

# JSNA 2018: End of Life Care

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## Contents

List of figures and tables .....	2
Executive summary .....	3
1 Introduction .....	4
2 Policy and evidence .....	5
4 Level of need in Ealing .....	18
5 EoLC service provision.....	33
6 Gap analysis – can we do better? .....	34
7 Action plans.....	37
8 Recommendations .....	40
Appendix 1 - NICE quality statements.....	42
Appendix 2 - Public perceptions and experiences of community-based end of life care initiatives: A qualitative research report.....	44
Appendix 3 – Further tables and figures.....	46

## List of figures and tables

Figure 1.	Ambitions for Palliative and End of Life Care: Six ambitions
Figure 2.	Ambitions for Palliative and End of Life Care: Foundations for the ambitions
Figure 3:	Proportion of Ealing residents aged 65+ by ethnic group
Figure 4:	Proportion of residents in each deprivation quintile, 2015
Figure 5:	Map of Deprivation in Ealing by LSOAs (IMD 2015)
Figure 6:	Number of deaths by age and gender in Ealing, 2011-2013
Figure 7:	Mortality rate in Ealing for people aged 55+ by age and gender
Figure 8:	Trend in place of death for all ages in Ealing, 2004-15
Figure 9:	Proportion of deaths that occurred in hospital, 2013 English Local Authorities.
Figure 10:	Place of death, Ealing, London & England, 2015
Figure 11:	Place of death by underlying cause for Ealing residents, 2011-2013
Figure 12:	Proportion of terminal admissions that are emergencies
Figure 13:	Proportion of terminal admissions that are 8 days or longer
Figure 14:	Average number of bed days per admission ending in death
Figure 15:	Total delayed transfers of care per 100,000 persons aged 18+
Figure 16:	Delayed transfers of care attributable to adult social care per 100,000 persons aged 18+
Figure 17:	Number of care homes per 1,000 population aged 75+, 2016
Figure 18:	Number of care home beds per 1,000 population aged 75+, 2011-17
Table 1.	Ambitions for Palliative and End of Life Care: Building blocks needed to realise our ambition
Table 2:	Proportion of population aged 65+ by age group
Table 3:	Proportion of population aged 65+ by ethnic group
Table 4:	Crude mortality rate per 100,000 population by age and gender
Table 5:	Percentage of care homes achieving Gold Standard Framework, 2016
Table 6	Community based Ealing EoLC services across health and social care

## Executive summary

Over one in ten people in Ealing are aged 65 or over and one in a hundred people in Ealing are aged 85 years or over. Over the next two decades the proportion of people aged 85 years or over will double.

There is significant variation across the country for the proportion of people that die within hospital of which Ealing has a higher proportion. At the moment, for every 10 people that die in Ealing, 5 will die within a hospital setting, 2 in a care home, 2 at home, and less than 1 within a hospice.

There are also recognised inequalities with particular population groups and communities, with regards to end of life care. People with learning disabilities, dementia, homeless, or from BME or LGBT groups are more likely to experience inequalities in end of life care. This is particularly relevant to Ealing as more than half of all people aged 65 and over in Ealing are from BME groups.

The increase in future demand for end of life care services and need to tackle inequalities and inequity pose a challenge to health & social care and voluntary sector services involved in end of life care both locally and across the country.

## Summary of key recommendations for Ealing EoLC stakeholders

1. Commissioners of EoLC services should consider opportunities to bring together a **stakeholder group or network to develop a locally shared vision and local plan to drive local delivery of the national six ambitions** as set out by the National Palliative and End of Life Care Partnership in the Ambition for Palliative and End of Life Care.
2. Local stakeholder should consider how EoLC service across Ealing **tackle nationally recognised inequalities** in particular for people living with a learning disability, people living with dementia, people who are homeless, people who are lesbian, gay, bisexual or transgender, people from gypsy or traveller communities and people from a black or minority ethnic group. This should include opportunities to implement CQC end of life care recommendations specific to each group.
3. There is a recognised gap in understanding locally expressed need by end of life care service users, carers and their families and friend. Organisations such as **Ealing Health Watch may be able to provide commissioners and stakeholders an independent review of end of life care services** available to Ealing patients and residents and explore the service user perspective to consider of how inequalities can be addressed within each vulnerable group.
4. It would be beneficial for end of life care commissioners & analysts to explore the Public Health England (PHE) **end of life economic analysis tool** which provides an opportunity to review cost-effective commissioning of end of life care services.

## 1 Introduction

End of life care (EoLC) is defined here, as in the national end of life care strategy, as care that:

*“helps all those with advanced, progressive and 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>1</sup>*

End of life care should encompass the World Health Organisation (2002) definition of palliative care as:

*“an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness; through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other symptoms; physical, psychological and spiritual.”*

The national policy context for EoLC comes under the broader health and social care agendas of personalisation and integration against a background of increasing demand due to an increasing ageing population, and increasing financial austerity.

Nationally the main strategic drivers shaping the EoLC agenda have included the Department of Health EoLC Strategy (2008), the Palliative Care Funding review (2011) and the NICE and DH quality standards around EoLC (2011, 2009) and the Liverpool Care Pathway review (2013).

In England about 500,000 people die every year, with the number expected to rise by 17% between 2012 and 2030. People will increasingly die at an older age, with the percentage of deaths among those aged 85 and over expected to rise from 32% in 2003 to 44% in 2030.

Those who die at an older age are more likely to be suffering from complex multiple morbidities, and addressing the issues this raises will be a major challenge for both commissioners and providers of care.

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<sup>1</sup> End of life care strategy. Department of Health. July 2008

## 2 Policy and evidence

### 2.1 National direction of travel

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020, published by the National Palliative and End of Life Care Partnership,<sup>2</sup> is one of the most recent reports that sets the national direction of travel. It builds upon a number of key national policies and guidance that address the broad topic of end of life care.

This national framework for local action sets the six ambitions for achieving good end of life care from the point of view of a person nearing the end of life (figure1), and details important foundations and building blocks that will support the achievement of this (figure 2, table 1). The importance of local leadership and decision making, and an equal duty and partnership of health and social care to seek new ways of improving quality and accessibility of end of life care are highlighted whilst recognising the backdrop of constrained resources and increasing demands.

Figure 1. Ambitions for Palliative and End of Life Care: Six ambitions



<sup>2</sup> <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

Figure 2. Ambitions for Palliative and End of Life Care: Foundations for the ambitions

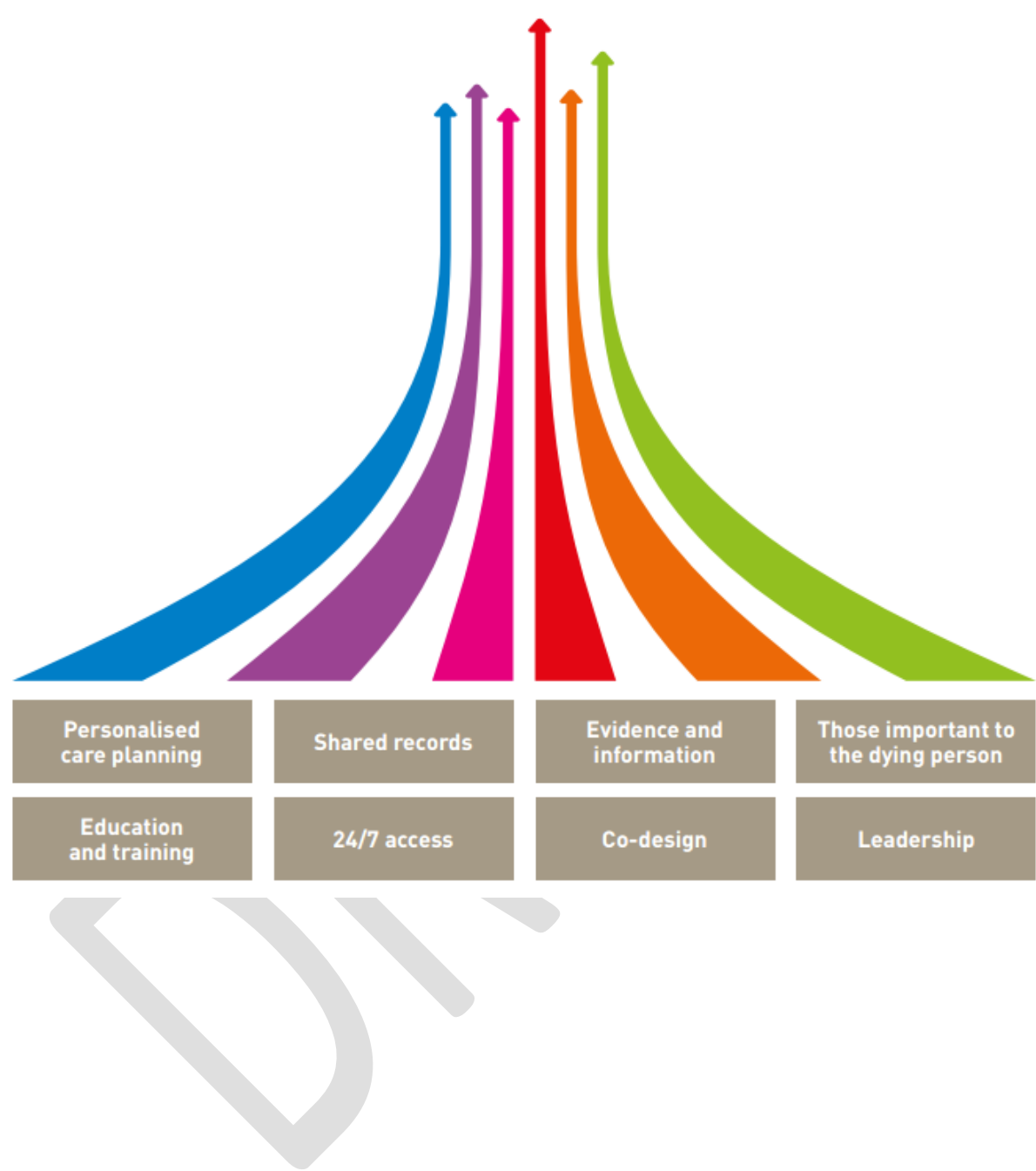


Table 1. Ambitions for Palliative and End of Life Care: Building blocks needed to realise our ambition

<b>Ambition</b>	<b>Building blocks</b>
Each person is seen as an individual	Honest conversations Clear expectations Helping people take control Systems for person centred care Access to social care Integrated care Good of life care includes bereavement services
Each person gets fair access to care	Using existing data Generating new data Population based needs assessment Community partnerships Unwavering commitment Person centred outcome measurement
Maximising comfort and wellbeing	Recognising distress whatever the cause Skilled assessment of symptom management Priorities of the dying person Addressing all forms of distress Specialist palliative care Rehabilitative palliative care
Care is coordinated	Shared records Clear roles and responsibilities A system wider response Everyone matters Continuity in partnership
All staff are prepared to care	Professional ethos Support and resilience Knowledge based judgement Using technology Awareness of legislation Executive governance
Each community is prepared to help	Compassionate and resilient communities Public awareness Practical support Volunteers

### 2.1.2 Other national policy

(2008) End of Life Care Strategy: promoting high quality care for all adults at the end of life. <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>

(2012) End of Life Care Strategy: 4th annual report. <https://www.gov.uk/government/news/end-of-life-care-strategy-fourth-annual-report>

(2012a) NHS Outcomes Framework 2013/14. <https://www.gov.uk/government/publications/nhs-outcomes-framework-2013-to-2014>

(2012b) First national Voices survey of bereaved people: key findings report.  
<http://www.dh.gov.uk/health/files/2012/07/First-national-VOICES-survey-of-bereaved-people-key-findings-report-final.pdf>

(2013) Palliative and End of Life Care for black, Asian and minority ethnic groups in the UK. [https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/palliative-care-bame\\_full-report.pdf](https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/palliative-care-bame_full-report.pdf)

Information Standards Board for Health and Social Care (2012) National Information Standard. <http://www.isb.nhs.uk/library/standard/236>

King's Fund (2010) Implementing the end of life care strategy: lessons for good practice. <http://www.kingsfund.org.uk/publications/implementing-end-life-care-strategy>

National Audit Office (2008) End of Life Care. London: NAO.  
[http://www.nao.org.uk/publications/0708/end\\_of\\_life\\_care.aspx](http://www.nao.org.uk/publications/0708/end_of_life_care.aspx)

National Council for Palliative Care (2011) Commissioning End of Life Care: initial actions for new commissioners. <http://www.ncpc.org.uk/sites/default/files/AandE.pdf>

National End of Life Care Intelligence Network (Public Health England).  
<http://www.endoflifecare-intelligence.org.uk/home>

### 2.1.3 NICE Guidance

The National institute for Health and Care Excellence (NICE) provides national guidance to improve health and social care.

