



*East and North Hertfordshire  
Clinical Commissioning Group*

# Palliative and End of Life Care Strategy

---

May 2017-March 2020

**Emily Byway and Stacey Oware**

## **Acknowledgements**

East and North Hertfordshire CCG would like to thank the following for their input and support in creating this strategy:

- Carers in Herts [www.carersinherts.org.uk](http://www.carersinherts.org.uk)
- East and North Herts NHS Trust [www.enherts-tr.nhs.uk](http://www.enherts-tr.nhs.uk)
- Garden House Hospice [www.ghospicecare.org.uk](http://www.ghospicecare.org.uk)
- Hertfordshire Community Trust [www.hct.nhs.uk](http://www.hct.nhs.uk)
- Hertfordshire County Council [www.hertfordshire.gov.uk](http://www.hertfordshire.gov.uk)
- Isabel Hospice [www.isabelhospice.org.uk](http://www.isabelhospice.org.uk)

## Contents

1. Executive Summary	5
2. Introduction	9
2.1 Palliative Care	9
2.2 'Approaching the End of Life'	9
2.3 End of Life Care	10
3. Background	11
3.1 National Context	11
3.2 East and North Herts CCG – The Local Picture	12
3.2.1 Local Context	12
3.2.2 Local Services	13
4. East & North Hertfordshire CCG's Vision for Palliative and End of Life Care	15
5. Palliative and End of Life Care Priority Areas	17
5.1. Improved, Personalised Care Coordination	17
5.1.1 Early Identification	18
5.1.2 Advance Care Plans	20
5.1.3 Care Co-ordination Across Providers	21
5.2 Equal Access	23
5.2.1 Understanding the Focus Areas	24
5.2.1.1 BAME Communities	24
5.2.1.2 Dementia	26
5.2.1.3 Learning Disabilities	27
5.2.1.4 Non-cancer Conditions	28
5.2.1.5 Older People	29
5.2.1.6 Other Hard to Reach Groups	29
5.2.2 Ensuring Equal Access	30
5.2.2.1 Communication	30
5.2.2.2 Understanding of Non-cancer Conditions	30
5.2.2.3 Commitment to Supporting People to Access Services	31
5.3 Support Services Available	32
5.3.1 Meeting Physical and Psychological Needs	33
5.3.2 Rehabilitative Palliative Care	33
5.4 Awareness of Options	34
5.5 Bereavement Support	38
5.5.1 What do We Mean by Grief and Bereavement	38
5.5.2 Complicated Grief	39
5.5.3 Bereaved Children	39
5.5.4 Ensuring High Quality Bereavement Support	39
5.6 Workforce Development	40
5.6.1 Competency of the Workforce	40

5.6.2 Working Environments	41
5.6.3 Aging Workforce	42
5.6.4 Volunteers	42
6. Implementing the Strategy and Next steps	43
6.1 How Will Success be Measured	43
Appendix A - Service Provision in east and north Herts	44
Appendix B - Mapping to Ambitions	46
Appendix C – Overview of Objectives by Priority Area	47
References	50

# 1. Executive Summary

East and North Herts Clinical Commissioning Group (CCG) are committed to improving the quality of care for those in need of palliative or end of life care and supporting their carers and families. The need for good quality, community based services is important in reducing the proportion of inappropriate hospital deaths, supporting people to achieve their preferred place of care and ultimately supporting people to achieve their preferred place of death.

This strategy outlines how the CCG proposes to improve palliative and end of life care over the next three years (May 2017-March 2020). It is intended that the strategy is considered as a framework, with detailed action plans subsequently being produced to deliver the overarching principles stated within this strategy.

Around half a million people die in England each year<sup>1</sup>; the majority of these deaths are in adults aged over 65, and many of these people will have had chronic illnesses and will require support from health and social care services as they approach the end of their lives<sup>2</sup>. Looking at the trends in relation to place of death it has been identified that the number of deaths each year and average age at death it is predicted to increase, with those dying more likely to have increasingly complex co-morbidities. This ageing and more complex population will have a significant impact on health services and the current collaboration between statutory, community and voluntary organisations across the CCG needs to be strengthened further to ensure people receive the best possible quality of care.

By delivering projects that improve palliative and end of life care under these priority areas, the CCG aims to achieve the following:

1. People who require palliative or end of life care are identified early, they receive the care and support they want in their preferred place of care, and are empowered to make decisions about their care
2. People approaching the end of life will have access to end of life healthcare support 24 hours a day, 7 days a week
3. Good information on all options of palliative and end of life care and support is available for patients and their families and carers
4. People die in their preferred place of death and have a positive experience of palliative and end of life care
5. People are only admitted to hospital when appropriate and at these times their stay in hospital is for the shortest time possible
6. Families and carers have access to services for bereavement support

---

<sup>1</sup> Whole Systems Partnership, National End of Life Care Programme: *Improving end of life care* (2013)

<sup>2</sup> National End of Life Care Intelligence Network, *"What We Know Now"* (2014)

7. All providers work collaboratively and communicate with each other to provide palliative and end of life care that is patient-centred, personalised, integrated, and patient led according to their preferences
8. Staff feel confident and capable of delivering high quality palliative and end of life care, and are given training in order to do so

In order for people to receive the appropriate support and care in their last stage of life, early identification is required. The Gold Standards Framework supports GPs to identify end of life patients, assess and record their needs and plan their care appropriately. Those identified under the framework should be placed on the end of life care register. It is estimated that approximately 1%<sup>3</sup> of patients within a practice should be on the register. By identifying who is in their last year of life the appropriate conversations and care planning can take place leading to a higher quality of end of life care, fewer inappropriate hospital admissions and a good death in their preferred place of death.

Although the emphasis is on those approaching their end of life, conversations with people with long term conditions regarding their preferences and plans should begin prior to being identified as end of life through advance care plans. All care plans need to be tailored to the individual and include as a minimum:

- what is important to the person
- who they wish to be involved in their care
- advance decisions to refuse treatment

It is not uncommon for many people who are in their last year of life to have multiple and complex conditions. The increase in conditions can lead to an increase in the number of people involved in an individual's care so it is vital that care is co-ordinated. The implementation of an Electronic Palliative Care Co-ordination System (EPaCCS) across east and north Herts will enable both health and social care practitioners to be aware of the latest treatment plan for those in their care. As well as having a care plan shared across providers, the needs of these patients should be reviewed on a regular basis. Monthly GSF meetings should take place and involve GPs, district nurses and palliative care community nurse specialists.

The increase in multiple and complex condition also requires organisations providing palliative and end of life care to work together with professionals and experts in a variety of fields to ensure services are developed to deliver the highest standard of care for all (e.g. dementia). Dementia is now one of the top 5 underlying causes of death and one in three people<sup>4</sup> over the age of 65 die with dementia. However, research indicates that many people with dementia are not supported to make choices in their end of life care, and they receive poorer end of life care, particularly palliative care and have less access to hospice care.

The role of the hospice, alongside other community services, for those with life-limiting conditions needs to be recognised with pathways in place for specific conditions (e.g. heart failure) to support people to access services. Access to services will need to be supported by those with the correct

---

<sup>3</sup> National End of Life Care Programme, *Find your 1%*

<sup>4</sup>Dixon et al, *Equity in the provision of palliative care in the UK: review of evidence* (2015)

skills, training and understanding of specific conditions so that staff and volunteers that work in palliative and end of life care settings feel able and equipped to provide care to those with non-cancer conditions. Given the spectrum of conditions for which palliative and end of life care is relevant, it is recognised that this strategy will need to link into other programmes across the CCG e.g. Stroke, respiratory and dementia.

The support people and their relatives have is key to achieving a good outcome in palliative and end of life care. Furthermore, access to good and early palliative care can improve outcomes for life expectancy as well as improve the quality of life<sup>5</sup>. Patients at or approaching the end of their life must also be helped to achieve maximal independence and social participation in accordance with their preferences. Quality of life and a peaceful, pain-free death are often cited as the preferences of those receiving palliative and end of life care and it the responsibility of those supporting individuals to develop their care plans to manage the expectations and provide a realistic approach to what can be achieved.

Raising awareness and promoting palliative and end of life care needs to be part of all aspects of health and social care and not the sole responsibility of those providing the services. Public Health England has developed a toolkit to support the implementation of Compassionate Communities Charter. Implementing the Compassionate Communities Charter alongside the Dying Well Charter *“encourages communities to support people and their families who are dying or living with loss. It aims to enable all of us to live well within our communities to the very end of our lives.”*<sup>6</sup> Social isolation can also be an issue for those with a long term health condition such as motor neurone disease or dementia. Implementing the Public Health toolkit will not only support people to live well in the community until the very end of life, but it will also provide those dealing with death and social isolation with support to achieve their preferred place of care and preferred place of death.

Good end of life care does not stop when the individual dies. Families and carers will need support as they go through the process of bereavement and grieving<sup>7</sup>. The national VOICES survey is conducted by the Office for National Statistics and collects information on bereaved peoples’ views on the quality of care provided to a friend or relative in the last three months of life, for England. It is equally important to assess the experiences of bereaved people with bereavement services, and to do so at a local level to enable continual improvements and development of services as needs emerge.

In order to promote and provide palliative and delivering end of life care that meets the needs of patients and their relatives, a motivated, appropriately skilled, compassionate workforce is essential. The Hertfordshire End of Life Education Group has developed a Palliative and End of Life Care Education Programme which seeks to train all staff involved in providing palliative and end of life care. However, training needs to be wider than just those providing palliative and end of life care as it can affect a wide range of people working in health and social care. Providing end-of-life care is emotionally and physically demanding and employers must support their workforce so that resilience is fostered, as well as being aware of the effects of burnout and how to prevent it.

---

<sup>5</sup> National Palliative and End of Life Care Partnership *Ambitions for palliative and End of Life Care* (2015)

<sup>6</sup> Murray Hall Community Trust, *An Overview of Compassionate Communities in England* (2013)

<sup>7</sup> National End of Life Care Intelligence Network, (2015). *‘What We Know Now 2014’*

Through implementing this strategy the key outcomes the CCG expect to see include:

1. An increase in the percentage of people achieving their preferred place of care and preferred place of death
2. All those identified as in need of palliative and end of life care will be offered the opportunity to have an advance care plan
3. An operational EPaCCS system across all providers
4. A single care plan document available to be used by all stakeholders
5. A reduction in unnecessary hospital admissions for those receiving end of life care



## 2. Introduction

This strategy outlines how East and North Hertfordshire CCG (Clinical Commissioning Group) proposes to improve palliative and end of life care (EoLC) over the next three years (May 2017-March 2020).

It is intended that the strategy is considered as a framework, with detailed action plans subsequently being produced to deliver the overarching principles stated within this strategy. The CCG will ensure that the views and opinions of the key stakeholders including local residents, patients and carers are engaged in the development of these action plans.

The scope of this strategy encompasses:

- All adults (defined for the purposes of this document as over the age of 18 years old) with any advanced, progressive, incurable illness
- Care provided in all settings such as and including Care Homes, Hospices etc.
- Care provided in the last year(s) of life.
- Patients, carers and family members (including care after bereavement).

This strategy will be reviewed annually to ensure that it is in line with the most current policies and takes into account up to date information, such as needs assessments and national data regarding preferred place of death.

For the purpose of this strategy the definitions of palliative care, approaching end of life and end of life care are:

### 2.1 Palliative Care

Palliative care aims to improve the quality of life for people with life-limiting illnesses, by controlling pain and other symptoms. It also helps those receiving care, families and carers deal with emotional, spiritual or practical issues arising from the illness.

People suffering from an incurable progressive illness may require palliative care - for example, those with heart failure, advanced respiratory disease, dementia, the end stages of progressive neurological diseases or cancer. People of all ages can benefit from palliative care at all stages of their illness.

### 2.2 'Approaching the End of Life'

People who are likely to die within the next 12 months are 'approaching the end of life'. This also takes into account people whose death is likely to be imminent in the next few days or hours. The General Medical Council (GMC) defines people 'approaching the end of life' as being 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<sup>8</sup>

Within this context, any palliative care received within the last 12 months of life is regarded as end of life care.

