PUBLIC



# End of Life Care Needs Assessment

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#### 1 Introduction

Traditionally, palliative care services have supported significantly more individuals with a cancer diagnosis compared to other terminal conditions. However, cancer and non-cancer terminal illnesses often have a similar symptom burden, requiring similarities in their management, particularly at the end of life.<sup>i</sup>

In addition, the number of individuals with multi-morbidity is increasing, particularly amongst the frail elderly population. An increasing proportion of people with a terminal illness will therefore have other co-existing diseases, thus increasing the complexity of their care needs at the end of their life.<sup>i</sup>

These factors, together with the fact that too many people die in a place not of their choosing, means that local commissioners will need to plan to ensure that local end of life care services meet the needs of the population, both now and in the future. This Health Needs Assessment has been written to inform these discussions within Derbyshire, and to identify the next steps that will build a more complete picture of local end of life care needs.

#### 2 Background information

#### 2.1 Definitions

The terms palliative care and end of life care are often used interchangeably, however there is a distinction between them:  $^{\rm ii}$ 

**Palliative care**: palliative care is the active, holistic care of people with advanced progressive illness, involving management of pain and other symptoms and the provision of psychological, social and spiritual support. Palliative care aims at ensuring the best possible quality of life for individuals at the end of life or with advanced illness and their families.

**End of life care:** palliative care can have applications in any situation where someone is experiencing distress associated with serious illness for which there is no potential cure. End of life care refers specifically to care provided in the last phase of life. This is often defined as approximately the last year, but end of life care can also sometimes be used to refer to the last weeks or even days of life and, for carers, can include care into bereavement.

#### 2.2 End of life care

The national strategy defines End of Life Care as:

"End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support."

The strategy also defines a "good death" as "where a dying person is treated as an individual, with dignity and respect, without pain and other symptoms, in familiar surroundings and in the company of close family and friends".

Identifying that someone is entering the last year of their life not only benefits the individual, to enable provision of supportive care that meets their needs and wishes, but can also reduce the burden on the health and social care system through the commissioning of more effective services.

End of life care services include both specialist and general provision (figure 1):

- Specialist palliative care is provided by multi-disciplinary teams that include palliative care consultants, nurse specialists, specialist social workers and experts in psychological care. Specialist services include inpatient units including hospices, hospital out-patient services, home care, day care and bereavement services
- Generalist palliative care is provided by general health and social care services, including GPs, district and other general community nursing teams, hospital staff, care home staff, social care staff and others. General services will provide general care for people at the end of their lives





Source: National Council for Palliative Care (2012)

#### 2.3 Health Needs Assessments

A Health Needs Assessment is a "systematic method for reviewing the health needs of a particular population, leading to agreed priorities and resource allocation, which will lead to improved health and reduced health inequalities".<sup>iv</sup> Health Needs Assessments traditionally combine information from published literature, data sources and the views of local stakeholders.

#### 2.3.1 Aims and Objectives

The aim of this Health Needs Assessment is to identify and quantify the population that could be predicted to die within the next twelve months in Derbyshire and would benefit from end of life care.

#### Objectives include:

- Creating a mortality profile for Derbyshire, by age, gender and cause of death
- Review routine end of life care indicators to identify variation in quality of provision across Derbyshire
- Review the evidence to identify the components of good quality and effective end of life care, with a focus on those that reduce avoidable hospital admissions

#### 2.3.2 Scope

The scope of the Health Needs Assessment is the adult population aged 18 years and over registered with Erewash, Hardwick, North Derbyshire and Southern Derbyshire CCGs. It includes:

- a summary of national and local policy
- a review of the available epidemiological information relating to end of life care
- a summary review of the effectiveness and cost-effectiveness of palliative care services

The end of life care needs of children and young people are not included for the following reasons:

- compared to deaths in adults, there are a relatively small number of deaths in under 18's; and
- the main causes of deaths in children are congenital conditions, cancers and injuries conditions that are either not amenable to end of life care or where the need for end of life care is predictable and services are in place for the majority of children

#### 2.4 Causes of deaths in the UK

In 2013, the leading cause of deaths in men in England and Wales was heart disease, accounting for 15% of male deaths. For women, the leading cause of death was dementia/Alzheimer's disease, accounting for 12% of female deaths.

The leading cause of death varies considerably by age (table 1). Amongst children and younger adults, congenital defects, accidents and suicide are the leading causes of death. From 35 to 80 years, heart disease, cancer (particularly lung and breast cancer) and liver disease are the leading causes of death, with heart disease and dementia/Alzheimer's disease the leading causes amongst older adults aged 80 years and over.<sup>V</sup> However, as the numbers of deaths vary considerably by age, the leading causes of death amongst children and younger adults contribute a relative small number to the total number of deaths. For example, there were approximately 175 deaths from land transport accidents amongst 5 to 19 year olds in 2013, compared to approximately 42,000 deaths from dementia/Alzheimer's disease amongst those aged 80 years and over.

Age band	Male	Female
All ages	1: Heart disease	1: Dementia/Alzheimer's disease
	2: Lung cancer	2: Heart disease
1-4 years	1: Congenital defects	1: Congenital defects
	2: Flu/pneumonia	2: Homicide
5-19 years	1: Land transport accidents	1: Land transport accidents
	2: Suicide	2: Congenital defects
20-34 years	1: Suicide	1: Suicide
	2: Accidental poisoning	2: Accidental poisoning
35-49 years	1: Suicide	1: Breast cancer
	2: Heart disease	2: Liver disease
50-64 years	1: Heart disease	1: Lung cancer
	2: Lung cancer	2: Breast cancer
65-79 years	1: Heart disease	1: Lung cancer
	2: Lung cancer	2: Heart disease
80 years and over	1: Heart disease	1: Dementia/Alzheimer's disease
	2: Dementia/Alzheimer's disease	2: Heart disease

Table 1: Leading causes of death in England and Wales in 2013

Source: ONS

#### 2.5 End of life trajectories

Four general trajectories of decline at the end of life have been described (figure 2). Approximately 14% of people will have a sudden death; 25% will remain in generally good health until experiencing a steep decline in the last few weeks or months of life, predominately related to a terminal cancer but may include other terminal illnesses; 19% will experience a slow deterioration punctuated by acute, partially reversible troughs, such as in severe heart failure; and 42% will undergo a gradual insidious decline such as might occur in the frail elderly.<sup>vi vii</sup> Understanding the differences in these trajectories can help healthcare professionals more appropriately meet patients' needs.