- (2012) CMG42: End of life care for adults (Commissioning Guide). Available at: <http://www.nice.org.uk/guidance/cm42>
- NICE Quality standards for end of life care for adults (QS13) 2011, last updated march 2017. See appendix for full list of EoLC quality standards.
- End of life care for infants, children and young people with life limiting conditions: planning and management (NG61) Dec 2016
- NICE is further developing guidance on end of life care for adults in the last year of life: service delivery which is expected in 2018.

### 2.1.4 Toolkits

Commissioning person centred end of life care. A toolkit for health and social care. (updated 2016) NHS England  
<https://www.england.nhs.uk/wp-content/uploads/2016/04/nhsiq-comms-eolc-tlkit-.pdf>

Cost-effectiveness of Public Health England  
<https://www.gov.uk/government/publications/end-of-life-care-economic-tool>



## 2.2 Tackling inequalities

*“People from certain groups in society experience poorer quality of care at the end of their lives because providers do not always understand or fully consider their needs.”<sup>3</sup>*

There has been increasing recognition of the inequalities that exist within end of life care services that are captured in the recent report: A different ending: addressing inequalities in the end of life care, by the Care Quality Commission (2016).<sup>4</sup> It identified that people with a diagnosis other than cancer, older people, people with dementia, people from equality groups and people who may be vulnerable because of their circumstances do not always experience good care in the last phase of their life. It has suggested that action is needed to make sure everyone receives good quality, personalised end of life care regardless of diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances. The report reviewed four aspects of care that were identified as particularly important to good EoLC for the equalities groups:

1. Identification of people likely to be in the last 12 months of life, and communication with people and those important to them.
2. Coordination of care, particularly for people with complex needs or vulnerabilities.
3. Timely and equitable access to good care, including 24/7 support.
4. Care in the last days and hours of life that delivers the five priorities for care of the dying person.

This report recognised that there is a variable experience of people during the last phase of life through the following themes:

- identifying the end of life phase can be difficult
- Communication about end of life care is not always good enough
- People are struggling to access the services they need
- End of life care is not well coordinated around the person
- Lack of knowledge about the needs of different groups

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<sup>3</sup> A different ending: addressing inequalities in end of life care. 2016 CQC

<sup>4</sup> <http://www.cqc.org.uk/content/different-ending-our-review-looking-end-life-care-published>

### 2.2.1 CQC recommendation to tackle inequalities in EoLC

1. Leaders of local health and care systems to **work together to develop a plan** for delivering good quality, equitable end of life care for everyone in their community.
2. Commissioners and providers to fulfil their duties under the NHS Constitution, the Health and Social Care Act 2012 and the Equality Act 2010 to **reduce inequalities, eliminate discrimination and advance equality** when developing, arranging or delivering end of life care.
3. Commissioners and providers to ensure that staff who care for people who may be approaching the end of life, including care home staff, have the **knowledge, skills and support** they need.
4. Hospices to **champion an equality-led approach**, engage communities, deliver equitable end of life care, and support others to do the same.
5. GPs to ensure that everyone with a life limiting progressive condition has the opportunity to have **early and ongoing conversations about end of life care**, and is given a **named care coordinator**.

### 2.2.2 People with Learning Disabilities

People with learning disabilities may experience difficulties in accessing end of life care that meets their specific needs. This can be due to failure to diagnose advanced disease early enough to plan and prepare for end of life care, and to communication difficulties with healthcare professionals.<sup>5</sup> Current communication models designed to assist healthcare professionals in breaking news of serious illness and poor prognosis do not meet the specific needs of people with learning disabilities.<sup>6</sup> This results in the risk of excluding this group of people from making informed choices for their future care at the end of life i.e. engaging in the process of advance care planning.

### 2.2.3 People with Dementia

It is estimated that for the over 85 age group prevalence of dementia is currently 45% in Ealing. In the terminal stages, people with dementia often have complex medical and social needs that require co-ordinated input from a number of agencies. Within Ealing, 1,264 people aged 85+ and suffering from dementia represent a significant

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<sup>5</sup> Keenan, P & Macintosh, P. (2000) Learning disabilities and palliative care. Palliative Care Today, 2000. 9(3) 11-13.

<sup>6</sup> McEnhill, L. S. (2008) Breaking bad news of cancer to people with learning disabilities. British Journal of Learning Disabilities, 2008. 36(3) 157-164.

group of patients whose needs, wishes and preferences for end of life care need to be identified to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing.<sup>7</sup>

A recent PHE report Dying with Dementia<sup>8</sup> identifies there has been a national increase in the reporting of deaths associated with dementia over the last decade; key contributors to this include healthy policy drivers eg to improve diagnoses and awareness, clinical practice and changes to coding on death certification which include: In 2011, deaths previously coded with an underlying cause of unspecified cerebrovascular disease were to be reclassified as vascular dementia and in the 2014 revision, dementia was to be coded as the underlying cause of death whereas previously this was assigned to chest infections and aspiration pneumonia.

People with dementia were more likely to die in care homes and less likely to die at home or in hospices which most likely reflects the complex needs of people with dementia, for example, significant changes in a person's function, capacity and behaviour. The majority of people with dementia would prefer to be cared for at home and prefer not to die in hospital. Dementia may not routinely be identified as a terminal illness for EoLC; the disease trajectory may also make it harder to identify terminal phases.

A higher proportion of the 'young-old' (those aged 65-74) who have died with dementia resided in the more deprived areas compared to the least deprived areas, the reverse is the case for people aged 95 and over. This suggests that people who reside in more deprived areas die younger with dementia. This relationship was more notable for deaths with vascular dementia, perhaps due to a higher prevalence of vascular risk factors such as smoking and obesity in more deprived areas.

A recent CQC report on EoLC in dementia<sup>9</sup> identifies that although dementia as a cause of death is increasing, health professionals do not always recognise it as a life limiting condition. As a result, the end of life phase is not always identified early enough or planned for effectively. Communication, unequal access to care and poor quality of care have been identified as national issues by this report. With regards to communication a case review reported less than half of all people with dementia individuals communication needs had been considered. Lack of mental capacity can contribute to this, however the case review found that health professionals understanding of mental capacity act (MCA) is varied evidenced by less than 40% of people with dementia having evidence of mental capacity assessment in their records.

Access to hospice care for people with dementia is also variable. Hospice UK published guidance<sup>10</sup> on hospice-enabled dementia care and checklists to support

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<sup>7</sup> Ealing Dementia JSNA chapter 2015.

<sup>8</sup>[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/611463/Dying\\_with\\_dementia\\_briefing.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/611463/Dying_with_dementia_briefing.pdf)

<sup>9</sup>[http://www.cqc.org.uk/sites/default/files/20160505%20CQC\\_EOLC\\_Dementia\\_FINAL\\_2.pdf](http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_Dementia_FINAL_2.pdf)

<sup>10</sup> <https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/hospice-enabled-dementia-care>

hospices develop their role further and make sure people with dementia can access their services and tackle the key areas of difficulty highlighted by hospices which were found to be:

- Limited applicability of existing model of care to respond to specific needs of people with dementia
- People with dementia are not seen as people who would typically benefit from hospice care
- Weak working relationships with external professionals
- The unsuitability of the hospice physical environment
- Concern about growing levels of needs and demand for hospice services
- Staff not having the right skills to care for people with dementia, even in dementia-specific care homes, was seen as another barrier to receiving good, personalised end of life care.

CQC encourage:

- **Health professionals, including GPs, to facilitate early conversations with people with dementia** and those who are important to them about their wishes and choices for end of life care, and help them to contribute to an advance care plan wherever possible.
- Commissioners and providers to make sure that **staff have the training and support** they need to care for people with dementia who are approaching the end of life, and to understand and implement the requirements of the Mental Capacity Act 2005.
- **Hospices to consider to what extent they are meeting the end of life care needs of people with dementia**, and take action where required in line with our definition of good end of life care in hospice services.

These findings are supported by PHE Public perceptions and experiences of community- based end of life care initiatives: A qualitative research report, prepared for PHE by Solutions Research, June 2016. The key inequality noted in this report was that people with terminal or life limiting illness appeared to have a clearer pathway than those with dementia and with better signposting to additional resources. It identifies that people living with dementia may face additional challenges. The research suggests that these carers want their loved one to live and manage on their own for as long as possible. Carers do not conceptualise dementia as a 'terminal illness' and the focus is more on living with dementia; subsequently it may take longer for carers to recognise they need help and identify the type of help this should be.

*'I don't think people look at it as somebody dying...If somebody says they've got cancer, people see it as how long have you got. When someone's got dementia, they don't look at that as a cause of death.'* (Carer of person with dementia)

This report found that barriers to accessing support include (i) unpredictable nature of illness (ii) patients may become isolated due to stigma and illness maybe 'invisible' from the outside (iii) the illness may affect people's behaviour which can impact upon abilities for day-to-day interactions (iv) change can be difficult for people living with dementia. Given these consideration, for people living with dementia and their carers the timing of conversations about end of life care are particularly important.

Older ethnic minority may have differing taboos and perceptions about EoLC conditions such as dementia; however there is evidence of changing attitudes to dementia, especially in second generation ethnic minority communities.

*'If you look at 10 years back it was unthinkable for Asian families to put their elderly parents in homes, but the attitude has changed now. It was a taboo in the community, but now their thinking has changed...'* (Carer of person with dementia, Indian respondent)

The changing role of a carer after the death of a family member and how death not only represents the loss of a family member, but can represent the loss of an identify and purpose.

In Ealing there is work to improve dementia diagnosis and address inequalities by raising awareness of dementia diagnosis in BME groups and communities, through voluntary sector projects and dementia awareness campaigns.

Recommendation:

- **Commissioners and providers of EoLC services should consider how services meet the needs of people living with dementia and their carers, including use of specific checklists such as the Hospice enabled dementia care – first steps checklists.**
- **Commissioners should consider communication opportunities to raise awareness of end of life care issues and support available for people with living with dementia and their carers.**

#### 2.2.4 Homelessness

Homeless people experience poorer levels of physical and mental health than the general population, and there is a substantial international evidence base which documents multiple morbidities with many homeless people dying from treatable

medical conditions, HIV, liver and other gastro-intestinal disease, respiratory disease, and consequences of drug and alcohol dependence.<sup>11</sup>

Research largely finds the average age of death of a homeless person as between 40-42 years of age. Crisis identified the average age of death for homeless people in England as 47 compared to 77 for the general population.<sup>12</sup> The National End of Life Care strategy states that high quality end of life care “should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere”.<sup>13</sup>

Recognising that homeless people are often overlooked when developing policy and are not often engaged in service development and that consequently the implementation of the strategy poses particular challenges in relation to homeless people, the National End of Life Care Programme report<sup>14</sup> a range of key considerations for end of life care for homeless people, including:

- The existing environment may not encourage privacy or be suitable for care and it may not be practicable to consider rebuilding or remodelling hostels
- Access to services may be problematic because of other professionals’ misconceptions– for instance, homeless people are often stigmatised as non-compliant and unreliable
- The homeless population often decline to engage with health services
- Access to placement at end of life for people with substance misuse problems can be difficult because many care facilities do not accept people with drug or alcohol issues. Staff need to be aware of those providers who do accept and provide for this
- Some outreach services can have bureaucratic barriers
  - Many hostels tend not to retain residents for a long time but help them move to supported or independent living. With collaborative working and planning, this should also be possible for those with end of life care needs
- Many residents have very complex needs including a high incidence of learning difficulties, mental health problems and dependency issues. As a result, hostels may not offer the best environment for end of life care.

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<sup>11</sup> Brodie, C., Perera, G., Carter, S., Jones, J., Rabee, S., Aboulhab, J., & Young, S. (2013) Rough sleepers: health and healthcare. London: NHS North West London.

<sup>12</sup> Crisis. (2011). Homelessness: a silent killer. A research briefing on mortality amongst homeless people

<sup>13</sup> Department of Health. (2008) End of Life Care Strategy: promoting high quality care for adults at the end of their life. London: Department of Health

<sup>14</sup> National End of Life Care Programme. (2012) Critical success factors that enable individuals to die in their preferred place of death. London: National End of Life Care Programme

St Mungos and Marie Cure Cancer have published a comprehensive resource pack that contains information and tools when supporting people who are homeless as they approach the end of their lives.<sup>15</sup>

### **The Healthy London Partnership Health care & people who are homeless, Commissioning Guide for London (Dec 2016)<sup>16</sup> recommends**

- CCG-commissioned providers of End of Life Care and Palliative Care should have care pathways and resources in place that enable people to die in their preferred place of death. The report recognises that this could be in a hostel or on the street, dependent on the individual patient's circumstances and wishes. It also suggests that medication management protocols for hostels should enable controlled drugs to be safely held there and in other accommodation where the person is choosing to die.

