Guide for commissioners on end of life care for adults

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1 Commissioning services for end of life care for adults

1.1 Aims and scope

This guide aims to support commissioners of end of life care by:

- providing support for the local implementation of the Department of Health End of Life Care Strategy and the NICE Quality Standard for end of life care for adults
- supporting commissioners with Quality, Innovation, Productivity and Prevention (QIPP) priorities and signposting to case examples
- supporting commissioning decisions on potential service reconfiguration for end of life care
- supporting the commissioning of high quality, evidence-based care for people and their families
- providing an interactive commissioning and benchmarking tool to help calculate and cost local service provision and identify cost savings
- assisting with the preparation of a business case
- highlighting relevant national priorities.

This guide includes the mapped areas of care for the NICE quality standard for end of life care for adults and covers settings in which care is provided by health and social care staff to adults (aged 18 years and older) approaching the end of life, and adults who die suddenly or after a very brief illness. It also includes support for the families and carers of people in these groups. This guidance does not include commissioning of condition-specific end of life care services and commissioners may wish to refer the NICE guides for commissioners on dementia, chronic obstructive pulmonary disease and heart failure, which provide condition-specific end of life care information.

This guide may be useful for various groups of commissioners, including:
• integrated health and social care commissioning teams
• health commissioners including those based within primary care clusters or emerging clinical commissioning groups
• local authority commissioners with responsibility for social care
• lead providers who sub-contract on behalf of commissioning organisations.

Lead commissioning arrangements may be appropriate if the commissioning population is small, or if an organisation provides services to more than one commissioner. These agreements need robust governance arrangements, and if they exist, they should link with existing networks[1]. End of life care involves a large number of third sector providers, notably hospices, and some are small organisations that could be unintentionally destabilised by changes in commissioning arrangements, including the impact of potentially having to work with multiple commissioning organisations. Consequently host commissioning may be particularly important in future years with the implementation of clinical commissioning groups.

1.2 Defining end of life

This commissioning guide uses General Medical Council's definition of end of life: people are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

• advanced, progressive, incurable conditions
• general frailty and coexisting conditions that mean they are expected to die within 12 months
• existing conditions if they are at risk of dying from a sudden acute crisis in their condition
• life-threatening acute conditions caused by sudden catastrophic events.

Defining when a person needs end of life care is individual and dependent on the person's perspective and that of their health and social care professional[1]. It could be marked by diagnosis of a condition that has a poor prognosis, or by exacerbation of a long-term condition that has resulted in a sudden and marked deterioration in the person's physical health and independence. For others death is an unforeseen event, and in this situation coroner involvement can be important. End of life care needs coexist with other health and social care needs and are influenced by a person's religious, cultural and social circumstances.
Consequently, end of life care services should be commissioned and delivered in an integrated and person-centred manner.

The complexities of defining when a person has entered the end-of-life phase means that, in practice, a group of people will need access to end of life services for a longer period than the final 12 months of life. Two notable groups are young adults and people with dementia. Advances in medical treatments means that many children, who would have died in childhood, now live into adulthood and consequently may need palliative care services for much longer than 12 months. In 2010 approximately 2,500 children and young people aged 15–24 years died. Adult services might not meet the specific needs of young adults therefore commissioners may also wish to consider the needs of this specific group when planning services for adults. Also, in the NICE guide for commissioners 'End of life care for people with dementia', the benchmark highlights that 66,000 people who die each year with dementia are likely to need end of life care before death and many of these people will need palliative and end of life services for much longer than 12 months.

1.3 Commissioning person-centred end of life care

The achievement of person-centered care can be hindered by the funding and commissioning levers that currently exist. For example, the indicator 'Proportion of deaths in usual place of residence' focuses on enabling more people to die in their usual place of residence and consequently a reduction in the proportion of deaths occurring unnecessarily in hospital. This indicator is based on consistent survey data showing that most people would choose to be cared for and to die at home. However, person-centered care is vital and needs services to find out about and act on individual preferences and changing circumstances rather than rigidly imposing any single model of care. If an acute hospital is the most appropriate place of death, then this should be supported, although it may appear to conflict with the target set. As the vignette in box 1 demonstrates, end of life care experiences are not linear and commissioners should guard against perverse incentives.

Box 1 Vignette
An 80 year old woman who has been living in a care home for the past year and has advanced chronic obstructive pulmonary disease (COPD) and diabetes. In the past 9 months she has had two hospital admissions for treatment of COPD exacerbations. Each time she has been discharged less well, and it has been agreed that she should probably not be readmitted next time she has an exacerbation. She is still mobile and enjoys using her walking frame to get around her room and the communal areas of the care home. She falls and fractures her hip and requires corrective surgery and pain relief. If she were not admitted to hospital to have her hip operated on, she would remain bedbound and adequate pain control would be difficult. With the woman’s consent she is taken to hospital where the surgical team operate and provide pain control. Two days after her surgery the woman starts to deteriorate and has a comfortable pain-free death in hospital.

In this situation, the woman needed surgical intervention independently of the plans for treating her COPD and hospital was the appropriate environment in which to ensure the woman had adequate pain control. Hence, although death in the usual place of residence may be the agreed goal, and may be achievable for many people who presently die in hospital, it is important to ensure that person-centered decisions are made.

1.4 The case for change

Just over 1% of people die each year. Around 455,000 people died in England in 2010, two-thirds of whom were 75 years of age or older\[3\]. Deaths in England and Wales are expected to rise by 17% from 2012 to 2030\[4\]. A large proportion of deaths are foreseeable, and a recent estimate suggests that approximately 355,000 people need good palliative care services every year but around 92,000 people are not being reached\[5\]. Despite some small improvements, there is still an enormous amount of progress needed to close the gap between preferred and actual place of death. Although 63% of people surveyed stated that home is their preferred place of death, in 2010 most deaths occurred in hospitals (53%) and only 21% occurred in the home with an additional 18% in care homes\[6\].

Traditionally, end of life care services have been orientated towards cancer care, however people with a whole range of other conditions including cardiovascular, respiratory, and neurological disorders and dementias should also be accommodated. In 2010 non-cancer related deaths accounted for over 70% of deaths\[3\]. Although the percentage and number of people with non-cancer diagnoses accessing specialist palliative care services has increased overall in the past 12 years, the proportions of people with conditions other than cancer who access these services
still remains very low\(^{[1]}\). The proportions ranged from 10% for inpatient and home care specialist palliative care services to 25% for outpatient specialist palliative care services.

It is difficult to put an exact cost on end of life care because of different funding mechanisms and multiple providers.

![Figure 1 Provision and funding of end of life care services](image)

**Figure 1 Provision and funding of end of life care services**

Source: Hughes-Hallet T, Craft A and Davies C. (2011) *Palliative Care Funding Review: Funding the Right Care and Support for Everyone* figure 4, page 21

DH = Department of Health  
DfE = Department for Education  
DWP = Department for Work and Pensions  
CLG = Department for Communities and Local Government  
NHS = National Health Service  
PCTs = Primary Care Trusts  
LAs = Local Authorities

Analysis of payment by results funding demonstrates the costs of admissions ending in death are large. The [commissioning and benchmarking tool](#) highlights that in England in 2010–11 approximately 215,000 hospital admissions ended in death, the estimated average cost of an
admission was £2,506 and the estimated total cost of acute admissions ending in death was over £520 million. The commissioning and benchmarking tool demonstrates that for all-cause admissions that result in death approximately 40% of people have a stay that is greater than 7 days.

Figure 2 Length of stay for hospital admissions ending in death in England and estimated average cost per admission for year ending March 2011

Source: Analysis of data presented within the commissioning and benchmarking tool

Approximately 15% of admissions ending in death have a stay of more than 21 days and these admissions are very costly to the commissioner and are likely to be poor care experiences for the person, and their relatives and carers. Expert opinion suggests that such long stays are often the result of gaps in services and an inability to discharge. The National Audit Office found that in one primary care trust, 40% of people who died in hospital did not need to be treated in hospital, and nearly a quarter of these people had been in hospital for over a month\(^1\).

The commissioning and benchmarking tool demonstrates that a 10% reduction in the number of admissions ending in death could potentially result in a saving of £52 million. These savings can be invested in alternative, community-based end of life care services.
1.5 Measuring care quality

Emerging evidence suggests that redesigning local end of life care pathways to enable provision of high quality end of life care resulting in more people being able to die in their usual place of residence, rather than in hospital, is at worst cost neutral and has the potential to be a more efficient and effective use of resources\[^9\],\[^10\]. Commissioners and providers should note that emerging evidence is currently localised and although no single service model exists that all commissioners can simply apply, a range of models can guide service redesign according to local needs and circumstances.

End of life care is one of 12 national workstreams of the Quality, Innovation, Productivity and Prevention (QIPP) programme. The national end of life care QIPP worksteam concentrates on:

- identifying people who are approaching the end of life
- planning for their care.

Key performance indicators are being developed to support the end of life care QIPP workstream and these are detailed in the End of Life Care Quality Assessment Tool (ELCQuA). ELCQuA is a free online tool for keeping track of progress in delivering end of life care services. It is aimed at commissioners and providers and includes the end of life care strategy, quality markers and measures for end of life care, the QIPP key performance indicators, Care Quality Commission prompts for end of life care and in future will include the statements and measures of the NICE quality standard for end of life care for adults.

1.6 NHS outcomes framework and adult social care outcomes framework

Refer to the NICE quality standard 'End of life care for adults' when commissioning services that contribute to delivering the following outcomes:

NHS outcomes framework 2012/13:

- Domain 2: enhancing the quality of life for people with long-term conditions.
Domain 4: ensuring that people have a positive experience of care. This includes indicator 4.6[1] which will be derived from the survey of bereaved relatives (see section 4.5.1 for further details)

Domain 5: treating and caring for people in a safe environment and protecting them from avoidable harm.

Adult social care outcomes framework

- Domain 1: enhancing quality of life for people with care and support needs.
- Domain 2: delaying and reducing the need for care and support.
- Domain 3: ensuring that people have a positive experience of care and support.
- Domain 4: safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm.

1.7 Key clinical and quality issues

Key clinical and quality issues in providing effective services for end of life care in adults are:

- **Reducing inequalities and improving identification** through de-stigmatising death and dying and encouraging healthcare professionals and people with end of life care needs and their families and carers to engage in open conversations.