## **2.3 End of Life Care**

According to the Department of Health (2008) End of life care is care which *“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”*.<sup>9</sup>

---

<sup>8</sup> General Medical Council Treatment and Care towards the End of Life: good practice in decision making

<sup>9</sup> Department of Health, *End of Life Care Strategy*, (2008)

### 3. Background

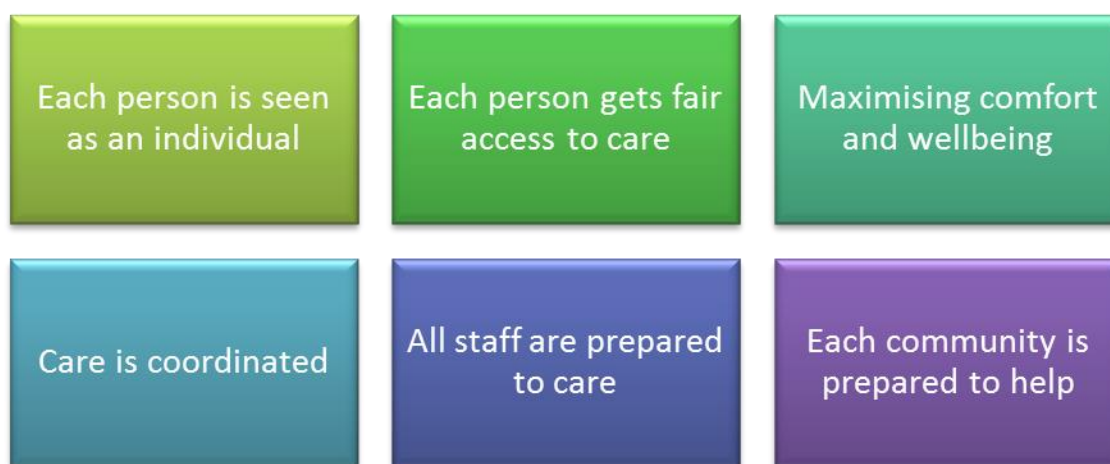
#### 3.1 National Context

Around half a million people die in England each year<sup>10</sup>; the majority of these deaths are in adults aged over 65, and many of these people will have had chronic illnesses and will require support from health and social care services as they approach the end of their lives<sup>11</sup>.

The Department of Health published the first comprehensive framework for the commissioning and delivery of palliative and end of life care in the form of the End of Life Care Strategy in 2008. Since then, National Institute for Health and Care Excellence (NICE) has released a guideline “NG31 Care of Dying Adults in the last days of life” and quality standards “QS13 End of life care for adults” and “QS144 Care of the Dying Adult in the last days of life” to promote clinical best practice in end of life care.

The National Palliative and End of Life Care Partnership released the “Ambitions for Palliative and End of Life Care” in 2015 to build upon the strategy and outlines 6 high-level ambitions (see **Figure 1**) that providers and commissioners should seek to achieve in order for people to have the best end of life care.

**Figure 1:** The six ambitions for palliative and end of life care<sup>12</sup>



Many people receive high quality care in hospitals, hospices, care homes and their own homes. However, it has been identified that one of the biggest challenges in providing end of life care is in helping people achieve their preferred place of death. The National Survey of Bereaved People 2015 (VOICES - Views of Informal Carers - Evaluation of Services) indicated that 81% of people would

<sup>10</sup> Whole Systems Partnership, National End of Life Care Programme: *Improving end of life care* (2013)

<sup>11</sup> National End of Life Care Intelligence Network, “*What We Know Now*” (2014)

<sup>12</sup> National Palliative and End of Life Care Partnership *Ambitions for palliative and End of Life Care* (2015)

prefer to die at home, however, despite this the national figures show that 49% of people die in hospital<sup>13</sup>.

A common theme throughout all the national documentation is the importance of earlier identification of those requiring of palliative and end of life care to enable the patients, health professionals, families and carers plan adequately and ensure the needs and preferences of the individuals are met. Approximately 1% of patients on a General Practice (GP) list die every year<sup>14</sup> and the Gold Standards Framework (GSF) was introduced to support health professionals to anticipate the needs of this 1%. Although originally developed for Primary Care, the GSF can be used in hospital and care homes to identify the appropriate end of life population estimated to be 30% of patients in hospital (per year) and 80% of residents in a care home (per year)<sup>15</sup>

## 3.2 East and North Herts CCG – The Local Picture

### 3.2.1 Local Context

East and North Herts CCG serve a population of 580,000 people, served by 60 GP practices making it a large CCG in comparison with others in the region.

As a whole the CCG is a generally affluent area with key healthcare priorities similar to those at national level (LTCs, Obesity, Cancer, and Heart Disease). Life expectancy is above national averages for England: 83.5 years for a woman<sup>16</sup> (compared to 83 years for England), 80.3 years for a man (compared to 79.3 years for England)<sup>17</sup>

The CCG has diverse populations and although deprivation across the whole of Hertfordshire is lower than the national average there are pockets of deprivation in East and North Herts. To recognise this diversity the CCG have a 'Locality Commissioning' structure with six localities that set priorities based on the needs of the local community.

1. Lower Lea Valley
2. North Herts
3. Stevenage
4. Stort Valley & Villages
5. Upper Lea Valley
6. Welwyn Hatfield

The division of the localities is shown in **Figure 2**.

---

<sup>13</sup> Office for National Statistics, *National Survey of Bereaved People, (VOICES)* (2015).

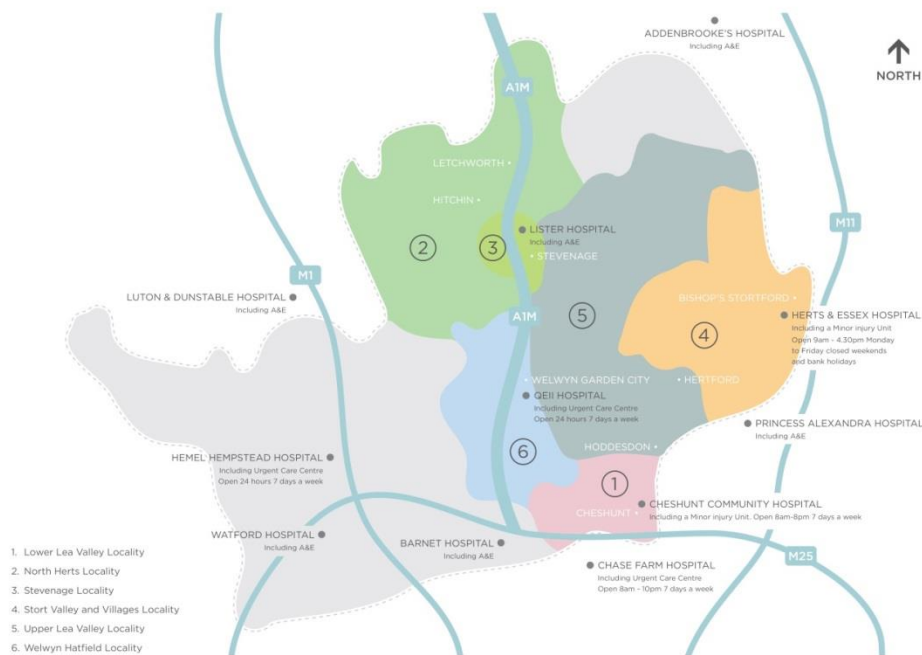
<sup>14</sup> Whole Systems Partnership, *National End of Life Care Programme: Improving end of life care* (2013)

<sup>15</sup> [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)

<sup>16</sup> Public Health England, *Local Health Profiles* (2016)

<sup>17</sup> Public Health England, *Local Health Profiles* (2016)

**Figure 2:** Division of localities in east and north Hertfordshire



The CCG is a patient-centred organisation. It aims to:

- *Work with patients, partners, managers and clinical colleagues from all sectors to commission the best possible healthcare for our patients within available resources*
- *Reduce health inequalities and achieve a stable and sustainable health economy by working together, sharing best practice and improving expertise and clinical outcomes*<sup>18</sup>

The CCG has 9 strategic ambitions, one of which is to improve end of life care and is committed to supporting people to achieve their preferred place of death and to reducing the proportion of deaths in hospital (referred to as hospital deaths).

Looking at the trends in relation to place of death it has been identified that the number of deaths each year and average age at death it is predicted to increase, with those dying more likely to have increasingly complex co-morbidities.

This ageing and more complex population will have a significant impact on health services and the current collaboration between statutory, community and voluntary organisations across the CCG needs to be strengthened further to ensure people receive the best possible quality of care.

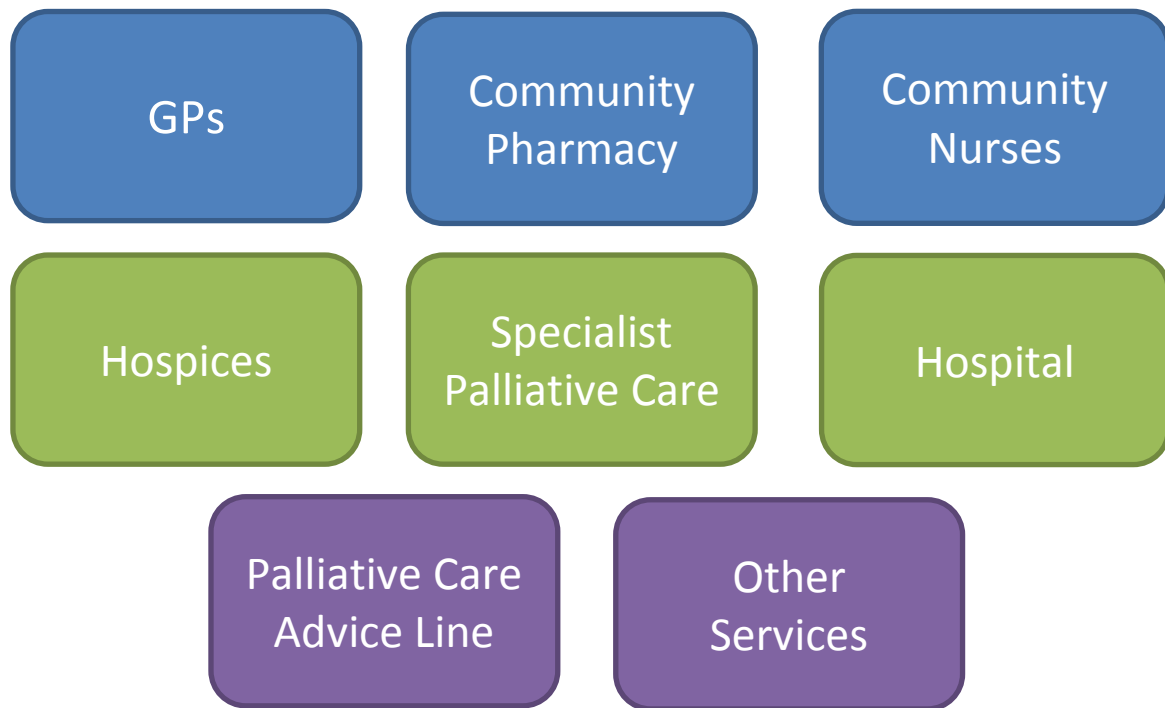
### 3.2.2 Local Services

The need for good quality, community based services is important in reducing the number of inappropriate hospital deaths and supporting people to achieve their preferred place of death.

<sup>18</sup> [www.enhertscg.nhs.uk/aboutus](http://www.enhertscg.nhs.uk/aboutus)

Palliative and end of life care in East and North Herts is not provided by a single source, but through a multi-organisation approach designed to support the needs of the individual. The majority of this is delivered in the community.

As the needs of the person become greater, the level of support available should increase. Palliative and end of life care and support is currently provided in the following ways:



Further descriptions of the role each of these providers plays in providing palliative and end of life care can be found in **Appendix A**.

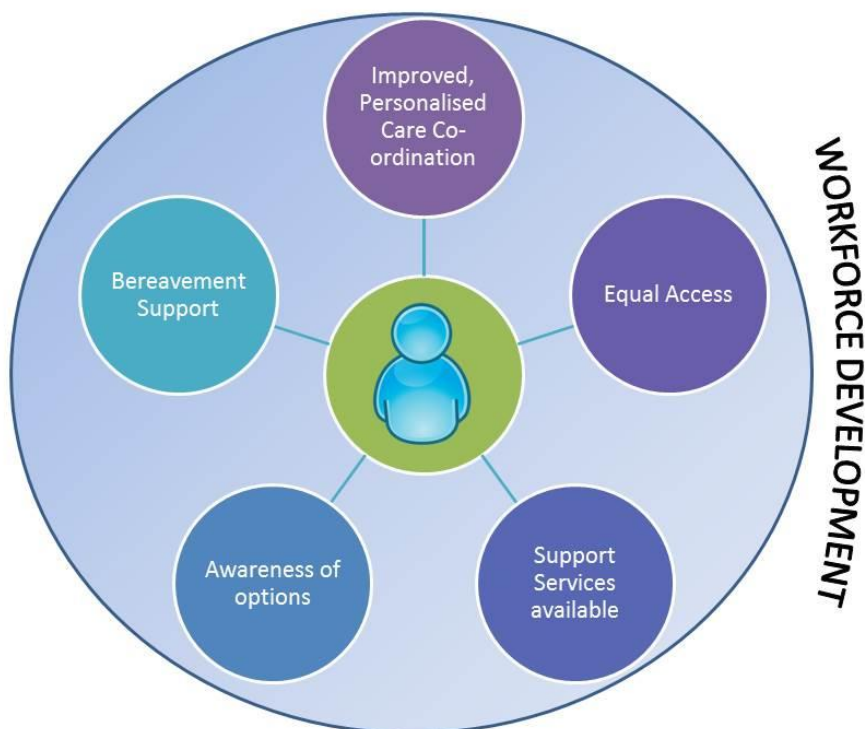
## 4. East & North Hertfordshire CCG’s Vision for Palliative and End of Life Care

When approaching the end stage of life people should have the care and support to enable them to live to the end in the best way that they can and die well in the place of their choice. To realise this vision East and North Herts CCG have adopted the eight foundations set out in the “*Ambitions for Palliative and End of Life Care: A National Framework for local action 2015-2020*” produced by the National Palliative and End of Life Care Partnership. These foundations are the pre-conditions for delivering the rapid and focused improvement that the CCG seeks.