NHS Improving Quality - End of life care - achieving quality in hostels and for homeless people

- CCG-commissioned providers of palliative care should proactively work with local multiagency partners to identify people with chronic health conditions, in hospital or in the community, who may be approaching the end of life.  
Some people who have been homeless for a long time and not in contact with mainstream services can have complex chronic health conditions but no formal diagnosis. This can become a barrier to accessing palliative care as referrals from non-NHS services are not accepted within formal diagnoses from a medical professional. Adopting an End of Life Care Co-ordinator role to focus on homeless and marginalised groups would support personalised emergency care planning, including Fast Track referrals and Continuing Care Assessments between NHS and non-NHS providers for those people who remain homeless through choice when they deteriorate unexpectedly and suddenly.

### **Recommendation**

- *Providers and commissioners of services for the homeless in Ealing should be aware of and utilise resources to support EoLC for homeless.*
- *Health and social care providers of EoLC and palliative services and related services, should be aware of HLP recommendations to enable identification of homeless people approaching end of life and enable them to die in their preferred place of death.*

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<sup>15</sup> [http://www.mungos.org/endoflifecare/resources\\_section](http://www.mungos.org/endoflifecare/resources_section)

<sup>16</sup> <https://www.healthy london.org/sites/default/files/Commissioning%20guidance%20for%20London%20-%20Homeless%20health.pdf>

### 2.2.5 Lesbian, Gay and Transgender communities

Lesbian, gay, bisexual and transgender (LGBT) communities can often feel let down by end of life care services, according to a 2013 report, 'Open to all - Meeting the needs of lesbian, gay, bisexual and transgender people nearing the end of life' by the National Council for Palliative Care (NCPC) and the Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations.<sup>17</sup> The report draws on a survey of more than 700 hospices, care homes and hospitals, as well as clinicians and service users. It provides an insight into perceptions of end of life care for the 22,000 LGBT people who die each year. With more than 3.7 million lesbian, gay and bisexual people and at least 12,500 transgender people in Britain, the report expresses concerns that a significant proportion of the population are not accessing appropriate care when they are dying because of their sexuality or gender identity.

Although lesbian, gay, bisexual and transgender (LGBT) people experience a higher incidence of life-limiting illness, the experience of LGBT people at the end of life has often been overlooked. Key themes include:

- Lack of awareness: Services and commissioners often told us there were low numbers of LGBT people in their area, but as there was little formal monitoring of sexual orientation or gender identity it was not clear how this was known.
- Attitude of staff: fear of discrimination has led to some older people hiding their sexual orientation and that staff made assumptions about their preferences. In settings such as nursing or care homes, LGBT may feel even more excluded due to other residents negative attitudes towards them as they grew up in times when there were significant prejudicial attitudes towards LGBT people.
- Open communication: there is a variety of experiences reported by LGBT people of EoLC services, both negative and positive (especially in hospices) as well as other health and care services.

CQC encourages:

- Commissioners, providers and health and care staff to consider the needs of LGBT people in planning and delivering end of life care services.
- Health and care staff to communicate openly and sensitively about sexual orientation and gender identity as a routine part of their delivering good quality, personalised end of life care.
- Commissioners and providers to collect data on sexual orientation and gender identity as part of an equalities approach to monitoring end of life care outcomes.

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<sup>17</sup>[http://www.cqc.org.uk/sites/default/files/20160505%20CQC\\_EOLC\\_LGBT\\_FINAL\\_2.pdf](http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_LGBT_FINAL_2.pdf)



## 2.2.6 BME groups, gypsies and travellers

The ethnic diversity of Ealing's older people draws attention to the need for both commissioners and providers, to ensure that health and social care services, including EoLC services, are sensitive to differing needs of different ethnic communities, especially as existing evidence suggests that BME groups have more unmet EoLC needs than people from white backgrounds and experience a number of barriers to accessing good and personalised care.

People from BME backgrounds in their last 3 months were more or as likely to receive help at home, less likely to rate care as outstanding or excellent (particularly those who had spent time in a care home, or hospice) and more likely to die in a hospital than a care home. The key barriers identified include:

- Lack of knowledge and information about EoLC services: palliative care is not a well understood concept for some groups, which means that they may be unaware of what palliative care aims to do, their rights and the quality of service they can expect
- Poor communication including language barriers: language barriers experienced by some people from BME communities further complicates difficult conversations.
- Lack of religious or cultural sensitivity including chaplaincy services. Spiritual and cultural sensitivity may not only be important to BME groups but to people from all ethnic groups, and many people from BME groups will have no spiritual or religious beliefs. PHE has released a Faith at the end of life resource for professionals, providers and commissioners working in communities.<sup>18</sup>

Gypsies and travellers have poor access to healthcare generally, often due to difficulty registering with primary care services, this includes EoLC services. There is also reported lack of cultural understanding, reported examples include experiencing discrimination against the need to have large numbers of visitors in the last days of life.<sup>19</sup>

### Recommendation

- *Commissioners of EoLC services should consider options to explore Ealing resident's and/or service user views and experiences of EoLC services to identify strengths and opportunities for improvement to support commissioning intentions and plans. These should also consider opportunities to explore inequalities or inequity that may relate to BME and other vulnerable groups including gypsy and traveller communities.*

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<sup>18</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/496231/Faith\\_at\\_end\\_of\\_life\\_-\\_a\\_resource.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/496231/Faith_at_end_of_life_-_a_resource.pdf)

<sup>19</sup> [http://www.cqc.org.uk/sites/default/files/20160505%20CQC\\_EoLC\\_Gypsies\\_FINAL\\_2.pdf](http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EoLC_Gypsies_FINAL_2.pdf)

- *Health and social care professionals, providers and commissioners should be aware and utilise resources to address improve knowledge and information, and improve communication of EoLC in BME groups, and resources that promote understanding of religious or cultural sensitivity including the Faith at the End of Life resource.*

## 4 Level of need in Ealing

### 4.1 Population characteristics

#### 4.1.1 Population aged over 65

Ealing has a young age profile compared to England. Nearly 12% of the population is aged 65+ compared to nearly 18% across England (Table 2).

Table 2: Proportion of population aged 65+ by age group

Persons	Age group	Ealing	London	England
<b>All persons</b>	65-74	6.2%	6.1%	9.5%
	75-84	3.9%	3.8%	5.7%
	85+	1.5%	1.6%	2.4%
	<b>65+</b>	<b>11.6%</b>	<b>11.5%</b>	<b>17.6%</b>
<b>Males</b>	65-74	5.8%	5.8%	9.3%
	75-84	3.5%	3.4%	5.2%
	85+	1.1%	1.1%	1.6%
	<b>65+</b>	<b>10.4%</b>	<b>10.3%</b>	<b>16.1%</b>
<b>Females</b>	65-74	6.5%	6.5%	9.7%
	75-84	4.3%	4.2%	6.2%
	85+	1.9%	2.0%	3.0%
	<b>65+</b>	<b>12.7%</b>	<b>12.7%</b>	<b>19.0%</b>

Source: ONS, MYE2 2014

Over the next 20 years the number of people aged 85+ in Ealing will more than double (113% increase). A similar trend is expected at a national level (120% increase).

#### 4.1.2 Ethnicity

Nearly 7 in 10 (69.7%)<sup>20</sup> Ealing residents are of Black and Minority Ethnic (BME) origin, which is higher than in London (55.2%) and England (20.4%) averages. Among BME groups in the borough, Asian/Asian British group is the largest (29.7% of the population) followed by Other White (18.6% of the population)<sup>21</sup>.

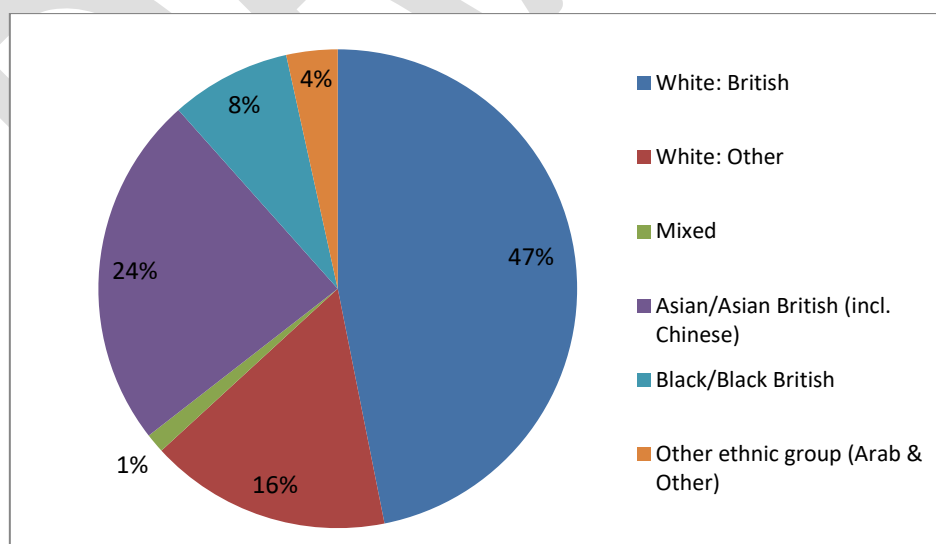
Of Ealing residents aged over 65, over half (53.1%) are of BME origin, which is higher than London (33.4%) and England (8.3%). Compared to London, Ealing has twice the proportion of Asian/British Asian people (Table 3). Consideration of ethnicity is important in planning end of life care services to ensure they are culturally appropriate and meet the needs of the whole population.

Table 3: Proportion of population aged 65+ by ethnic group

Area	All people aged 65+	White: British	White: Other	Mixed	Asian/Asian British (incl. Chinese)	Black/Black British	Other ethnic group
Ealing	36,227	46.9%	16.3%	1.3%	23.9%	8.1%	3.5%
London	904,227	66.6%	11.4%	1.3%	11.4%	7.7%	1.6%
England	8,660,529	91.7%	3.6%	0.4%	2.7%	1.3%	0.3%

Source: NOMIS, Age by Ethnic Group table download (Census 2011)

Figure 3: Proportion of Ealing residents aged 65+ by ethnic group



Source: NOMIS, Age by Ethnic Group table download (Census 2011)

<sup>20</sup> National Census 2011

<sup>21</sup> Note: National Census 2011 included Chinese ethnic group into Asian/Asian British category, for the first time

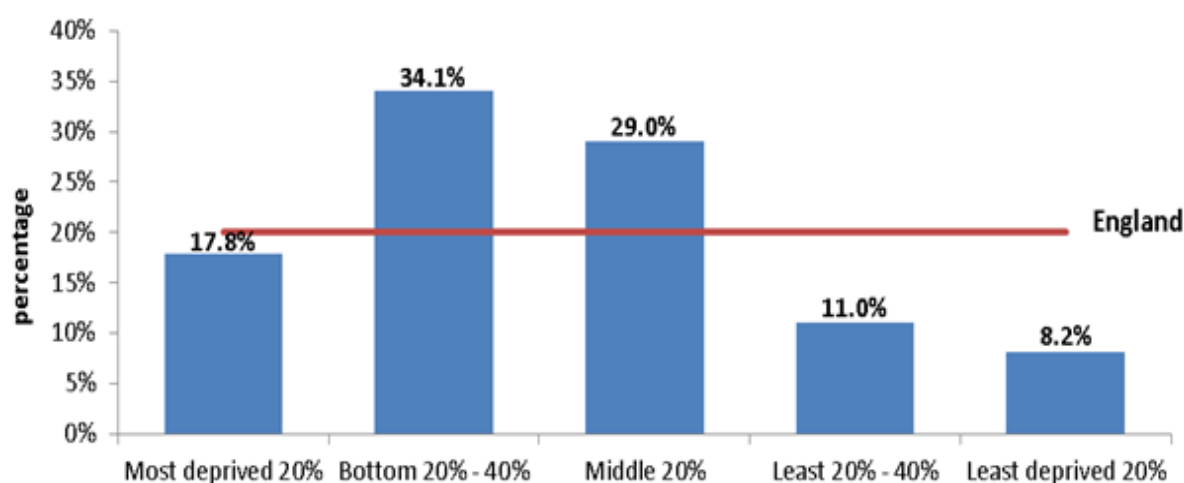
### 4.1.3 Deprivation

Higher rates of socioeconomic deprivation are associated with higher rates of mortality. Despite receiving similar access to community-based support, individuals in more deprived areas are less likely to die at home compared to individuals from less deprived communities.<sup>22</sup>

Analysis by the National End of Life Care Intelligence Network<sup>23</sup> shows that there are fewer deaths (16% of the total) in the least deprived quintile (20%) of the population. The analysis shows clear socioeconomic gradients, highlighting how inequalities affect the whole of society, not just the most deprived.

According to the latest Indices of Multiple Deprivation (2015), 17.8% of the Ealing population live in the most deprived areas of the country (compared to 20% nationally). Nearly two-thirds (63.1%) of residents live in the bottom 20-40% and middle 20% of deprived areas (compared to 40% nationally). Less than 20% of residents live in the least deprived 40% areas of the country (compared to 40% nationally) (Figure 4). Wards with highest proportion of residents in the most deprived 20% of areas include Norwood Green (72.6%), Dormers Wells (51.7%) and South Acton (45.6%) (Figure 5)<sup>24</sup>.

