Harrow
JSNA Online

PUBLIC HEALTH REPORT

PALLATIVE AND END OF LIFE CARE

Harrow Palliative and End of Life Care JSNA - 2019

Introdution

Every year, over half a million people die in England and Wales, almost half of these in a hospital setting. The national End of Life Care Strategy1 published in 2008 provides a framework on which local health and social care services to build end of life care (EoLC). Following the Neuberger review, More Care, Less Pathway, 2013, and the phasing out of the Liverpool Care Pathway (LCP)2, the Leadership Alliance published 'One Chance To Get It Right, 2014'3, setting out the five priorities for care of the dying person.

The Priorities for Care are that, when it is thought that a person may die within the next few days or hours:

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

The patient-centred development of an individualised care plan is central to the guidance. The 'NHS Long Term Plan, 2019[4]' places a continuing emphasis on personalisation of end of life care to enable people's choices on type of care and location to be supported. In England and Wales round a quarter of a million people die in hospital each year and, the National Audit of Care at the End of Life

[1] End of Life Care Strategy - Promoting high quality care for all adults at the end of life, DoH, 2008. Online available from: https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life (Last accessed: 22-10-2019)
[2] https://www.nhs.uk/news/medical-practice/new-guidelines-on-end-of-life-care-published-by-nice/
[3] Leadership Alliance for the Care of Dying People, 'One Chance to get it right', 2014, Online available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf [Last accessed: 22-10-2019]
[4] NHS, NHS Long Term Plan, 2019. Online available from: www.longtermplan.nhs.uk [Last accessed: 22-10-2019]

(NACEL), 2018/19[5] results suggest 75% of bereaved people feel that this was the right place for the person important to them to die. The audit 2018/19 reviews how people's preferences regarding care at the end of life are identified, discussed and implemented during their last admission in acute and community hospitals.

Much work has been done to improve and deliver robust and appropriate end of life care across North West London including Harrow. Care Quality Commission (CQC) 'End of Life Care-Quality report' for London North West Healthcare NHS Trust, 2019 (not published yet) indicates that Hospice for Evidencing that Single Point of Access (SPA) working with London Ambulance Service (LAS) has increased EoLC patients avoiding transfer to hospital in an emergency to 82% (Presentated at Hospice UK Conference 2019). The report also states that Harrow integrated care programme has already improved patient experience by Innovating a new transferable drug administration record between hospital and community High access to hospice beds for dying patients. It continues that Harrow integrated care programme has ambitions to increase identification and care planning for people in the last phase of life.

Deaths from respiratory diseases: variation in place of death[6]

Patients with advanced respiratory diseases have a very high symptom burden near end of life, with a particularly high prevalence of breathlessness, fatigue, anxiety and depression. There is evidence that the symptom burden is even higher for those with advanced non-malignant respiratory diseases (such as chronic obstructive pulmonary disease (COPD) and interstitial lung disease (ILD) than for those with advanced lung cancer. The benefits of palliative care are very well recognised for patients with advanced lung cancer, with improvements in quality of life and even increases in survival when introduced early in the disease trajectory. There is also a strong body of evidence on the benefits of palliative care for patients with COPD and ILD, including a possible survival benefit, although this is less widely known.

There is limited data at national level on access to palliative care and good quality end of life care for patients with advanced respiratory diseases. A commonly used indicator of choice at end of life is place of death, with evidence that with good advanced care planning patients are more likely to die in their preferred place.

General surveys have found that home is the preferred plac of death for most people,[7] but there is limited evidence on where patients with specific diseases, including advanced respiratory diseases, would prefer to die. In a small study from Denmark,[8] home or hospice were the most common

[5] National Audit of Care at the End of Life, First round of the audit (2018/19) report, England and Wales. Online available from https://www.hqip.org.uk/wp-content/uploads/2019/07/National-Audit-of-Care-at-the-End-of-Life-National-Report-2018-FINAL.pdf [Last accessed: 21-10-2019]

[6] PHE, 2019, The 2nd Atlas of variation in risk factors and healthcare for respiratory disease in England

[7] Gomes B, Calanzani N and Higginson I (2011) Local preferences and place of death in regions within England 2010 [Last accessed 23-10-2019]

[8] Skorstengaard M, Neergaard M, Andreassen P and others (2017) Preferred Place of Care and Death in Terminally Ill Patients with Lung and Heart Disease Compared to Cancer Patients J Palliat Med 20(11) doi: 10.1089/jpm.2017.0082 [Last accessed 23-10-2019]

preferred places of death for terminally ill patients with both non-malignant respiratory diseases (COPD and ILD) and cancer (41.2% and 35.8% for home and 40.7% and 33.3% for hospice respectively). However, those with nonmalignant respiratory diseases were more likely to choose hospital as a preferred place to die than those with cancer (9.8% vs 1.2%).