Figure 2: End of life trajectories



Source: NHS Improving Quality, 2015

#### 3 National and local context

#### 3.1 National policies and guidance

The End of Life Care Strategy identified the need for end of life care to address the needs of patients and their families in the last phase of their life, including the management of pain and other symptoms and the provision of psychological, social, spiritual and practical support.<sup>III</sup> The strategy recommends six key elements of an end of life care pathway:

- Discussions as the end of life approaches
- Assessment, care planning and review
- Co-ordination of care for individual patients
- Delivery of high quality services in different settings
- Care in the last days of life
- Care after death

The *One chance to get it right* report sets out the approach to caring for dying people that health and care organisations should adopt, applied irrespective of the place where someone is dying.<sup>viii</sup> The approach focuses on five priorities of care that make the dying person the focus of care in the last few hours and days of their life. The approach follows from the agreement in 2013 to phase out the use of the Liverpool Care Pathway for the Dying Patient in health and social care settings. The Priorities of Care are that, when it is thought that a person may die within the next few days or hours:

- 1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly
- 2. Sensitive communication takes place between staff and the dying person, and those identified as important to them
- 3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants
- 4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
- 5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support is agreed, co-ordinated and delivered with compassion.

The NICE Quality Standards for end of life care sets out 16 markers of high-quality care for adults who require end of life care that should be applied in health and social care settings.<sup>ix</sup> Applied systematically and collectively, the standards should improve the effectiveness, safety and experiences of people approaching the end of their life, by ensuring that care is provided aligned to their needs and preferences. Implementation locally should also result in an increased length of time spent in preferred place of care during the last year of life, a reduction in potentially avoidable admissions during end of life, and a reduction in deaths in hospitals. The list of standards is provided in Appendix 1.

A number of guidance documents recognise that individuals with terminal illnesses other than cancer would benefit from provision of palliative care services, including the following conditions :

- chronic heart failure<sup>x</sup>
- chronic obstructive pulmonary disease<sup>xi</sup>
- dementia<sup>xii</sup>
- liver disease<sup>xiii</sup>
- motor neurone disease (MND)<sup>xiv xv</sup>
- Parkinson's disease and other long-term neurological conditions<sup>xvi</sup>

A number of barriers for people with conditions other than cancer accessing the palliative care that they need have been identified (box 1), as have "triggers", which could act as indicators for healthcare professionals that an individual with a terminal illness may benefit from palliative care (box 2).<sup>i</sup>

#### Box 1: Barriers to accessing palliative care

- Prognostic uncertainty and hard to predict disease trajectories.
- A failure or reluctance to identify certain conditions (eg dementia) as terminal by professionals.
- A lack of understanding of what palliative care is, and what it can achieve for people with conditions other than cancer, by both professionals and people with a terminal illness and their families.
- For some conditions, such as COPD, a paucity of research which demonstrates potential benefits of palliative care on patient's health outcomes (compared to the amount of research on lung cancer, for example).
- A lack of confidence from professionals in delivering care appropriate for people approaching the end of their life, for example, thinking that initiating end of life care discussions is someone else's role or concerns about the legal standing of advance decisions.
- Under-developed links between condition specialists and palliative care specialists.

# *Box 2: Triggers for considering palliative care*

- Complex or persistent problems with symptoms such as:
  - o intractable pain
  - o difficult to manage breathlessness
  - o nausea
  - $\circ$  vomiting
  - o mouth problems
  - o difficulty sleeping and fatigue
  - psychological issues, such as depression and anxiety.
- High levels of hospital use, especially unplanned admissions.
- Having more than one condition (multimorbidity).
- Factors relating to nourishment and eating habits in people with cognitive impairment (eg dementia).
- The introduction of new interventions (eg gastrostomy feeding or ventilator support).
- For some conditions, such as MND, at the point of diagnosis.
- When a screening tool indicates that it would be appropriate.

#### 3.2 Local context

Within Derbyshire, both the South and North Units of Planning have included consideration of end of life care services within their strategic transformational plans.

#### 4 Evidence review

#### 4.1 Estimating the need for end of life care

The causes of death now widely recognised where palliative care may be beneficial are:xvii xviii

- advanced cancers
- end stage organ failures (heart failure, respiratory disease, renal failure and liver failure)
- neurodegenerative diseases such as motor neurone disease, multiple systems atrophy, Parkinson's disease, Huntington's disease
- advanced dementia/Alzheimer's disease

There is significant evidence however that those with terminal conditions other than cancer are less likely to be offered or to access palliative care services.<sup>ii</sup> In 2012, 29% of deaths in England had a cancer diagnosis, but 88% of people receiving specialist palliative care in in-patient units had cancer.<sup>i</sup>

A number of models have been published that estimate the need for palliative care services. Early models focussed on deaths from cancer only, or cancer and a limited number of other chronic progressive diseases. These models estimated that palliative care would be needed in 60%<sup>xix</sup>, 37-97%<sup>xvii</sup> and 75%<sup>xx</sup> of all deaths.

A national snapshot of end of life care in primary care collated information from 502 GP practices in England.<sup>xxi</sup> Practice staff identified that 42% of deaths were predictable, with 27% of deaths on the palliative care register, and a further 15% of deaths thought by practice staff to have been predictable but not put on the register.

Hughes-Hallet et al (2011) used the methodology devised by Rosenwax,<sup>xvii</sup> together with information on conditions likely to require palliative care in children, and data on admissions to hospital with conditions likely to imply a need for palliative care.<sup>xxii</sup> They concluded that between 70 and 80% of deaths are likely to require palliative care input.

