differ, in order to see what is working well and where there are gaps or opportunities to share good practice.

At Marie Curie, we believe everyone has the right to access high quality palliative and end of life care, regardless of their personal circumstances or where they live. Sadly, we know that one in four people in the UK do not get the palliative care they need at the end of life⁵. As the age distribution of populations across England, Scotland, Wales and Northern Ireland shifts, more people will live longer with and die from complex conditions, often more than one, that require supportive and palliative care. Our analysis of palliative care need in each of the nations - which we present in this report alongside the Sheffield Hallam findings – suggests that, already, there is a tendency to underestimate how many people should be receiving this care towards the end of their life.

Having an effective approach to providing care and support for people who have a terminal illness and their families will need to be a national priority if we have any chance of that care being high quality and as close to peoples' homes as possible and, critically, coping with current and future levels of demand.

This paper presents the outcome of our work applying the Murtagh et al (2014) approach to estimating need to 2012-14 data across the UK and summarises the findings of the Sheffield Hallam review, which looks at “top down” or government policy documents rather than “bottom up” policy proposals produced by, for example, voluntary organisations and professional associations.

In addition to increases in absolute numbers of deaths, we demonstrate that palliative care need has increased proportionately from 63% of all deaths to at least 74% of all deaths (minimal estimate), across the UK in the last six years, and is likely to continue to grow. This particularly reflects changes in age distribution in the population and increases in long term conditions needing palliative care.

A further resounding message is that a proliferation of policy documents does not of itself address the challenges each nation faces in terms of the current and future palliative care needs if there is not a concerted effort to effectively resource and drive these policies through, measure their success against meaningful indicators, and adjust them in light of robust evidence of good outcomes and improved experiences of care.

The message is both similar and very different for each of the nations of the UK. Some are better placed already to respond to today's and tomorrow's challenges. All will have to step up to the plate and ensure that coherent policies and strategies are in place as need and demand for services supporting terminally ill people increase over coming years.

The full Sheffield Hallam University report is available online at <https://goo.gl/mvc4Ad>

What is the level of palliative care need across the nations of the United Kingdom?

The majority of people living with a terminal illness, will require some form of palliative care at some point in their illness trajectory. Any comprehensive end of life care strategy or approach to caring for people with a terminal illness should therefore take into account the size of the population that will need palliative care. This is essential to inform effective commissioning and provision of services.

Some of the nations' strategies set out an estimate of population palliative care need. The Strategic Framework for Action on Palliative and End of Life Care in Scotland recognises that 'up to 8 out of 10 people who die have needs that could be met through the provision of palliative care'⁶, and the Welsh Government state in their End of Life Care annual report that "It is estimated that 75% of people dying have some form of palliative care need"⁷. However, none set out a comprehensive overview of palliative care need for their population.

Murtagh et al. (2014) developed a refined method for estimating population-based need for palliative care using English mortality data from 2006 to 2008. The method they followed produced a range of estimates including:

- a minimal estimate of 63.0% (based on the number of people whose death has a condition likely to require palliative care as the underlying cause);
- an upper mid-range estimate of 81.9% (based on the number of people with any mention on the death certificate of these conditions), and
- a maximal estimate of 96.6% (all deaths except poisoning, injury, and maternal, neonatal or perinatal deaths).

The conditions recognised by Murtagh et al as needing palliative care are:

- cancer
- heart disease, including heart failure
- cerebrovascular disease, (stroke)
- renal disease (chronic renal failure)
- liver disease
- respiratory disease (chronic respiratory disease and respiratory failure)
- neurodegenerative diseases
- dementia, Alzheimer’s disease, and senility
- HIV AIDS

We have replicated the Murtagh method⁸ using official mortality data for the three year period from 2012 to 2014 to develop a recent picture of palliative care need across the UK nations⁹. The table below shows the estimated number and proportion of people with a need for palliative care in each of the nations according to each estimate:

		Total deaths (2012-14)	% of total deaths
England	Minimal estimate	1,047,584	74.3
	Upper mid-range estimate	1,260,791	89.5
	Maximum estimate	1,351,524	95.9
	Total deaths	1,409,206	

Wales	Minimal estimate	70,013	73.6
	Upper mid-range estimate	82,839	87.1
	Maximum estimate	91,181	95.9
	Total deaths	95,079	

Northern Ireland	Minimal estimate	32,663	73.6
	Upper mid-range estimate	39,485	88.9
	Maximum estimate	42,062	94.7
	Total deaths	44,402	

Palliative care need is growing over time, but is similar across the UK nations.