- **Improving the quality of care** including care after death, through holistic assessments and timely interventions in the right place by a knowledgeable, caring and competent workforce.

- **Increasing choice and personalisation** through care planning and advance care planning, including advance statements and advance decisions to refuse treatment and provision of resources that enable these choices to be achieved.

- **Ensuring care is coordinated and integrated** across all sectors involved in delivering end of life care.

- **Improving the psychological, physical and spiritual well being** of people with end of life care needs and their carers through access to an appropriately trained and resourced workforce
• **Timely access to information and support** to enable people with end of life care needs and their families and carers to make informed decisions.

• **Timely provision of continuing NHS healthcare funding** to support people to die in their place of choice.

• **Supporting carers and ensuring access to an assessment of need** as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004.

• **Timely access to generalist and specialist palliative care services** on the basis of need and not diagnosis. This includes the provision of community based support and access to specialist advice (which may be via telephone) 24 hours a day, 7 days a week.

• **Reducing unnecessary hospital admissions** and length of stay by developing capacity to deliver expertise to the person's usual place of residence through pathway redesign and workforce development. This includes supporting staff in social care settings such as care homes and domiciliary workers; supporting relatives and friends who are caring for a person with end of life care needs; and providing the necessary clinical expertise, medicines and equipment.

• **Improving cross-boundary and partnership working**, through close working between health and social care services to ensure flexible and integrated services that have the infrastructure to enable this (for example shared IT networks). This should improve care coordination, minimise unnecessary duplication and reduce costs.

• **Improving knowledge and skills** in generalist and specialist palliative care settings, and in social care settings including independent residential and nursing homes and domiciliary workers.

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2. Hughes-Hallet T, Craft A and Davies C. (2011) Palliative Care Funding Review; Funding the Right Care and Support for Everyone


4. The National Council for Palliative Care and the National End of Life Care Intelligence Network (2009-10) National Survey of Patient Activity Data for Specialist Palliative Care Services


6. Marie Curie Delivering Choice Programme

7. Department of Health End of Life Care Family Liaison Service Case Study

2 A pathways approach to commissioning high-quality integrated end of life care for adults

The Department of Health's 'End of life care strategy' (2008) promotes a whole system approach to commissioning end of life services and highlights the importance of integrated and coordinated services. Commissioners should consider using a care pathway approach to commissioning. This is particularly important in end of life care where services are interconnected and span different sectors and settings. Care pathway commissioning supports commissioning for outcomes and can lead to streamlining of services.

This guide is structured to reflect the areas of care map for the NICE quality standard 'End of life care for adults'.

Figure 3 Areas of care for the NICE quality standard 'End of life care for adults'
QS = quality statement.

Table 1 Quality statements for end of life care for adults
<table>
<thead>
<tr>
<th>No.</th>
<th>Quality statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>People approaching the end of life are identified in a timely way.</td>
</tr>
<tr>
<td>2</td>
<td>People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.</td>
</tr>
<tr>
<td>3</td>
<td>People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.</td>
</tr>
<tr>
<td>4</td>
<td>People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.</td>
</tr>
<tr>
<td>5</td>
<td>People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.</td>
</tr>
<tr>
<td>6</td>
<td>People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.</td>
</tr>
<tr>
<td>7</td>
<td>Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.</td>
</tr>
<tr>
<td>8</td>
<td>People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.</td>
</tr>
<tr>
<td>9</td>
<td>People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.</td>
</tr>
<tr>
<td>10</td>
<td>People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>11</td>
<td>People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.</td>
</tr>
<tr>
<td>12</td>
<td>The body of a person who has died is cared for in a culturally sensitive and dignified manner.</td>
</tr>
<tr>
<td>13</td>
<td>Families and carers of people who have died receive timely verification and certification of the death.</td>
</tr>
<tr>
<td>14</td>
<td>People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.</td>
</tr>
<tr>
<td>15</td>
<td>Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.</td>
</tr>
<tr>
<td>16</td>
<td>Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.</td>
</tr>
</tbody>
</table>
3 Assessing service levels for adults needing end of life care services

3.1 Information and data to support the provision of end of life care

Around 455,000 adults died in England in 2010, two-thirds of which were 75 years of age or older\[12]\textsuperscript{[12]}.

The majority of these deaths, 53\%\textsuperscript{[12]}, occurred in an acute hospital. 75\% of NHS hospital deaths are from diseases of circulatory system, respiratory system or cancer\textsuperscript{[13]}.

The number of deaths each year in the United Kingdom is expected to rise by 17 per cent between 2012 and 2030\textsuperscript{[14]}.

In addition, the average age at death is predicted to increase\textsuperscript{[13]}, and those dying are likely to have increasingly complex co-morbidities.

Commissioners and their partners should conduct a local needs assessment in order to estimate local service need, to plan capacity and develop plans to improve the accessibility and inclusivity of services. A local needs assessment for end of life care for adults is likely to include:

- number of people who may need end of life care including annual number of deaths by condition and place of death (see section 3.1)
- additional factors that influence local service need (see section 3.2)
- existing current and optimal local practice (see section 3.3).

3.1.1 Identification of the number of adults at end of life

In England, approximately 455,000 adults died in 2010\textsuperscript{[12]} which equates to approximately 1.12\% of the adult population\textsuperscript{[15]}.

A proportion of this population will not need end of life care before death because the cause of death is sudden, either through unpredictable onset of disease or an external cause. Recent analysis of all deaths in England by the National End of Life Care Intelligence Network estimate that at least 25\% of all deaths in England are unexpected deaths from sudden causes\textsuperscript{[16]}. This is in line with the palliative care funding review\textsuperscript{[17]}, which estimated that between 70\% and 80\% of all deaths are likely to need end of life care.
All people whose deaths are not sudden or unexpected (approximately 75% of all deaths) should have their end of life care needs recognised and provided for in the last year of life. Therefore, the number of adults needing end of life care services is 0.83% or 830 per 100,000 population aged 18 years or over; this is around 341,000 people in England\(^{[4]}\).

### 3.1.2 Number of deaths by underlying cause

Figure 4 illustrates that three-quarters of people who died in 2010 died from diseases of the circulatory system, respiratory system or cancer. The cause of death can affect the type of care needed in the last year of life and the appropriate place of death. It should be noted that the cause of death does not necessarily reflect the main condition needing care in the last year of life, and many people will have comorbidities.

![Figure 4: Underlying cause of death England and Wales 2010\(^{[4]}\)](image)

Commissioners may wish to pay particular attention to people with respiratory disease. The report 'Deaths from respiratory diseases: implications for end of life care in England' shows that, of the three main causes of death, respiratory diseases (excluding lung cancer) is the category for which there is the highest proportion of emergency hospital admissions, the highest proportion of people who die in hospital (69%) and the lowest proportion who die in their own residence (13%). Also:

- there are relatively few respiratory (excluding lung cancer) deaths in hospices;
・ there is a higher proportion of respiratory (excluding lung cancer) deaths in the most deprived quintile

・ the proportion of deaths due to respiratory diseases increases with age.

### 3.1.3 Place of death

The Office for National Statistics data "Mortality Statistics: Deaths registered in England and Wales (Series DR), 2010", sets out the place of death. The most common place of death is NHS hospitals where over 53% of deaths occur (table 2) for all causes.

#### Table 2 Place of death: all causes [\[2\] , [\[2\]]

<table>
<thead>
<tr>
<th>Place of Death</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>20.8%</td>
</tr>
<tr>
<td>Care homes</td>
<td></td>
</tr>
<tr>
<td>Local authority</td>
<td>1.3%</td>
</tr>
<tr>
<td>Non-local authority</td>
<td>16.8%</td>
</tr>
<tr>
<td>Hospices</td>
<td></td>
</tr>
<tr>
<td>NHS</td>
<td>0.5%</td>
</tr>
<tr>
<td>Non-NHS</td>
<td>4.7%</td>
</tr>
<tr>
<td>Hospitals (acute or community, not psychiatric)</td>
<td></td>
</tr>
<tr>
<td>NHS</td>
<td>53.5%</td>
</tr>
<tr>
<td>Non-NHS</td>
<td>0.2%</td>
</tr>
<tr>
<td>Other communal establishment</td>
<td>0.3%</td>
</tr>
<tr>
<td>Elsewhere</td>
<td>1.9%</td>
</tr>
</tbody>
</table>

Place of death for just cancers (table 3) shows a higher number of deaths in hospice and at home with lower numbers of deaths in NHS hospitals. The national audit office report 'End of life care' suggests that a large proportion of people (40%) who currently die in hospital have no medical reason to do so.

The majority of people said that they would prefer to die at home if circumstances allowed (section 3.1.4) but the number of people who are able to do so varies with age, geographical area and, most significantly, by condition[\[3\]].

#### Table 3 Place of death: cancer only [\[4\]]
3.1.4 Preferred place of death

Commissioners should ensure that they engage with the public and service users when developing their needs assessment to understand service user experience and local barriers to accessing end of life care. This information should be used to inform commissioning plans and to improve the accessibility of local services.

The actual place of death (section 3.1.3) contrasts sharply with the report, "Local preferences and place of death in regions within England\(^{[23]}\) which showed public preferences for place of death in the nine English Government Office regions.

The majority of participants in all regions said that they would prefer to die at home if circumstances allowed, this ranged from 60% of participants in the West Midlands to 67% in the north east. This preference was lower (45%) for the older age group (75+) overall. The older age group (75+) also expressed the greatest preference to die in hospice care, despite being the least likely to do so. Hospital was the least preferred place of death in all regions except for the north east, where 34% reported 'care home' as their least preferred place (against 31% for hospital).

It should be noted that this was a telephone survey of participants (not necessarily people who were dying) in their own home, thus excluding care home residents. People's preferences for where they are cared for and die are not yet currently systematically captured or routinely reviewed as their illness progresses and their needs change, it is not possible to get a clear
picture of how many people would prefer to die somewhere other than their actual place of death. For the future, this gap may be filled nationally through the 'Views of informal carers – evaluation of services' (VOICES) survey of carers and bereaved relatives and locally through the growing use of electronic palliative care coordination systems which will record this information.