Murtagh et al (2014) refined the methodology of previous models by incorporating a wider range of non-cancer conditions (including stroke and dementia). The authors estimated that between 63% and 82% of all deaths needed palliative care.<sup>xviii</sup>

An alternative approach that has been used to estimate the need for palliative care is to attempt to quantify the number of unexpected deaths, that is "a death that is not due to a terminal illness, or a death that the family were not expecting", and assume that the remainder of deaths are therefore predictable.<sup>xxiii</sup> Using this methodology, the National End of Life Care Intelligence Network estimated that between 2006 and 2008 a quarter of deaths in England were unexpected, based on a pre-defined list of conditions as detailed in Appendix 2.<sup>xxiv</sup> The proportion of unexpected deaths varied by age, with 17% of deaths of those aged 65 years and below deemed to be unexpected, rising to 31% of deaths among those aged 85 years and above. This would equate to 75% of all deaths requiring palliative care. A small proportion of individuals with a terminal illness may die from an unexpected cause of death (i.e. from a condition identified in Appendix 2), and using this methodology may under-estimate the need for palliative care.

#### 4.2 Estimating the level of end of life care services

The Commissioning Guidance for Specialist Palliative Care draws together evidence and guidance from a variety of sources and makes the following recommendations<sup>xxv</sup>:

- For a population of 250,000 the minimum requirements for community specialist palliative care are:
  - 2 WTE consultants in palliative care
  - o 2 WTE additional supporting doctors
  - 5 WTE community specialist palliative care nurses
    - 20-25 inpatient specialist palliative care beds, with a 1.2 nurse:bed ratio
- For a 250 bed hospital, the minimum requirements for specialist palliative care are:
  - 1 WTE consultant/associate specialist in palliative care
  - o 1WTE hospital specialist palliative care nurse

However, the report also states that the methodology behind the recommendations is based on information largely relating to palliative care needs amongst cancer patients only. In addition, they do not take account of the ageing population, and the increase in multiple co-morbidities which will result in a need for palliative care for individuals requiring more complex management, and therefore likely to be more resource-intensive. The recommendations also do not consider other local factors, such as rurality, the ethnic diversity of the population, or the level of socio-economic deprivation. All of these will increase the need for specialist palliative care services in a locality.

#### 4.3 Prognostic tools

Key to provision of end of life care is healthcare professionals being able to identify individuals in the last year of life that can be offered end of life care services.

Within the UK, one of the most widely-promoted tools is the Gold Standard Framework's Prognostic Indicator Guidance.<sup>xxvi</sup> The tool is designed to ensure that the individual's needs are met to ensure that the right care is provided at the right time, as opposed to giving defined timescales as to the remainder of an individual's life. It requires professionals to use three triggers to identify individuals who may benefit from end of life care:

- Ask the surprise question: Would you be surprised if the patient were to die in the next few months, weeks or days?
- Review general indicators: are there any general indicators of decline and increasing needs, such as decreased Activities of Daily Living scores, progressive weight loss, choice of no further active treatment, repeated unplanned or crisis admissions
- Review specific clinical indicators: does the individual have one or more of the specific clinical indicators for their condition that would indicate a need for end of life care (for example repeated hospital admissions due to the condition or difficult physical or psychological symptoms despite optimal tolerated therapy)

The guidance suggests that if any of the following are identified then the professional should begin preparations for end of life care, including:

- Recording the patient on the QOF palliative care register
- Assessing needs and likely support requirements with the patient and carer, and record advance care planning discussions
- Plan and provide proactive care to improve coordination and communication

Other tools used in the identification of palliative care patients include

- the Radbound indicators of Palliative Care Needs (RADPAC) which provides GPs with indicators for patients with congestive heart failure, chronic obstructive pulmonary disease and cancer<sup>xxvii</sup>
- the Sheffield Profile for Assessment and Referral for Care (SPARC) which uses 45 questions to assess individuals' physical, psychological, independence and treatment needs<sup>xxviii</sup>
- The Supportive and Palliative Care Indicators Tool (SPICT) is a guide that describes clinical signs that can help primary care teams identify patients who are at risk of deteriorating and dying from one or more advanced conditions<sup>xxix</sup>

The effectiveness of these prognostic tools has not been reviewed as part of this HNA.

#### 4.4 Effectiveness of end of life care services

Despite the high prominence of end of life care, there are few high quality studies that have published that review the effectiveness of palliative care services compared to usual care, or between different palliative care interventions. The literature review undertaken for this HNA focussed on the effectiveness of palliative care services in reducing hospital admissions during end of life.

Research in the 2000's suggested that between 30-40% of admissions amongst individuals with palliative care needs were potentially avoidable.<sup>xxx xxxi</sup> Gott et al (2013) challenged this by reporting that only 7% of patients identified with palliative care needs had been admitted inappropriately. The median age of study participants was 84 years, and half of them lived in residential or nursing homes and the authors concluded that most of the inappropriate admissions could have received care within this setting.<sup>xxxii</sup> A similar proportion of potentially avoidable admissions (7%) were also identified when reviewing admissions of 483 individuals who died within one year of admission.<sup>xxxiii</sup> However, other recent studies have reported higher levels of potentially avoidable admissions, similar to the levels reported in the 2000's.<sup>xxxiv</sup>

Gomes et al (2013) reviewed whether home based palliative care services were a) effective at improving the likelihood of recipients dying at home, b) effective at improving clinical and other outcomes and c) cost effective.<sup>xxxv</sup> The majority of participants in the studies had a diagnosis of cancer, but other conditions included congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), HIV/AIDS and multiple sclerosis. The authors reported a doubling of the odds of dying at home when receiving palliative care compared to usual care and a reduction in symptom burden. There was limited evidence reported on the cost-effectiveness of home-based palliative care services.