These data indicate that overall palliative care need is growing over time, but that the level of need appears consistently larger across different parts of the UK. Comparing the 2012-14 data for England with the 2006-08 data in Murtagh (2014) demonstrates that the minimal estimate of palliative care need is about 10 percentage points higher than the 2006-08 Murtagh estimate. The upper mid-range estimate has also risen, such that if we take into account the contributory causes of death listed on death certificates between 2012 and 2014, the estimated level of palliative care need rises from approximately three in every four deaths to almost nine in every ten deaths.

These data also show that the minimal estimate of palliative care need is approximately 74% across the UK nations and the upper mid-range estimate is between 87 – 89.5%. These are fairly consistent across England, Wales and Northern Ireland, suggesting a similar level of need across these three nations.

Based on these results, estimates of palliative care need at 75-80% – as included in the Scottish and Welsh strategies and reports – do not take into account the level of need.

Drivers of growing palliative care need, and considerations for the future.

Comparing the 2012-14 data for England with the 2006-08 data shows why estimates of palliative care need require updating. Even though more deaths occurred in 2006-08 than in 2012-14, the number of people who died from conditions which are likely to require palliative care grew in this time period for all categories except HIV and AIDS.

Our comparison shows that the growing number of deaths recorded with Alzheimer's, dementia and senility as the underlying cause has a significant role to play in understanding the rising need for palliative care. Almost 75,000 more deaths were recorded with dementia as the underlying cause over the three year period 2012-14, representing an 88% increase on the 2006-08 figures. We also found notable increases in the number of deaths attributed to heart disease (more than 47,000 deaths, representing a 15.6% increase), and renal disease (3,030 deaths, or an increase of 58%).

It will be the case that some of the increase in dementia deaths in particular is as a result of better recording of cause of death. This owes both to better recognition of dementia as a cause of death in its own right and changes to official coding practices by the Office for National Statistics; for example, the decision to record deaths from aspiration pneumonia as being a consequence of another condition. This led to a 7.1% change in the total number of deaths where dementia was recorded as the underlying cause in 2012¹⁰.

Over the coming years, official projections show the number of deaths will rise across each of the UK nations¹¹. In England 16% more people will die every year in 25 years' time compared to 2014¹². The changing distribution of age within the UK population means that more people will be living with and dying from complex chronic illnesses, often more than one. In particular, the significant increase in the number of people living with and dying from dementia is likely to continue into the future .

This replication of the population-based palliative care need estimates show that in only six years the level of need for palliative care has grown considerably. With the changing distribution of age it is likely that palliative care need will continue to grow as more people die from conditions which may require palliative care.

It is essential that each of the uk nations have robust strategies in place to ensure everyone at the end of their life is able to access the specialist care and holistic support they need and that these strategies take account of robust estimates of palliative care need.

What the Sheffield Hallam report tells us

There have clearly been efforts to address the needs of people who have a terminal illness through policy, in all of the UK nations. The Sheffield Hallam research shows that each of these identifies core components for ensuring high quality palliative and end of life care. Some have also developed initiatives to meet the challenges these represent.

Across the UK, these relate to:

- Raising awareness of death and dying
- Identification and assessment of service users and their families with palliative care needs
- Planning and delivery of fast and effective care in a variety of settings
- Education of the public, services users and professionals
- Research and audit
- Commissioning and funding

What are the issues?

The sheer number of documents compromises interpretation and implementation

The Sheffield Hallam review assessed the number of ‘Level 1’ policy documents (ie government documents which constitute a nation’s approach to terminal illness).

In England and to some extent Scotland, there are large numbers of this sort of policy document. Although this does mirror that these nations have larger populations, there is a risk that the sheer number of documents and amount of information makes it difficult for providers and commissioners to digest all of it. Ever more additions to the policy stockpile of policy and strategy documents are more and more likely to dilute focus on the issue and not attract sustained attention. Uncertainty about the purpose and nature of documents outlining strategies, guidelines, reviews and best practice cases, and the fact that often these aren’t all hosted on one platform, is likely to be having an impact on regional and local implementation.