1. Personalised Care Planning
2. Shared Records
3. Evidence and Information
4. Involving, supporting and caring for those important to the dying person
5. Education and training
6. 24/7 access
7. Co-design
8. Leadership

The national priorities for palliative and end of life care include the sharing of care records and an increase in the number of people achieving their preferred place of death. The 8 foundations have been mapped along with the national priorities for palliative end of life care and 5 priority areas have been identified, underpinned by workforce development. The mapping of the foundations and the ambitions can be found in **Appendix B**

**Figure 3 – Palliative and End of Life Care Priority Areas**



By delivering projects that improve palliative and end of life care under these priority areas, the CCG aims to achieve the following:

1. People who require palliative or end of life care are identified early, they receive the care and support they want in their preferred place of care, and are empowered to make decisions about their care
2. People approaching the end of life will have access to end of life healthcare support 24 hours a day, 7 days a week
3. Good information on all options of palliative and end of life care and support is available for patients and their families and carers
4. People die in their preferred place of death and have a positive experience of palliative and end of life care
5. People are only admitted to hospital when appropriate and at these times their stay in hospital is for the shortest time possible
6. Families and carers have access to services for bereavement support
7. All providers work collaboratively and communicate with each other to provide palliative and end of life care that is patient-centred, personalised, integrated, and patient led according to their preferences
8. Staff feel confident and capable of delivering high quality palliative and end of life care, and are given training in order to do so

The principles and outcomes for each of the priority areas are explored in the next section of this strategy.



## 5. Palliative and End of Life Care Priority Areas and Objectives

### 5.1. Improved, Personalised Care Coordination

***“All people approaching the end of life need to have their needs assessed, their wishes and preferences discussed and an agreed set of actions reflecting the choices they make about their care recorded”***

**National End of Life Strategy (2008)<sup>19</sup>**

The Leadership Alliance for the Care of Dying People in 2014 identified 5 priorities for end of life care including *“An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support”*<sup>20</sup>. Numerous reports and studies both before and after this identify personalised care planning as essential for providing quality care to those who are dying and support to families and carers.

Palliative and end of life care plans are often instigated when the person is identified as in the last year of life, however, the point of at which and way in which people are identified can vary greatly depending on the condition the person has. In 2013 a study found that *“75% of patients with cancer had been identified formally for palliative care compared with 20% of non-cancer patients”*<sup>21</sup> indicating that for some conditions, people are not being identified at all. The same study found that for all conditions, palliative care often was introduced too late and that for some people it was only in their last few weeks of life that they were identified as end of life stage.

East and North Herts CCG has seen an increase in the number of people on the end of life register, suggesting that improvements have been made in identifying people approaching the end of life. However, the post death audits received from practices for 2015/16 showed that only 45% of people who had died, had a preferred place of death recorded within their notes. Where a care plan is in place and the preferred place of death recorded, this is achieved for 79% people.

People who have been identified for palliative and end of life care and who have a personalised care plan, either for the last year of life or earlier through an advance care plan are more likely to achieve their preferred place of death.

In order to ensure that patients received quality and personalised end of life care, three components are required:

- 1) Early identification
- 2) Advance Care Plans
- 3) A system for sharing care plans across care settings in a co-ordinated way

---

<sup>19</sup> Department of Health (2008), *End of Life Care Strategy*

<sup>20</sup> Leadership Alliance for the Care of Dying People (2014), *One Chance to get it Right*

<sup>21</sup> European Journal of Palliative Care (2013), *How good is primary care at identifying patients who need palliative care?*

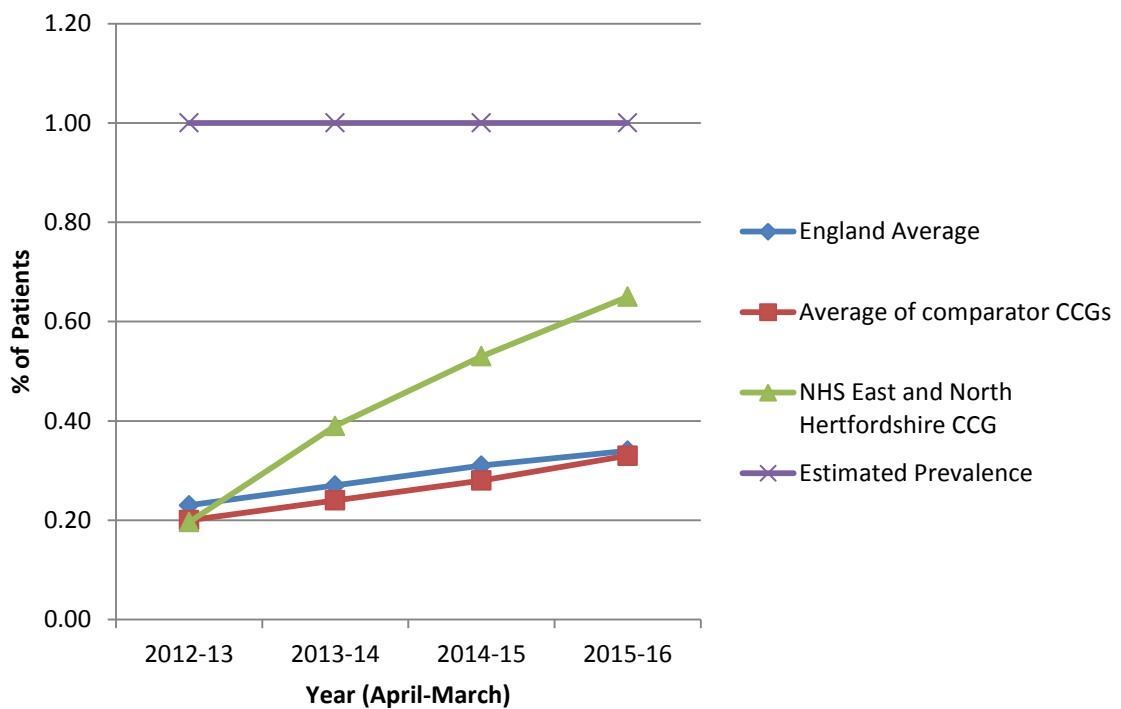
Where these three components are achieved patients and their families feel supported and good palliative and end of life care is delivered which can have a lasting impact on how families and carers grieve.

Within these three areas East and North Herts CCG have set a number of objectives which it aims to achieve through the implementation of this strategy and the subsequent action plans derived from it.

### 5.1.1 Early Identification

In order for people to receive the appropriate support and care in their last stage of life, early identification is required. The Gold Standards Framework supports GPs to identify end of life patients, assess and record their needs and plan their care appropriately. Those identified under the framework should be placed on the end of life care register. It is estimated that approximately 1%<sup>22</sup> of patients within a practice should be on the register. For East and North Herts CCG this is approximately 5878 people a year.

**Figure 4: % of patients register on an End of Life register (QoF 2015-16)<sup>23</sup>**



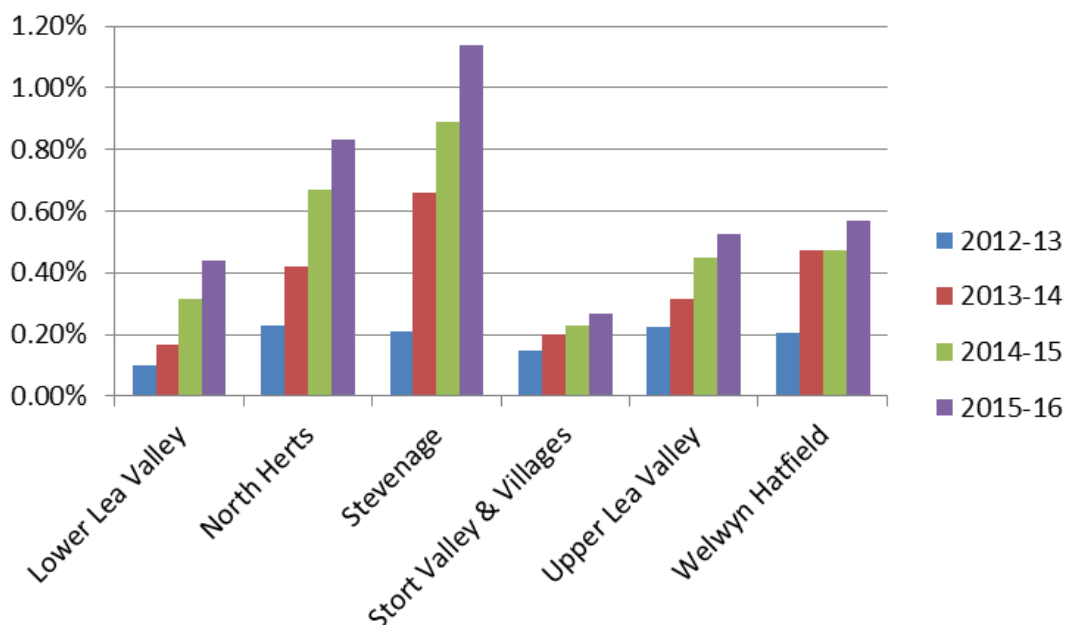
There has been a steady increase in east and north Herts in the percentage of patients on an End of Life register and not only above the England Average, but East and North Herts CCG is the best

<sup>22</sup> National End of Life Care Programme, *Find your 1%*

<sup>23</sup> NHS Digital, *Quality Outcomes Framework 2015-16*

performing CCG when compared to 10 similar CCGs<sup>24</sup>. However, when looking at the breakdown by locality, Stort Valley and Villages have a much lower percentage of patients recorded on the end of life register.

**Figure 5: % of patients register on an End of Life register by locality (QoF 2012-16)<sup>25</sup>**



**Objective 1**

Every patient ‘approaching the end of life’ must be on their General Practice’s Gold Standards Framework (GSF) Register (with the exception of those who have life-threatening acute conditions caused by sudden catastrophic events).

By identifying who is in their last year of life the appropriate conversations and care planning can take place leading to a higher quality of end of life care, fewer inappropriate hospital admissions and a good death in their preferred place of death. There are a range of tools available to support GPs to identify their patients, such as the GSF.

**Objective 2**

End of Life patients must be identified early using best practice tools such as The GSF Proactive Identification Guidance and the Supportive and Palliative Care Indicators Tool (SPICT) and the Minimum data set Mortality Risk Index – Revised (MMRI-R).

Once identified and recorded on the GSF register, the needs of these patients should be reviewed on a regular basis. Monthly GSF meetings should take place and involve GPs, district nurses and palliative care community nurse specialists. The Quality and Outcomes Framework target is for

<sup>24</sup> 10 Comparator CCGs taken from NHS England Right Care Packs

<sup>25</sup> NHS Digital, *Quality Outcomes Framework 2015-16*

practices to hold these meetings as a minimum every 3 months. However, given the number of patients that may need to be discussed and the rapid deterioration that some patients will experience, the CCG expect this to be a monthly discussion.

### **Objective 3**

Each General Practice must hold at least one meeting a month to discuss the needs of patients known to be 'approaching the end of life' and must complete a proforma to evidence this. This meeting should be in conjunction with the long term and chronic conditions meeting, in order to identify patients as they transition to 'approaching the end of life'.

## **5.1.2 Advance Care Plans**

The NICE Quality Standard for end of life care states that people approaching their end of life should be *"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."*<sup>26</sup>

Although the emphasis is on those approaching their end of life, conversations with people with long term conditions regarding their preferences and plans should begin prior to being identified as end of life through advance care plans. For some conditions e.g. dementia, the last year of life may be too late for the individual to make decisions as they lack capacity, so the responsibility may fall to a family member/carer. This added responsibility can be difficult to cope with and so having an advance care plan will help to relieve some of the pressures and stress from carers and families.

### **Objective 4**

Everyone with a long-term condition or life-limiting condition must be offered the chance to have an Advance Care Plan (ACP) and a record of this discussion and whether they decided to have an ACP must be documented in their notes.

It is not uncommon for many people who are in their last year of life to have multiple and complex conditions. The increase in conditions can lead to an increase in the number of people involved in an individual's care and so it is vital that care is co-ordinated. In order to simplify processes and streamline the transition for people across the health and social care system, there should be one advance care plan document used across East and North Herts. A number of other CCGs already have this in place including West Essex and so there is an option to adopt this in East and North Herts which would ensure those using services at the Princess Alexandra Hospital (PAH) and within the CCG have continuity and reduce duplication from having multiple plans.

### **Objective 5**

Develop and implement one ACP document to be used across all health and social care

<sup>26</sup> NICE End of Life Care for Adults, Quality Standard 13

All care plans need to be tailored to the individual and include as a minimum:

- what is important to the person
- who they wish to be involved in their care
- advance decisions to refuse treatment

It should be recognised that advance care planning is an ongoing, interactional process to support shared decision making and individual choice. It should not be a one off conversation and should be regularly revisited while the person is receiving support. It is important to emphasise that end of life care planning is not limited to the plans that are developed for a person who is in the last few days of life. Rather end of life planning should start early on and can be seen as the preparation for worsening of a person's symptoms or condition so that they can have the care they want in all circumstances.