Seow et al (2014) reviewed the effectiveness of eleven specialist community-based palliative care services in reducing inpatient and emergency department use in the last weeks of life, and dying in hospital.<sup>xxxvi</sup> Different models of care were in place, but there were some consistent features across the services, including 24/7 coverage and collaboration between specialist palliative care clinicians and GPs. Pooling the results reported by the different services, the authors reported a 32% reduction in being admitted to hospital in the last 2 weeks of life, a 23% reduction in emergency department visits and a 54% reduction in dying in hospital for those receiving community-based specialist palliative care.

With a focus on Australia's health system, Luckett et al (2014) undertook a review of the literature to identify elements of effective palliative care models.<sup>xxxvii</sup> Elements of successful models included case management extending beyond an individual's health needs to also include social and pastoral care, integrated care between specialist teams and generalist services, an identified lead clinician working alongside other health professionals, and good communication between services. The authors suggest that due to an ageing population, with an increase in the number of people with life-limiting illnesses, reserving specialist palliative care services for those with the most complex needs whilst supporting non-complex cases within generalist services would create a sustainable approach.

An evaluation of a Macmillan medical-consultant led service that provided 24/7 care to individuals in their home, community hospitals or nursing/residential homes reported lower levels of emergency admissions and patient stays in hospital, and 71% of people dying at home.<sup>xxxviii</sup> 85% of referrals to the team were for individuals with a terminal cancer diagnosis. Post-referral costs were similar to hospice-based models of provision, however due to the earlier referrals to the community- based team, the authors concluded that approximately 20% of the costs accumulated in the final year of life were avoided.

Temel et al (2010) reported that patients with lung cancer for whom palliative care was introduced shortly after diagnosis had improved quality of life.<sup>xxxix</sup> Compared to those assigned standard care patients who received early palliative care also had less aggressive end of life care and longer survival.

#### 4.5 Cost effectiveness of end of life care services

In the UK estimates of the proportion of hospital bed days taken up by end of life care vary, from approximately 20%<sup>x1</sup> to nearly 30%<sup>x1</sup>. In Wales in 2012, emergency and elective hospital admissions in the last year of life accounted for more than 1 million bed days – nearly a quarter (23.8%) of all hospital bed days. <sup>x111</sup> Shifting towards a more community-based provision of end of life care services therefore has the potential to reduce healthcare costs, though there is lack of robust evidence to confirm this as it can be difficult to undertake a like for like comparison of hospital and community based care. If community based care is more cost effective, it needs to be recognised that it also places even greater financial, physical, and emotional demands on carers<sup>x1111</sup>.

Despite there being significant variation between the design of services and settings for provision of palliative care included in their review, Smith et al (2014) reported that palliative care has

consistently shown to be less costly compared to comparator groups (in general the comparator was receipt of usual care).<sup>xliv</sup> This was replicated across a range of settings, both hospital and community-based.

An alternative approach to reducing the acute care costs of end of life care is to reduce the length of stay of end of life care patients. In two large acute hospital trusts in the UK, Gardiner et al (2014) reviewed the records of 483 patients who died within 1 year of admission to hospital. The authors estimated cost savings of £5.9million per year by reducing the level of potentially avoidable admissions, but annual savings of £47.5million by reducing the length of stay amongst all end of life care patients by 14%.<sup>xxxiii</sup>

By reviewing individual data, the Nuffield Trust was able to estimate average health and social care costs in the last 90 days of life.<sup>xiv</sup> In-patient hospital costs were the largest element, followed by local authority funded social care costs (due to the comparatively high costs of nursing and residential care). Hospice care, community nurse contacts and GP contacts contributed less to the overall end of life costs. Based on a previous evaluation that reported that the Marie Curie nursing service was effective at reducing hospital admissions and individuals receiving care were more than twice as likely to die at home than those receiving usual care,<sup>xivi</sup> the authors quantified whether investment in community based end of life care would be offset by reduced hospital activity. They concluded that investment in community-based specialist services could result in approximately £500 lower costs per person.

#### 5 Epidemiological information

#### 5.1. Population statistics

The combined population of Erewash, Hardwick, North Derbyshire and Southern Derbyshire CCGs is 1,031,154. There is an equal split between males (515,677) and females (515,477). Each of the four CCGs has an older population compared to England, with 19% of the combined CCG population aged over 65 years (compared to 17% nationally), and 9% aged over 75 years (compared to 8% in England) (table 2).

North Derbyshire CCG has the highest proportion of its population aged over 75 years. Southern Derbyshire CCG has the lowest proportion of older adults in its population, reflecting the fact that the CCG's geography includes the population of Derby City, which has a younger population than Derbyshire. The population structure of each CCG, and of Derbyshire County and Derby City is provided in Appendix 3.

	Total population	Proportion aged 65 years and older (%)	Proportion aged 75 years and older (%)
Erewash CCG	97,300	19.1	8.5
Hardwick CCG	102,308	20.6	9.0
North Derbyshire CCG	290,477	21.7	9.6
Southern Derbyshire CCG	541,069	17.6	7.9
Combined CCG population	1,031,154	19.2	8.5
England	57,011,772	17.1	7.8

#### Table 2: Population by CCG

Source: ONS

# 5.1.1. Changes in population structure

Between 1993 and 2014 the populations of Derby and Derbyshire increased, by 11 and 8% respectively. Projections suggest that the population of Derby will increase at approximately the same rate as the national population over the next fifteen years, but that the increase in Derbyshire will be less. In 2030 it is projected that the total population in Derbyshire will be 841,300 and in Derby City will be 281,200. (figure 3).

Between 1993 and 2014, the populations of those aged 75 years and over in Derby and Derbyshire also increased, but with a larger increase in Derbyshire (28% increase in Derbyshire, and 23% increase in Derby City). Projections suggest that the increase in the population of those aged 75 years and over will continue to be greater in Derbyshire over the next fifteen years. By 2030, the over 75 years population is projected to be 117,700 in Derbyshire and 27,000 in Derby. This compares to the current population of 69,400 in Derbyshire and 19,600 in Derby City (figure 4).