Figure 4: Proportion of residents in each deprivation quintile, 2015



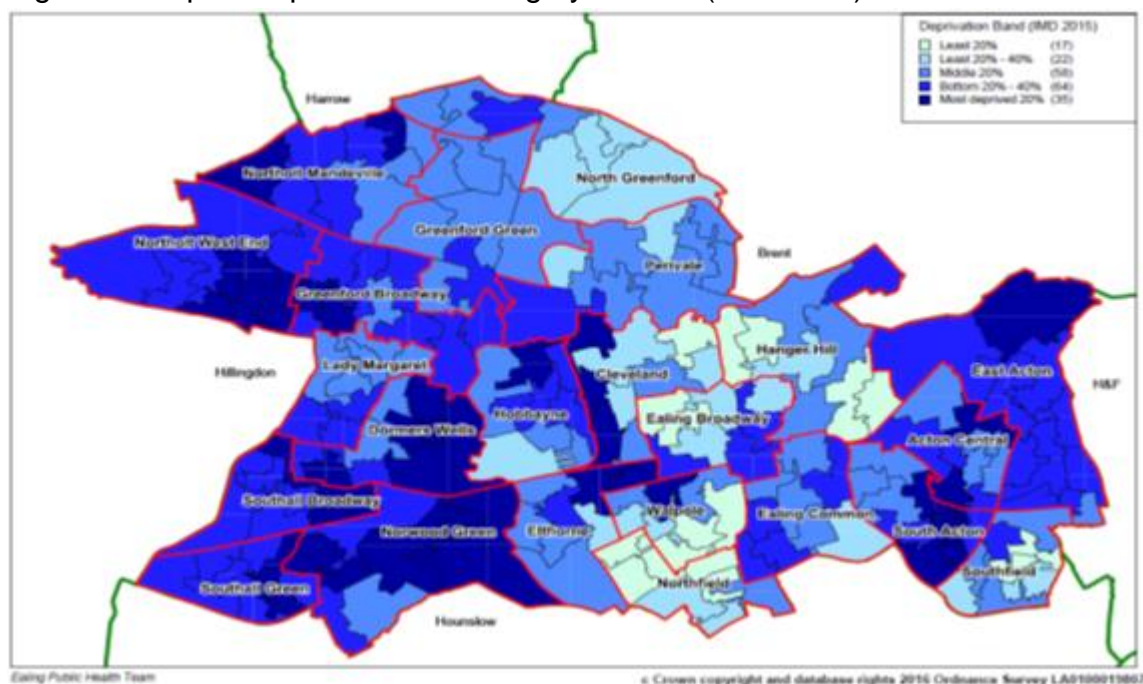
Data source: Indices of Multiple Deprivation 2015

<sup>22</sup> Dixon, J. et al (2015) Equity in the provision of palliative care in the UK: Review of Evidence

<sup>23</sup> National end of life care intelligence network (2012) Deprivation and death: Variation in place and cause of death

<sup>24</sup> For a deprivation band by ward data, please refer to the Appendix 3, Figure A1

Figure 5: Map of Deprivation in Ealing by LSOAs (IMD 2015)



Data source: Indices of Multiple Deprivation 2015

## 4.2 Number of deaths and mortality rates

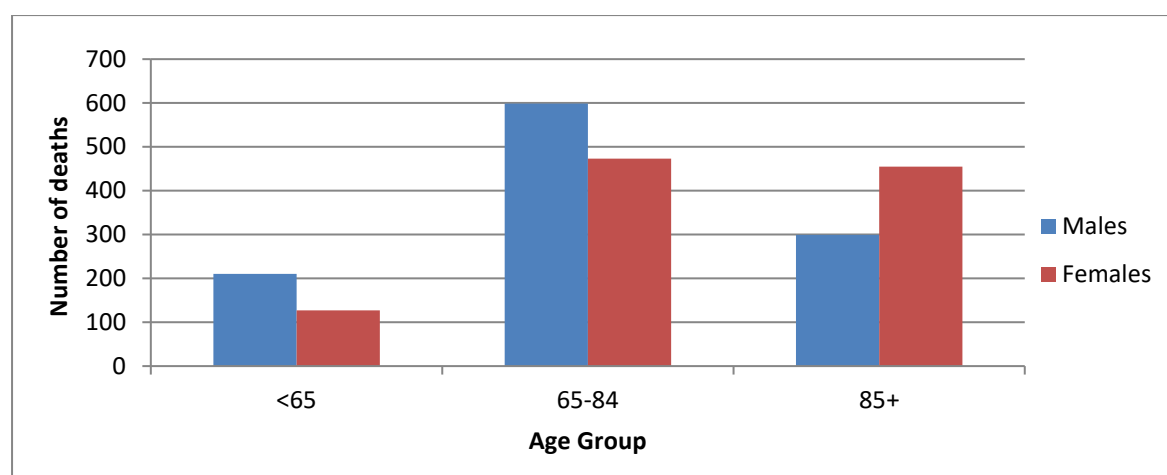
The National End of Life Care Intelligence Network End of Life profiles summarise key indicators benchmarked against England averages<sup>25</sup>. The profiles give an overview of variations in cause and place of death, by age and sex, for each clinical commissioning group (CCG) in England. These profiles support commissioners and providers of end of life care develop their understanding of *comparative epidemiological* needs of their local populations, to help with the planning and delivery of services and support drives locally towards improving end of life care.

### 4.2.1 Number of deaths

In the period 2011-2013, there were on average 1,876 deaths per year in Ealing. There are differences between the proportion of men and women who died at different ages. A smaller proportion of female deaths occurred in people under 65 years old and 65-84 years (Figure 6).

<sup>25</sup> [http://www.endoflifecare-intelligence.org.uk/end\\_of\\_life\\_care\\_profiles/ccg\\_profiles](http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/ccg_profiles)

Figure 6: Number of deaths by age and gender in Ealing, 2011-2013



Source: The National End of Life Care Intelligence Network End of Life profiles, 2015

Compared to England, the proportion of people who died whilst aged 75+ and 85+ is lower in Ealing. In Ealing, 62% of all deaths were among people aged 75+ (compared to 68.2% in England) and 35.2% of all deaths were among people aged 85+ (compared to 40.4% in England).<sup>26</sup>

#### 4.2.2 Mortality rate

The crude mortality rate in Ealing across different age groups in 2015 was similar or lower when compared to England. Among those aged 75+ the Ealing mortality rate was substantially lower than across England (Table 4 and Figure 7).

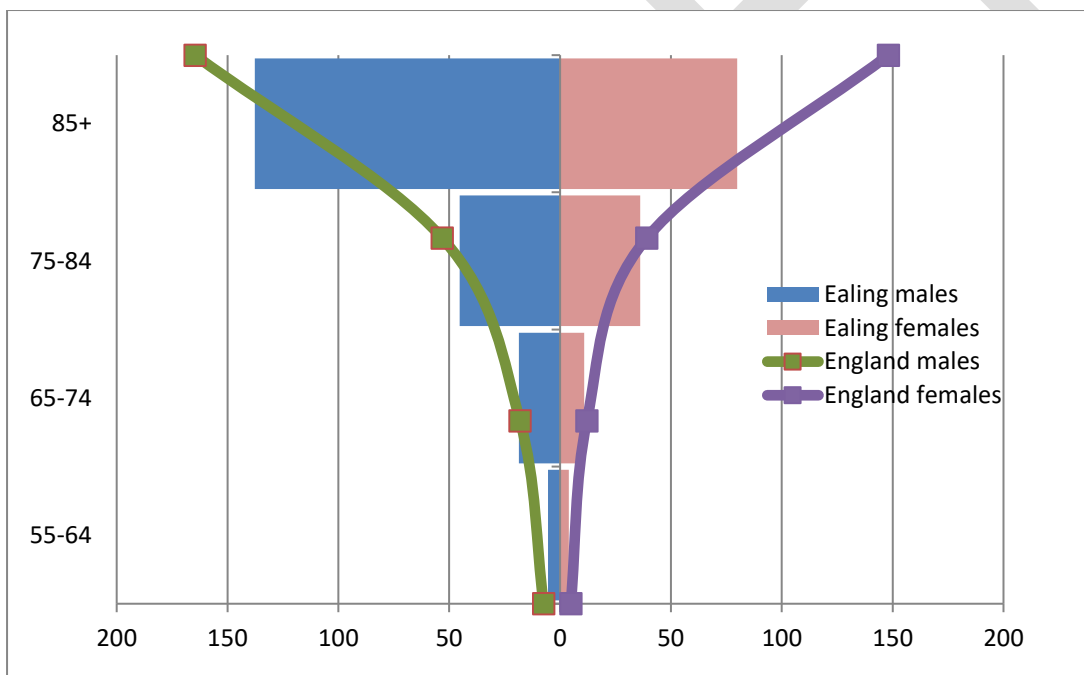
Table 4: Crude mortality rate per 100,000 population by age and gender

<sup>26</sup> End of Life Care Profiles (ONS), 2016

Age	Mortality rate per 1,000 population (2015)			
	Ealing males	England males	Ealing females	England females
0-4	0.6	1.0	0.4	0.8
5-14	0.0	0.1	0.0	0.1
15-24	0.6	0.4	0.1	0.2
25-34	0.7	0.7	0.6	0.3
35-44	1.7	1.4	0.9	0.9
45-54	2.4	3.0	1.6	2.0
55-64	5.5	7.5	3.9	4.8
65-74	18.5	18.1	10.9	12.1
75-84	45.3	53.2	36.2	39.1
85+	137.7	164.7	79.9	148.1

Source: VS Tables, Mortality Data 2015 & ONS MYE 2015

Figure 7: Mortality rate in Ealing for people aged 55+ by age and gender



Source: VS Tables, Mortality Data 2015 & ONS MYE 2015

## 4.3 Place of death

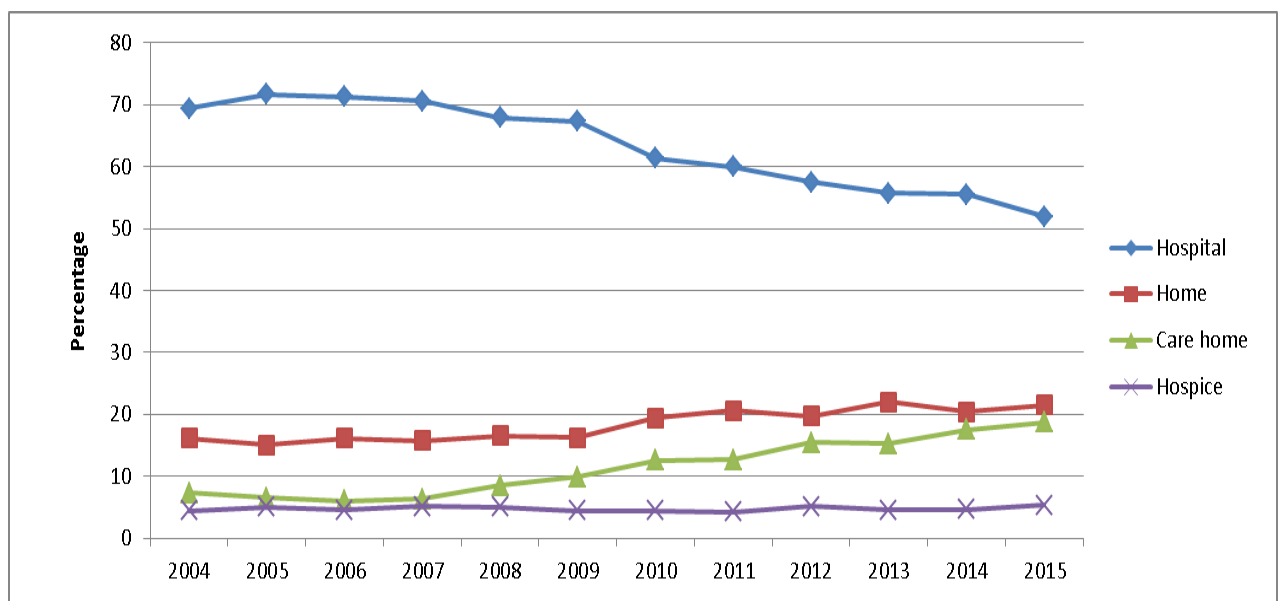
### 4.3.1 Trend

Hospitals continue to be the most common place of death. However, over the last 10 years there has been a decrease in the proportion of deaths occurring in hospital (Figure 8). Over the same period there has been an increase in deaths occurring in homes, care homes and hospices. This reflects the aging population and increase in life expectancy.