Those involved in the person's care, should have an awareness of the support services available to help them make decisions about their future. There will be the need to have the single ACP document available in different formats e.g. Easy Read and dementia friendly, with people given a choice about how much or little they wish to complete.

#### **Objective 6**

Care plans should be personalised and those involved in the persons care should be aware of all the options available to help them make decisions about their care and end of life preferences.

### **5.1.3 Care Co-ordination Across Providers**

It is easy for people to find themselves repeating their needs multiple times and a lack of coordination of care can be frustrating for individuals, their families and their carers. There is little point in having a well-constructed and detailed care plan if it is not visible to all involved in the person's care. Statement 8 of the NICE Quality Standard for end of life care specifies that *"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."*<sup>27</sup>

The implementation of an Electronic Palliative Care Co-ordination System (EPaCCS) across east and north Herts will enable both health and social care practitioners to be aware of the latest treatment plan for those in their care. They will also be able to view the individual's wishes regarding preferred place of care and preferred place of death. A review of end of life care by the National End of Life Care Intelligence Network (NELCIN) found that *"people who have an EPaCCS record are more likely to die in their preferred place of death"*<sup>28</sup>

---

<sup>27</sup> NICE End of Life Care for Adults, Quality Standard 13

<sup>28</sup> National End of Life Care Intelligence Network, (2015). 'What We Know Now 2014'

**Objective 7**

Every patient on the GSF register must be offered the opportunity to have an Electronic Palliative Care Co-ordination System record (EPaCCs) and where they consent this must be created.

The roll out of EPaCCS across all health and social care providers in east and north Herts is being undertaken in a phased approach. Currently the EPaCCS record is generated by GPs and the community team are able to view this. IT systems are being put into place in both hospices in east and north Herts and it is expected that by June 2017, hospices will also be able to view and record on to the EPaCCS record. The next stage is for the acute trust to have access to EPaCCS records, followed by social care and the ambulance service.

Although the EPaCCS system will provide a mechanism for coordinating information electronically, the monthly GSF meetings mentioned previously will be vital in ensuring that care is co-ordinated and reviewed to continue to meet the needs and preferences of the individual.

## 5.2 Equal Access

*“People should be able to access high quality palliative and end of life care, regardless of factors like who they are, where they live or the conditions they have”*

**Equity in the provision of palliative and end of life care in the UK**

**(Marie Curie, 2015)<sup>29</sup>**

The National End of Life Strategy is clear that all people should have the same choices around their palliative and end of life care and place of death regardless of gender, race, disability or any of the other protected characteristics identified in the Equality Act 2010.

Palliative and end of life care should be based on need and take into account personal preferences and so it is important to note that unequal provision does not necessarily mean inequitable provision, so long as the differences can be justified, the person is aware of their options and happy with the care they are receiving. At the time of writing this strategy, a health needs assessment was being undertaken for east and north Herts. The outcomes of this should be used to inform the action plans that are developed to support the implementation of this strategy particularly to ensure equal access to services.

Anyone receiving palliative and end of life care has the right to understand what they are being told about their diagnosis, treatment and options. This may require reasonable adjustments to be made to ensure that they fully understand, such as the use of interpreters, information in a variety of formats or simply allowing more time during appointments for the patient.

The Care Quality Commission in May 2016 released a report which identified inequalities in end of life care<sup>30</sup>. The report identified 10 focus areas where inequalities were found regarding palliative and end of life care:

- 1) BAME Communities
- 2) People with Learning Disabilities
- 3) People with Dementia
- 4) People with non-cancer life-limiting conditions
- 5) Older People
- 6) People who are Homeless people
- 7) Lesbian, Gay, bisexual and transgender people
- 8) People with a mental health condition
- 9) Gypsies and Travellers
- 10) People in a secure or detained setting

---

<sup>29</sup> Marie Curie, *Equity in the provision of palliative and end of life care in the UK* (2015)

<sup>30</sup> Care Quality Commission, *A different ending – addressing inequalities in end of life care* (2016)

The “*Equity in the Provision of palliative care in the UK: Review of Evidence*” (2015)<sup>31</sup> report highlighted that for a number of groups of people there is a lack of literature and research into palliative and end of life care. This includes the following groups:

- 1) People who are homeless
- 2) Lesbian, Gay, Bisexual and Transgender people
- 3) People with a mental health condition
- 4) Gypsies and Travellers
- 5) People in a secure or detained setting

For the purpose of this aspect of the strategy, these areas will be grouped together under the heading “**Other hard to reach groups**” as the Care Quality Commission (CQC) report “*A different ending: End of life care review*” (2016) found common themes that affected these groups of people.

As there is more information regarding the other focus areas, these have been looked at in more depth in relation to improving equal access to palliative and end of life care in east and north Herts.

Consideration also needs to be given to how people from different cultures and with different levels of understanding are provided with bereavement support, however this will be addressed in section 5.5 – Bereavement Support.

## 5.2.1 Understanding the Focus Areas

The outcomes that from this chapter will be relevant to multiple areas and so by understanding each of the focus areas, it will be possible to identify where outcomes cross over and have a systematic approach for ensuring equal access to all services.

### 5.2.1.1 BAME Communities

A review by the Care Quality Commission in May 2016 found that people from Black, Asian and Minority Ethnic (BAME) communities may come up against barriers when accessing palliative and end of life care which include “*a lack of understanding, knowledge and information about end of life care, lack of religious and cultural sensitivity, language barriers and poor communication*”.<sup>32</sup>

A wider review of palliative and end of life care for Black, Asian and Minority Ethnic Groups in the UK<sup>33</sup> (2013) found that across a number of studies there was a common theme of low uptake of palliative and end of life care services for BAME groups. The review highlighted religious and family issues, lack of knowledge and awareness, location of services and previous experiences of the health care system as reasons for low uptake among BAME groups. Religion and culture contribute greatly

---

<sup>31</sup> Dixon et al, *Equity in the provision of palliative care in the UK: review of evidence* (2015)

<sup>32</sup> Care Quality Commission, *People from Black and minority ethnic communities* (2016)

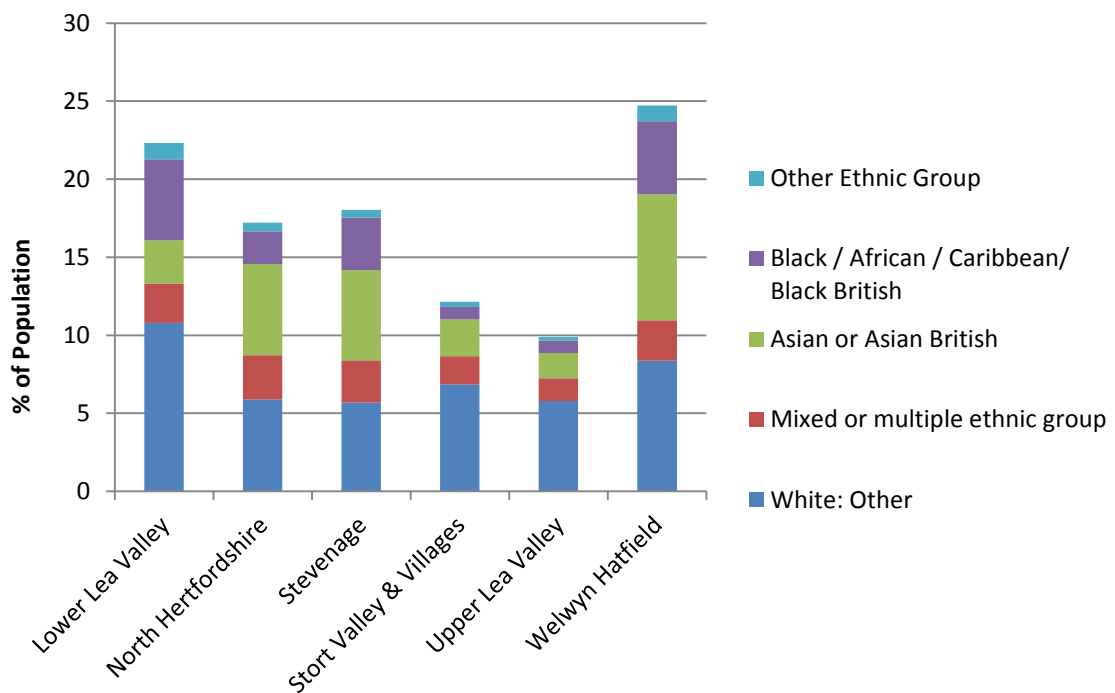
<sup>33</sup> *Palliative Care for Black, Asian and Minority Ethnic groups in the UK*, 2013



to an individual’s identity and in some cases will be of greater importance to the individual and their families/carers receiving palliative and end of life care.

The National End of Life Care Intelligence Network (NELCIN) stated that from 2012 to 2013 “on average, 7% of new people accessing palliative care were described as non-white compared to 6.2% between 2011 and 2012.”<sup>34</sup> Although the report recognised that there was an increase in uptake, it was “still lower than would be expected given that a total of 14% of the population in England is reported as being of a non-white ethnicity”<sup>35</sup> The ethnicity of the BAME population in east and north Herts is shown in Figure 6.

**Figure 6:** The percentage population of east and north Herts according to ethnicity<sup>36</sup>



Not only is the identification of BAME communities important to ensure equal access, but to support the CCG in identifying the skills needed by palliative and end of life care staff. For example, “Multiple Sclerosis (MS) disease progression is more aggressive among black Caribbean people compared to white British people. The former were also found to be more cognitively impaired and referred to feelings of extreme frustration and unresolved loss/confusion associated with their rapidly advancing disease compared to the latter.”<sup>37</sup>

Although the prevalence of MS is generally higher in White populations<sup>38</sup>, where the diagnosis is made for someone whose ethnicity is Black Caribbean, disease progression will be more aggressive.

<sup>34</sup> National End of Life Care Intelligence Network, (2015). ‘What We Know Now 2014’

<sup>35</sup> National End of Life Care Intelligence Network, (2015). ‘What We Know Now 2014’

<sup>36</sup> Herts Insight – Locality Profiles

<sup>37</sup> National End of Life Care Intelligence Network, (2015). ‘What We Know Now 2014’

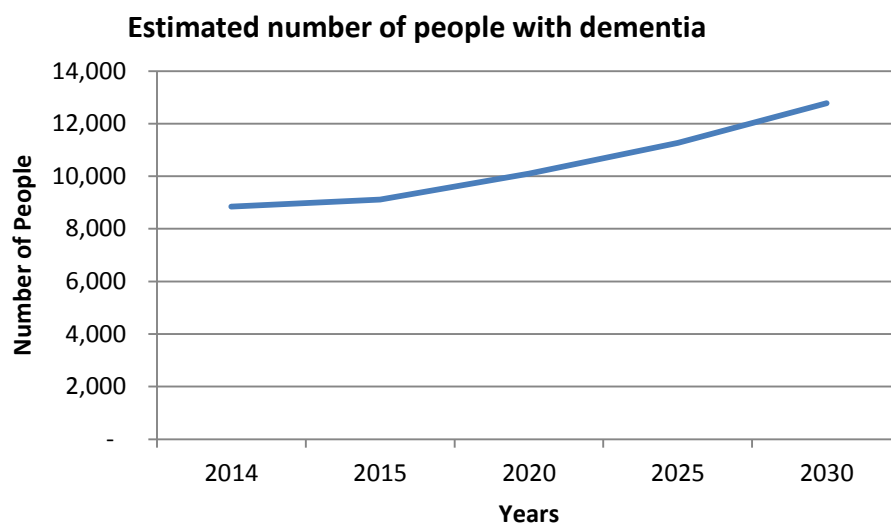
<sup>38</sup> Multiple Sclerosis Journal, *Ethnicity and prevalence of multiple sclerosis in east London*

This highlights the need for all populations, including BAME groups to have advance care planning initiated at an early stage.

### 5.2.1.2 Dementia

In east and north Herts it is estimated that by 2030 nearly 13,000 people over the age of 65 will have dementia<sup>39</sup>

**Figure 7:** Estimated population of people living with Dementia in East and North Herts CCG



Dementia is now one of the top 5 underlying causes of death and one in three people<sup>40</sup> over the age of 65 die with dementia. However, research indicates that many people with dementia are not supported to make choices in their end of life care, and they receive poorer end of life care, particularly palliative care and have less access to hospice care.

The Alzheimer’s Society and Marie Curie identified barriers to palliative and end of life care in their 2014 report *Living and Dying with Dementia in England: Barriers to care*. They found that “People with dementia are not being appropriately identified for end of life care, and that they have less access to, and receive poorer quality care than people with other terminal illnesses”<sup>41</sup>

Advance care planning has been identified as both a national and a local priority and it is particularly important that people with dementia have the opportunity to engage in end of life care discussions in the early stages of their illness, while they have the mental capacity and ability to make their wishes known and be in agreement with planned future care.