Figure 3: Change, and projected change, in population size 1993 to 2030, all ages

Source: ONS

Figure 4: Change, and projected change, in population size 1993 to 2030, over 75 years only



Source: ONS

#### 5.2 Socio-economic deprivation

Higher rates of socioeconomic deprivation are associated with higher rates of mortality.<sup>xlvii</sup> In addition, despite receiving similar access to community-based support, individuals in more deprived areas are less likely to die at home compared to individuals from less deprived communities.<sup>ii</sup>

Derby City has a higher proportion of its population (29%) living in the most socio-economically deprived areas compared to Derbyshire (12%). Across the city and county, there are approximately 168,000 individuals living in an area that is within the 20% most socio-economically deprived areas in England. Within Derbyshire, the proportion living in the most deprived communities varies by district, from over one in four of the population in Chesterfield and Bolsover to approximately 1 in 50 in Derbyshire Dales and South Derbyshire (table 3).

Local authority	Total population	Number living in most deprived national quintile	Proportion living in most deprived national quintile (%)
Derby City	251,423	72,901	29.0
Derbyshire County	776,160	95,046	12.2
Amber Valley	123,498	11,042	8.9
Bolsover	76,729	21,033	27.4
Chesterfield	104,030	26,985	25.9
Derbyshire Dales	71,266	1,598	2.2
Erewash	113,170	1,836	16.2
High Peak	91,111	4,171	4.6
North East Derbyshire	99,281	10,201	10.3
South Derbyshire	97,075	1,649	1.7

#### Table 3: Level of socio-economic deprivation by district

Source: ONS

Figure 5 shows that the most socio-economically deprived areas in Derbyshire are located primarily in Chesterfield, Derby City, and towards the eastern side of the county. However, there are also communities with high levels of socio-economic deprivation in Glossop, Buxton, Matlock and Swadlincote.

Figure 5: Distribution of most socio-economically deprived communities in Derbyshire



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#### 5.3 Ethnicity

Consideration of ethnicity is important in planning end of life care services to ensure they are culturally appropriate and meet the needs of the whole population.

According to the 2011 census, there were 32,652 individuals from BME groups living within Derbyshire, comprising 4% of the population. This is significantly lower than the England and Wales proportion, where BME groups comprise 20% of the population. The largest BME groups within Derbyshire are White Other, Indian, White and Black Caribbean and White Irish. The highest rates of BME groups are located in Chesterfield, Long Eaton and the communities adjacent to Derby City. However, there are areas with higher rates of BME population within the majority of urban areas in Derbyshire.

Derby City has a higher proportion of its population from BME groups. In the 2011 census, there were 61,366 individuals from BME groups living in Derby, 25% of the population. There are six wards in Derby where BME groups comprise more than a quarter of the population Normanton (67%), Arboretum (67%), Blagreaves (36%), Abbey (35%), Sinfin (35%) and Littleover (34%). The largest BME groups in Derby are Pakistani, Indian and Other White groups.

#### 5.4 Mortality statistics

#### 5.4.1 All-cause mortality

In 2014, there were 9,636 deaths of individuals registered with Derbyshire CCGs, which equates to <1% of the combined CCG population. There were a similar number of deaths by gender (4,786 male deaths and 4,849 female deaths).

The incidence of deaths varied significantly by CCG (table 4). The highest incidence was in Hardwick CCG. Erewash, Hardwick and North Derbyshire CCGs had a significantly higher incidence of deaths compared to England, with Southern Derbyshire CCG having a similar rate. As this crude incidence does not account for differences in age profiles between populations, then the difference in incidence will most probably reflect the older population in Erewash, Hardwick and North Derbyshire CCGs.

#### Table 4: Count and incidence of deaths in 2014, by CCG

	Number of male deaths	Incidence of deaths per 1,000 male population (95% Cls)	Number of female deaths	Incidence of deaths per 1,000 female population (95% Cls)	Incidence of all deaths per 1,000 population (95% Cls)
Erewash CCG	459	9.44 (8.60, 10.34)	480	9.86 (9.00, 10.78)	9.65 (9.04, 10.29)
Hardwick CCG	551	10.82 (9.93, 11.76)	567	11.04 (10.15, 11.98)	10.93 (10.30, 11.59)
North Derbyshire CCG	1,445	10.04 (9.53, 10.57)	1,526	10.41 (9.89, 10.95)	10.23 (9.86, 10.60)
Southern Derbyshire CCG	2,331	8.56 (8.22, 8.92)	2,276	8.47 (8.12, 8.82)	8.52 (8.27, 8.77)
Combined CCG	4,786	9.28 (9.02, 9.55)	4,849	9.41 (9.14, 9.68)	9.34 (9.16, 9.53)
England	-	-	-	-	8.63 (8.61, 8.66)

Source: Primary care mortality database

As would be expected, the number of deaths varies by age. For all CCGs, the majority of deaths occur in older adults, with deaths amongst adults aged 65 years and over comprising in excess of 80% of all deaths (figure 6).



Figure 6: Proportion of deaths by age group, 2014, by CCG

Figure 7 maps the distribution of deaths in 2014 for individuals registered with a GP practice in Erewash, Hardwick, North Derbyshire and Southern Derbyshire CCGs. The count of deaths amongst the Lower Super Output Areas (LSOA) in Derbyshire County and Derby City ranged from 1 to 65. There appears to be no obvious pattern to the distribution of deaths, but a higher numbers of deaths in a LSOA may be due to the presence of residential and nursing homes within that community.

Source: Primary care mortality database



Figure 7: Number of deaths in 2014, by Lower Super Output Area

#### 5.4.2 Causes of death

For the combined CCG population, the highest proportions of deaths were due to cancer (29%) and circulatory disease (26%) (Figure 8). Respiratory disease was responsible for 14% of deaths, dementia for 11% and liver disease for 3.0%. Males have a higher proportion of deaths from cancer and liver disease compared to females. However, dementia accounts for twice the proportion of deaths among women (14%) compared to men (7%).

There are no significant differences between the proportions of deaths for each of the major causes of death for Erewash CCG and Southern Derbyshire CCG, compared to the England figures (table 5). North Derbyshire CCG has a significantly lower proportion of deaths due to cancer compared to England and a significantly higher proportion of deaths due to circulatory disease. Hardwick CCG has a significantly higher proportion of deaths due to respiratory disease.