3.2 Additional factors that influence local service needs

Commissioners should conduct a local needs assessment for health and social care to determine local service levels for people with end of life care needs. To determine local commissioning priorities, end of life care commissioners should conduct or review their baseline assessment of local practice in line with the 'End of life care strategy', NICE cancer service guidance and the 'Operating framework'.

Commissioners will need to use intelligence on local demography to inform their needs analysis. The following are in addition to the areas covered in section 3.1 and can have a significant impact on the local need and uptake of end of life care:

- age distribution and sex of the person
- regional and local variation
- non-malignant diseases
- deprivation
- cognitive impairment (dementia)
- religious or cultural groups within the local community
- lesbian, gay, transgender and transsexual people
- children and young adults.

3.2.1 Age and sex

The trend for life expectancy to increase has been observed for many years in the United Kingdom, as the age at death increases those dying are likely to have increasingly complex comorbidities. The World Health Organization (WHO) 'European health for all database' 2009
data shows life expectancy in the UK (table 4) has increased dramatically in the years since 1970.

**Table 4 Life expectancy at birth, in years**

<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>United Kingdom</td>
<td>71.95</td>
<td>73.71</td>
<td>75.92</td>
<td>78.06</td>
<td>80.55</td>
</tr>
</tbody>
</table>

Commissioners should be aware that the number of deaths by age and sex varies significantly from region to region. The office of national statistics publication 'Deaths registered in England and Wales by area of usual residence' splits the number of deaths by Government Office region. Around two-thirds of all deaths occur in the 75 and older age group (74% of females and 59% of males[^12]). However, older people may be at risk of over-identification if assumptions about their prognosis and end of life care needs are based on age alone.

![Figure 5, Deaths by age and sex](image)

### 3.2.2 Regional and local variation

Identifying groups of people at the end of life is complex and the profile of these groups will differ regionally. The 'Health profile of England' 2009 shows a distinct 'north/south' divide for both male and female life expectancy at birth. In all northern regions, as well as both the East Midlands and...
West Midlands, life expectancy is significantly shorter than in the regions to the south. For both sexes, those living in the north east or north west live approximately 2 years less than those in the South East or South West.

In England two-thirds of all deaths are in people aged 75 years of age or older[12]. Around 17% of deaths are in people aged 65 or under. However, this varies with some inner city primary care trusts recording over 30% of deaths in the 65 or under age group.

3.2.3 Comorbid conditions

In the last year of life many people will have comorbid conditions. The cause of death is not necessarily the main condition that will be treated in the last year. Dementia has a relatively low number of deaths. However, studies have shown that a large proportion of older people have dementia.

The NICE commissioning guide ‘End of life care for people with dementia’ reported the number of deaths in hospital for people with dementia. The prevalence of dementia increases with age, from around 1.6% in people aged 65–69 to over 30% in those people aged 90 or over. 66,000 people who die each year with dementia are likely to need end of life care before death. This is equivalent to around 800 deaths per 100,000 people aged 65 and older, per year.

Some groups (such as people with non-malignant disease) are currently under-identified when providing end of life care. The association of public health observatories disease prevalence models[24], the health needs of a population derive from the prevalence of diseases, that is, the numbers of people with different types of illness. This disease prevalence model can help commissioners to identify and address those needs.

3.2.4 Deprivation

The National End of Life Care Intelligence Network report 'Variations in place of death in England' examines the complexity and appropriateness of different end of life care settings for different groups, depending on age, sex and socioeconomic status.

The 'Health profile of England' 2009 shows inequalities in the determinants of health across England; for example, approximately 34% of people living in the north-east live in the most deprived fifth of neighborhoods in England. This compares with approximately 6% of people in the south-east who live in the most deprived fifth of neighborhoods.
Risk factors for diseases such as cancer and circulatory diseases, including smoking, physical inactivity and obesity, increase with greater levels of deprivation. The Marmot report ‘Fair society, healthy lives: a strategic review of health inequalities in England post-2010’ identified that the burden of disease falls disproportionately on people living in deprived conditions.

3.2.5 Household composition

Household composition will impact on the level of care needed for a person; household composition differs for men and women. Data from the Office for National Statistics showed that in 2010, 7.5 million people in UK households lived alone, of which 3.4 million were aged 65 and over, of these, 70% were women.

The National End of Life Care Intelligence Network report ‘Deaths in older adults in England’ again shows the proportion of older men living alone is lower than for older women, with more men living as a married couple and fewer who are widowed compared with women. Similarly, north west public health observatory reports the proportion of older men living in a communal establishment is lower than for women.

Factors that are thought to contribute to differences in living arrangements include a greater life expectancy\(^{[12]}\) for women than men and a tendency for women to marry men who are older than themselves. Living alone will affect the level of care needed for a person and their ability to continue to live in their own home. This may also affect the person’s aspirations to die in their own home and the levels of care needed.

3.2.6 Religious or cultural groups in the local community

Local communities may contain small or large pockets of people with particular religious or cultural beliefs, in which discussions about death may be considered to be inappropriate and the management of death is handled in a particular manner. These communities may also be from particular black and minority ethnic groups (but this is not necessarily the case). Differing language, religious and cultural needs should be considered when identifying and providing end of life care services.

3.2.7 Lesbian, gay, transgender and transsexual people

Any service provided for people at the end of their lives must be equitably and sensitively provided to lesbian, gay, transgender and transsexual people and their partners and families.
3.2.8 Children and young people

Around 2,500 children and young people aged 15–24 years old died in 2010. However, as a result of advances in medical care, many children with life-limiting, long-term conditions live into adulthood. 'Better care better lives' (Department of Health 2008) identifies the need to ensure that transition should be 'a planned and purposeful process'.

3.2.9 Sources of data for the needs analysis

A comprehensive compendium of data sources, publications and research is available on the National End of Life Care Intelligence Network website. The National End of Life Care Intelligence Network has further developed a set of tools to help to identify and understand variation in end of life care across England. The indicators focus on place and cause of death, broken down by age and sex, by local authority area in England.

3.3 Current practice

3.3.1 Hospital episode statistics

The 'Hospital episode statistics (HES)' is a data warehouse that contains information about hospital admissions and outpatient attendances in England. The data in HES comes from the Secondary Uses Service, which collects data that have passed between healthcare providers and commissioners. It includes private patients treated in NHS hospitals, people resident outside England who were treated in an NHS hospital and care delivered by treatment centres (including those in the independent sector) funded by the NHS.

In 2010/11 HES data show that over 200,000 in people died in hospital. Over 40% of these people had a final length of stay of 8 days or more. Figure 6 below illustrates the length of stay and primary chapter (diagnosis area) for people who died in hospital in 2010/11.

The length of stay may be appropriate for many of these people; however, it is possible that the length of stay could be reduced for some people at the end of life through providing alternative care options, if appropriate.

Further, detailed analysis of the HES data, split by primary care trust, can be found in the commissioning and benchmarking tool. Figure 7 illustrates the English regions that have the largest number of episodes per 100,000 population of long length of stay (8 days or more).
Commissioners should use the commissioning and benchmarking tool to model service capacity at each step of care.

Figure 6 Length of stay of hospital admissions which result in death
Figure 7 Episodes per 100,000 people who died in hospital, with a length of stay of 8 days or more

Figure 7 categorises strategic health authority (SHA) regions based on the number of hospital episodes ending in death, with a length of stay of 8 days or more per 100,000 people ("Hospital episode statistics [HES]" data). Of the 10 SHA regions, the highest three are marked as high in relation to the other regions. The next three are marked as medium and the last four are marked as low. Further analysis and more detail, including a split by primary care trust is available in the commissioning and benchmarking tool.

3.3.2 Palliative care registers

One source of data for people who are currently identified as needing end of life care is palliative care registers. Quality and outcomes framework (QOF) data for 2009/10 show the number of people on a palliative care register (people in need of palliative care or support) is 0.1% of the population or 75,000 people in England. This is approximately 16% of the number of people who die every year.
People with cancer tend to be over-represented on the QOF palliative care register. Data extracted from IMS Disease Analyzer, a database that holds data from a sample of GP practice systems, show that 73% of people available in their practice for the 12 months from 1 April 2010 to 31 March 2011 new to the QOF palliative care register during the study year, had a diagnosis of cancer anywhere in the record ([International Classification of Disease 10](#) cancer definitions[^25]). This compares with less than 30% who had cancer as their primary cause of death.[^26]

Electronic palliative care coordination systems that link together all the organisations involved in a person's care (currently being piloted) have been considered a potentially useful tool for improving end of life care and enabling people to be supported in their place of choice and to die in their usual place of residence.

The process of placing an individual on a palliative care register or electronic palliative care coordination system should be sensitive to the possibility that not all people will want to be recognised as approaching the end of life. Some people choose not to acknowledge their prognosis and others, such as those with sensitive conditions, may worry about potential stigma if they are identified.

### 3.4 Conclusion

Based on the epidemiological data and other information outlined above, based on the following, it was concluded that:

- around 455,000 adults died in England in 2010
- 75% of all deaths were not sudden or unexpected

Therefore, the indicative benchmark rate for the number of adults needing end of life care services is 0.83% or 830 per 100,000 population aged 18 years or over. This equates to 341,000 adults in England.

Commissioners should use their local needs assessment to determine optimum levels for local service provision. Commissioners should note that the benchmark rates do not represent NICE’s view of desirable, or maximum or minimum, service levels.

Commissioners should use this benchmark and local data to facilitate local discussion on optimum service levels. There is considerable variation in the identification of people in the last...
year of life. This is influenced by the social, economic and demographic profile of the local population, therefore commissioners are encouraged to consider local assumptions.

Use the end of life care commissioning and benchmarking tool to determine the level of service that might be needed locally and to calculate the cost of commissioning the service using the indicative benchmark and/or your own local data.


[16] Blackmore S, Pring A, Verne J (2011) Predicting death: estimating the proportion of deaths that are 'unexpected.' National End of Life Care Intelligence Network

[17] Hughes-Hallet T, Craft A and Davies C. (2011) Palliative Care Funding Review; Funding the Right Care and Support for Everyone

[18] This figure is for end of life care prior to death. Care after death is examined in section 4.5. See also section 3.2, which examines the areas that will have the greatest influence locally on the above figure, principally the age profile of the population and the expected number of deaths.