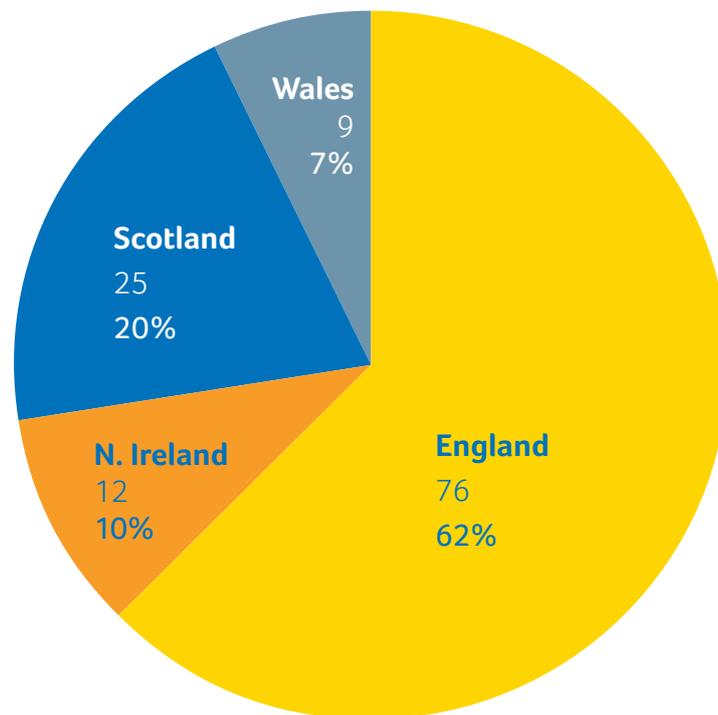


Figure 1: Comparison of total Level 1 documents by nation

Many documents also appear to restate or refashion what has gone before. As the amount of documents increases over time it becomes difficult to identify what has been removed, added or remains unchanged.

Largely generic approaches to interventions do not reflect different population groups

Evidence suggests that bespoke approaches to policy-making which take into account the specific needs and wants of certain populations are better than a ‘one-size-fits-all’ approach. However, the review found that, across the nations, it is not always clear which population certain recommendations relate to.

Although policy documents which focus on children and young people have been or are in development – and there have been some improvements in outlining how adaptations to services should be made for some population groups – more work is needed to ensure approaches are appropriate for people with different conditions and from different social and cultural backgrounds.

Effective interventions are one thing, but effective implementation of interventions are quite another

Across the UK there are comprehensive national strategies which aim to improve palliative and end of life care for that nation's population. In many cases delivery mechanisms are in place to achieve these aims. However, there is only limited evidence of pilot and evaluative work which relates to these strategies, and delivery mechanisms and evidence of policy implementation is typically supported only through local self-report mechanisms and review of documentation. This means it is very difficult to know how well policy is being implemented, although this does not necessarily mean that implementation is bad.

Even more problematically, delivery mechanisms are not consistently linked to the outcomes measures which are identified in key strategy documents. Therefore, any attempt to measure the robustness of implementation must be considered in the light of a limited evidence base. Collecting the necessary national data to monitor and drive improvements in care is complex. National surveys are used to give an indication of improvement in some of the nations (for example VOICES in England), and Wales is notable for providing discrete measures which can be measured (for example, measuring the percentage of people who receive palliative care based on medical specialty and ICD-10 coding). However, it is not clear that even these measures are sensitive enough to capture whether the overall aims of the strategy are being met. Northern Ireland has the least evidence of defined outcome measures. This does not necessarily mean implementation is poor, but it does make it difficult to assess either way.

Evidence of national reporting is not always accessible or clear. Annual reports are produced in Wales, but in other nations it can be difficult to know where to find recent evidence of implementation. In England and Scotland, national reports have been replaced by other government and non-government documents. Although across the UK there is growing recognition of the need to adopt a public health and Compassionate Communities approach to end of life care, few service evaluations consider the impact of end of life care in public health terms.

Wider health and social care changes and the changing interface between national and local government, along with other institutions, also have an impact on implementation. This has been the case in England in particular, where reform of the health landscapes has removed critical central levers to drive through national policy changes.