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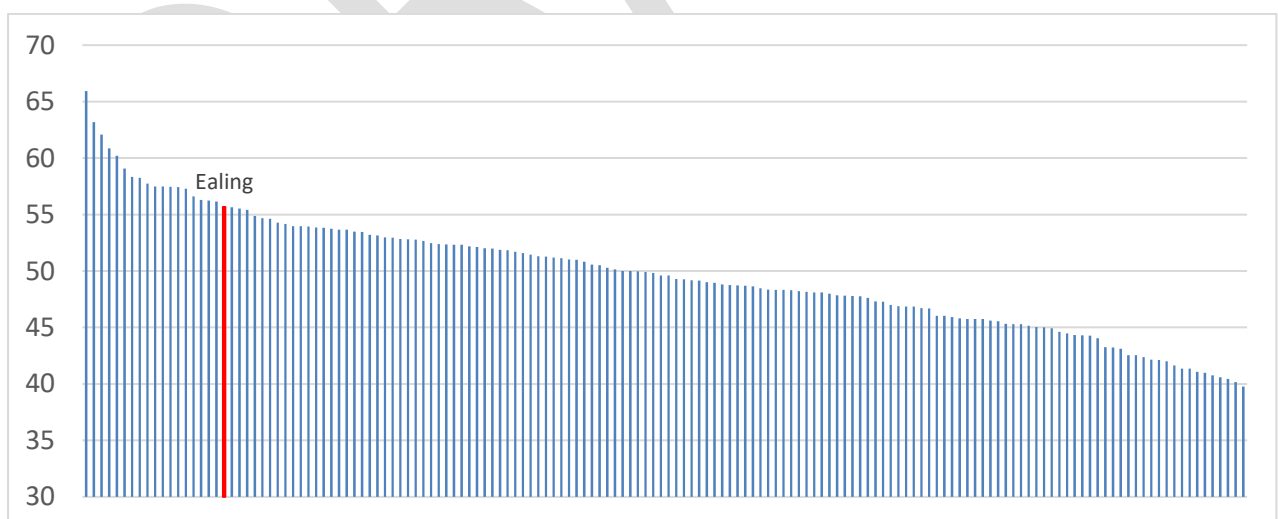
Figure 8: Trend in place of death for all ages in Ealing, 2004-15



Source: End of Life Care Profiles (ONS), 2016

Ealing had a higher proportion of deaths that occurred in hospital (56%) than most other local authorities across England (Figure 9).

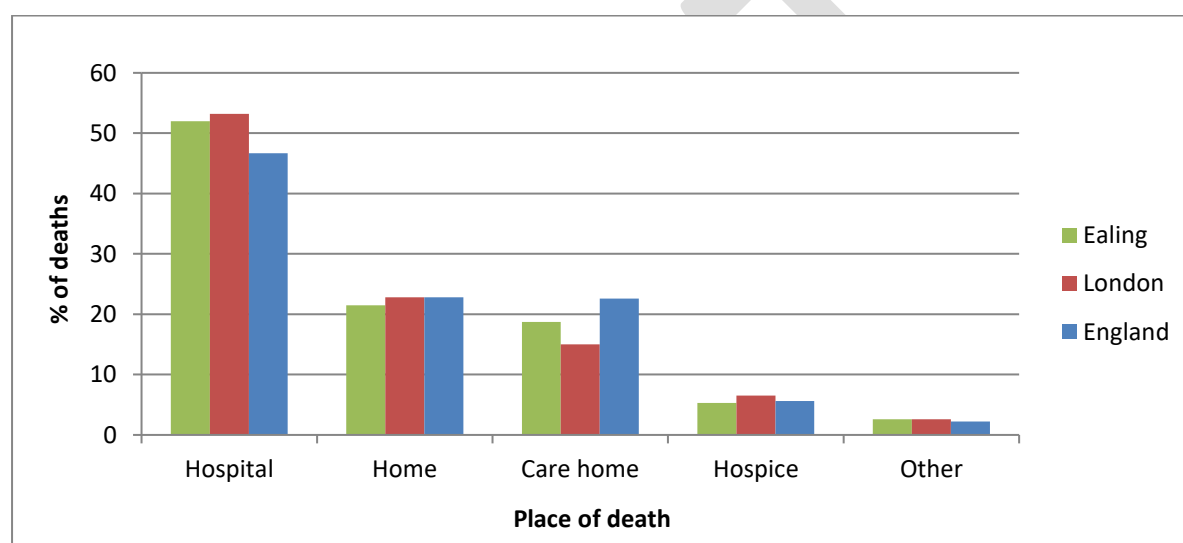
Figure 9: Proportion of deaths that occurred in hospital, 2013 English Local Authorities



### 4.3.2 Regional and national comparators for place of death in 2015

In Ealing there were 1,915 deaths in 2015; of these over half (52%) occurred in a hospital; a fifth (22%) in a home, 19% in care home, 5% in a hospice and 3% elsewhere (Figure 10). The percentage of deaths occurring at a person's usual residence (either their home or care home) in Ealing (40.2%) is significantly lower than the national average (45.4%). Conversely, the proportion of in hospital deaths is higher in Ealing (52.0%) than England (46.7%)

Figure 10: Place of death, Ealing, London & England, 2015



Source: Data collated from End of Life Care Profiles (ONS), 2016<sup>27</sup>

### 4.3.3 Place of death by age group

Tables A1-A3 (see Appendix 3) give greater detail about the location of death by age group in 2015.

The proportion of in hospital deaths in Ealing was higher among those aged 75-84 years compared to other age groups (Ealing 58% compared to England 50%).

The proportion of in hospital deaths has decreased over recent years. In Ealing this is most notable among people aged 85+, with a decrease from 59% (2011) to 49% (2015). In London the decrease among those aged 85+ over the same period was from 57% to 52%. The reduction in hospital deaths is in line with the national end of life care strategy. Further action is required to meet targets regarding people's wishes about where they would like to die and policy ambitions related to reducing the proportion of people who die in hospital.

<sup>27</sup> Data limitation: note that hospices situated within a hospital cannot be differentiated from the hospital itself. Hence, the number of deaths within a hospital will be an overestimate.

In Ealing the proportion of deaths in care homes is significantly lower among those aged 85+ (31%) compared to the national average (38%). National and international literature suggests that palliative care and end of life care provision for BME groups is often inadequate and that they are less likely to die at home or in a care home.

#### 4.3.4 Place of death by gender

There are continued gender variations in place of death in Ealing. In the period 2011-2013, higher proportions of female deaths continue to occur in care homes than for male deaths (18% vs. 11%). Higher proportions of male deaths also continue to occur in hospital and at home in comparison to female deaths. The higher proportion of care home deaths in females reflects the lower life expectancy in men.

#### 4.3.5 Place of death by underlying cause of death

In 2015 the main causes of death in Ealing were cancer (27%), cardiovascular disease, including heart disease, stroke and diabetes (28%) and respiratory disease (13%). The overall proportion of people who die from different causes and at different ages is not significantly different from the England average.

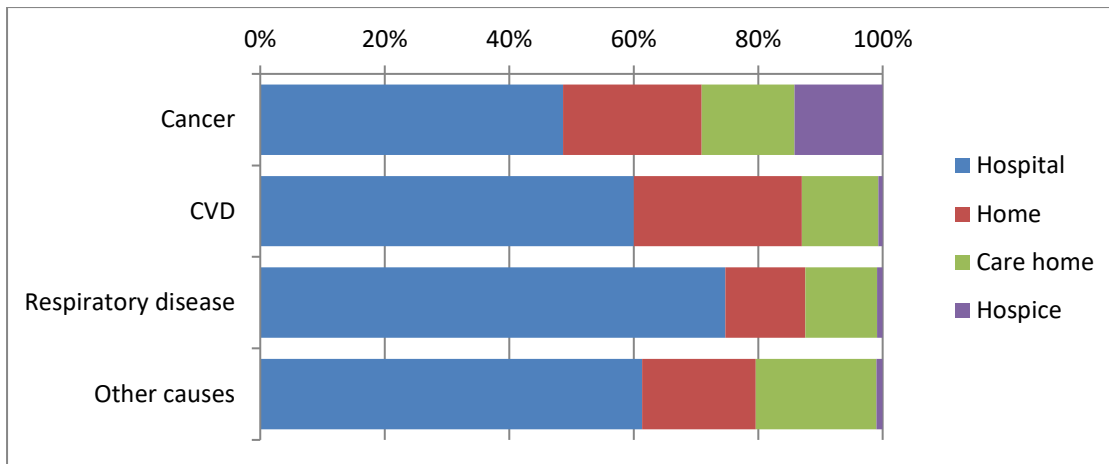
There are notable differences in the place of death for different underlying causes. Ealing differs from England by having:

- A lower proportion of people aged 75-84 who die from cancer compared to England (24 % vs 31%)
- A higher proportion of people aged 75-84 who die from cardiovascular disease compared to England (32% vs 27%).

The majority of both cancer and non-cancer deaths occur in hospital. In 2011-2013, the highest proportion of home deaths were among those who died from cardiovascular disease (26%) and cancer (22%) (Figure 11). People who died from respiratory disease were more likely to die in hospital (74%). This suggests an inequality in the end of life care services received for patient with different underlying cause of disease. It could be that the end of life phase in non-cancer patients is less predictable than is generally seen with cancer.

These findings may suggest that non-cancer services and commissioners could improve EoLC for their patient groups by learning from EoLC approach from cancer services.

Figure 11: Place of death by underlying cause for Ealing residents, 2011-2013

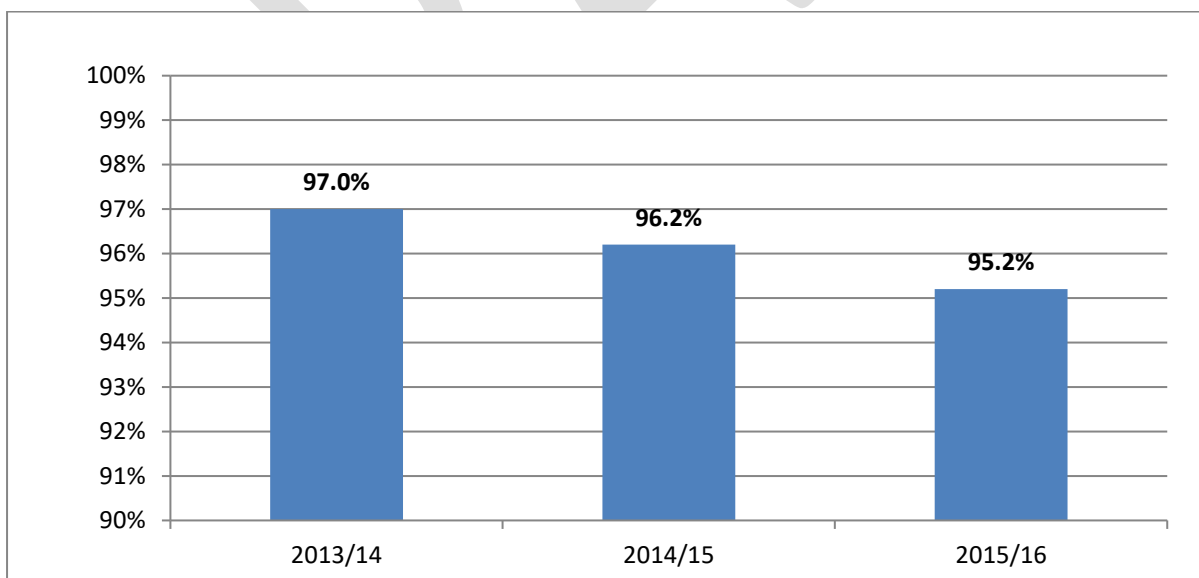


Source: The National End of Life Care Intelligence Network End of Life profiles, 2015

#### 4.3.6 Terminal hospital admissions

A terminal admission is a hospital admission that concludes with the patient dying in hospital. In recent years there has been a reduction in the proportion of terminal admissions that are emergency admissions (Figure 12).