[21] Place of death is defined using a revised place of death classification. deaths at home are those at the usual residence of the deceased (according to the informant), where this is not a
communal establishment. Care homes includes homes for the chronic sick; nursing homes; homes for people with mental health problems and non-nhs multi function sites. Hospices include Sue Ryder Homes; Marie Curie Centres; oncology centres; voluntary hospice units; and palliative care centres. Other communal establishments include schools for people with learning disabilities; holiday homes and hotels; common lodging houses; aged persons' accommodation; assessment centres; schools; convents and monasteries; nurses' homes; university and college halls of residence; young offender institutions; secure training centres; detention centres; prisons and remand homes. Elsewhere includes all places not covered above such as deaths on a motorway; at the beach; climbing a mountain; walking down the street; at the cinema; at a football match; while out shopping; or in someone else's home. This category also includes people who are pronounced dead on arrival at hospital.


[n] Prevalence models provide estimates of underlying prevalence derived from population statistics and scientific research on the risk factors for each disease. This enables commissioners to assess the true needs of their community, calculate the level of services needed and invest the appropriate level of resources for prevention, early detection, treatment and end of life care.

[g] ICD-10 Chapter II: Neoplasms (C00- D48)

[g] Death registrations in England and Wales, selected data tables 2010, Office for National Statistics (ONS); London 2011
4 Specifying end of life care for adults

Implementation of the NICE quality standard for end of life care for adults is expected to contribute to the following outcomes for people approaching the end of life:

- Care that is aligned to needs and preferences.
- Increased length of time spent in preferred place of care during the last year of life.
- Reduction in unscheduled care hospital admissions leading to death in hospital (where death in hospital is against their stated preference).
- Reduction in deaths in inappropriate places such as on a trolley in hospital or in transit in an ambulance.

This guide focuses on the following areas of care for people with end of life care needs:

Section 4.1 – identification and assessment (including care planning)

Section 4.2 – holistic support

Section 4.3 – access to services (including co-ordination of care)

Section 4.4 – care in the last days of life

Section 4.5 – care after death

Section 4.6 – workforce
4.1 Identification and assessment (quality statements 1, 2 and 3)

4.1.1 Identification (quality statement 1)

The benchmark referred to in section 3 highlights that:

- 1.12% of the adult population in England die each year and of this approximately 25% have unexpected deaths. Therefore it is calculated that the number of adults needing end of life care services is 0.83% or 830 per 100,000 population aged 18 years or over.

The benchmark has synergy with the end of life QIPP programme 'Find your 1% campaign', which has some resources to assist commissioners and providers.

As highlighted previously QOF data show the number of people on a palliative care register (people in need of palliative care or support) is 0.1% of the population or 75,000 people in England. This is approximately 16% of the number of people who die every year (see section 3) and 73% of these registrations are of people with a cancer diagnosis. Commissioners may wish to use their local QOF palliative care register as a starting point for understanding how effective current services are in recording and identifying people with end of life needs. Alternatively, if electronic palliative care registers exist (see section 4.3.1) commissioners may wish to use these as an alternative to QOF palliative care registers.

Successful identification of people entering end of life needs a willingness on the part of the individual and the healthcare professional to enter into a conversation about end of life. A lack of open and honest communication between health and social care staff and individuals about end of life care can hinder this identification\[27\]. This barrier is related to the taboo around discussing death and dying. To support the implementation of the 'End of life care strategy' the Dying Matters Coalition is delivering a programme of national work to raise awareness of death and dying, thereby helping to make conversations about death and dying more commonplace. Commissioners may wish to consider resourcing local awareness raising activities and the Dying Matters Coalition provide a variety of resources, such as posters and leaflets, which can assist with relatively low cost local promotional activities.

Although localities should work to identify people approaching the end of life, it is important to recognise that not all people will wish to have conversations about death and accept that their
death is approaching. For some people who do not wish to engage in the conversation, the healthcare team still needs to plan services that best support the person's needs, although these might not be formally recognised by the person as part of end of life care services. For example, appropriate social care support, respite care, or provision of benefit support. Commissioners may wish to ask providers to demonstrate they have local guidance in place regarding approaching conversations about the end of life and the 'Finding the words' workbook and DVD provides useful information. The 'Dying matters' website provides a range of resources to support both the public and professionals in this sensitive area.

4.1.2 Communication and information (quality statement 2)

The National End of Life Care Programme has identified communication as one of the core competencies (see section 4.6). Commissioners should specify that providers can demonstrate that all staff involved in end of life care have the required competencies in communication. The level of competency is dependent on an individual's role and the National End of Life Programme provide specific guidance on commissioning end of life care communication training and a benchmarking tool to help commissioners, providers and educationalists assess the quality of communication education. The Department of Health has commissioned an electronic learning course to support the implementation of the 'End of life care strategy' and this includes a number of different sessions relating to communication skills. It is available free to health and social care staff (see section 4.6). There will be costs involved in staff time to undertake this training. Sensitive communication includes ensuring that the physical environment is appropriate and the documents 'Routes to success: achieving quality environments for care at end of life' and 'Environments for care at the end of life' identify important factors to consider when planning environments for the delivery palliative and end of life care services.

Commissioners may wish to specify that information (for people with end of life care needs and their families and carers) is available in a variety of accessible formats and is culturally appropriate and accessible to people with additional needs such as physical, sensory or learning disabilities and for people who do not speak or read English. People approaching the end of life and their families and carers, should have access to an interpreter or advocate if needed. A comprehensive health and social care needs assessment will help commissioners to better understand the resources needed to ensure that local services are equitable and fair and appropriate for the needs and preferences of people in the local population. Written information for people, their family and carers is available through the NHS Choices website, the National End of Life Care Programme, Dying Matters Coalition, The Marie Curie Palliative Care Institute.
Liverpool and the Childhood Bereavement Network. These may provide a starting point for the development of local literature.

4.1.3 Assessment, care planning and review (quality statement 3)

The local care pathway should provide the opportunity for people who have been identified as approaching the end of life to be offered comprehensive and regular holistic assessments, to discuss their preferences and needs and to document these in a care plan. If appropriate, this may include advance care planning and could result in advance statements, for example preferred priorities for care, advance decisions to refuse treatment, and do not attempt cardio-pulmonary resuscitation decisions.

A comprehensive assessment is multidisciplinary and may need the input of health and social care professionals, as well as other support services. It is important that assessments from multiple professionals are undertaken in a coordinated manner, and the 'End of life care strategy' highlights poorly coordinated services resulting in people being subjected to numerous assessments by different health and social care staff without reference to each other's assessments. For further information about coordinating services see section 4.3.1.

With the person's permission, if appropriate, care plans should be accessible to all staff who have a legitimate reason to need it including out of hours and accident and emergency units. Electronic care plans are a means of facilitating this sharing. An information standard is being developed to support electronic palliative care coordination systems, and development of electronic care plan systems should correspond with this standard. In section 4.3, the use of electronic palliative care coordination systems is discussed and commissioners may wish to explore opportunities to link together electronic palliative care coordination systems and care plans. Further details are available in the 'End of life locality registers evaluation' report.

Commissioners may wish to specify use of a locally developed integrated care pathway or a nationally available resource. National resources include the following tools which include holistic assessment and care planning:

- The Gold Standards Framework is a common toolkit and framework which can be used in many health and social care settings.
The Liverpool Care Pathway is used to support people during the last hours and days of life.

Preferred Priorities for Care is an advance care planning tool which enables people to consider and document their preferences regarding their future care.

Commissioners may wish to refer to 'Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff'. The publication 'Holistic common assessment of supportive and palliative care needs for adults requiring end of life care' may also be helpful to commissioners because it highlights a range of existing assessment and planning tools, guidance and relevant policy, signposting to other resources if appropriate.


4.2 Holistic support (quality statements 4, 5, 6 and 7)

4.2.1 Physical and psychological (quality statement 4)

The NICE quality standard for end of life care for adults states the following:

'Safe, effective and appropriate symptom and side-effect management at any time of day or night may require coordinated input from a number of different professionals and services. As a minimum, essential 24/7 care services should include:

- generalist medical services (including GPs)
- nursing services (defined as visiting, rapid response services and provision of one-to-one care at home, including overnight)
- personal care services
- access to pharmacy services
- access to equipment and adaptations
- specialist palliative care advice for generalists on symptom and side-effect management.

(definition section within quality statement 4)

Commissioners may also wish to consider the importance of specialist palliative care social workers. Specialist palliative care services should be able to offer advice on symptom management, in all settings and at all times of day and night (see section 4.3.3 for further details). Prompt physical and psychological management may be a particular challenge for people residing in prisons, psychiatric hospitals, hostels and other vulnerable populations and commissioners may wish to pay particular consideration to meeting the needs of these groups. Medication and appropriate equipment may not be easily available in these settings. Some areas have found the provision of medicines during out of hours challenging and the South West Ambulance Service NHS Trust and Dorset Cancer Network provide a case study example of how one area is meeting this challenge.

Psychological symptoms may include agitation, depression and anxiety. Psychological support includes general emotional support and empowerment as well as specialist psychological care, if
appropriate. Psychological support and care may be provided by members of generalist or specialist palliative care staff and in some instances will need input from specialist psychological services for example, Improving Access to Psychological Therapies. For further information about commissioning mental health services including Improving Access to Psychological Therapies, refer to the NICE Guide for commissioners on Commissioning stepped care for people with common mental health disorders.

### 4.2.2 Social, practical and emotional (quality statement 5)

Evidence demonstrates that when social care and health services work in an integrated way, this leads to a more seamless service, so commissioners of health and social care should work closely to ensure integration of services. For example, health and social care services in Portsmouth have developed an integrated discharge bureau, which has helped to ensure prompt and effective hospital discharge for people who need a package of health and social care. In Worcestershire the Citizens Advice Bureau, hospices, social care and the primary care trust have formed a partnership and implemented a new Citizens Advice Service for people with end of life care needs.

Commissioners should ensure that national guidance on the implementation of NHS continuing healthcare funding is adhered to and the fast track tool is used if speedy funding decisions are needed. The National End of Life Care Programme has developed a factsheet about the fast track process, which commissioners may find helpful. Prompt funding decisions are particularly important when a person is rapidly deteriorating in hospital and chooses to die in a non-hospital setting. Commissioners should ensure that the local care pathway incorporates services that meet people’s social, practical and emotional needs and that clear mechanisms are in place for prompt access and referral. Referrals may be to occupational therapy services for assessment for equipment such as pressure relieving mattresses and commodes, to respite and day care services and benefits services. Because social care includes a broad range of settings, there may be particular training needs for staff working in certain sectors and there are examples of many areas providing education and training to domiciliary and home care staff and these can be accessed on the National End of Life Care Programme website.