As shown in Table 1 (adapted from PHE, 2019)[9], there are significant differences in place of death for patients with lung cancer, COPD and ILD. At national level, 33.0% of lung cancer patients die at home and 37.1% die in hospital, compared with 23.4% and 61.1% for patients with COPD, and 22.1% and 64.4% for those with ILD. This reflects the situation internationally.

Table 1 Number of deaths by recorded main cause of mortality by place of death, England, 201-7

Respiratory Condition	Hospital	Home	Care Home	Hospice
COPD	61.1%	23.4%	12.9%	1.6%
ILD	64.4%	22.1%	8.5%	4.2%
Lung Cancer	37.1%	33.0%	12.3%	15.9%

Source: PHE, 2019, The 2nd Atlas of variation in risk factors and healthcare for respiratory disease in England

A study across 14 countries showed that in almost all countries patients with COPD and ILD were significantly more likely to die in hospital, and less likely to die at home or in a palliative care institution, than those with lung cancer.[10] This study also found that the presence of co-morbidities and deprivation were independent risk factors for dying in hospital, with stronger effects for those with ILD than COPD.

There are several potential reasons why patients with COPD and ILD are more likely than those with lung cancer to die in hospital. Predicting time to death is more difficult in patients with COPD and ILD, and aggressive treatment can lead to reversal of an acute exacerbation even when a patient could be near end of life[11]. In England, the median age at death for lung cancer patients is 74 years, both COPD and ILD patients have a median age at death of 80 years. However, there is also considerable evidence that despite their higher symptom burden, and the recommendations in national and international guidelines, patients with COPD and ILD have much poorer access to palliative care.

For all patients with advanced respiratory disease, good quality palliative care should be initiated early and address the holistic needs of patients and their families, and will require appropriate community resources to support patients who prefer to die at home.

9

10 Cohen et.al. (2017) Differences in place of death between lung cancer and COPD patients: A 14-country study using death certificate data. Online available form: *https://www.ncbi.nlm.nih.gov/pubmed/28258277* [Last accessed 23-10- 2019]

11 Claessens M, et.al. (2000) Dying with lung cancer or chronic obstructive pulmonary disease: Insights from SUPPORT. Online available from: *https://www.ncbi.nlm.nih.gov/pubmed/10809468* [Last accessed 23-10-2019]

Place of Death

Over half a million people die in England each year: approximately half of these deaths occur in hospital, approximately 40% of deaths are either in a person's own home or in a residential care home (these two settings combined are referred to as deaths "in usual place of residence"-DiUPR), and fewer than 10% of deaths occur in a hospice, although hospice services are often involved in supporting many more dying people and their families through the activity of hospice and hospital community outreach teams. In England in 2013:

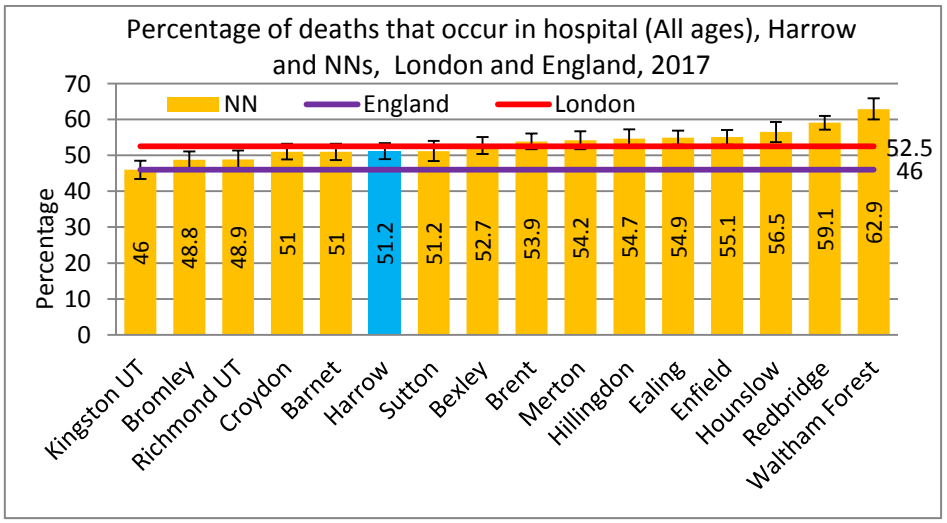
- 48.3% of all deaths occurred in hospital;
- 44.5% of all deaths occurred at a person's usual place of residence, but in nearly one-quarter of CCGs, less than 40% of people died at their usual place of residence;
- 5.5% of all deaths occurred in a hospice.

If possible, people should have the opportunity to die in a place of their choosing. Survey results suggest that many people would, given the choice and right circumstances, prefer to die at home, and fewer people wish to die in hospital.

In England in 2013, 84% of deaths were in people aged 65 years or older; elderly patients are more likely to be suffering from multiple morbidities at death. People should be admitted to hospital on the basis of need, regardless of factors such as age or frailty alone[12].