Figure 8: Cause of deaths in 2014, by CCG

Source: Primary care mortality database

	Proportion of deaths from (%):				
	Circulatory Respiratory Oth disease disease				
England	28.2	27.7	14.7	29.4	
Erewash CCG	27.6	28.7	14.1	29.6	
Hardwick CCG	29.7	27.3	16.8	26.2	
North Derbyshire CCG	26.2	29.9	14.1	29.8	
Southern Derbyshire CCG	27.6	28.2	14.5	29.7	

Table 5: Proportion of total number of deaths by cause in 2013, by CCG

Source: PHE Fingertips EOL

#### 5.5 Place of death

Respondents to the national 2014 VOICES survey reported that more than 82% of people would prefer to die at home, with 8% preferring to die in a hospice, 6% in a care home, 3% in a hospital and 1% somewhere else.<sup>xlviii</sup> However, individual preferences change as death approaches, with fewer individuals wanting to die at home and more wanting to die in a hospice.<sup>xlix</sup>

Approximately half of all deaths in Derbyshire in 2011-13 occurred in hospital, with one fifth occurring at home, and another fifth occurring in care homes (figure 8). One in twenty deaths in Derbyshire occurred in a hospice. There is a similar picture across all four CCGs, but Erewash had a significantly lower proportion of deaths occurring in a hospice compared to the other CCGs, primarily due to the lack of hospice provision within its area.



Figure 9: Place of death in 2013, by CCG

Source: PHE Fingertips EOL

Erewash CCG also has a significantly higher proportion of deaths in hospital, and a significantly lower proportion of deaths in hospices compared to England (there is no hospice provision in the Erewash area). Hardwick has a lower proportion of deaths at home and in other places compared to England. North Derbyshire CCG has a similar proportion of deaths in each place category compared to England, apart from deaths in other places, where it has a significantly lower proportion of deaths. There are no significant differences between the proportions in Southern Derbyshire CCG compared to the England figures.

	Hospital	Home	Care home	Hospice	Other place
England	48.3	22.4	21.6	5.5	2.2
Erewash CCG	53.4	22.5	18.2	2.9	3
Hardwick CCG	52	20	20.5	6	1.5
North Derbyshire CCG	48.7	20.8	22.7	6.3	1.5
Southern Derbyshire CCG	50.9	21.2	21.3	4.7	1.9

Table 6: Percentage of deaths by place, 2013

Source: PHE Fingertips EOL

The highest proportion of hospital deaths in Derbyshire was from other causes, with cancer and circulatory diseases both comprising approximately 1 in 4 hospital deaths (table 7). Cancer and circulatory disease comprised approximately 1 in 3 home deaths. Dementia was the cause for the highest proportion of care home deaths and deaths from cancer were responsible for nearly 90% of deaths in a hospice.

	Place of death – per centages:						
	Hospital (n) Home (n) Care home (n) Hospice (n) Oth						
Cancer	23.6 (1,135)	37.0 (782)	16.4 (332)	89.2 (455)	21.4 (39)		
Circulatory disease	28.9 (1,389)	30.8 (651)	20.4 (411)	2.9 (15)	19.8 (36)		
Dementia	5.1 (243)	3.6 (76)	34.4 (695)	0.4 (2)	1.1 (2)		
Liver disease	3.3 (158)	3.8 (81)	1.1 (23)	4.3 (22)	1.7 (3)		
Other	39.2 (1 <i>,</i> 883)	24.9 (526)	27.6 (558)	3.1 (16)	56.0 (102)		
Total	100 (4,808)	100 (2,116)	100 (2,019)	100 (510)	100 (182)		

Table 7: Cause of death by place of death for Derbyshire CCGs, 2011-13

Source: EOLC intelligence network

For cancer and liver disease, the highest proportion of deaths occurred in hospital, for dementia the majority of deaths happened in care homes and for circulatory disease there were similar proportions of deaths in hospital and at home. Approximately 1 in 6 cancer deaths was in a hospice. Approximately 1 in 4 cancer and circulatory deaths occurred at home. For the main causes of death, there were few differences in the proportion of deaths by place for each CCG. The proportion of cancer deaths in a hospice was significantly lower in Erewash CCG and higher in Hardwick and North

Derbyshire CCGs compared to the combined figure. The proportion of cancer deaths in a hospital was significantly higher in Erewash CCG compared to the combined proportion.

Diaco of	Cause of death – per centages:						
death	Cancer (n)	Circulatory disease (n)	Dementia (n)	Liver disease (n)	Other (n)		
Hospital	41.4 (1,135)	28.9 (1,389)	23.9 (243)	55.1 (158)	61.0 (1,883)		
Home	28.5 (782)	30.8 (651)	7.5 (76)	28.2 (81)	17.1 (526)		
Care home	12.1 (332)	20.4 (411)	68.3 (695)	8.0 (23)	18.1 (558)		
Hospice	16.6 (455)	2.9 (15)	0.2 (2)	7.7 (22)	0.5 (16)		
Other	1.4 (39)	19.8 (36)	0.2 (2)	1.0 (3)	3.3 (102)		
Total	100 (2,743)	100 (2,116)	100 (1,018)	100 (287)	100 (3,085)		

Table 8: Place of death for each condition for Derbyshire CCGs, 2011-13

Source: EOLC intelligence network

At a CCG level, both Erewash and Southern Derbyshire CCGs had a significantly higher proportion of deaths from cancer occurring in hospitals compared to the England rate. North Derbyshire and Southern Derbyshire CCGs had a significantly lower proportion occurring in care homes compared to the England rate, and Southern Derbyshire CCG also had a significantly lower proportion occurring at home. Erewash CCG had a significantly lower proportion occurring in hospices. For circulatory and respiratory diseases, there were no differences between the proportion of deaths by place for Derbyshire CCGs and the England rate (see additional data tables in Appendix 3).