### 4.2.3 Spiritual and religious (quality statement 6)

A systematic review of spiritual care commissioned by the Department of Health reported evidence of a widespread need for training in all aspects of spiritual care. The second round
(2008–09) of the ‘National care of the dying audit – hospitals reports that assessments of psychosocial and religious or spiritual well-being were carried out with the person and their families and carers every 12 hours in nearly two-thirds of cases. Provision of services to meet people’s spiritual and religious needs potentially includes all services involved in end of life care provision, along with some services that deal more specifically with these needs such as chaplaincy services, self-help groups and counseling services. Some services that support end of life needs may be provided through local religious organisations such as churches, mosques, temples and synagogues. Commissioners may wish to ensure that these services are accurately reflected in the local care pathway and that appropriate mechanisms for signposting and referral to such services are in place.

The physical environment of different settings, including hospitals and care homes, can have a direct impact on the experience of care for people at the end of life and on the memories of their carers and families (‘End of life care strategy', Department of Health 2008). Commissioners should refer to ‘Routes to success in end of life care – achieving quality environments for care at end of life’ and ‘Environments for care at the end of life’ which identify a number of key environmental principles.

Commissioners may wish to specify that spiritual needs are part of the assessment and care planning processes and that through this people and their families and carers have the opportunity to discuss and review their spiritual needs and preferences at regular intervals. The Mount Vernon Cancer Network has developed a spiritual care assessment tool which incorporates three key prompt questions and is part of a local pathway, service directory (including details of local chaplains and spiritual advisers in the network) and a staff training programme. Commissioners may wish to refer to the ‘Marie Curie cancer care spiritual and religious care competencies’ for specialist palliative care. These outline four different competency levels for staff working in all areas of care, whether specialist or not.

4.2.4 Families and carers (quality statement 7)

Carers often have a central role in delivering support and care for people that are approaching death and the 'End of life care strategy advocates that carers should be treated as 'co-workers' who have their own needs. The quality standard highlights that carers are a broad group and for example might include a spouse, partner, child or close friend. The types of support that carers may need include information, training, emotional support and residential or day respite services and overnight one to one care in the person's home.
Commissioned services need to be able to appropriately accommodate the needs of all carers and the 'End of life care strategy' highlights that those people 'providing a substantial amount of care on a regular basis' are entitled to a community care assessment by the local authority. Providing support for carers can help reduce costs to society. The Princess Royal Trust for Carers commissioned a study into the social impact of carer’s centres, which found that the £5 million invested in five carers’ centres generated £73 million of gains to society.

Despite the need for comprehensive support for carers, the current evidence suggests gaps in services. Despite all carers being entitled to an assessment of their health and social care needs, the National Audit Office survey of primary care trusts found that only 29% provided these assessments routinely, and many do not have a process for recording these assessments. Furthermore, 24% of Primary Care Trusts stated that they do not offer respite care to all those who need it[32]. When undertaking a joint health and social care needs assessment for end of life care it is important that carers’ needs are taken into consideration. Local pathways should incorporate a system for identifying carers who should have a needs assessment and have processes in place for documenting and reviewing such assessments. Commissioners should also consider the role of third sector providers when developing local pathways. Local third sector organisations including local hospices are likely to provide support for families and carers. There are also national organisations for example, Carer’s UK, The Princess Royal Trust for Carers, Age UK, Cruse Bereavement Care and Citizens Advice Bureau provide different types of support for carers.


4.3 Access to services (quality statements 8, 9 and 10)

4.3.1 Coordinated care (quality statement 8)

The 'End of life care strategy' promotes a whole system approach to commissioning end of life services and identifies better coordination of services as one of the key areas for improvement. The coordination of care for people, their relatives and carers will depend in part on strategic coordination of the pathway. A pathway approach to commissioning is particularly important in end of life care because services are interconnected and span different sectors and settings.

Pathway commissioning supports commissioning for outcomes, can lead to a streamlining of services and can help when considering opportunities for redistributing resources. The potential partners that commissioners may wish to involve in strategic coordination of services are:

- Specialist palliative care providers (NHS, social care and third sector)
- Primary care (GPs and practice nurses)
- Social care including domiciliary workers
- Secondary care providers
- Community nursing service
- Care homes
- Out of hours services (GP and community nursing)
- Emergency care services
- Ambulance services
- Religious leaders and spiritual services
- Service user groups and lay people
- Mental health teams including those with responsibility for dementia care and psychology services
- Condition-specific teams, for example heart failure specialists, respiratory specialists, renal specialists.
If it exists, a local strategy group may link in with existing clinical networks and develop a strategy which details the local needs assessment, service user feedback and priorities for end of life care service development. The ELCQuA tool may be useful in monitoring and benchmarking local progress in implementing the end of life care strategy quality markers and measures, the QIPP key performance indicators and the NICE quality standard 'End of life care for adults'.

Electronic palliative care coordination systems (formerly called locality registers) are an important tool for coordinating an individual's care. Because the system is electronic, with the person's permission, it enables key information about them and their end of life decisions (such as advance care planning decisions) to be shared with relevant health and social care professionals. This results in improved care coordination and greater satisfaction for people and their relatives and carers. The 'Palliative care funding review' also recommends the implementation of these registers and the introduction of care coordinators, whose role is to guide the person and their family and signpost them to services which may or may not be funded.

If an electronic palliative care coordination system is not already in place commissioners may wish to commence plans to implement one. Registers offer distinct benefits including ensuring that a person's choices and priorities are recorded and accessible to members of the care team (meaning the person, their family and/or carers are not asked the same questions by multiple professionals), facilitating end of life care and death in the person's preferred place and reducing unwanted and unnecessary secondary care admissions. Although the cost benefits are not fully understood, reductions in unscheduled care and streamlining of information sharing are likely to generate some cost and productivity savings.

A 'key worker' is one example of how consistent, coordinated care might be facilitated. A key worker is either one or possibly a small number of named workers who, with the consent and agreement of the person approaching the end of life, take an important role in coordinating the individual's care. They promote continuity, ensuring the individual, and their families and carers, know who to access for information and advice. Further definition of the key worker role is available from NICE cancer service guidance on supportive and palliative care (recommendation 1.29).

The Marie Curie Delivering Choice Programme was set up to improve the coordination and effectiveness of services to enable all people with end of life needs – regardless of type of illness.
– to be cared for and to die in their place of choice. Transfers and transportation are an important element of effective care coordination. In some areas generic transport services are not able to meet the needs of people who need end of life care, and in the Tayside and Leeds projects of the Marie Curie Delivering Choice Programme, a dedicated palliative care ambulance has been commissioned.

4.3.2 Urgent care (quality statement 9)

A lack of prompt access to community services and ineffective coordination of care (particularly poor information sharing between services and sectors) are commonly cited as reasons why people have unnecessary emergency hospital admissions and do not die in their place of choice[^34][^35][^36]. Commissioners may wish to consider the range of urgent care services (which could include daytime and out-of-hours GP visits in the community, as well as emergency 999 ambulance response, and accident and emergency walk-in attendances) and be sure that care is coordinated effectively across these settings. If an electronic palliative care coordination system has been implemented, it should be available to services providing urgent and unscheduled care. If an electronic system is not available, an alternative system should be used to ensure urgent care services have access to a person’s care plan and advance care plan if the person has one.

A case study of an integrated out of hours service provides an example of how introducing a palliative care handover form, a 24-hour advice line and mandatory training for all out of hours doctors lead to improved service user experience and a reduction in unnecessary hospital admissions.

4.3.3 Specialist palliative care (quality statement 10)

Generalist and specialist palliative care services[^37] should be available on the basis of need and not diagnosis. Evidence demonstrates that although progress is being made, there is considerable work needed to ensure equity for people with a non-cancer diagnosis. The National survey of patient activity data for specialist palliative care services (2009–10) found that although there has been an overall increase in the percentage and number of people with non-cancer diagnoses accessing specialist palliative care services over the past 12 years, the proportions of people with conditions other than cancer accessing these services still remains very low. Commissioners will need to consider the local resource implications for ensuring equitable service provision.
There are some key recommendations and standards about the provision of specialist palliative care that commissioners should consider in the context of service provision across the whole end of life pathway.

### Table 5: Recommendations and standards for specialist palliative care

<table>
<thead>
<tr>
<th>Recommendation</th>
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<tbody>
<tr>
<td>Specialist palliative care inpatient facilities should be responsive to emergency need and able to admit people approaching the end of life at any time of day or night.</td>
</tr>
<tr>
<td>Specialist community palliative care services and hospital palliative care teams should ensure provision to:</td>
</tr>
<tr>
<td>1. Visit and assess people approaching the end of life face-to-face in any setting 09.00–17.00, seven days a week (provision for bed-side consultations outside these hours is high quality care).</td>
</tr>
<tr>
<td>2. Provide specialist palliative care advice at any time of day or night, which may include telephone advice.</td>
</tr>
</tbody>
</table>

(Definition section within Quality statement 10)

The definitions section of quality standard 15 refers to the Royal College of Physicians 'Consultant physicians working with patients' (5th edition) guidance, which recommends between 1.56 and 2.00 whole-time equivalent consultants in palliative medicine per 250,000 population.

(Referred to within the definitions section of Quality Standard 15)

Commissioners and providers, working through cancer networks, should ensure they have an appropriate range and volume of specialist palliative care services to meet the needs of the local population, based on local calculations. These services should, as a minimum, include specialist palliative care in-patient facilities and hospital and community teams. Specialist palliative care advice should be available on a 24 hour, seven days a week basis. Community teams should be able to provide support to people in their own homes, community hospitals and care homes.