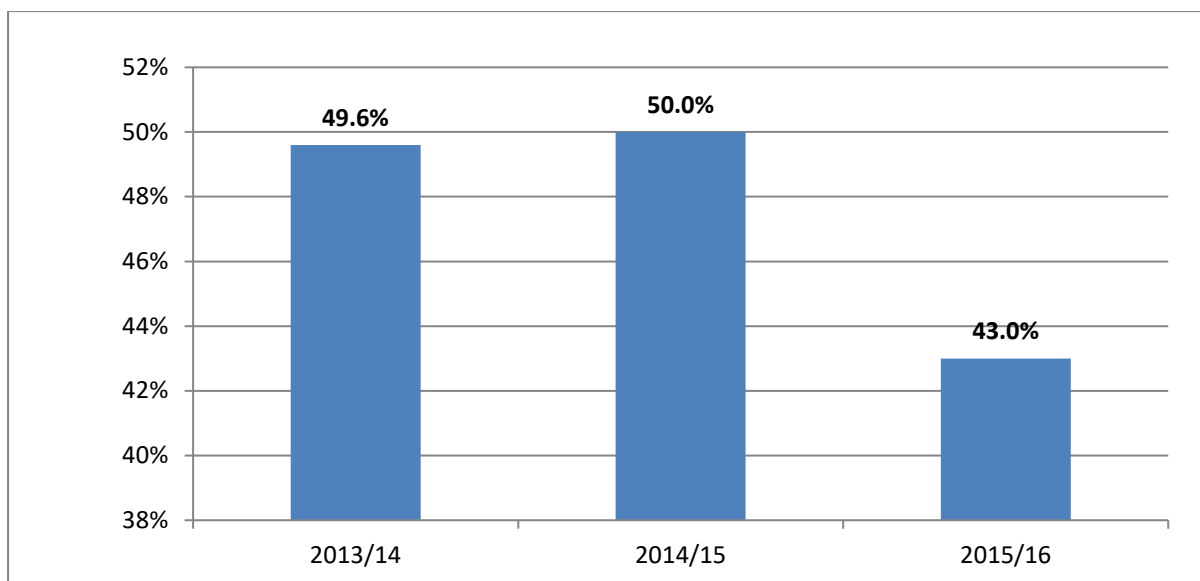
Figure 12: Proportion of terminal admissions that are emergencies



Source: SUS data, NHS Ealing CCG

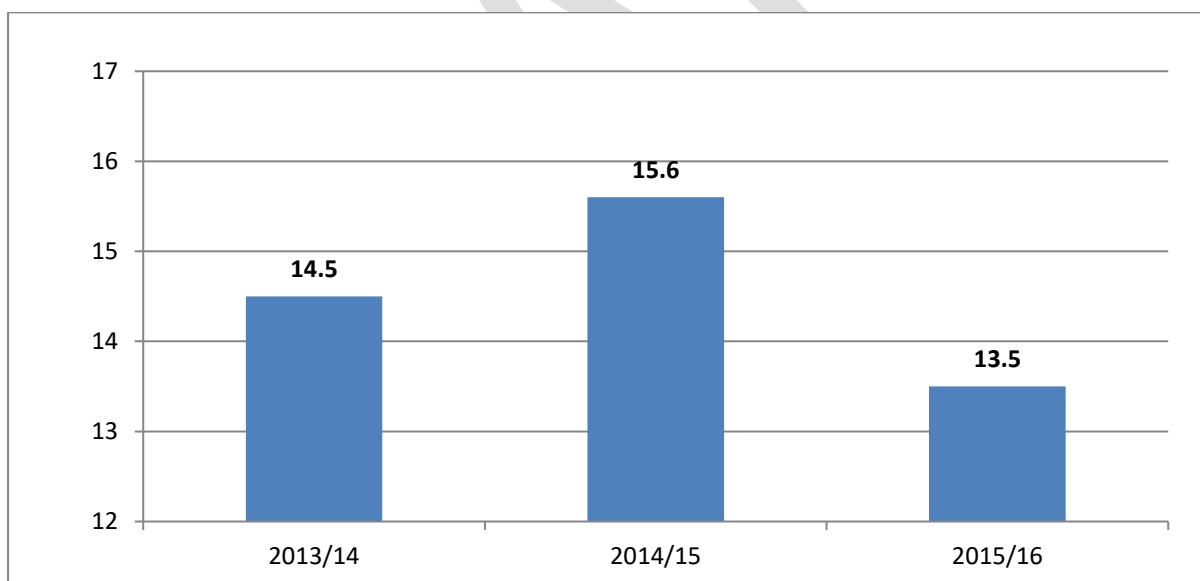
There have been reductions in the proportion of emergency admissions that last 8 days or longer and the average number of bed days per terminal admission (Figures 13 and 14).

Figure 13: Proportion of terminal admissions that are 8 days or longer



Source: SUS data, NHS Ealing CCG

Figure 14: Average number of bed days per admission ending in death



Source: SUS data, NHS Ealing CCG

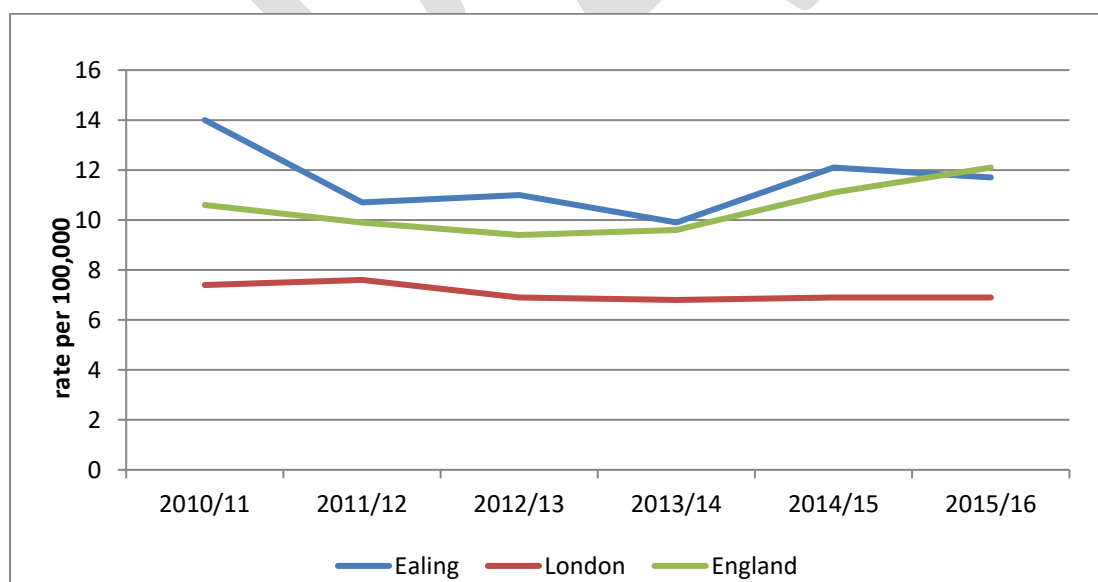
## 4.4 Delayed transfers of care

According to NHS England, a 'delayed transfer of care' occurs when an adult inpatient in hospital is ready to go home or move to a less acute stage of care but is prevented from doing so. Sometimes referred to as 'bed-blocking', delayed transfers of care are a problem for the NHS as they reduce the number of beds available to other patients who need them, as well as causing unnecessarily long stays in hospital for patients. Minimising delayed transfers of care and enabling people to live independently at home is one of the desired outcomes of social care.

Over the period 2010-11 to 2015/16 the trend in total delayed transfers of care has been similar to the trend in delayed transfers of care attributable to adult social care. The trend has seen a decrease between 2010/11 and 2013/14 followed by an increase over the last two years to 2015/16 (Figure 15 and Figure 17). The overall rate of delayed transfers of care in Ealing and England has been similar. In London the trend has been relatively flat and the overall rate has been consistently lower than Ealing and England.

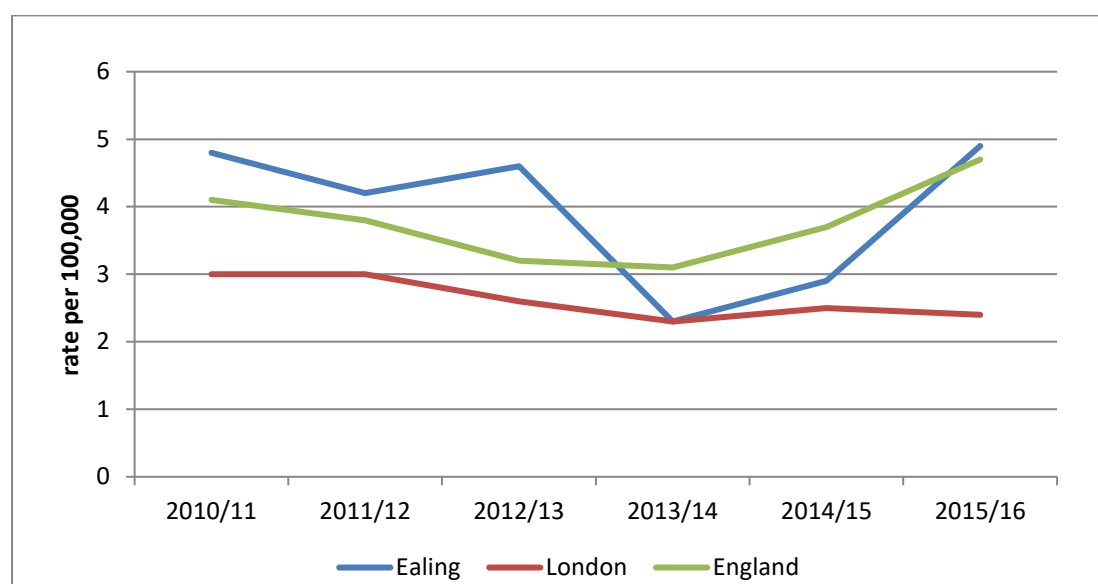
It should be noted that this is a broad system indicator and is not specific to end of life care services or patients using end of life care services.

Figure 15: Total delayed transfers of care per 100,000 persons aged 18+



Source: Department of Health (End of Life Care Profiles), 2016

Figure 16: Delayed transfers of care attributable to adult social care per 100,000 persons aged 18+



Source: Department of Health (End of Life Care Profiles), 2016

## 4.5 Care homes

Data obtained from the Care Quality Commission (CQC) shows that there are 56 care homes in the borough – down from 68 in 2012<sup>28</sup>. Ealing has fewer than the national average number of care homes per 1,000 population aged 75+ (3 compared to 3.8) and fewer beds (8.7 per 100 population aged 75+ compared to a national average of 10.4).

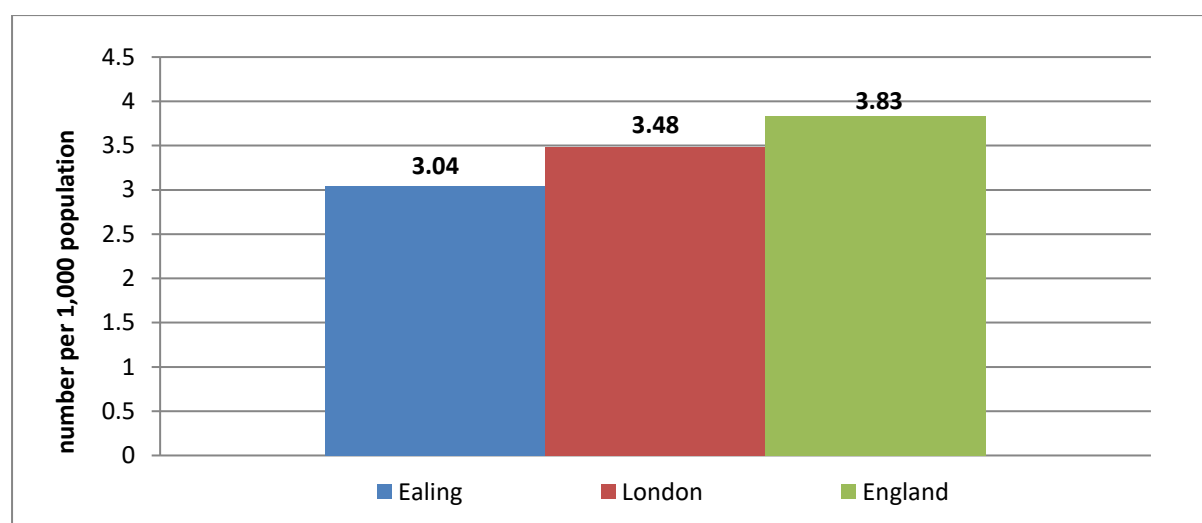
Table 5: Percentage of care homes achieving Gold Standard Framework, 2016

Ealing Number	Ealing Indicator value	London Number	London Indicator value	England Number	England Indicator value
3	5.4%	61	3.8%	350	2.1%

Source: CQC database at 27 October 2015 (received from CQC Data Request Team, April 2016)

<sup>28</sup> End of life Care Local Authority Profile – Ealing, National End of Life Care Intelligence Network, 2012.

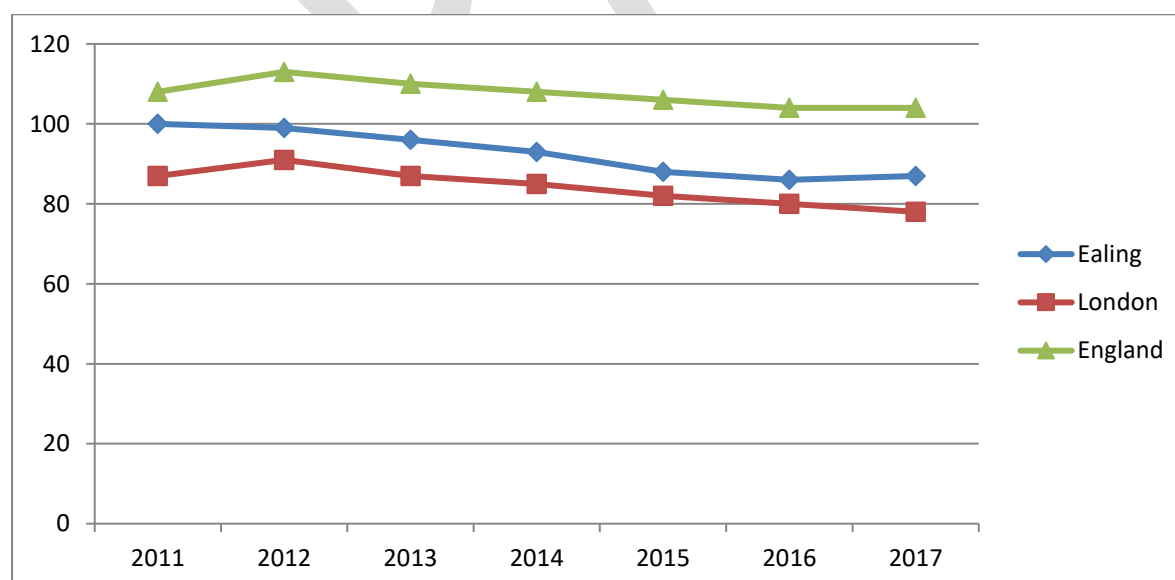
Figure 17: Number of care homes per 1,000 population aged 75+, 2016



Source: CQC Data Extract, April 2016, population figures based on ONS MYE2, 2014

Between 2011 and 2017, the number of care home beds in Ealing has dropped from 100 to 87 per 1,000 population aged 75+. This drop has been steeper over the last seven years than in London (from 87 to 78 beds per 1,000 population) or in England (from 108 to 104 beds) (Figure 18).