The funding of terminal illness care is neither clearly reported nor defined

There appears to be a lack of clarity when defining the resources and budgets that should be provided to end of life care. While there is an expectation that costs will be considered separately, in reality the budgets are subsumed within general health and social care costs. This can make it difficult to see what priority is being given to end of life care specifically and impossible to relate to spend on other services.

An approach to measuring palliative care outcomes

The Australian Palliative Care Outcomes Collaboration (PCOC) is a national programme that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. The collaborative is made up of four universities in Australia. Though participation in PCOC is voluntary, the rise in participation has been significant since it started in 2006.

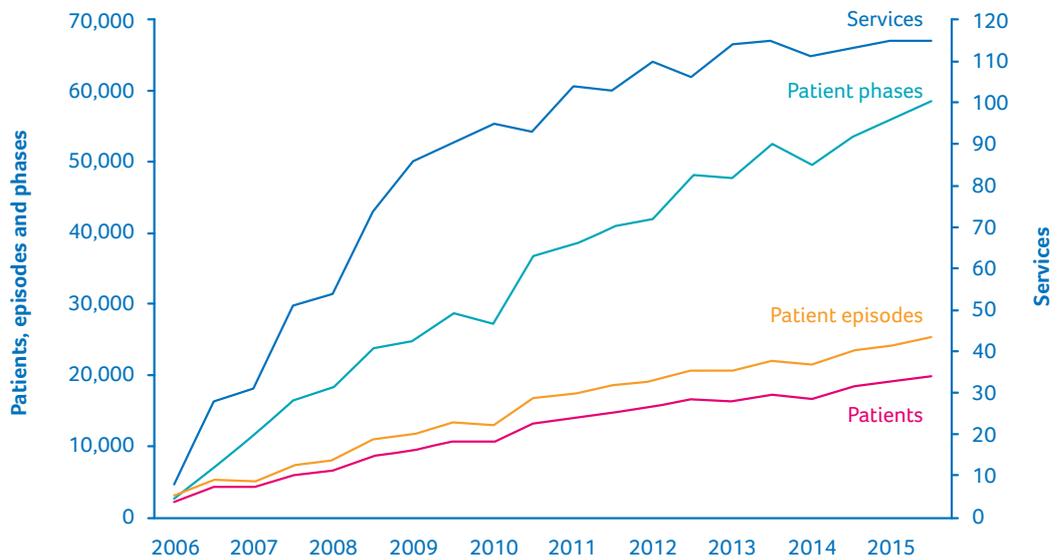


Figure 2: Participation in PCOC

The aim of the collaborative is to assist palliative care service providers in improving practice and meeting standards which they have been set.

This is achieved through a multi-purpose framework designed to:

- provide clinicians with an approach to systematically assess individual patient experiences
- define a common clinical language to streamline communication between palliative care providers
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking.

The data that PCOC collates is drawn from a range of clinical assessment tools.

The assessments are undertaken

Information is collected at 3 levels – patient, episode and phase



Patient level includes data items relating to patient demographics.

Episode level includes data items that focus on characterising the setting of palliative care service provision. They also provide information relating to the reasons why and how a palliative care episode starts/ends, the level of support a palliative care patient received both before and after an episode and, where applicable, the setting in which the patient died.

Phase level data items describe a palliative care patient’s stage of illness, functional impairment and levels of pain and symptom distress, using five clinical assessment tools. The information may be entered directly into an electronic patient record or on a clinical form to be entered into a data system at a later date. Information is collected on people who are in all care settings including their own homes.