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[3] Ipsos MORI Social Research Institute (June 2011) End of life locality registers evaluation


[7] This definition is taken from the NICE Quality standard 'End of life care for adults'. Generalist and specialist palliative care are defined specifically for cancer in the NICE cancer service guidance on supportive and palliative care. This definition is expanded and adapted to cover both malignant and non-malignant conditions: providing supportive and palliative care should be an integral part of every health and social care professional's role. However for most, such care is likely to form only a small part of their workload. Many of these professionals are 'generalists' (GPs, district nurses and hospital medical and surgical staff for example), and others are specialists who may have received specific training and qualifications in supportive and/or palliative care, or acquired substantial practical experience. These specialists, frequently dedicating all or most of their time to the care of people approaching the end of life, include: physicians in palliative medicine, palliative care nurses, specialist allied health professionals.
4.4 Care in the last days of life (quality statement 11)

The 'End of life care strategy' recommends that the Liverpool Care Pathway or equivalent integrated care pathway is adopted nationally and its use audited. Staff should be competent in the use of this tool and commissioners should ensure that processes are in place to establish that providers are assessing the competencies of their staff. Commissioners should ensure that care plans are implemented in all end of life care settings. In the context of dying it is important that services have access to a person's care plan (if they have made one), including advance statements, advance decisions to refuse treatment and do not attempt cardiopulmonary resuscitation decisions, if these exist. Problems have been identified when different services in the same local pathway have not had compatible resuscitation policies, and commissioners may wish to ensure that policy is coordinated across the care pathway. The Mental Capacity Act 2005 is important to consider and the National End of Life Care Programme publication 'Capacity, care planning and advance care planning in life limiting illness' contains guidance on this.

There may be training needs regarding the use of the Liverpool Care Pathway or equivalent and a report in 2008 from the National Audit Office[^38] found that 54% of general nurses and a third of doctors reported being trained in the use of at least one of the Gold Standards Framework, Liverpool Care Pathway, and Preferred Priorities for Care post registration. This compares with 91% of nurses and 95% of doctors specialising in palliative care. Training in the Liverpool Care Pathway is available at [The Marie Curie Palliative Care Institute](http://www.mariecurie.org.uk/).

[^38]: Department of Health and University of Hull (2011) Spiritual care at the end of life: a systematic review of the literature.
4.5 Care after death (quality statements 12, 13 and 14)

4.5.1 Care of the body (quality statement 12), verification and certification (quality statement 13) and bereavement support (quality statement 14)

Commissioners should ensure providers can demonstrate that staff who are involved in care of the body and verification and certification of death have received the appropriate training and are competent. Training may need to be tailored locally to accommodate the needs of minority ethnic groups.

The End of life care strategy made a commitment to build on the 'Views of informal carers – evaluation of services' work to support the development of a national survey of the bereaved. This would capture invaluable information about the quality of care provided to the deceased. This was subsequently reiterated in the NHS Outcomes Framework (2012/13), which set out the intention to implement a survey of the bereaved which would support the development of an end of life care indicator. Data collection for the 2011 national survey runs for 3 months from October 2011 and will report in March 2012. In addition a toolkit was developed as part of the pilot study to provide support to those organisations that prioritised resources to undertake these local surveys. These local surveys should avoid clashing with the national survey, because that would risk approaching bereaved people more than once.

The second round (2008–09) of the 'National care of the dying audit – hospitals (NCDAH)' found that care after death is one of the areas most in need of attention. More than 50% of data was missing in the care after death section and just 11% of hospitals reported having a report in the previous 12 months assessing the views of carers regarding care of people who were dying. A synthesis of UK literature on bereavement was recently commissioned by the Department of Health and found that reported bereavement service provision varies in its coverage, including the extent and form of bereavement care and the training to support this provision. A recent systematic review on GP and district nurse bereavement care found that GPs and community nurses view bereavement care as an important and satisfying part of their work, although one for which they have received little training.

In 2009 46% or 229,883 of all deaths in England and Wales were referred to the coroner. Of this number, 46% needed either a full post-mortem and inquest, post-mortem only or inquest only.
Coroner involvement following a death can cause particular distress to family, friends and carers and this is exacerbated if information is unclear or disjointed.

A small study undertaken by the National End of Life Care Programme found that the introduction of bereavement services can lead to productivity savings through reductions in hospital complaints. In the study an investment of £3240 to establish a bereavement pathway project delivered by volunteers, resulted in a productivity saving of £10,059. This saving was from a reduction in the number of staff hours spent responding to complaints from bereaved relatives and carers. Initial indications also suggested reductions in the incidence of referrals to formal counselling services for non-counselling needs.

Commissioners should consider 'When a person dies: guidance for professionals on developing bereavement services', 'UK standards for bereavement care and 'Guidance for staff responsible for care after death' when commissioning bereavement services. Staff involved in delivering immediate support after death and bereavement support could be situated in a variety of health or social care settings (for example practice nurses, community nurses, specialist palliative care staff, bereavement workers, care workers) and commissioners should ensure that appropriate education opportunities and assessment of competences are in place. For further information on training see section 4.6. Commissioners may also wish to consider the role of local and national third sector providers when developing local pathways for bereavement support. Carer's UK, The Princess Royal Trust for Carers, Age UK, Cruse Bereavement Care are some of the third sector organisations that provide different types of bereavement support.


[40] Department of Health and University of Nottingham (2011) Bereavement care services: a synthesis of the literature (final report of review commissioned by DH to support implementation of the End of life care strategy)

[41] Department of Health and University of Hull (2011) Spiritual care at the end of life: a systematic review of the literature
4.6 Workforce (quality statements 15 and 16)

4.6.1 Training and planning (quality statements 15 and 16)

A key element of the high quality end of life care is a competent workforce which is resourced appropriately. The definitions sections of the NICE quality standard 'End of life care for adults', and the NICE Cancer service guidance on supportive and palliative care (2004) highlight several areas that are important with regards the types of services and operating hours of services and these are detailed in sections 4.2.1 and 4.3.3 of this guide.

Audits have demonstrated some considerable gaps in the knowledge and education of the workforce, and this is particularly so for people employed in generic roles for whom caring for people at the end of life forms part of their workload. A report in 2008 from the National Audit Office found that only 29% of doctors and 18% of nurses had received any pre-registration training in end of life care, although 54% of general nurses and a third of doctors reported being trained in the use of at least one of the Gold Standards Framework, Liverpool Care Pathway, and Preferred Priorities for Care after registration. The National End of Life Care Programme in collaboration with others have outlined the 'Core competencies for end of life'. The five key competencies are:

- communication skills
- assessment and care planning
- symptom management, comfort and wellbeing
- advance care planning
- values and knowledge developments.

The Department of Health has commissioned an e-learning programme that supports these competencies. There are also specific modules in social care, bereavement and spirituality. This programme is free and available to a wide range of health and social care staff and is intended for use as part of blended learning. Commissioners may also wish to consider other relatively low cost methods of ensuring the local workforce is competent. NHS Berkshire provides a QIPP example, which is a practical case study about improving the end of life care core competencies of staff and Warrington Community Service Unit provides a case study of how a 'care home team' was established to provide professional support and advice to staff, carers and residents in
a number of homes in the area. The results were that residents were given greater choice about where they died and the number of unnecessary hospital admissions was cut.

The National Council for Palliative Care specialist palliative care workforce survey commenced in 2005 and is undertaken annually. The national response rate is measured over the 28 cancer networks in England, and in 2009 the response rate was 67.2% (excluding nil returns received). The survey revealed that overall the number of full-time equivalent staff is increasing across all staff groups, with most increases in the voluntary sector. However, some concerning results included the high vacancy rates for physiotherapists (21.7%) and the large proportion of specialist palliative care staff who are over 50, meaning a potential future issue with recruitment and training (physiotherapists 38%, social workers 42%). The findings of this survey are available at a regional level and commissioners may wish to liaise with providers to ensure appropriate measures are being taken locally to address any current or potential future gaps in staff numbers and groups. This is particularly pertinent given the rising number of people needing access to end of life care services.

4.7 Service models

Commissioners may wish to consider commissioning end of life care service components in different ways, and mixed models of provision may be appropriate across a local health economy. Commissioners may wish to consider shifting the focus of investment from secondary care services to community and primary care.

Commissioners may wish to work with their local Quality, Innovation, Productivity and Prevention (QIPP) lead and develop service models for end of life care for adults. The NHS evidence QIPP collection examples were all assessed against a set of criteria and then subjected to an external peer review process. The best of these are highlighted on the NHS evidence website as 'highly recommended' examples.

Commissioners may wish to consider working with clinicians when using the Commissioning for Quality and Innovation payment (CQUIN) framework as a lever for service change in acute settings. See examples of CQUIN schemes on the NHS Institute for Innovation and Improvement website, which lists over 180 examples of local end of life CQUIN schemes used in 2010–11. Please note – these examples are offered to share good practice and NICE makes no judgement on the compliance of this service with its guidance.

Table 6 Service examples for end of life care

<table>
<thead>
<tr>
<th>Component</th>
<th>Examples of service models and case studies</th>
</tr>
</thead>
</table>

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NHS North East has developed a charter for 'a good death', which stresses the importance of normalising death and is used as a tool for raising the profile of end of life care.

The Dying Matters Coalition provides a variety of resources, such as posters and leaflets, which can assist local promotional activities.

A case study of providing communication skills education to district nurses and nursing home staff resulting in improved staff confidence and skill.

A variety of resources to support quality communication skills education including specific guidance on commissioning end of life care communication training and a benchmarking tool.

The Gold Standards Framework is a common toolkit and framework that can be used in many health and social care settings.

The Liverpool Care Pathway is used to support people during the last hours and days of life.

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South West Ambulance Service NHS Trust and Dorset Cancer Network provide a case study example of developing a coordinated service to supply palliative care medicines and advice in the community.

In Portsmouth joint working between the council, primary care trust and acute trust has led to the introduction of an integrated discharge bureau, which helped to reduce bed blocking and ensured that when a person is ready for discharge from hospital, the appropriate social care package is in place to ensure the discharge happens promptly.

In Worcestershire, the Citizens Advice Bureau, hospices, social care and the primary care trust formed a partnership and implemented a new Citizens Advice Service for people with end of life care needs.

Mount Vernon Cancer Network has developed a spiritual care assessment tool.
### Access to Services

The **End of Life Locality Registers Evaluation report** provides feedback from pilot sites about implementing locality registers.

This QIPP example provides details of how improvements to a community dysphagia services helped people with terminal illness to be cared for at home. Productivity gains were made through reduced referrals and admissions.