<sup>39</sup> Institute of Public Care - Projecting Older People Population Information

<sup>40</sup> Dixon et al, *Equity in the provision of palliative care in the UK: review of evidence* (2015)

<sup>41</sup> Alzheimer’s Society and Marie Curie, *Living and Dying with Dementia in England: Barriers to care* (2014)

The report also identified that *“Managing pain is more complicated for people with dementia and this means that people with dementia are more likely to experience inadequate pain management than people with some other terminal conditions”*.<sup>42</sup>

It must also be noted that data suggests people who live in more deprived areas die younger with dementia<sup>43</sup>, and that learning disabilities is a risk factor both for developing dementia, and doing so at a younger age<sup>44</sup>.

The Public Health England End of Life fingertips profiles<sup>45</sup> provide details on the place of death for people with dementia. This allows for comparisons to be made with the similar CCGs and the England average for place of death for people with these conditions.

**Figure 8:** Place of death for people with Dementia (over 65 years old)

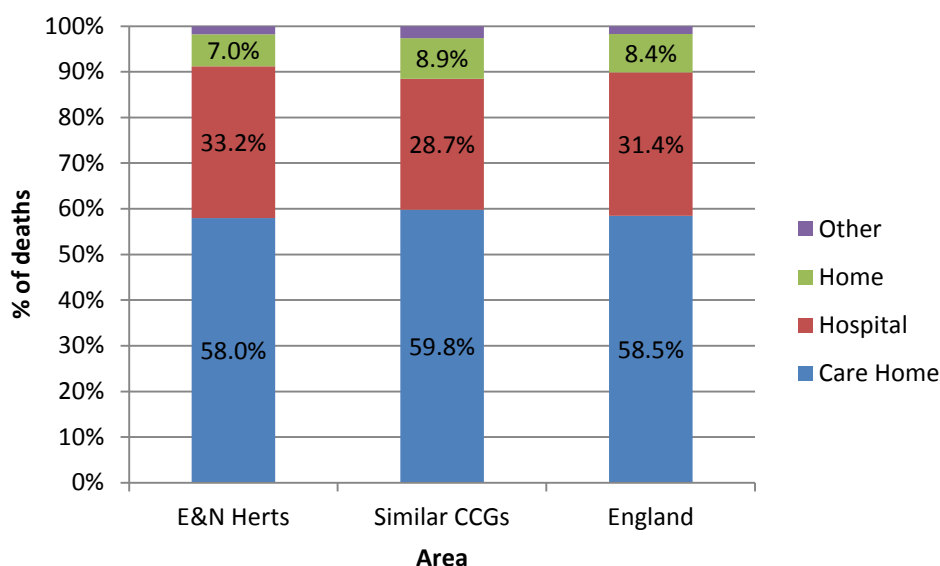


Figure 8 shows that in East and North Herts CCG more people with dementia die in hospital than when compared with the average for comparator CCGs and the average for England.

### 5.2.1.3 Learning Disabilities

The NELCIN found that *“People with learning disabilities are less likely to have access to specialist palliative care services, receive less opioid analgesia in their final illness and to have their deaths described as not being planned for, uncoordinated and poorly managed”*<sup>46</sup>

<sup>42</sup> Alzheimer’s Society and Marie Curie, *Living and Dying with Dementia in England: Barriers to care* (2014)

<sup>43</sup> Public Health England, *Data Analysis Report - Dying With Dementia* (2016)

<sup>44</sup> Help the Hospices, *Towards Excellence in Hospice Care – widening access to palliative care for people with learning disabilities*, (2012)

<sup>45</sup> Public Health England, <http://fingertips.phe.org.uk/>

<sup>46</sup> National End of Life Care Intelligence Network, (2015). ‘What We Know Now 2014’

In east and north Herts it was estimated that in 2015 there were 10,539<sup>47,48</sup> people over the age of 18 with a learning disability. Using the 1% estimate of number of deaths per year, approximately 105 people with learning disabilities will die each year<sup>49</sup>. Services need to be able to adapt to ensure they are able to meet the needs of people with learning disabilities and offer support to those receiving palliative and end of life care, their families and carers.

Communication is often cited as a barrier for people in need of palliative and end of life care. In 1993 the Department of Health suggested that at least 50% of adults with a learning disability have significant impairments with regards to communication. Communication impairments can mean it is difficult for staff to differentiate between when a person is distressed and when they are in pain. A lack of understanding of what is happening can cause the patient to become distressed, but this could be misinterpreted as pain.

Communication regarding explaining serious illness and preferences for care also needs to be considered as some people with a learning disability will apply a very literal understanding to what they are being told. For example referring to someone who has died as “gone to sleep” is unhelpful as it has a different literal meaning.

As with BAME communities, identifying those who are in need of palliative or end of life care and with a learning disability can support the CCG in ensuring suitable provisions are in place and that staff are equipped to respond to the needs of the individual. For example, research has shown people with a learning disability and a respiratory disease are more likely to die from this disease compared with the rest of the population. *“While 15.5% of the general population develop respiratory disease, only 17% of these people die of it, In comparison 19.8% of people with a learning disability develop the disease but about 50% of these die of it.”*<sup>50</sup>

### 5.2.1.4 Non-cancer Conditions

Around 70% of all deaths are due to non-cancer conditions<sup>51</sup>. However, the National Survey of Patient Activity Data for Specialist Palliative Care Services: Minimum Data Set for 2012-13 reports that although 29% of deaths are attributable to cancer, 88% of palliative care inpatients and around 75% of new referrals to hospital support and outpatient services in the UK (excluding Scotland) are for people with cancer<sup>52</sup>. This suggests people with non-cancer conditions may have difficulty or face barriers to accessing palliative care.

Furthermore, the NELCIN found that opportunities for the identification of people with non-cancer conditions are being missed and that *“only 20% of patients diagnosed with organ failure (heart, lung, liver or kidney) or dementia, either requested or were identified for palliative care before dying*

---

<sup>47</sup> Institute of Public Care - Projecting Adult Needs and Service Information

<sup>48</sup> Institute of Public Care - Projecting Older People Population Information

<sup>49</sup> National End of Life Care Programme, *Find your 1%*

<sup>50</sup> Help the Hospices, *Towards Excellence in Hospice Care – widening access to palliative care for people with learning disabilities*, (2012)

<sup>51</sup> Dixon et al, *Equity in the provision of palliative care in the UK: review of evidence* (2015)

<sup>52</sup> National Survey of Patient Activity Data for Specialist Palliative Care Services

compared to 75% of cancer patients”<sup>53</sup>. When people with non-cancer conditions do access palliative care it has been found that their experiences are less satisfactory and they are less likely to achieve their preferred place of death<sup>54</sup>. Research indicates that people with non-cancer conditions were significantly less likely to receive district nursing, care from a GP and other health and social care services, and they were also likely to report less satisfaction with the quality of this care.

The British Heart Foundation has found that *“whilst two-thirds of relatives of people who died from cancer felt that the person had enough choice over their place of death (65 per cent) this compared to about 40 per cent of non-cancer deaths”*<sup>55</sup>

Regardless of the disease, more than 50% of people in need of palliative or end of life care will experience pain, breathlessness and fatigue<sup>56</sup>. The palliative and end of life service in east and north Herts can support people to manage these three symptoms and so more should be done to ensure these people are accessing the services.

### 5.2.1.5 Older People

It has been identified that there are differences in the proportion of people from different age groups accessing palliative and end of life care. The NELCIN report *“What we know now”* found that for *“people aged 100 years plus, dying in hospital is more likely to be associated with; pneumonia or heart disease – not dementia; Having four or more contributing causes of death; Living in a deprived area; Living in an area with a lower care-home bed capacity.”*

By splitting the older population into two cohorts (over 85 year old and those under 85 years old) differences in access is clear. Those over 85 years old are much less likely to access palliative or end of life care. The National Council for Palliative Care (NCPC) found that *“people aged 85 or over account for 39% of deaths (excluding deaths from external causes) but only 16.4% of people in this age group access specialist palliative care services (NCPC, 2014), although this proportion has increased from 8.8% in 2000 (NCPC, 2014) and 11% in 2012” (2013).*<sup>57</sup>

Although there does not appear any difference in need and preference between these age groups, it is possible that the difference is due to perceptions of older people and dying and the social support network surrounding the dying person.

### 5.2.1.6 Other Hard to Reach Groups

The CQC report *“A different ending: End of life care review”* (2016) identified that there were common themes preventing people from accessing palliative and end of life care. These themes included:

---

<sup>53</sup> National End of Life Care Intelligence Network, (2015). *‘What We Know Now 2014’*

<sup>54</sup> National End of Life Care Intelligence Network, (2015). *‘What We Know Now 2014’*

<sup>55</sup> House of Commons Health Committee, *End of Life Care, Fifth Report of Session 2014-15*

<sup>56</sup> Dixon et al, *Equity in the provision of palliative care in the UK: review of evidence* (2015)

<sup>57</sup> National End of Life Care Intelligence Network, (2015). *‘What We Know Now 2014’*

- Communication
- Care co-ordination
- Awareness of services
- Understanding of care available
- Skills of staff to deal with particular conditions
- Support for staff who are not used to dealing with those at the end of life e.g. homeless hostel staff

These themes are common across all aspects of palliative and end of life care. They have been recognised throughout this strategy and it is expected that by working to address these, there will be an improvement in the access to palliative and end of life care for all hard to reach groups.

## 5.2.2 Ensuring Equal Access

### 5.2.2.1 Communication

People receiving palliative and end of life care should be made aware of the options available to them and feel informed regarding their care and treatment. Reasonable adjustments should be made to suit the needs of the individual. The NICE guidelines identify that *“For a person who is unable to effectively explain that they are in pain, for example someone with dementia or learning disabilities, use a validated behavioural pain assessment to inform their pain management.”*<sup>58</sup>

#### Objective 8

Information, support materials and appropriate tools must be promoted that are diverse and meet the needs of all people approaching the end of life, including for those people with dementia, those with Learning Disabilities from BAME communities and any of the other protected characteristics under the Equality Act (2010).

### 5.2.2.2 Understanding of Non-cancer Conditions

Between 1<sup>st</sup> April 2015 and 31<sup>st</sup> March 2016 1617 referrals were made to the 2 hospice providers within East and North Herts CCG (Garden House Hospice and Isabel Hospice). Of these referrals, 22.5% were for non-cancer illnesses. The role of the hospice, alongside other community services, for those with life-limiting conditions needs to be recognised with pathways in place for specific conditions (e.g. heart failure) to support people to access services. This will allow people to start engaging with community support prior to approaching the end of life stage. It will help to change the public perception that hospices are where people with cancer die and provide people with the

<sup>58</sup> NICE End of Life Care for Adults, Quality Standard 13

support to live well up until the very end of life. Support will also be accessible for families and carers of the dying person both pre and post death.

**Objective 9**

Increase number of people living with life-limiting non-cancer conditions accessing palliative and end of life care.

Access to services will need to be supported by those with the correct skills, training and understanding of specific conditions so that staff and volunteers that work in palliative and end of life care settings feel able and equipped to provide care to those with non-cancer conditions.

### **5.2.2.3 Commitment to Supporting People to Access Services**

It is important that all people within East and North Herts are able to access End of Life services and to enable this, services need to be able to respond to the different needs of the population. There are already a number of schemes and programmes designed to encourage organisations to adapt their processes and environments to make them dementia or learning disability friendly. Hertfordshire County Council recognises services that make provision for people with learning disabilities by awarding them a purple star which is recognised throughout the county, this is part of the councils Purple Star Strategy. The Council's Community Learning Disability Nurses (CLDNs) can provide advice and guidance and have developed a range of tools to support people with care planning and access to treatment and interventions. CLDNs working with palliative and end of life care teams are key to supporting people with a learning disability to achieve a good death.

There are similar specialist workers for conditions such as dementia and hard to reach groups and the skills of these professionals should be utilised to ensure services are suitable for all.

**Objective 10**

Organisations providing palliative and end of life care should seek to work together with professionals and experts in the relative field to ensure services are developed to deliver the highest standard of care for all (e.g. dementia).

In order to support the CCG in its commitment to provide equal access to services, monitoring of service provision is required. The demographic details of those accessing services will support the CCG in identifying where the gaps in uptake lies and support proactive work to bridge these gaps.

**Objective 11**

Undertake regular reviews of services offered and usage to ensure that hard to reach groups are being offered support.

## 5.3 Support Services Available

***“Every Person at the end of life should have access to 24/7 services as a matter of course”***

**Ambitions for Palliative and End of Life Care (2015)<sup>59</sup>**

The support people and their relatives have is key to achieving a good outcome in palliative and end of life care. Furthermore, access to good and early palliative care can improve outcomes for life expectancy as well as improve the quality of life<sup>60</sup>. Patients at or approaching the end of their life must also be helped to achieve maximal independence and social participation in accordance with their preferences.

### **Objective 12**

Information on the range of support services available for people requiring palliative care, those approaching the end of their life and their families/carers should be provided and signposted to key services. This should include services provided by the voluntary sector.