#### 6 Modelled need for end of life care

### 6.1 Marie Curie model

Using a methodology based on Higginson's estimate of the need for palliative care, Marie Curie has published estimates of the numbers within each CCG's population that have palliative care needs. Across the four CCGs in Derbyshire, there are an estimated 7,011 individuals with palliative care needs (table 8). The highest proportions are in Hardwick and North Derbyshire CCGs.

Uplifting the figure to reflect the increase in population in 2014 provides an updated estimate of 7,262 individuals with palliative care needs (642 in Erewash CCG, 808 in Hardwick CCG, 2,295 in North Derbyshire CCG and 3,517 in Southern Derbyshire CCG).

The model also estimates the proportion of those with palliative care needs who are recorded on QOF registers. All of the CCGs in Derbyshire have a higher proportion recorded than nationally. According to the model, North Derbyshire CCG has a higher number of individuals recorded on the QOF register than would be expected. This would indicate either a higher proportion of the population has end of life care needs in North Derbyshire CCG than the model suggests, or that the registers include individuals who may not require end of life care.

	% of population with palliative care need (n)	% of population with palliative care need identified
England average	0.67 (1,796)	37.0
Erewash CCG	0.66 (622)	77.9
Hardwick CCG	0.79 (864)	60.0
North Derbyshire CCG	0.79 (2,150)	110.0
Southern Derbyshire CCG	0.65 (3,375)	51.3

#### Table 8: modelled need for palliative care, by CCG

Source: Marie Curie

# 6.2 Unexpected deaths

Using the causes of death identified by the End of Life Intelligence Network as being "unexpected" (see Appendix 2), in 2014 22% of deaths in the 4 CCGs could be classified as unexpected (n=2,109). There was no significant variation in the proportion of unexpected deaths between CCGs (figure 9).

A higher proportion of deaths amongst 0-64 year olds and 85 and over are unexpected (24% and 25% respectively) compared to 65-84 year olds (19%). Amongst 0-64 year olds, this is due to a higher proportion of deaths being due to injury, poisoning and other external causes. Amongst 85 and over this is due to a higher proportion of deaths from cerebrovascular disease and acute respiratory disease.

There are issues with this methodology in calculating predicted need for palliative care services, as it will underestimate numbers if a terminal illness is an underlying cause of death as opposed to the defined cause of death. Amongst the frail elderly, this may significantly underestimate the proportion of predictable deaths. However, assuming the other deaths are predictable, then there

were 7,526 deaths that would have benefitted from palliative care in 2014 (755 in Erewash CCG, 890 in Hardwick CCG, 2,288 in North Derbyshire CCG and 3,593 in Southern Derbyshire CCG).



Figure 10: Estimated proportion of unexpected deaths, by CCG, 2014

Source: Primary Care Mortality Database

#### 6.3 Quality and Outcomes Framework palliative care register

The Quality and Outcomes Framework (QOF) requires that GP practices maintain a register of all patients in need of palliative care irrespective of age. GPs are asked to include patients on the register if they feel that their death can be reasonably predicted within the next 12 months, OR they have advanced or irreversible disease and clinical indicators of progressive deterioration, OR they are entitled to a DS 1500 form to speed up the payment of financial benefits in the terminal stages of an illness.<sup>1</sup>

In 2013/14, there were 5,345 individuals on GP practice QOF palliative care registers in Derbyshire (figure 10). This equates to an overall prevalence of 0.5%. Prevalence was highest in North Derbyshire CCG practices (0.8%) and lowest in the Glossop practices (0.3%). Erewash, Hardwick, North Derbyshire and Southern Derbyshire CCGs all had a significantly higher prevalence compared to England, with the Glossop practices having a prevalence similar to the national figure. The majority of practices across Derbyshire had less than 1% of their practice population recorded on the palliative care register, but six practices had a prevalence that exceeded 1.5%.



Figure 11: Proportion of patients on QOF Palliative Care register, by GP practice, 2013/14

Source: Health and Social Care Information Centre

#### 6.4 Estimates from other published models

Using the models outlined in section 4.1, and the number of deaths in 2014, it is possible to estimate the number of individuals in each of the four CCGs that could benefit from palliative care services. The estimated need for the combined CCG population is between 4,047 and 7,891, the broad range reflected the differences in need provided by the models.

	Modelled need (%)	Estimated number requiring palliative care services
Erewash CCG		
Primary care survey	42	394
Hughes-Hallet	70-80	657-751
Murtagh	63-82	592-769
Hardwick CCG		
Primary care survey	42	470
Hughes-Hallet	70-80	783-894
Murtagh	63-82	704-916
North Derbyshire CCG		
Primary care survey	42	1,248
Hughes-Hallet	70-80	2,080-2,377
Murtagh	63-82	1,872-2,433
Southern Derbyshire CCG		
Primary care survey	42	1,935
Hughes-Hallet	70-80	3,225-3,686
Murtagh	63-82	2,902-3,773
Combined CCG population		
Primary care survey	42	4,047
Hughes-Hallet	70-80	6,745-7,708
Murtagh	63-82	6,070-7,891

Table 9: Estimated need for palliative care services, by CCG

#### 6.5 Estimated need for quantity of service provision

Based on the recommended level of palliative care service provision stated in the Commissioning Guidance for Specialist Palliative Care, table 10 provides an estimate of the need for services within each of Derbyshire's CCGs. As stated in section 4.2, this does not reflect local factors that may increase or decrease need from the national average.

	WTE consultants	WTE other specialist doctors	WTE nurses	Inpatient beds
Erewash CCG	0.8	0.8	1.9	8-10
Hardwick CCG	0.8	0.8	2.0	8-10
North Derbyshire CCG	2.3	2.3	5.1	23-29
Southern Derbyshire CCG	4.3	4.2	10.2	43-54
Combined CCG population	8.3	8.3	20.6	82-103

# Table 10: Estimated need for the quantity of palliative care services, by CCG

Source: Commissioning Guidance for Specialist Palliative Care

#### 7 Economic analysis

Estimates of area-based variation of spend on palliative care services cover Primary Care Trusts, the fore-runners of CCGs. Estimates are based on a Department of Health survey of spend on palliative care services, however concerns about the quality of the data returns have been expressed. In 2010/11, the latest routine data available, local spend was lower than the England average, with spend in Derbyshire County PCT in the lowest quartile of all PCTs (table 11).