Figure 18: Number of care home beds per 1,000 population aged 75+, 2011-17



Source: Care Quality Commission (CQC) and ONS (End of Life Care Profiles), 2017



## 5 EoLC service provision

End of life care provision spans across a number of services, commissioning organisations, and delivery settings. A presentation of EoLC in Ealing, by the NHS Ealing CCG EoLC Clinical Lead summarises the community based EoLC service in Ealing across the health and social care landscape (Table 6).

Table 6: Community based Ealing EoLC services across health and social care

Specialist/ Generalist	Name of Service & Service Provider	Service Description/ Activity Level
Specialist	Specialist Palliative Care (SPC) Meadow House Hospice	<ul style="list-style-type: none"> <li>• In-patient Care</li> <li>• Day Hospice</li> <li>• Community Specialist Nursing Service</li> <li>• Palliative Medicine Consultant. Out-patient service</li> <li>• Out of hours Service</li> </ul>
Specialist	Marie Curie: Rapid Response Planned Nursing Care	<ul style="list-style-type: none"> <li>• Provision of flexible and responsive palliative nursing care at short notice to palliative patients in their home</li> <li>• Provision of specialist nursing care for patients at the end of life.</li> </ul>
Generalist	London North West Healthcare Trust (LNWH)	District Nursing Service –provides nursing care to housebound patients. The service is accessible via a Single Point of Access, 365 days a year from 8.30am until 11pm.
Generalist	Health	These include; <ul style="list-style-type: none"> <li>• GPs support</li> <li>• Community nursing care</li> <li>• Community Pharmacy</li> </ul>
Generalist	Ealing Integrated Intermediate Care Service - Homeward	Multi-agency service to provide intensive support to patients discharged from acute settings to enable them to recover at home, thereby preventing avoidable re-admission
Generalist	Social Care	These include; <ul style="list-style-type: none"> <li>• Care home Support</li> <li>• Domiciliary Care</li> <li>• Care Management</li> <li>• Social Care</li> </ul>
Generalist	Continuing Health Care (CHC)	CHC funding is used to ensure that patients with rapidly deteriorating conditions, who may be entering into terminal phase, are supported in their preferred place of care as quickly as possible via a fast track pathway and assessment

Source: Presentation by VT. EoLC Clinical Lead, NHS Ealing CCG (2016).

## 6 Gap analysis – can we do better?

The broad issues challenging health and social care systems with regards to end of life care services include:

- Increase in projected demand for services due to an increasing ageing population
- Meeting the gap between expressed need, as evidence by national surveys, in which patients expressed wishes regarding place of choice for end of life care and the current demand for EoLC services which in contrast highlight where patients are actually receiving end of life care.

Going forward, the quality makers for end of life will focus on identifying gaps in service delivery to support:

- NHS England Mandate objective and the vision in the North West London Strategic Transformation Plan that by 2020 there will be ***an increase in the number of people able to die in the place of their choice, including at home.***
- Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020<sup>29</sup> in all aspect of service delivery in Ealing. The framework sets out six ambitions for how care for those nearing death should be delivered at local level and eight principles which are the foundations to build and realise the ambitions.
- Government's response to the 'Choice Review'<sup>30</sup> including the six point 'End of Life Care Commitment'
- Access to person centred and whole system coordinated care
- Access to care 24/7 in the community setting and rapid Response via Single Point Access (SPA)
- Access to Anticipatory Medicine

### 6.1 Measuring and tackling inequalities

There are number of recognised inequalities in end of life service provision, as reported by the Care Quality Commission (CQC), and summarised in section 3.2. A recognised gap in this needs assessment is exploring and understanding the extent of local inequalities that exist amongst different groups and communities, and inequity that may exist within Ealing patients and residents accessing local EoLC service provision.

***Recommendation: Commissioners should review the reporting data they receive from community based specialist and generalist end of life care service***

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<sup>29</sup> <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

<sup>30</sup> [http://www.ncpc.org.uk/sites/default/files/CHOICE%20REVIEW\\_FINAL%20for%20web.pdf](http://www.ncpc.org.uk/sites/default/files/CHOICE%20REVIEW_FINAL%20for%20web.pdf)

*providers with an inequalities perspective, to consider whether particular vulnerable groups are able to equally access services.*

## 6.2 NICE Quality standards

There are a number of NICE quality standards that relate to end of life care services for adults as listed in the appendix. It is unclear to what extent NICE quality standards are being met locally or across the NWL sector.

NICE has reported the uptake of some of the adult end of life care service quality standards (1,2,3,6,7,13) using direct or proxy measures from national reports or audits. This highlighted some interesting findings for example, only 25% of people, audited in RCP EoLC Audit, dying in hospitals had documented evidence of discussion with their healthcare professional about their imminent death and less than half (42%) of people identified as approaching EOL has documented discussion of their physical, psychological, spiritual and cultural needs and preferences.

***Recommendation: Local commissioners and stakeholders to collectively review the NICE quality standards and consider how confident they are in that the quality standards are being met by local providers.***

## 6.3 Ealing EoLC service users expressed need

The *national* 2014 VOICES survey reports that more than 82% of respondents expressed a preference to die at home, with 8% preferring to die in a hospice, 6% in a care home, 3% in a hospital and 1% somewhere else.<sup>31</sup> However importantly individual preferences may change as death approaches, with fewer individuals wanting to die at home and more wanting to die in a hospice.<sup>32</sup>

It is important to note that we do not have a local survey for Ealing residents nearing the end of life to capture this group's preference with regards to EoLC such as preferred place of death. There are a number of limitations to applying these survey results to our local population including variation in both populations profile and services available.

There is a recognised gap in understanding the local expressed need of end of life care service users, carers and their families and friend.

***Recommendation: Commissioners of EoLC services should consider options to explore Ealing resident's and service user views and experiences of EoLC services to identify strengths and opportunities for improvement to support commissioning intentions and plans. Ealing Health Watch may wish to provide***

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<sup>31</sup> ONS (2015) National Bereavement Survey (VOICES), 2014  
<http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/2015-07-09>

<sup>32</sup> Sue Ryder (2013) A time and a place: what people want at the end of life

*commissioners and stakeholders an independent review of end of life care service available to Ealing patients and residents and additionally the service user perspective to consider of how inequalities can be addressed within each vulnerable group.*

## 6.4 Cost-effectiveness

Public Health England has recently published the following report: Cost-effective commissioning of end of life care, Understanding the health economics of palliative and end of life care (2017)

PHE commissioned Optimity Advisors to undertake the analysis, which involved the following: a consideration of the wider policy context to which this analysis contributes; a review of the available literature on the costs and effectiveness of different initiatives and schemes designed to improve patients and carers experiences at the end of the patient's lives; a health economic model designed to inform commissioners when making commissioning decisions.

There is an accompanying end of life care economic analytical tool for local use. The tool is aimed at end of life care programme leads and commissioners who are interested in health and social care interventions for patients at the end of their lives.

**Recommendation: NHS Ealing CCG EoLC commissioners should review the PHE End of life care economic analytical tool to inform strategic direction of travel for commissioning of EoLC service in Ealing**

<https://www.gov.uk/government/publications/end-of-life-care-economic-tool>

## 7 Action plans

### 7.1 Key ambitions

**The key ambitions for change for end of life care services, between 2015 and 2020, are set in North West London Sustainability Transformation Plan.**

The North West London Sustainability Transformation Plan (NWL STP) aims to improve health and wellbeing, care and quality and efficiency to balance the budget.

Improving the quality of care for people in their last phase of life, enabling them to die in their place of choice is one of the nine STP priorities, and relates to Delivery Area 3 Achieving better outcomes and experiences for older people:

- Commissioning services on an outcome basis from accountable care partnerships, using new contracting and commissioning approaches to change the incentives for providers
- Develop plans with partners to significantly expand pooled budgets and joint commissioning for delivery of integrated and out of hospital care, especially for older people services, to support the development of the local and NW London market
- Increasing the co-ordination of care, with integrated service models that have the GP at the heart
- Increasing intermediate care to support people to stay at home as long as possible and to facilitate appropriate rapid discharge when medically fit
- Identifying when someone is in the last phase of life, and care planning appropriately to best meet their needs and to enable them to die in the place of their choice

To improve care at the end of life, **the NWL STP has committed the sector to achieve**

By 2016/17:

- Improve identification and planning for last phase of life; - identify the 1% of the population who are at risk of death in the next 12 months by using advanced care plans as part of clinical pathways and 'the surprise test'
- identify the frail elderly population using risk stratification and 'flagging' patients who should be offered advanced care planning - patient initiated planning to help patients to self-identify
- Improving interoperability of Coordinate my Care with other systems (at least 4), including primary care to ensure that people get the care they want
- Reduce the number of non-elective admissions from care homes – demonstrate a statistically significant reduction in admissions and 0 day LOS (i.e. >10%)

By 2020/21:

- Every patient in their last phase of life is identified
- Every eligible person in NW London to have a Last Phase of Life (LPoL) care plan, with a fully implemented workforce training plan, and additional capacity to support this in the community.
- Meet national upper quartile of people dying in the place of their choice
- Reduce non elective admissions for this patient cohort by 50%

## 7.2 Current actions and planned actions

The CCG continue to work towards avoiding unwanted admissions to acute settings in the last phase of life to meet patients' choices and also to improve consistency and quality of care. To achieve the plan in the North West Sustainability Transformation Plan, the CCG will;

- Continue to provide enhanced support and clinical intervention in care homes to reduce unnecessary conveyance into acute setting if this is not the patients choice
- Continue to provide training and support in end of life care for staff who care for people at the last phase of life
- Develop and implement end of life pathway for crisis management.
- Continue to work with Coordinate My Care to ensure early identification and to create electronic care plan for patients at the end of life. This will ensure that patients' information is available in accessible format by key stakeholders.
- Continue to ensure rapid response and intermediate services are accessible to facilitate smooth discharges and to avoid unnecessary admission into acute settings.

## 7.3 Macmillan GP

A Macmillan GP role for Ealing has been funded by Macmillan Cancer Services to provide both cancer and end of life support in primary care. The role will support the vision to improve patients' outcomes and experience at the end of life.

The role will work alongside local GPs to;

- Provide peer support to fellow GPs
- Enhance knowledge and skills around the delivery of improved services for patients.

- Identify areas for improvement which could support early identification, intervention and proactive care in the both primary and community settings.

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## 8 Recommendations

1. Commissioners of EoLC services should consider opportunities to bring together a **stakeholder group or network to develop a locally shared vision and local plan to drive local delivery of the national six ambitions** as set out by the National Palliative and End of Life Care Partnership in the Ambition for Palliative and End of Life Care.
2. Local commissioners and stakeholders to collectively review the NICE quality standards (appendix 1) and consider how confident they are in that the quality standards are being met by local providers.
3. Local stakeholders should consider how EoLC service across Ealing **tackle nationally recognised inequalities** in particular for people living with a learning disability, people living with dementia, people who are homeless, people who are lesbian, gay, bisexual or transgender, people from gypsy or traveller communities and people from a black or minority ethnic group. This should include opportunities to implement CQC end of life care recommendations specific to each group as set out below.

### Overarching CQC recommendations to tackle inequalities in EoLC

- a) *Leaders of local health and care systems to **work together to develop a plan** for delivering good quality, equitable end of life care for everyone in their community.*
  - b) *Commissioners and providers to fulfil their duties under the NHS Constitution, the Health and Social Care Act 2012 and the Equality Act 2010 to **reduce inequalities, eliminate discrimination and advance equality** when developing, arranging or delivering end of life care.*
  - c) *Commissioners and providers to ensure that staff who care for people who may be approaching the end of life, including care home staff, have the **knowledge, skills and support** they need.*
  - d) *Hospices to **champion an equality-led approach**, engage communities, deliver equitable end of life care, and support others to do the same.*
  - e) *GPs to ensure that everyone with a life limiting progressive condition has the opportunity to have **early and ongoing conversations about end of life care**, and is given a **named care coordinator**.*
- Commissioners should review the reporting data they receive from community based specialist and generalist end of life care service providers



with an inequalities perspective, to consider whether particular vulnerable groups are able to equally access services.