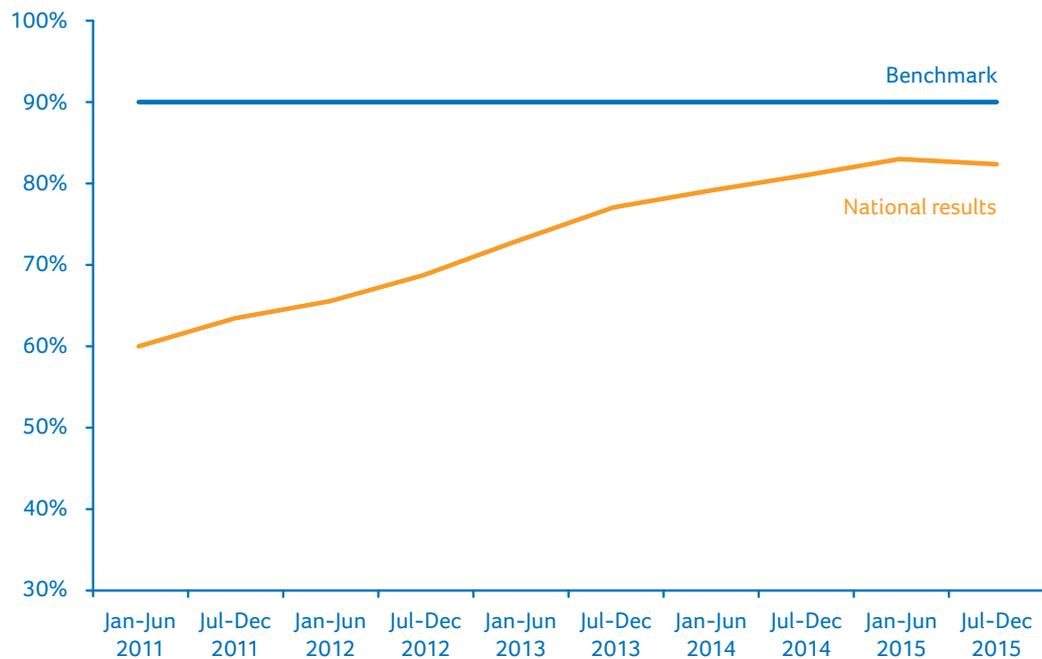
Benefits of standard assessments



National benchmarks (standards of performance that all services are measured against) have been adopted for each measure. Below is an example of how these benchmarks are presented.

Time a patient spends in the unstable phase

Figure 3: Percentage of patients in the unstable phase for three days or less national results



Outcomes against benchmarks are presented at a national and state level but not by participating care setting¹⁴

What the Sheffield Hallam report tells us about England

The backdrop of NHS reorganisation

Since the introduction of England's End of Life Care Strategy in 2008 there has been significant reorganisation within the NHS, and further restructures are on-going. The Health and Social Care Act 2012 effectively removed responsibility for the public's health from the Secretary of State for Health. It also introduced Clinical Commissioning Groups (CCGs), of which there are now 209. These groups took on responsibility for planning and commissioning health services in their local area, with NHS England playing a supporting role.

In October 2014 NHS England published the Five Year Forward View¹⁵, which sets out a shared vision for the future of the NHS based around new models of care. Shared planning guidance¹⁶ for delivering the Forward View followed in December 2015. This introduces a place-based approach to planning led by 44 'Footprint areas', which will each develop their own Sustainability and Transformation plan. The guidance specifies that plans should address how implementation of choice in end of life care will play an integral part in handing power to patients. This reflects the contents of the Government's mandate to NHS England for 2016/17¹⁷.

Limited national drivers, unequal local improvements

These changes have shaped the environment in which policies that aim to improve the care for people who have a terminal illness can be delivered, and impact on the delivery mechanisms for driving these through. For example, the removal of the Secretary of State's authority over the NHS has diminished the central power to drive through interventions at the local level. This contributes to a situation in which initiatives such as those proposed in the 2015 document Ambitions for Palliative and End of Life Care¹⁸ – the national framework for local action, which builds on the 2008 strategy and is backed by 27 partner organisations including Marie Curie and NHS England – are not effectively implemented across the board. Without CCGs among the partners and with limited national drivers, there is little to incentivise localities which do not wish to prioritise end of life care to adopt the framework in their area.

Currently more than one in four (27%) CCGs do not have a strategy for addressing end of life care in their area, and progress by Health and Wellbeing Boards on improving local care and support for people approaching the end of their life seems to have stalled since 2014¹⁹. Without a change of tack, we run the risk of deepening existing inequities in the system, regardless of how many frameworks or guidelines are produced. Areas which already prioritise and perform well in delivering high quality end of life care are likely to keep getting better, while others will get worse. The care somebody with a terminal illness can expect to receive will increasingly become dependent upon where they live.

Similarly, while NICE guidelines and quality statements provide an evidence-based view of what good care looks like, palliative and end of life care providers are not obliged to deliver on these recommendations. National audit data shows that, in 2015, almost two-thirds (63%) of hospitals were still unable to meet the 2011 quality standard for specialist palliative care provision of 9am–5pm availability every day of the week²⁰.