The national bereaved people’s survey VOICES found that 76% of people rated the quality of care they received as excellent when it was provided by hospices however, when care was provided by urgent care services this rating became 26%<sup>61</sup>. This reflects an acknowledged issue that too often care in the community is not provided in a timely manner when people are in need or have a crisis, and this leads to avoidable emergency department attendances and hospital admissions.

### **Objective 13**

All people in need of palliative and end of life care should have access to support 7 days a week to address their medical, nursing and social needs and preferences, and to carer support services.

The *‘Ambitions for Palliative Care’* highlighted the need for services to be available 24/7. Currently east and north Herts have night-sitting respite services for carers provided by Marie Curie for people who require this. Isabel Hospice also provides a night service of nursing support assistants and offer registered nurses for Hospice at Home overnight when required. They work with Marie Curie to pan the service allocation. There are out-of-hours advice lines for professionals, patients and their families/carers to access advice from specialist palliative care teams. East and North Herts CCG will be further enhancing out-of-hours service provision by commissioning an Integrated Urgent Care service to provide palliative and end of life advice and signposting.

---

<sup>59</sup> National Palliative and End of Life Care Partnership *Ambitions for palliative and End of Life Care* (2015)

<sup>60</sup> National Palliative and End of Life Care Partnership *Ambitions for palliative and End of Life Care* (2015)

<sup>61</sup> Office for National Statistics, *National Survey of Bereaved People, (VOICES)*, (2015)



**Objective 14**

All patients and their families/carers must be informed of the function of the Integrated Urgent Care service to help them in times of needing urgent support (including out-of-hours), concerning how to manage a person's clinical condition.

### 5.3.1 Meeting and Physical Psychological Need

Furthermore, NICE Quality Standards for End of Life Care state that people approaching the end of life should 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<sup>62</sup>. Patients and their families/carers should be informed and have a clear understanding of how to access medicines and equipment as part of a rapid response to changing needs. To meet these needs East and North Herts CCG commission 100 hour pharmacies which provide out-of-hours access to palliative 'just-in-case' medications.

**Objective 15**

Palliative care medications must be available out-of-hours at a defined list of pharmacies each locality and patients and their families/carers must be informed of how to access these.

Anecdotal evidence from both professionals and the family/carers of people who have received palliative and end of life care often identifies frustration regarding lack of access to specific equipment. Equipment can support the individual to remain in their preferred place of care which can often also be their preferred place of death.

**Objective 16**

All equipment orders for patients in the last few days of life should be processed via a fast-track pathway.

### 5.3.2 Rehabilitative Palliative Care

The '*Ambitions for Palliative Care*' highlighted that people with life-limiting illnesses should be empowered so they can maximise their independence and social participation for as long possible and as long as they wish to do so. This is what rehabilitative palliative care aims to achieve with a focus on integrating "rehabilitation, enablement, self-management and self-care into the holistic model of palliative care"<sup>63</sup>. It is important for people to be able to discuss their expectations and to form realistic goals so that they can be supported to achieve them.

**Objective 17**

Every patient 'approaching the end of life' must be offered information about rehabilitative palliative care and the opportunity to engage in these services should they wish to do so.

<sup>62</sup> NICE End of Life Care for Adults, Quality Standard 13

<sup>63</sup> Hospice UK – *What is Rehabilitative Palliative Care*

## 5.4 Awareness of Options

Death and dying are not easy conversations to have and the reluctance to talk about these issues increases the likelihood of people's preferences not being discussed or met. It also increases the likelihood of people not being aware of all the options available to them when it comes to their care.

In a survey by East and North Herts CCG in March 2017 asked what considerations the CCG should take into account when deciding which treatments and services to fund. The answers received rate quality of life over longevity as demonstrated in some of the response received below:

- *"Post 75 consider quality of life in terms of comfort i.e. freedom from pain or distress – rather than longevity of life( I am 81)"*
- *"Prolonging lives already of poor quality seems cruel as well as wasteful especially if the individual has requested no extreme measures"*
- *"Whether the patient will get lasting benefit from the treatment; whether the patient wants to live"*
- *"Limit the use of expensive treatments which extend life marginally but do not add significantly to the quality of life"*

The NELCIN found that *"An international comparative study which explored people's priorities for treatment, care and information if faced with serious illness, has found most people would prioritise improving the quality of life for the time they have left. Common across all countries was the public's low priority for extending life regardless of health status".<sup>64</sup>*

Quality of life over extending life is a personal decision which is why conversations with individuals need to occur as early as possible. Whether the conversation is with a family member or friend, or with one of the individuals involved in a person's care, personalised care cannot take place without honest and informed discussions.

### **Objective 18**

Anyone identified as approaching the end of life, and their families/carers should be able to have face-to-face honest, sensitive and informed discussions about dying, death and bereavement. This should be with member(s) of their care team and should allow the individual and their family/carers to take part in shared decision-making about their care, with the outcomes recorded, shared and regularly reviewed.

The national VOICES survey found that *"more than 5 out of 6 bereaved people (86%) understood the information provided by health care professionals, but 1 out of 6 (16%) said they did not have time to ask questions to health care professionals".<sup>65</sup>* In order to have an informed conversation with a

<sup>64</sup> National End of Life Care Intelligence Network, (2015). 'What We Know Now 2014'

<sup>65</sup> Office for National Statistics, *National Survey of Bereaved People, (VOICES)*, (2015)

person and their families and carers about their preferences and wishes, time needs to be given to allow information to be processed and it should not be a one off event. Dealing with death and dying can be difficult to process mentally and so conversations need to be revisited with information and resources readily available for individuals to digest in their own time. There are a number of leaflets and websites that provide useful and reliable information covering a wide range of issues that affect people who are dying and their families and carers. However, there is no central location where this information is held. Having a single point to direct people to where they can access reliable and up to date information on a number of topics from “making a will” to “what happens to my pets when I die” will support people to develop a clear understanding of the decisions and choices they will need to make regarding their palliative and end of life care.

#### **Objective 19**

Have a single information point for palliative and end of life care in east and north Herts that aims to answer questions people have and provide an insight into the experience of others that have been in a similar situation.

The experience of others can be a great asset when it comes to supporting people to make informed decisions about their future. People’s expectations of palliative and end of life care didn’t always match with reality. The NECLIN found that:

- *“expectations of a more medical experience in care homes were proved wrong, while more personal and environmental factors were stronger than expected (although from a low base)*
- *in the absence of experience, peoples’ expectations of hospital’s ability to deliver the things that matter to them (with the important exception of pain relief) – the calm, dignified, loving death that people say they would like – are extremely low. These are confirmed with experience*
- *those who had experience of loved ones dying at home were slightly less positive about it than those who had not had that experience; in particular mentioning that dying at home creates complications and difficult experiences that no one anticipates*
- *there were very different perceptions about hospice care between those with and without previous experience of loved ones receiving hospice care, with some aspects more positive (calm, peaceful atmosphere surrounded by loved ones), and some more negative (availability of medical and professional support), than expected”<sup>66</sup>*

Quality of life and a peaceful, pain-free death are often cited as the preferences of those receiving palliative and end of life care and it the responsibility of those supporting individuals to develop their care plans to manage the expectations and provide a realistic approach to what can be achieved.

#### **Objective 20**

Everyone and their families/carers should be supported to make decisions about their priorities for the remainder of their life, as early as possible, including managing expectations.

---

<sup>66</sup> National End of Life Care Intelligence Network, (2015). ‘What We Know Now 2014’

Conversations about death and dying can be made easier by increasing public awareness and there are a number of public campaigns throughout the year to support providers to do this.

### **Objective 21**

Organisations providing palliative and end of life services will use every opportunity to promote their service supported by the CCG e.g. Dying Matters week, Children's Grief Awareness week.

Raising awareness and promoting palliative and end of life care needs to be part of all aspects of health and social care and not the sole responsibility of those providing the services. Public Health England has developed a toolkit to support the implementation of Compassionate Communities Charter. A compassionate community is one that:

- *“Has local health policies that recognise compassion as an ethical imperative*
- *Meets the special needs of its aged, those living with life threatening illnesses, and those living with loss*
- *Has a strong commitment to social and cultural differences*
- *Involves grief and palliative care services in local government policy and planning*
- *Offers its inhabitants access to wider variety of supportive experiences, interactions and communication*
- *Promotes and celebrates reconciliation with indigenous peoples and memory of other important community losses*
- *Provides easy access to grief and palliative care services”<sup>67</sup>*

Implementing the Compassionate Communities Charter alongside the Dying Well Charter *“encourages communities to support people and their families who are dying or living with loss. It aims to enable all of us to live well within our communities to the very end of our lives.”<sup>68</sup>* Other expected outcomes include:

- *“Death, dying and bereavement would cease to be taboo subjects and would become more normalised within society*
- *People's expectations of death and dying would change, as would how death is managed*
- *Palliative care would re-orientate, supporting health and social care staff to work with the community in providing care to those at the end of life, and their loved ones”<sup>69</sup>*

One of the biggest barriers to people receiving palliative and end of life care is having the conversation about death and dying. Only by encouraging these conversations and changing perceptions to death and dying will the wishes and preferences of the individual be met.

There is an increasing concern nationally regarding social-isolation in older generations and consideration needs to be given to those who may not have family or carers to support them.

---

<sup>67</sup> Murray Hall Community Trust, *An Overview of Compassionate Communities in England* (2013)

<sup>68</sup> Murray Hall Community Trust, *An Overview of Compassionate Communities in England* (2013)

<sup>69</sup> Murray Hall Community Trust, *An Overview of Compassionate Communities in England* (2013)

A review of *“Equity in the provision of palliative care in the UK”* found that *“having a carer was the single most important factor associated with home death, whereas living alone or being unmarried increased the likelihood of a hospital death.”*<sup>70</sup> Social isolation can also be an issue for those with a long term health condition such as motor neurone disease or dementia. Implementing the Public Health toolkit will not only support people to live well in the community until the very end of life, but it will also provide those dealing with death and social isolation with support to achieve their preferred place of care and preferred place of death.

**Objective 22**

Implement the Public Health End of Life toolkit and promote palliative and end of life care, exploring the use and benefits of the Compassionate Communities Charter.

---

<sup>70</sup> Dixon et al, *Equity in the provision of palliative care in the UK: review of evidence* (2015)

## 5.5 Bereavement Support

*“Good end of life care does not stop at the point of death. If a person’s wishes are not respected, the bereaved not well supported and the impact of the death not acknowledged, there can be long lasting impact on how people grieve, their health and their memories of the person who has died.”*

National End of Life Care Intelligence Network (2014)<sup>71</sup>

It is imperative to recognise that good end of life care does not stop when the individual dies. Families and carers will need support as they go through the process of bereavement and grieving<sup>72</sup>.

### 5.5.1 What do We Mean by Grief and Bereavement?

Bereavement is the time we spend adjusting to the death of a loved one, and grief is the emotional process that occurs following that loss. Grief involves a range of emotions, and although different stages of grief have been identified (Denial and isolation, Anger, Bargaining, Depression and Acceptance) people do not necessarily go through all these stages or experience them in a particular order<sup>73</sup>.

The practical aspects of bereavement must also be addressed and undue distress can be caused by delay in death certification or referral of a death for coroner review, which prevents families, friends and carers from planning funerals. With regard to this the specific cultural needs of people have to be taken into account concerning timely burials etc. In addition initiatives like the national *Tell Us Once* service<sup>74</sup>, which gains consent to notify multiple government agencies about someone’s death, can help facilitate information sharing without increasing the emotional burden placed on a deceased’s loved ones by having to provide similar information repeatedly.

#### **Objective 23**

Promote the timely verification and certification of death or referral to the coroner.

#### **Objective 24**

End of Life Care providers are aware of and communicate the availability of immediate and longer-term bereavement support services, including emotional and spiritual support, to family/friends/carers should they require it. This support should be in a respectful and culturally and spiritually sensitive manner, appropriate to their needs and preferences.

<sup>71</sup> National End of Life Care Intelligence Network, (2015). ‘*What We Know Now 2014*’

<sup>72</sup> National End of Life Care Intelligence Network, (2015). ‘*What We Know Now 2014*’

<sup>73</sup> Cancer Research UK, *Coping with Grief* (2016)

<sup>74</sup> Hertfordshire County Council, *Tell Us Once Service*

## 5.5.2 Complicated Grief

Furthermore, it has to be appreciated that while grief is a normal process, at times it can become overwhelming and people can feel ‘stuck’ in grief – this is known as complicated grief, and these people will need specialist help with their bereavement<sup>75</sup>. Bereavement is also a trigger factor associated with increased risk of persistent physical and mental health problems, and it is important that people receive timely and appropriate support<sup>75</sup>.

### Objective 25

Health and social care staff are able to identify people with bereavement risk factors and complicated grief, and to signpost to appropriate support, including access to counselling as appropriate.

## 5.5.3 Bereaved Children

It must be remembered that grieving can be especially difficult for children and that they may need to make use of specialist children’s bereavement services<sup>76</sup>.