- Commissioners of EoLC services should consider options to explore Ealing resident's and/or service user views and experiences of EoLC services to identify strengths and opportunities for improvement to support commissioning intentions and plans. These should also consider opportunities to explore inequalities or inequity that may relate to BME and other vulnerable groups including gypsy and traveller communities.
  - Health and social care professionals, providers and commissioners should be aware and utilise resources to address improve knowledge and information, and improve communication of EoLC in BME groups, and resources that promote understanding of religious or cultural sensitivity including the Faith at the End of Life resource.
  - Providers and commissioners of services for the homeless in Ealing should be aware of and utilise resources to support EoLC for homeless.
  - Health and social care providers of EoLC and palliative services and related services, should be aware of HLP recommendations to enable identification of homeless people approaching end of life and enable them to die in their preferred place of death.
  - Commissioners and providers of EoLC services should consider how services meet the needs of people living with dementia and their carers, including use of specific checklists such as the Hospice enabled dementia care – first steps checklists.
  - Commissioners should consider communication opportunities to raise awareness of end of life care issues and support available for people with living with dementia and their carers.
4. There is a recognised gap in understanding locally expressed need by end of life care service users, carers and their families and friend. Organisations such as **Ealing Health Watch may be able to provide commissioners and stakeholders an independent review of end of life care services** available to Ealing patients and residents and explore the service user perspective to consider of how inequalities can be addressed within each vulnerable group.
5. It would be beneficial for end of life care commissioners & analysts to explore the Public Health England (PHE) **end of life economic analysis tool** which provides an opportunity to review cost-effective commissioning of end of life care services.

## Appendix 1 - NICE quality statements

[Statement 1](#). People approaching the end of life are identified in a timely way.

[Statement 2](#). People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

[Statement 3](#). People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

[Statement 4](#). People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

[Statement 5](#). People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

[Statement 6](#). People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

[Statement 7](#). Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

[Statement 8](#). People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

[Statement 9](#). People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

[Statement 10](#). People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

[Statement 11](#). This statement has been removed and replaced by NICE's quality standard on [care of dying adults in the last days of life](#). For more details see [update information](#).

[Statement 12](#). The body of a person who has died is cared for in a culturally sensitive and dignified manner.

[Statement 13](#). Families and carers of people who have died receive timely verification and certification of the death.

[Statement 14](#). People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

[Statement 15](#). Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.

[Statement 16](#). Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

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## Appendix 2 - Public perceptions and experiences of community-based end of life care initiatives: A qualitative research report<sup>33</sup>

What is a community approach to end of life care?

The public health **community approach to end of life care** is concerned with social efforts led by a coalition of initiatives from governments, their state institutions, and communities, often in partnerships with health and other social care organisations, to improve health in the face of life-threatening/limiting illnesses, care giving and bereavement. These efforts may occur through public education, improvement of social capital (trust, empathy and cooperation) and community development, enactment of laws, partnerships with health services and their professionals, and the creation of safe and sustainable social and physical environments.

What is a compassionate community?

**Compassionate communities** are community development efforts that aims to accommodate death, dying, loss and care into our public health ideas, and to create supportive environments for those experiences; they may involve policies created by communities themselves in order to actively involve citizens in their own end of life care concerns. In doing so they change social environments, cultures, conduct, and attitudes towards end of life experiences and care.

Key findings emerging from this research include:

An **individual's journey** through this stage of life is affected by many things including their age and whether they have a condition that is considered terminal or one which is not e.g. dementia, COPD, neurological conditions. The concept of 'my local community' varies widely; this may impact upon on willingness to engage in community end of life initiatives and whether their local community is seen as a natural resource.

For **carers of people with terminal illness** an area of difficulty is not just attending to their own needs, but even in recognising that they have needs beyond getting through each day. Their lives feel consumed by caring for their loved one and their concerns are focused on the other person's needs, not their own. It is recognised that conversations and relationships are helped if there is an opportunity for frank and honest discussion about the future and end of life planning, although it is acknowledged that this is difficult across audiences and taboo surrounding this discussion is evident.

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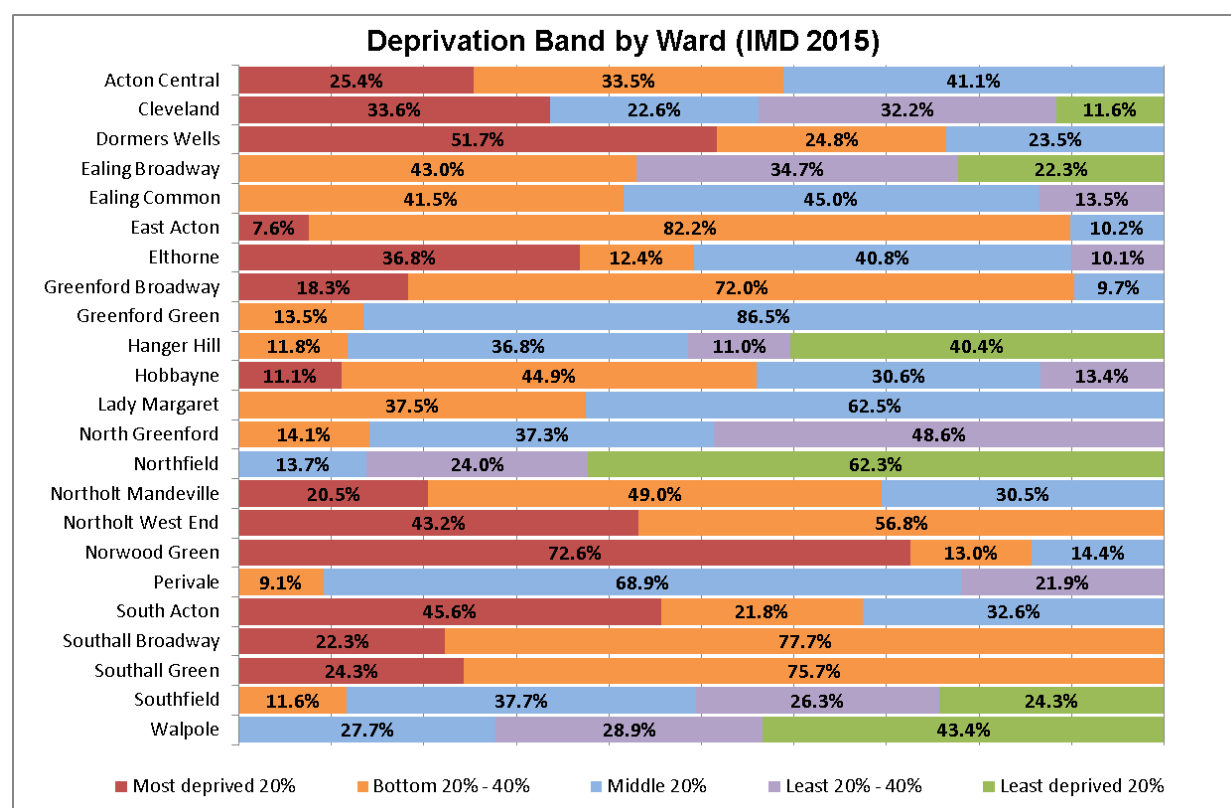
<sup>33</sup> Prepared for Public Health England by Solutions Research. June 2016

## **Expectations of care**

- The NHS is positively seen to provide medical care, and not usually expected or provide non-medical support eg emotional or practical support although signposting to such services is expected.
- Community initiatives can feel poorly signposted; knowledge about and access to community based support feels variable in particular for those people with dementia.
- The concept of community based care and support was welcomed although this was considered challenging in terms of how well this is understood and how this could be realised in different communities. Barriers to accessing such initiatives were reported as: acceptance of the situation, lack of awareness of availability, signposting (ideally from the NHS) is seen as crucial, logistical barriers such as pride and stigma. For patients with dementia trust and loss of dignity, variability of the condition which impact on social interaction are also reported.
- To encourage engagement older people such as new retirees or empty nesters are seen as natural volunteers to help in community-based initiatives. People who have previously been bereaved or previously been a carer are also seen as potential volunteers.

## Appendix 3 – Further tables and figures

**Figure A1: Deprivation Band by Ward (IMD 2015)**



**Table A1: Place of death by age at death for Ealing, 2015<sup>34</sup>**

Age at death	Hospital		Home		Care home		Hospice		Other		All	
	N	%	N	%	N	%	N	%	N	%	N	%
<65	191	50.7	105	27.9	13	3.4	30	8.0	38	10.1	377	19.7
65-74	157	49.8	92	29.2	39	12.4	23	7.3	4	1.3	315	16.4
75-84	319	58.2	108	19.7	97	17.7	20	3.6	4	0.7	548	28.6
85+	328	48.6	106	15.7	209	31.0	28	4.1	4	0.6	675	35.2
All	995	52.0	411	21.5	358	18.7	101	5.3	50	2.6	1,915	100.0

Source: Data collated from End of Life Care Profiles (ONS), 2016

<sup>34</sup> Data limitation: note that hospices situated within a hospital cannot be differentiated from the hospital itself. Hence, the number of deaths within a hospital will be an overestimate.

**Table A2: Place of death by age at death for London, 2015**

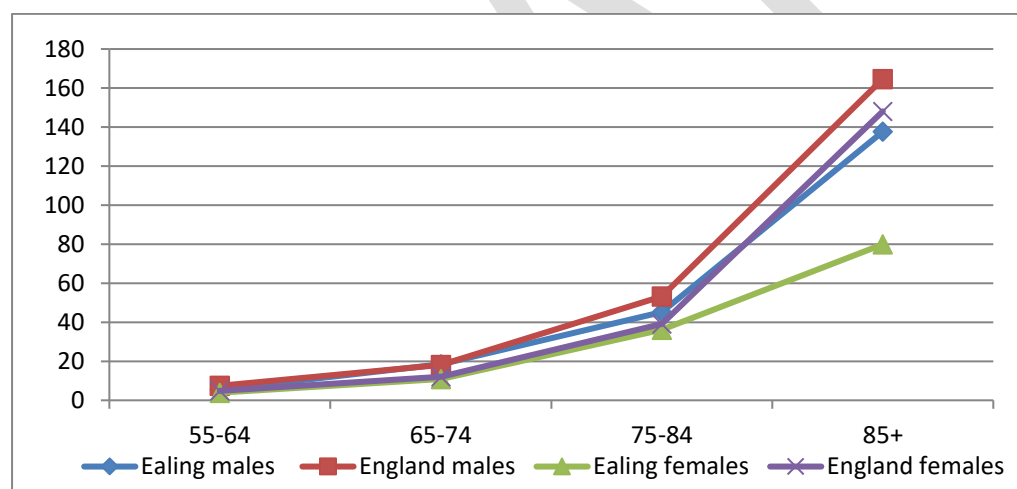
Age at death	Hospital		Home		Care home		Hospice		Other		All	
	N	%	N	%	N	%	N	%	N	%	N	%
<65	4,693	48.9	2,900	30.2	205	2.1	1000	10.4	790	8.2	9,588	19.1
65-74	4,255	53.6	2,186	27.5	549	6.9	800	10.1	154	1.9	7,944	15.8
75-84	7,930	57.2	3,038	21.9	1,817	13.1	892	6.4	176	1.3	13,853	27.6
85+	9,857	52.3	3,310	17.5	4,960	26.3	565	3.0	171	0.9	18,863	37.5
All	26,735	53.2	11,434	22.8	7,531	15.0	3,257	6.5	1,291	2.6	50,248	100.0

Source: Data collated from End of Life Care Profiles (ONS), 2016

**Table A3: Place of death by age at death for England, 2015**

Age at death	Hospital		Home		Care home		Hospice		Other		All	
	N	%	N	%	N	%	N	%	N	%	N	%
<65	33,123	45.5	24,574	33.7	2,135	2.9	7,714	10.6	5,285	7.3	72,831	14.8
65-74	38,719	48.9	24,231	30.6	6,650	8.4	7,983	10.1	1,614	2.0	79,197	16.0
75-84	71,683	50.4	32,930	23.2	27,657	19.5	8,029	5.6	1,848	1.3	142,147	28.8
85+	87,171	43.7	30,935	15.5	75,296	37.8	3,989	2.0	1,932	1.0	199,323	40.4
All	230,696	46.7	112,670	22.8	111,738	22.6	27,715	5.6	10,679	2.2	493,498	100.0

Source: Data collated from End of Life Care Profiles (ONS), 2016

**Figure A2: Mortality rate per 1,000 population, Ealing, England, 2015**

Source: VS Tables, Mortality Data 2015 & ONS MYE 2015