A murky national picture

Ensuring the effective implementation of interventions which aim to improve care for people who have a terminal illness is further hampered by a lack of national data and assurance processes. The recent announcement from NHS England and Public Health England that the palliative care clinical data set will not, as originally intended, be introduced at a national level and will instead be available for local use on a voluntary basis²¹ is a prime example of a missed opportunity to take a broader view of what is working well across different providers and to hold underperforming Trusts and CCGs to account.

What will make the difference?

The NHS was set up to provide care from the cradle to the grave. It must continue to do so in all parts of England. No CCG should be able to abstain from the responsibility of providing high quality care to dying people. Everyone should have a right to palliative care when they need it regardless of their disease, where they live or who they are.

The Government has explicitly stated that it will not introduce legislative changes that would oblige all CCGs to implement identical solutions to the challenge of providing palliative care for all who need it, instead preferring a bottom-up approach to “universalising the best”. While CCGs should be free to develop an approach to palliative care that is based on an evidenced understanding of the needs of their local population, no CCG should be able to avoid having a palliative care strategy as there is nowhere in the country where people do not die.

Recommendations for England

- The Government must commit to ensuring that everyone has a right to palliative care, as the Scottish Government has done, and to providing the resources necessary to make this happen.
- The Government must work with NHS England to find ways of ensuring that all CCGs and Health and Wellbeing Boards develop and implement palliative and end of life care strategies that take into account the health and social care needs of their local populations.
- A more sophisticated system of measuring success must be adopted alongside and underpinning the introduction of palliative care CCG strategies. This should include:
 - An expansion of the National Survey of the Bereaved so that its findings work at the CCG level;
 - Development of outcome measure reporting structured in a similar way to that operated in Australia (PCOC see p.12) and building on the work being led by the Cicely Saunders Institute (Outcome Assessment and Complexity Collaborative – OACC²²);
 - Gathering real time patient experience including complaints.

Endnotes

- 1 The Economist Intelligence Unit (2015), *2015 Quality of Death Index*.
- 2 OECD (2016) *OECD Reviews of Health Care Quality: United Kingdom 2016*.
- 3 Murtagh F, Bausewein C et al (2014) *How many people need palliative care? A study developing and comparing methods for population-based estimates*. *Palliative Medicine* Vol. 28(1) 49–58.
- 4 Data for Scotland unavailable at time of publication. A further report will be published later in 2016 containing the Scottish figures.
- 5 Based on figures from the Palliative Care Funding Review (2011), *Funding the Right Care and Support for Everyone: the Final Report of the Palliative Care Funding Review*.
- 6 The Scottish Government (2015) *Strategic Framework for Action on Palliative and End of Life Care 2016–21*.
- 7 End of Life Care annual report 2015.
- 8 Our replication omits an estimate of the lower mid-range estimate, which included linked hospital activity data. Murtagh et al (2014) concludes that: ‘Death registration data using both underlying and contributory causes can give reliable estimates of the population-based need for palliative care, without needing symptom or hospital activity data’, therefore this omission should not affect the reliability of our findings.
- 9 See endnote 4.
- 10 ONS (2014) *Impact of the Implementation of IRIS Software for ICD-10 Cause of Death Coding on Mortality Statistics, England and Wales*.
- 11 ONS (2015) *National Population Projections: 2014-based Principal Projections*.
- 12 Ibid.
- 13 Marie Curie and Alzheimer’s Society (2014) *Living and dying with dementia in Wales: Barriers to Care*.
- 14 Australian Health Services Research Initiative. *Palliative Care Outcomes Collaboration* [accessed 21 June 2016].
- 15 NHS England (2014) *Five Year Forward View*
- 16 NHS England (2015) *Delivering the Forward View: Shared Planning Guidance 2016/17*
- 17 Department of Health (2016) *The Government’s Mandate to NHS England for 2016/17*
- 18 National Palliative and End of Life Care Partnership (2015) *Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020*
- 19 Hospice UK (2016) *A low priority: How local health and care plans overlook the needs of dying people*
- 20 Royal College of Physicians (2016) *End of Life Care Audit - Dying in Hospital: National report for England in 2016*
- 21 Public Health England and NHS England (2016) *Joint statement from NHS England and Public Health England on plans for the palliative care clinical data set (PCCDS) and Palliative Care Currencies*
- 22 King’s College London. OACC [accessed 21 June 2016]; <http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/oacc/index.aspx>

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

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