### Objective 26

Access to children’s bereavement support services must be offered to children following the death of a parent, carer or sibling.

## 5.5.4 Ensuring High Quality Bereavement Support

The national VOICES survey is conducted by the Office for National Statistics and collects information on bereaved peoples’ views on the quality of care provided to a friend or relative in the last three months of life, for England. It is equally important to assess the experiences of bereaved people with bereavement services, and to do so at a local level to enable continual improvements and development of services as needs emerge.

### Objective 27

Conduct an annual bereaved relative’s survey including feedback on bereavement and mortuary services

---

<sup>75</sup> National End of Life Care Intelligence Network, (2015). ‘*What We Know Now 2014*’

<sup>76</sup> National End of Life Care Intelligence Network, (2015). ‘*What We Know Now 2014*’

## 5.6 Workforce Development

***“Caring for and supporting people approaching the end of their life is considered among the most challenging work any health and social care worker faces. It can also be the most rewarding - if they have the right knowledge, skills and attitude to provide the care and support they need.”***

**National End of Life Care Intelligence Network<sup>77</sup>**

A motivated, appropriately skilled, compassionate workforce is integral to delivering end of life care that meets the needs of patients and their relatives. For this to be achieved the following issues need to be considered:

### 5.6.1 Competency of Workforce

Workforce development ensures that health and social care staff are competent and feel confident when providing end-of-life care, and is also the driving force behind service improvements and shifting behavioural change in end of life care<sup>78</sup>. However, the ‘One Chance to Get It Right’ report identified that some staff do not have the appropriate knowledge and skills to deliver high-quality end-of-life care<sup>2</sup>. In addition, the national audit of acute hospitals found that training in care of the dying was mandated for doctors in 19% of acute hospital trusts and for nurses in 28%<sup>79</sup>.

National Common Core Competences and Principles for End of Life Care were developed by ‘Skills for Care and Skills for Health’ in partnership with the Department of Health and the NHS End of Life Care Programme, in addition to core principles relating to end of life care. The purpose of this was to support workforce development, training and education across the health and social care system.

The Common Core Competences (underpinned by values and knowledge)<sup>80</sup> are:

- Communication skills
- Assessment and care planning
- Symptom management, comfort and well being
- Advance care planning

The Hertfordshire End of Life Education Group has developed a Palliative and End of Life Care Education Programme which seeks to train all staff involved in providing palliative and end of life care.

---

<sup>77</sup> National End of Life Care Intelligence Network, ‘What We Know Now 2014’, (2015).

<sup>78</sup> Department of Health, *End of Life Care Strategy*, (2008),

<sup>79</sup> Leadership Alliance for the Care of Dying People, *One Chance to Get it Right*, (2014)

<sup>80</sup> Skills for Care and Skills for Health, *Common Core Principles and Competencies for Social Care and Health Workers Working with Adults at the End of Life*, (2014 )



**Objective 28**

To champion and support training and education initiatives to improve the skills of the workforce in the effective and compassionate delivery of palliative and end of life care including symptom management, advanced communication skills and referral to other services.

**Objective 29**

Palliative and end of life care must be integral to training curricula for all staff groups. Organisations that employ people who work in palliative and end of life care must identify, communicate and publicise all available training.

The advance of digital technology enables training to occur via virtual platforms such as online learning modules. Health Education England has developed an e-learning programme on end of life care that has interactive sessions called End of Life Care for All (e-ELCA).

**Objective 30**

Promote the use of digital technology in palliative and end of life training that is provided for health and social care staff, including the use of e-ELCA, apps etc.

## 5.6.2 Working Environments

The *“Ambitions for Palliative Care”* Report acknowledged that *“to give care day in and day out requires organisational and professional environments in all settings that ensure psychological safety, support and resilience.”*<sup>81</sup> Providing end-of-life care is emotionally and physically demanding and employers must support their workforce so that resilience is fostered, as well as being aware of the effects of burnout and how to prevent it.

**Objective 31**

Ensure that all health and social care staff are trained in delivering high quality end of life care and have access to clinical supervision, where appropriate to support them.

**Objective 32**

Promote psychological support for health and social care staff working in environments where death happens frequently.

---

<sup>81</sup> National Palliative and End of Life Care Partnership, *Ambitions for palliative and End of Life Care*, (2015)

### 5.6.3 Ageing Workforce

There is widespread acknowledgement that the palliative and end of life workforce is ageing and this poses a risk to providing end-of-life-care. The NCPC's Specialist Palliative Care Workforce Survey found that in 2013 approximately 44% of the Specialist Palliative Care (SPC) nursing workforce was over the age of 50, with the proportion between each group varying between approximately 41% for bands 5/6 and 53% for band 8<sup>82</sup>. The survey also found that the percentage of all medical staff over the age of 50 was 21.5% in 2013. The ageing workforce comes amid concerns over the potential impact that changes in people's place of care may lead to an increasing demand on the nursing workforce.

To address the challenges facing the medical workforce as a whole the government has introduced various schemes including new roles such as Nursing Associates and Physician's Assistants; this role will serve to bridge the gap between health care assistants and nurses.

#### **Objective 33**

Review innovative approaches (such as the use of Physician's Assistants and Nursing Associates) to ensuring the workforce is comprised of sufficient numbers of staff and skill-mix.

### 5.6.4 Volunteers

Volunteers are a significant, highly-valued resource who contribute to enhancing end of life care for people 'approaching the end of life'. Providers of palliative and end of life care hospices within east and north Herts benefit from a group of dedicated volunteers who are able to support patients and their families and enable them to maximize opportunities for social participation.

#### **Outcome 34**

Promote the role of volunteers and volunteering opportunities within palliative and end of life care.

---

<sup>82</sup> National Council for Palliative Care, *Specialist Palliative Care Workforce Survey* (2013)

## 6. Implementing the Strategy and Next steps

East and North Herts CCG are committed to improving the quality of experience for those in need of palliative or end of life care and supporting their carers and families.

Following the agreement of this strategy, further work will be taken to develop an implementation plan with stakeholders in order to achieve the objectives identified throughout the strategy. The complete list of all objectives can be found in **Appendix C**.

Given the spectrum of conditions for which palliative and end of life care is relevant, it is recognised that this strategy will need to link into other programmes across the CCG e.g. Stroke, respiratory and dementia.

### 6.1 How Will Success be Measured?

The implementation plan will have outcome measures which will be used to monitor and evaluate the impact of the delivery of the strategy against the identified objectives.

Key outcomes include:

- An increase in the percentage of people achieving their preferred place of care and preferred place of death
- All those identified as in need of palliative and end of life care will be offered the opportunity to have an advance care plan
- An operational EPaCCS system across all providers
- A single advance care plan document available to be used by all stakeholders
- A reduction in unnecessary hospital admissions for those receiving end of life care

The success against the achievement of these outcomes will be regularly monitored, evaluated and reported using national and local quantitative and qualitative information and data. Updates will be provided through the CCG's stakeholder forum.

## Appendix A

### Palliative and End of Life Care Provision in east and north Herts

The information here is liable to change but offers an overview of current services in E & N Herts.

#### GPs

- There are 60 GP practices in east and north Herts
- The GP is often the lead clinician in the care of a person in need of palliative care or approaching the end of life while they remain in the community
- Care needs are very individual to the specific requirements of that patient, their condition and their social situation
- These needs of the individual are discussed every 4-6 weeks at GSF meetings
- GPs will have the biggest impact in supporting people to achieve their preferred place of care and death as early identification and referral into support services is key

#### Community Pharmacy

- Community pharmacy provides advice on prescription writing and medications, and access to specialist palliative care medications
- A Local Enhanced Service (LES) for Palliative Care – Stock Holding and Provision of Specialist Drugs is provided and funded for pharmacies across the CCG
- This means people are able to get access to specialist palliative care medications out-of-hours

#### Community Nurses

**Provider: Hertfordshire Community NHS Trust**

- The community nursing service provides skilled nursing care at home
- Community nurses are based locally and have a good knowledge of local services and resources
- Community nurses are often with people and their families during the dying phase
- They take a pivotal role in the planning and co-ordination of palliative and end of life care and often provide supportive visit

#### Hospices

**Provider: Garden House Hospice and Isabel Hospice**

- There are 2 local hospices that provide specialist care to people with life-limiting conditions to enable them to have the best quality of life possible
- The hospices also support relatives/carers throughout the different stages of a person's illness
- The hospices provide in-patient, hospice and home and day hospice services as well as physiotherapy, spiritual support and counselling
- They also provide CNS advisory service to patients, carers and GPs
- **St Clare Hospice** in East Herts border area, including Bishop's Stortford and Sawbridgeworth also provides services to some ENHCCG residents

## Appendix A

### Specialist Palliative Care

**Provider: East and North Herts Hospital Trust, Hertfordshire Community Trust, Isabel Hospice**

- Specialist palliative care (SPC) teams are made up of doctors, nurses (known as Macmillan nurses in hospitals), pharmacists, occupational therapists, physiotherapists, dieticians and other allied health workers
- SPC services provide advice and support for patients and carers with complex problems
- This may include emotional support, advice on pain and symptom control, and help to deal with spiritual questions
- They can also refer to other services to make sure palliative care needs are met.
- Care can be delivered at home, as an outpatient, in hospital or at a local hospice
- Provide an educational role to the workforce

### Hospitals

**Provider: East and North Herts Hospital Trust**

- Lister Hospital employs a hospital based specialist palliative care (SPC) service
- The team work closely with the local hospice and community palliative care service to ensure that patients experience a seamless service as they move between the hospital, hospice and home setting
- **Princess Alexandra Hospital and Barnet Hospital** are both on the borders of the CCG and provide services to ENHCCG residents

### Palliative Care Advice Line

- Isabel Hospice and Garden House Hospice both provide an out-of-hours palliative care telephone advice line for patients and carers, with direct access telephone advice available for healthcare professionals
- It gives direct access to nurses with experience in specialist palliative care who can provide advice and support or signpost you to other appropriate agencies
- The CCG has recently commissioned further palliative care advice through the 111 service

### Other Services

- The CCG commissions Marie Curie to provide a Hospice at Home night-sitting service to provide care to patients in their normal place of residence overnight to give respite to relatives/carers
- The charity Cruse offers bereavement support to relatives/carers and helps signpost them to services
- Carers in Herts and Crossroads Care both provide support to those caring for someone with a life-limiting illness
- Hertfordshire County Council in partnership with Macmillan cancer support deliver specialist benefits advice for those with cancer. The focus is on early intervention at specific pathway points to enable income maximisation.
- Specialist services are available to support people with specific conditions e.g. Admiral nurses for people with dementia and Community learning disability nurses.

## Appendix B

### Mapping the CCG Priorities to the Ambitions for Palliative Care

#### Improved, personalised care coordination

- Ambition 1: Each person is seen as an individual
- Ambition 2: Each person gets fair access to care
- Ambition 3: Maximising comfort and wellbeing
- Ambition 4: Care is coordinated

#### Equal Access

- Ambition 1: Each person is seen as an individual
- Ambition 2: Each person gets fair access to care
- Ambition 3: Maximising comfort and wellbeing
- Ambition 5: All staff are prepared to care

#### Support Services Available

- Ambition 1: Each person is seen as an individual
- Ambition 2: Each person gets fair access to care
- Ambition 3: Maximising comfort and wellbeing
- Ambition 4: Care is coordinated
- Ambition 6: Each community is prepared to help

#### Awareness of Options

- Ambition 1: Each person is seen as an individual
- Ambition 2: Each person gets fair access to care
- Ambition 3: Maximising comfort and wellbeing
- Ambition 6: Each community is prepared to help

#### Bereavement Support

- Ambition 1: Each person is seen as an individual
- Ambition 2: Each person gets fair access to care
- Ambition 3: Maximising comfort and wellbeing
- Ambition 5: All staff are prepared to care
- Ambition 6: Each community is prepared to help

#### Workforce Development

- Ambition 4: Care is coordinated
- Ambition 5: All staff are prepared to care
- Ambition 6: Each community is prepared to help