Death in place of choice has been used in the **Commissioning for Quality and Innovation** payment framework.

A **case study** of an integrated out of hours service, provides an example of how introducing a palliative care handover form, a 24-hour advice line and mandatory training for all out of hours doctors has improved service user experience and led to a reduction in unnecessary hospital admissions.

The **Marie Curie Delivering Choice Programme** provides insight into the lessons learnt when establishing additional community based services to support people to receive care and die in their place of choice. Projects include a dedicated palliative care ambulance service, care homes end of life support service, complex and palliative care continuing care service, rapid response team, palliative care coordination centre, discharge community link nurses.

The **caring together** projects are examples of how the British Heart Foundation, Marie Curie and NHS Greater Glasgow and Clyde aims to include the quality of and access to services for people in the advanced stages of heart failure.

### Care in the last days of life

This QIPP example provides details of how a nurse-led palliative care service enabled people to be supported to die at home. Feedback from people and carers about the service has been positive and savings have been made through reductions in accident and emergency attendances and reduced bed days.

The **Liverpool Care Pathway** is used to support people during the last hours and days of life.
| Care after death | Bereavement Pathways Project 2007–10 provides an example of a pilot study in Solihull Hospital to provide early intervention support and guidance following a death in hospital. This pilot study demonstrated productivity savings through reductions in hospital complaints relating to perceived poor end of life care. |
| Workforce | NHS Berkshire provides a QIPP example, which is a practical case study about improving end of life care core competencies of staff working in a community hospital and generated productivity savings through providing end of life care in a community hospital setting as an alternative to the acute hospital.  
NHS South Central provides a case study of how locality based practice facilitators are providing education to care home and hospital staff. This case study is available on page 56 of the 'End of life care strategy: second annual report'  
NHS East of England provides a case study of how advanced level communication skills training for senior generalist health and social care professionals working with people (adults) and their families in end of life care was delivered through cancer networks. This case study is available on page 60 of the 'End of life care strategy: second annual report.'  
NHS South West provides a case study of how the skills and expertise of hospice staff have been used to provide education to ambulance staff and domiciliary care workers. This case study is available on page 58 of the 'End of life care strategy: second annual report.' |
5 Service specification for end of life care for adults

Commissioners should collaborate with clinicians, local stakeholders, and service users, when determining what is needed from services for people with end of life care needs. The end of life care pathway should be person-centred and integrated with other elements of clinical care.

Commissioners may wish to consider commissioning end of life care in different ways, and mixed models of provision are likely to be appropriate in a local area. Commissioners may wish to take action to stimulate the local market if shortages of providers are identified at any point in the pathway and should note that any qualified provider may include health services, local authorities, other statutory partners, private or third sectors.

Commissioners should ensure that providers implement the recommendations stipulated in the 'End of life care strategy' and that providers are taking steps to achieve the standards set out in the NICE quality standard 'End of life care for adults'.

Commissioners should ensure the services they commission represent value for money and offer the best possible outcomes for their service users. Commissioners should refer to the NICE quality standard 'End of life care for adults' when commissioning services and should include quality statements and measures in the service specification element of the standard contract if appropriate. If poor performance is identified, commissioners can discuss the level of performance with their providers and address any issues and concerns before introducing more formal contractual remedies.

Commissioners may choose to use quality standards to ensure that high-quality care is being commissioned through the contracting process, to establish key performance indicators as part of a tendering process and/or to add incentives to provider performance by using the indicators in association with incentive payments such as CQUIN.

Commissioners should ensure that they consider both the clinical and cost effectiveness of the service, and any related services, and take into account clinicians' and service users' and carers' views and those of other stakeholders when making commissioning decisions.

Table 7 includes considerations for commissioners when developing a contract specification for End of life care for adults. Commissioners may find it helpful to refer to the example service specifications provided on the National End of Life Care Programme website.
Table 7 Considerations for contract specification

<table>
<thead>
<tr>
<th>Heading</th>
<th>Subheading</th>
<th>Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purpose</td>
<td>Policy context</td>
<td>• National policy drivers for end of life care including the Department of Health (2008) 'End of life care strategy'</td>
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<tr>
<td></td>
<td></td>
<td>• Evidence base, for example NICE guidance and quality standards, NHS evidence and national strategy consultation</td>
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<tr>
<td></td>
<td>Local strategic context</td>
<td>• Local commissioning drivers (for example reducing hospital admissions and length of stay, QIPP, CQUIN)</td>
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<td>• Invest to save</td>
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<td>• Results of joint strategic needs assessment</td>
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<tr>
<td></td>
<td>Aims and objectives of service</td>
<td>• The expected outcomes of the services</td>
</tr>
<tr>
<td>Service scope</td>
<td>Define service user groups</td>
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<tr>
<td></td>
<td>• Demographic profile of the local population (age, gender, ethnicity, socioeconomic status)</td>
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<td></td>
<td>• Local recorded and expected need for end of life care</td>
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<td></td>
<td>• Expected proportions of people needing end of life care services who have cancer and non-cancer diagnoses and, if appropriate, a breakdown of non-cancer diagnoses</td>
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<td></td>
<td>• Estimated prevalence of comorbidities (for example, hypertension, stroke, heart failure, depression)</td>
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<td></td>
<td>• Evidence of inequalities in outcomes between specific groups</td>
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<td></td>
<td>• Number of wholly-attributable and partially-attributable end of life-related hospital admissions, bed days and readmissions</td>
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<tr>
<td></td>
<td>• Number of people currently being treated in primary care, community-based and specialist palliative end of life services and other relevant services</td>
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<td></td>
<td>• Number of people who see their GP and are entered on the GP end of life care register</td>
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<tr>
<td></td>
<td>• Population-groups that will be targeted</td>
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<tr>
<th>Exclusion criteria</th>
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<tbody>
<tr>
<td></td>
<td>• Define exclusion criteria in accordance with NICE guidance and locally determined criteria.</td>
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<table>
<thead>
<tr>
<th>Geographical population</th>
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<tbody>
<tr>
<td></td>
<td>• Proportion of people living in urban and/or rural areas.</td>
</tr>
<tr>
<td></td>
<td>• Areas of higher-than average need for example, areas with a high population of older people.</td>
</tr>
<tr>
<td></td>
<td>• Population coverage needed or geographical boundaries</td>
</tr>
<tr>
<td>Service delivery</td>
<td></td>
</tr>
<tr>
<td>------------------</td>
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</tr>
</tbody>
</table>
| **Service description / care package** | • Mapping existing services for people with end of life care needs  
• Commissioning of core service components  
• Interface with other local services including social care, residential and nursing care, hospices, intermediate care services, ambulance service, out-of-hours services, community mental health services |
| **Location** | • Service location, defining accessibility requirements and discreet locations  
• Integration with other services for people with end of life needs  
• Home-based, locality-based services and centrally-based services |
| **Days/hours** | • Expected hours of operation, including days, evenings and weekends.  
• Expected number of people for case finding, assessment, treatment, care coordination or case management, aftercare, end-of-life care, taking into account potential increased flow through the system over defined periods |
| **Referral processes** | • Referral criteria and processes for people with end of life care needs.  
• Management of people who are 'unable to attend' and 'did not attend' |
| **Response times** | • Should be needs-based and outcomes-based  
• Setting specific times, which may be particularly important for people identified as rapidly approaching death |
| Care pathways | • Agreed clinical protocols or guidelines to support decision-making in the care pathway  
• Pathways for people with complex needs and comorbidities  
• Use of third sector organisations  
• Care coordination |
<table>
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<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Discharge Processes</td>
<td>• Process for discharge from end of life services, including aftercare and communication with other teams</td>
</tr>
</tbody>
</table>
| Staffing | • Profile of existing health and social care workforce  
• Staffing levels to be funded: minimum band or levels of experience and competency and expected skill mix  
• Skill mix and competencies of staff for specific areas of care |
| Information sharing | • Define information-sharing, confidentiality and audit needs, including IT support and infrastructure  
• Raising awareness of end of life care services. Do people with end of life needs and health and social care professionals know how to access services and know what services exist? |
<table>
<thead>
<tr>
<th>Quality assurance and clinical governance</th>
<th>Patient and public involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Processes to understand service user experience of end of life services in order to develop and monitor services. See also 'Patient experience online network'</td>
<td></td>
</tr>
<tr>
<td>• Expectations of how service user opinions, preference and experience will be used to inform service delivery for example, focus groups, representation on working groups, and surveys</td>
<td></td>
</tr>
<tr>
<td>• Monitoring of complaints and compliments and how used to inform service</td>
<td></td>
</tr>
<tr>
<td>• Views of informal carers – evaluation of services (VOICES) national survey of the bereaved may be adapted using the toolkit to develop a local survey</td>
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<table>
<thead>
<tr>
<th>Quality indicators</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Use NICE quality standards to define high-quality care including NICE quality standard for end of life care for adults</td>
<td></td>
</tr>
<tr>
<td>• Satisfaction surveys and access to treatment</td>
<td></td>
</tr>
<tr>
<td>• Define outcomes and (proxy) measures including outcomes provided in the NICE quality standard for end of life care for adults</td>
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</table>

<table>
<thead>
<tr>
<th>Performance monitoring</th>
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<tbody>
<tr>
<td>• Local need and demand for treatment, including brief interventions.</td>
<td></td>
</tr>
<tr>
<td>• Impact of services on admissions to accident and emergency, inpatient hospital care and length of stay in hospital</td>
<td></td>
</tr>
<tr>
<td>• Measurement of referrals and discharges</td>
<td></td>
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</tbody>
</table>
| Equality | Measures to ensure equality of access to services, taking into account the risks of unintentional discrimination against groups who are often under-represented, such as people who do not speak English as a first language  
| Consider equity of access for people living in residential and nursing homes, those who are housebound, or those in prison |
| Staff training and competency | Training and competencies on recruitment and for ongoing development  
| Processes for monitoring clinical practice and competency, including professional registration and clinical supervision arrangements  
| Skill mix and competencies required across the care pathway. See 'Skills for health' and Core competencies for end of life  
| Staff development – appraisal and personal development plans, and mandatory training |
| Audit and surveys | Specify expectations for audit, which may include assessment, intervention, prescribing practices and successful treatment outcomes  
| It may be useful to specify that providers participate in the following audits and surveys:  
| The National care of the dying audit – hospitals collects data on communication with primary care.  
| National Council for Palliative Care specialist palliative care workforce survey.  
<p>| Views of informal carers – evaluation of services (VOICES) national survey of the bereaved may be adapted using the toolkit to develop a local survey |</p>
<table>
<thead>
<tr>
<th>Activity Plan</th>
<th>Staff and patient safety</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Procedures for risk assessment</td>
<td>• Likely cost of new or additional services</td>
</tr>
<tr>
<td></td>
<td>• Formal procedures for incident reporting and monitoring</td>
<td>• Anticipated set-up costs</td>
</tr>
<tr>
<td></td>
<td>• Address any safeguarding concerns and promote the welfare of children and vulnerable adults</td>
<td>• How will pricing be set?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Potential for better value for money</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Are people receiving most appropriate end of life services?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Cost of facilities, for example venue hire</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Cost of staff travel to services and people's homes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• QIPP.</td>
</tr>
</tbody>
</table>
6 The commissioning and benchmarking tool

Download the end of life care commissioning and benchmarking tool

Use the commissioning and benchmarking tool for end of life care to determine the volume of service that may be needed locally, to consider the costs of commissioning some elements of end of life care services and to provide estimates for potential cost savings.