	Spend per head of population (£)	Rank*	Spend per head of population over 65 (£)	Rank*
Derby City PCT	6.80	69	43.66	66
Derbyshire County PCT	4.08	16	22.32	14
England average	7.43	-	45.65	-

Table 11: Spend on palliative care by PCT, 2010-11

\* out of 150 PCTs, where 1=lowest spend

Source: Department of Health

There is no more up-to-date analysis of how local spend compares to national figures. However, the Yorkshire and the Humber Co-Design Model is a decision-making support tool to aid understanding of the financial impact of moving end of life care out of hospital and into alternative care settings. It can be populated with local hospital admission and length of stay data to look at actual and alternative costs and volume of end of life care now, in five years with no service change, and in five years with service change.<sup>II</sup> The model has not been populated for inclusion within this HNA, however, use of the model will provide estimates of local costs of alternative palliative care provision using local data, as opposed to reliance on approximating national data.

#### 8 Summary and next steps

The population of England is ageing, and with this older population comes individuals with more complex needs in the final stages of life. There is also an increasing recognition that individuals with a non-cancer terminal illnesses benefit from good end of life care that traditionally have been provided to those with terminal cancer. The evidence of the effectiveness of community-based end of life care in improving quality of life, providing a "good death" in line with a patient's and their family's wishes, and increasing the proportion of people dying at home is now more convincing than previously. There also appears to be a significant potential for community-based end of life care services to provide cost-savings by reducing use of other health and social care services in the final phase of life, particularly through reducing potentially avoidable admissions. However, the size of these savings is still being debated.

Derbyshire has a greater proportion of its population aged 75 years and over than England, with the proportion projected to increase further over the next 15 years. This will result in an increased need for end of life care services. Over 80% of deaths in Derbyshire are from cancer, circulatory disease, respiratory disease, dementia and liver disease, causes of death where a terminal pathway could be identified. Currently, approximately half of all deaths in Derbyshire occur in hospital, but there is variation by cause of death. For deaths in a hospice, over 90% of patients have a cancer diagnosis, but only one in six of all cancer deaths occurs in a hospice. Using modelled data, approximately 7,200 to 7,900 deaths in Derbyshire each year will require end of life care. At the moment, there are 5,345 individuals on GP palliative care registers, though it is not known what end of life care individuals on the registers will receive.

This HNA has been compiled to provide some introductory information to inform the end of life care planning discussions in Derbyshire. The following next steps are suggested to further inform discussions:

- Map local specialist end of life care services, including activity and financial information where possible to determine whether services are provided equitably across the county and in relation to need
- Map of local generalist end of life care services
- Engage with clinicians to develop a local understanding of the roles and responsibilities of generalist and specialist end of life care services, including a gap analysis to estimate the need for specialist and generalist services
- Audit provision of current end of life care services against the NICE Quality Standards for end of life care
- Obtain local hospital activity data to use in conjunction with national models to explore potential cost savings to the local health and social care economy by investing in community-based end of life care services
- Consult with clinicians in primary and secondary care to understand local practice and behaviour in identifying individuals on a terminal trajectory

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#### Appendix 1: NICE Quality Standards for end of life care

- 1 People approaching the end of life are identified in a timely way.
- 2 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.
- 3 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.
- 4 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.
- 5 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.
- 6 People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
- 7 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.
- 8 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.
- 9 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.
- 10 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.
- 11 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.
- 12 The body of a person who has died is cared for in a culturally sensitive and dignified manner.
- 13 Families and carers of people who have died receive timely verification and certification of the death.
- 14 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.
- 15 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.
- 16 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.

# Appendix 2: Causes of deaths deemed to be unexpected deaths

Cause of death	ICD-10 codes
Acute myocardial infarction	121*, 122*
Pulmonary embolism	126*
Pulmonary aneurysm	1281
Sudden cardiac death	1461
Cerebrovascular disease	160-69
Aortic aneurysm	171*
Acute respiratory disease, including influenza and pneumonia	J10-29, J85-86, J91-96
Injury, poisoning, other consequences of external causes	S00-T98
External causes	V01-Y98

#### Appendix 3: Additional data tables and charts



#### Population pyramids, by CCG and top-tier local authority



Source: ONS

# Location of cancer deaths, 2011-13 by CCG

	Proportion of cancer deaths occurring at (%):			
	Hospital	Home	Care home	Hospice
England	37.8	29.6	13.3	17.8
Erewash CCG	46.3	34.4	9.7	7.8
Hardwick CCG	40.4	27.8	12.6	18.3
North Derbyshire CCG	38.5	29.9	10.6	19.9
Southern Derbyshire CCG	44.6	26.8	11.2	15.8

Source: EOLC intelligence network

# Location of deaths from circulatory disease, 2011-13 by CCG

	Proportion of circulatory disease deaths occurring at (%):			
	Hospital	Home	Care home	Hospice
England	54.9	25.5	16.9	0.6
Erewash CCG	58.1	24.4	13.5	0.1
Hardwick CCG	58.3	23.8	14.7	0.5
North Derbyshire CCG	55.6	24.5	17.6	0.7
Southern Derbyshire CCG	57.3	23.8	16.8	0.4

Source: EOLC intelligence network

# Location of deaths from respiratory disease, 2011-13 by CCG

	Proportion of respiratory disease deaths occurring at (%):			
	Hospital	Home	Care home	Hospice
England	63.4	15.4	19.5	0.9
Erewash CCG	66.2	15.9	17.1	0.0
Hardwick CCG	59.7	19.3	19.9	0.7
North Derbyshire CCG	61.5	15.8	21.8	0.5
Southern Derbyshire CCG	66.7	12.9	19.6	0.4

Source: EOLC intelligence network