## Appendix C

### Overview of Objectives by Priority Area

<b>Improved, Personalised Care Coordination</b>
<ul style="list-style-type: none"><li>• Every patient 'approaching the end of life' must be on their General Practice's Gold Standards Framework (GSF) Register (with the exception of those who have life-threatening acute conditions caused by sudden catastrophic events).</li></ul>
<ul style="list-style-type: none"><li>• EoL patients must be identified early using best practice tools such as The GSF Prognostic Indicators of Decline and the Supportive and Palliative Care Indicators Tool (SPICT) and the Minimum data set Mortality Risk Index – Revised (MMRI-R).</li></ul>
<ul style="list-style-type: none"><li>• Each General Practice must hold at least one meeting a month to discuss the needs of patients known to be 'approaching the end of life' and must complete a proforma to evidence this. This meeting should be in conjunction with the long term and chronic conditions meeting, in order to identify patients as they transition to 'approaching the end of life'.</li></ul>
<ul style="list-style-type: none"><li>• Everyone with a long-term condition or life-limiting condition must be offered the chance to have an Advance Care Plan (ACP) and a record of this discussion and whether they decided to have an ACP must be documented in their notes.</li></ul>
<ul style="list-style-type: none"><li>• There should be only one ACP used across all health and social care organisations.</li></ul>
<ul style="list-style-type: none"><li>• Care plans should be personalised and those involved in the persons care should be aware of all the options available to help them make decisions about their care and end of life preferences.</li></ul>
<ul style="list-style-type: none"><li>• Every patient on the GSF register must be offered the opportunity to have an Electronic Palliative Care Co-ordination System record (EPaCCs) and where they consent this must be created.</li></ul>
<b>Equal Access</b>
<ul style="list-style-type: none"><li>• Information, support materials and appropriate tools must be promoted that are diverse and meet the needs of all people approaching the end of life, including for those people with dementia, those with Learning Disabilities from BAME communities and any of the other protected characteristics under the Equality Act (2010).</li></ul>
<ul style="list-style-type: none"><li>• Increase number of people living with life-limiting non-cancer conditions accessing palliative and end of life care.</li></ul>
<ul style="list-style-type: none"><li>• Organisations providing Palliative and End of Life Care should seek to work together with professionals and experts in the relative field to ensure services are developed to deliver the highest standard of care for all (e.g. dementia).</li></ul>
<ul style="list-style-type: none"><li>• Undertake regular reviews of services offered and usage to ensure that hard to reach groups are being offered support.</li></ul>

## Appendix C

### Support Services Available

- Information on the range of support services available for people requiring palliative care, those approaching the end of their life and their families/carers should be provided and signposted to key services. This should include services provided by the voluntary sector.
- All people in need of palliative and end of life care should have access to support 7 days a week to address their medical, nursing and social needs and preferences, and to carer support services.
- All patients and their families/carers must be informed of the function of the 111 service to help them in times of crisis (including out-of-hours), concerning how to manage a person's clinical condition.
- Palliative care medications must be available out-of-hours at a defined list of pharmacies each locality and patients and their families/carers must be informed of how to access these.
- All equipment orders for end-of-life patients should be processed via a fast-track pathway.
- Every patient 'approaching the end of life' must be offered information about rehabilitative palliative care and the opportunity to engage in these services should they wish to do so.

### Awareness of options

- Anyone identified as approaching the end of life, and their families/carers should be able to have face-to-face honest, sensitive and informed discussions about dying, death and bereavement. This should be with member(s) of their care team and should allow the individual and their family/carers to take part in shared decision-making about their care, with the outcomes recorded, shared and regularly reviewed.
- Have a single information point for palliative and end of life care in east and north Herts that aims to answer questions people have and provide an insight into the experience of others that have been in a similar situation.
- Everyone and their families/carers should be supported to make decisions about their priorities for the remainder of their life, as early as possible, including managing expectations.
- Organisations providing Palliative and end of life services will use every opportunity to promote their service supported by the CCG e.g. Dying Matters week, Children's Grief Awareness week.
- Implement the Public Health End of Life toolkit and promote palliative and end of life care, exploring the use and benefits of the Compassionate Communities Charter.



## Appendix C

<b>Bereavement Support</b>
<ul style="list-style-type: none"><li>• Promote the timely verification and certification of death or referral to the coroner.</li></ul>
<ul style="list-style-type: none"><li>• End of Life Care providers are aware of and communicate the availability of immediate and longer-term bereavement support services, including emotional and spiritual support, to family/friends/carers should they require it. This support should be in a respectful and culturally and spiritually sensitive manner, appropriate to their needs and preferences.</li></ul>
<ul style="list-style-type: none"><li>• Health and social care staff are able to identify people with bereavement risk factors and complicated grief, and to signpost to appropriate support, including access to counselling as appropriate.</li></ul>
<ul style="list-style-type: none"><li>• Access to children’s bereavement support services must be offered to children following the death of a parent, carer or sibling.</li></ul>
<ul style="list-style-type: none"><li>• Conduct an annual bereaved relative’s survey including feedback on bereavement and mortuary services.</li></ul>
<b>Workforce Development</b>
<ul style="list-style-type: none"><li>• To champion and support training and education initiatives to improve the skills of the workforce in the effective and compassionate delivery of palliative and end of life care including symptom management, advanced communication skills and referral to other services.</li></ul>
<ul style="list-style-type: none"><li>• Palliative and end of life care must be integral to training curricula for all staff groups and the CCG and ALL organisations that employ people who work in palliative and end of life care must identify, communicate and publicise all available training.</li></ul>
<ul style="list-style-type: none"><li>• Promote the use of digital technology in palliative and end of life training that is provided for health and social care staff, including the use of e-ELCA, apps etc.</li></ul>
<ul style="list-style-type: none"><li>• Ensure that health and social care staff are trained in delivering high quality end of life care and have access to clinical supervision, where appropriate to support them.</li></ul>
<ul style="list-style-type: none"><li>• Promote psychological support for health and social care staff working in environments where death happens frequently.</li></ul>
<ul style="list-style-type: none"><li>• Review innovative approaches (such as the use of Physician’s Assistants and Nursing Associates) to ensuring the workforce is comprised of sufficient numbers of staff and skill-mix.</li></ul>
<ul style="list-style-type: none"><li>• Promote the role of volunteers and volunteering opportunities within palliative and end of life care</li></ul>

## References

- <sup>1,10,14</sup> Whole Systems Partnership, National End of Life Care Programme: improving end of life care (2013). *Improving end of life care through early recognition of need*
- <sup>2,7,11,28,34,35,37,46,53,54,57,64,66,71,72,75,76,77</sup>
- National End of Life Care Intelligence Network, Public Health England (2015). 'What We Know Now 2014'
- <sup>3,22,49</sup> Dyingmatters.org. (2017). *Find Your 1%: supporting GPs in delivering quality end of life care | Dying Matters*. [online] Available at: <http://www.dyingmatters.org/gp> [Accessed 07.01.2017].
- <sup>4,31,40,51,56,70</sup> Dixon et al, *Equity in the provision of palliative care in the UK: review of evidence* (2015)
- <sup>5,12,59,60,81</sup> National Palliative and End of Life Care Partnership (2015). *Ambitions for palliative and End of Life Care: A national framework for local action 2015-2020*
- <sup>6,67,68,69</sup> Murray Hall Community Trust and the National Council for Palliative Care (NCPC), Dying Matters Coalition (2013). *An Overview of Compassionate Communities in England*. London: NCPC. Available at: [www.compassionatecommunities.org.uk/files/PDF/CC\\_Report\\_Final\\_July\\_2013-2.pdf](http://www.compassionatecommunities.org.uk/files/PDF/CC_Report_Final_July_2013-2.pdf) [Accessed 01.03.2017]
- <sup>8</sup> General Medical Council (GMC) (2010). *Treatment and care towards the end of life: good practice in decision making*. London: GMC. Available at: [www.gmc-uk.org/static/documents/content/Treatment\\_and\\_care\\_towards\\_the\\_end\\_of\\_life\\_-\\_English\\_0914.pdf](http://www.gmc-uk.org/static/documents/content/Treatment_and_care_towards_the_end_of_life_-_English_0914.pdf) [Accessed 07.01.2017].
- <sup>9,19,78</sup> Department of Health (2008), *End of Life Care Strategy: Promoting high quality care for all adults at the end of life*. London: HMSO.
- <sup>13,61,65</sup> Office for National Statistics (2015). *National Survey of Bereaved People, (VOICES): England, 2015* [online]. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015> [Accessed 07.01.2017].
- <sup>15</sup> Goldstandardsframework.org.uk. (2017). *Welcome to Gold Standards Framework*. [online] Available at: <http://www.goldstandardsframework.org.uk> [Accessed 10.02.2017].
- <sup>16,17</sup> (Public Health England) localhealth.org.uk. (2017), *Local Health Profiles*. Available at: [www.localhealth.org.uk](http://www.localhealth.org.uk) [Accessed 10.02.2017].
- <sup>18</sup> Enhertscg.nhs.uk. (2017), *About Us*. Available at: [www.enhertscg.nhs.uk/aboutus](http://www.enhertscg.nhs.uk/aboutus) [Accessed 07.01.2017].
- <sup>20,79</sup> Department of Health (2015). *One Chance to Get it Right: One Year On Report: An overview of progress on commitments made in Once Chance to Get it Right: the systemwide response to the Independent Review of the Liverpool Care Pathway*. London: Department of Health 2015. Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/450391/One\\_chance\\_-\\_one\\_year\\_on\\_acc.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/450391/One_chance_-_one_year_on_acc.pdf) [Accessed on 10.02.2017]
- <sup>21</sup> Zheng L, Finucane AM, Oxenham D, McLoughlin P, McCutcheon H, Murray SA. How good is primary care at identifying patients who need palliative care? A mixed-methods study. *European Journal of Palliative Care* 2013; 20: 216–222
- <sup>23,25</sup> Qof.digital.nhs.uk. (2017). *QOF 2015/16 | NHS Digital*. [online] Available at: <http://qof.digital.nhs.uk/> [Accessed 10.02.2017].

## References

- <sup>24</sup> RightCare, N. (2017). *NHS RightCare » Midlands and East*. [online] England.nhs.uk. Available at: <https://www.england.nhs.uk/rightcare/intel/cfv/data-packs/mids-east/#44> [Accessed 10 Feb. 2017].
- <sup>26,27,58,62</sup> NICE (2011, last updated 2013). 'QS13 End of life care for adults'. London: NICE.
- <sup>29</sup> Marie Curie (2015). *Equity in the provision of palliative and end of life care in the UK*. [online] Available at: [https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/a042-equity-in-the-provision-palliative-eol-care-in-uk\\_v11-copy.pdf](https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/a042-equity-in-the-provision-palliative-eol-care-in-uk_v11-copy.pdf) [Accessed 10.02.2017].
- <sup>30</sup> Care Quality Commission (2016). *A different ending – addressing inequalities in end of life care*. Newcastle.
- <sup>32</sup> Care Quality Commission (2016). *People from Black and minority ethnic communities*. Newcastle.
- <sup>33</sup> Calanzani N, Koffman J, Higginson I, *Palliative Care for Black, Asian and Minority Ethnic groups in the UK*, 2013
- <sup>36</sup> Hertfordshire.gov.uk. (2017). *Welcome to Herts Insight*. [online] Available at: <https://www.hertfordshire.gov.uk/microsites/herts-insight/home.aspx> [Accessed 10.02.2017].
- <sup>38</sup> Journals.sagepub.com. (2017). *Ethnicity and prevalence of multiple sclerosis in east London - Christo Albor, Timothy du Sautoy, Narmadha Kali Vanan, Benjamin P Turner, Kambiz Boomla, Klaus Schmierer, 2017*. [online] Available at: <http://journals.sagepub.com/doi/abs/10.1177/1352458516638746> [Accessed 01.03.2017]
- <sup>39,48</sup> Institute of Public Care - Projecting Older People Population Information Available at: <http://www.poppi.org.uk/> [Accessed 01.03.17]
- <sup>41,42</sup> Alzheimer's Society and Marie Curie, *Living and Dying with Dementia in England: Barriers to care* (2014)
- <sup>43</sup> Public Health England, *Data Analysis Report - Dying With Dementia* (2016)
- <sup>44,50</sup> Help the Hospices, *Towards Excellence in Hospice Care – widening access to palliative care for people with learning disabilities*, (2012)
- <sup>45</sup> (PHE), P. (2017). *Public Health Profiles*. [online] Fingertips.phe.org.uk. Available at: <http://fingertips.phe.org.uk/> [Accessed 01.03.2017]
- <sup>52</sup> National Council for Palliative Care (NCPC) (2014). *National survey of patient activity data for specialist palliative care services, minimum data set for 2012-13 (MDS)* [online]. Available from: <http://www.ncpc.org.uk/freedownloads?keys=mds.> [Accessed 07.01.2017].
- <sup>55</sup> House of Commons Health Committee, *End of Life Care, Fifth Report of Session 2014-15* [online]. Available from: <https://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf>. [Accessed 01.03.2017].
- <sup>63</sup> Hospiceuk.org. (2017). *What is rehabilitative palliative care | What we offer | Hospice UK*. [online] Available at: <https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/rehabilitative-palliative-care/what-is-rehabilitative-palliative-care> [Accessed 28.04.2017].

## References

<sup>73</sup> Cancer Research UK (2016). *Coping with Grief* [online]. Available from: <http://www.cancerresearchuk.org/about-cancer/coping-with-cancer/dying/after/coping-with-grief> [Accessed 01.03.2017]

<sup>74</sup> Hertfordshire.gov.uk. (2017). *Tell Us Once service*. [online] Available at: <https://www.hertfordshire.gov.uk/services/births-deaths-marriages-and-citizenship/deaths/tell-us-once-service.aspx> [Accessed 01.03.2017 May 2017].

<sup>80</sup> Skills for Care (2014). *Common Core Principles and Competencies for Social Care and Health Workers Working with Adults at the End of Life*. Leeds.

<sup>82</sup> The National Council for Palliative Care (2014). *NCPC Specialist Palliative Care (SPC) Workforce Survey 2013*.