6.1 Identify indicative local service needs

There are two indicative benchmark rates used in the tool:

The indicative benchmark for total deaths per annum is 1.12% or 1120 per 100,000 population aged 18 years and older.

The indicative benchmark of people who may need end of life care per annum is 0.83% or 830 per 100,000 population aged 18 years and older.

The commissioning and benchmarking tool helps you to assess local service needs using the indicative benchmarks as a starting point. With knowledge of your local population and its demographic, you can amend the benchmarks to better reflect your local circumstances. For example, if your population is significantly younger or older than the average population you may need to provide services for fewer or more people.

6.2 Length of hospital stay for admissions ending in death

HES data were used in the tool to allow users to benchmark length of hospital stay for admissions ending in death by primary care trust against the national average. This should be used to help inform users about their current position relative to the national average. It is not intended to be used as a judge of performance or services in any area as there are many different factors which can influence the length of hospital stay. However, it may give commissioners data about local services and give information about local data analysis to inform local needs assessments.
6.3 Investment in end of life care services

Use the commissioning and benchmarking tool to give an indicative cost of certain aspects of end of life care services. Commissioners should be clear that each locality has specific needs and new services need to be compatible with the existing services in an area. No one type of service will be needed in every locality. Similarly, the costs of a given service will vary significantly depending on local conditions and needs.

The tool allows users to add data on the potential cost elements that may need to be considered in future service planning. The tool also shows the average costs per 100,000 population of investments made by PCTs in 2010/11 which can help inform decisions about the levels of investment that may be required. It should be noted that this is additional investment on top of current spend on services, and not the full investment in end of life care services.

It should be noted that primary care trusts are not the only commissioners of end of life care related services and funding comes from many other sources (as seen in figure 1 of this commissioning guide).

Commissioning decisions should consider both the clinical and economic viability of the service, and take into account the views of local people. Commissioning plans should also take into account the costs of monitoring the quality of the services commissioned.

6.4 Potential savings

You can use the commissioning and benchmarking tool to calculate the potential savings from reduced hospital admissions and reduced length of stay that may come about because of improved commissioning of end of life care services across the whole pathway.

Service redesign and investment in the whole end of life care pathway may increase the proportion of people who die in their own home. This may decrease the number of hospital admissions and the lengths of stay experienced in the last weeks and months of their life. These savings may offset some of the investment made in the rest of the pathway, and could potentially provide an overall cost saving.

Reduced hospital activity leads to a direct saving to a commissioner via reduced charges through the national tariff. However, for a hospital provider, only the costs of consumables will be saved.
in the short term and overheads will be unchanged. A step change needs to be brought about so
capacity can be released if savings are to be reflected in hospital expenditure.

An average unit cost of a hospital bed day and example reductions of 1%, 5% or 10% are
modelled in the tool. Users should amend these figures to reflect local expectations.

The tool does not look at stays not ending in death in the last weeks and months of life due to a
lack of robust data. If end of life care commissioning leads to any reduction in such admissions,
further savings may be possible.
7 Further Information

Table 8 summarises national drivers that are relevant to commissioning end of life care services for adults. Local service redesign may address only one or two of them.

Table 8 National policy on end of life care

<table>
<thead>
<tr>
<th>Document</th>
<th>Author</th>
<th>Year</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Outcomes Framework 2012/13</td>
<td>Department of Health</td>
<td>2011</td>
<td>Domain 4: ensuring that people have a positive experience of care. This includes indicator 4.6 which will be derived from the survey of bereaved relatives (see section 1.6).</td>
</tr>
<tr>
<td>NICE quality standard for end of life care for adults</td>
<td>National Institute for Health and Clinical Excellence</td>
<td>2011</td>
<td>The Quality Standard sets out markers of high-quality care</td>
</tr>
<tr>
<td>Quality, innovation, prevention and productivity (QIPP)</td>
<td>Department of Health</td>
<td>2011</td>
<td>End of life care QIPP workstream</td>
</tr>
<tr>
<td>Transparency in outcomes: a framework for adult social care</td>
<td>Department of Health</td>
<td>2011</td>
<td>All four domains of the framework have relevance with end of life care (see section 1.6)</td>
</tr>
<tr>
<td>NHS operating framework for 2012/13</td>
<td>Department of Health</td>
<td>2011</td>
<td>QIPP is highlighted in 2011/12 operating framework as continuing to be important for 2011/12 financial plans.</td>
</tr>
<tr>
<td>Information and links for professionals who support people and their families at the end of life</td>
<td>Social Care Institute for Excellence</td>
<td>2011</td>
<td>SCIE have produced a resource for people who work with adults who are approaching the end of life. It aims to provide access to tools and resources to assist professionals in providing high-quality end of life care.</td>
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<tr>
<td>End of life care strategy: third annual report</td>
<td>Department of Health</td>
<td>2011</td>
<td>Includes a chapter about commissioning end of life care and includes service model examples</td>
</tr>
<tr>
<td>Commissioning End of Life Care: initial actions for new commissioners</td>
<td>National End of Life Care Programme / National Council for Palliative Care / National End of Life Care Intelligence Network (NEoLCIN) / Dying Matters Coalition</td>
<td>2011</td>
<td>Helps commissioners to identify the immediate priority actions to commission effective end of life care.</td>
</tr>
<tr>
<td>Critical success factors that enable individuals to die in their preferred place of death</td>
<td>National End of Life Care Programme</td>
<td>Expected February 2012</td>
<td>Presents an analysis of the critical success factors in improving end of life care</td>
</tr>
<tr>
<td>Using the Commissioning for Quality and Innovation (CQUIN) payment framework – a summary guide</td>
<td>Department of Health</td>
<td>2010</td>
<td>Makes a proportion of providers’ income conditional on quality and innovation.</td>
</tr>
</tbody>
</table>
Useful sources of information for developing a service specification may include:

- **The standard NHS contracts for acute hospital, mental health, community and ambulance services.**

- **NHS Evidence**: provides free access to clinical and non-clinical information – local, regional, national and international. Includes a QIPP library with case studies, commissioning for long-term conditions section and commissioning zone.

- **The NICE shared learning database** offers examples of how commissioners and service providers have used NICE guidance to create innovative and effective local implementation programmes for service improvements.

- **NHS Institute for innovation and improvement**: The rough guide to experience and engagement for GP Consortia. Guidance for GP Consortia on the emerging national framework governing engagement and experience and an introduction to the Engagement Cycle tool.

- **NICE guides for commissioners on** dementia, chronic obstructive pulmonary disease and heart failure, which provide condition-specific end of life care information.

General information on quality and corporate assurance can be obtained from the following sources:
Guide for commissioners on end of life care for adults

- **Indicators for Quality Improvement Programme** from the NHS Information Centre. A resource of robust indicators to help local clinical teams select indicators for local quality improvement and a source of indicators for benchmarking.

- **NHS Alliance online resources.** NHS Alliance is the representational organisation of primary care and primary care trusts, and provides them with an opportunity to network and exchange best practice. The alliance supports its members with an open-access helpline, in-house and joint publications and briefings, internal newsletters and a website.

- **NHS Institute for Innovation and Improvement** support for commissioners, includes products; *The Productive Leader* programme to enable leadership teams to reduce waste and variation in personal work processes, and 'Better care, better value indicators' to help inform planning, to inform views on the scale of potential efficiency savings in different aspects of care, and to generate ideas on how to achieve these savings.

- **QOF** is a voluntary quality incentive scheme that rewards general practices for implementing systematic improvements in the quality of patient care.

- **Skills for health** works with employers and other stakeholders to ensure that those working in the sector are equipped with the right skills to support the development and delivery of healthcare services.

Sources of further information to help you in assessing local health needs and reducing health inequalities include:

- **The National End of Life Care Intelligence Network** provide a wealth of resources including local profiles and a compendium of data sources.

- **NHS Evidence** provides free access to clinical and non-clinical information - local, regional, national and international. Information includes evidence, guidance and Government policy.

- **Department of Health** Delivering quality and value – focus on benchmarking.

- **NICE** Health equity audit – learning from practice briefing.

- **NHS Comparators** provides comparator data for NHS commissioning and provider organisations to enable users to investigate aspects of local activity, costs and outcomes.
The Disease management information toolkit is a good-practice tool for decision-makers, commissioners and deliverers of care for people with long-term conditions, which presents data on conditions that contribute to high numbers of emergency bed days. It models the effects of possible interventions that may be commissioned at a local level and helps users to consider the likely impact of commissioning options.

PARR (Patients at risk of rehospitalisation) is a risk-prediction system for use by primary care trusts to identify people at high risk of hospital re-admission.

PRIMIS+ provides support to general practices on information management, recording for, and analysis of, data quality, plus a comparative analysis service focused on key clinical topics.

The SHAPE (Strategic health asset planning and evaluation) application provides support to strategic health authorities and primary care trusts on strategic planning across a whole health economy.
8 Topic Advisory Group: end of life care for adults

A topic-specific advisory group was established to review and advise on the content of the commissioning guide. This group met once, with additional interaction taking place via email and telephone.

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National Commissioning Champion, Royal College of General Practitioners

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