Death in Hospital: The total number of death in Harrow that occurred in 'Hosptial' During 2017 was 763 from which 571 (88%)were 65 years old and over and 92 (12%) were under 65 years old. Harrow's rate was similar to London but significantly higher than the England average rate at 46% (Fig 1).

Fig 1 Percentage of deaths that occured in hospital (All ages), Harrow and NNs, London and England, 2017

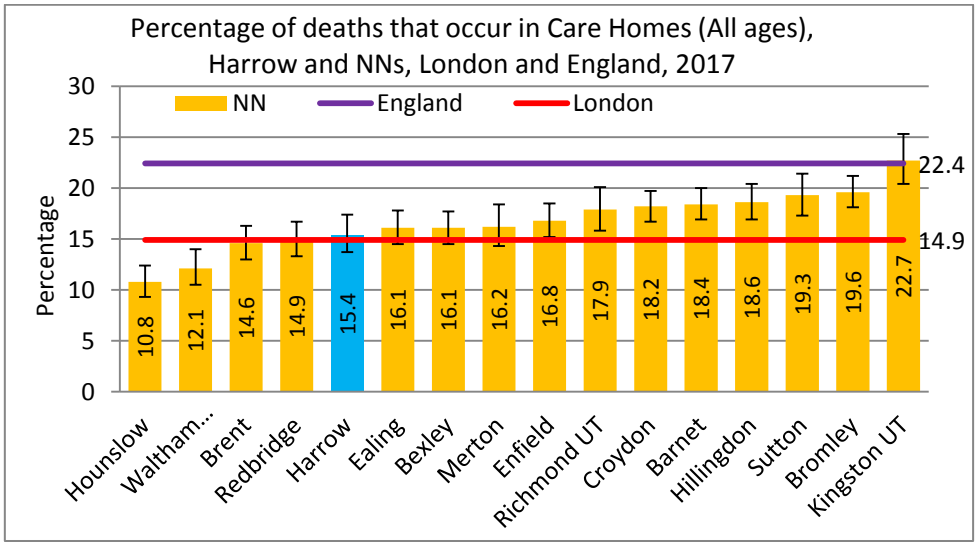


Source: PHOF

[12] PHE, Atlas_2015_EndofLife , documents, Online, available from: https://fingertips.phe.org.uk [Last accessed: 29/10/2019]

Death in Care Home: The total number of death in Harrow that occurred in 'Care Home' During 2017 was 230 (15.4% of the total death) from which 222 (96.5%) were 65 years old and over and 8 (3.5%) were under 65 years old. In 2017, Harrow had the fifth lowest rate of deaths in hospital between NNs, it was similar to London (14.9%)but significantly lower than the England average rate of 22.4% (Fig 2).

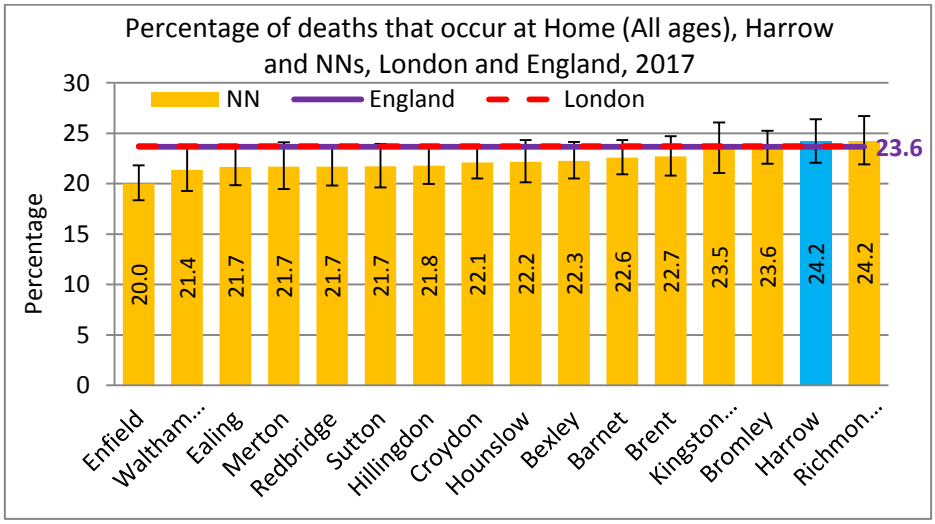
Fig 2 Percentage of deaths that occured in Care homes (All ages), Harrow and NNs, London and England, 2017



Source: PHOF

Death at Home: The total number of death in Harrow that occurred at 'Home' During 2017 was 360 (24.2% of the total death)from which 283 (79%) were 65 years old and over and 77 (21%) were under 65 years old. In 2017, Harrow had the 2nd highest rate of deaths occurred at home between NNs, it was similar to the London and England average rate of 23.8% and 23.6% respectively (Fig 3).

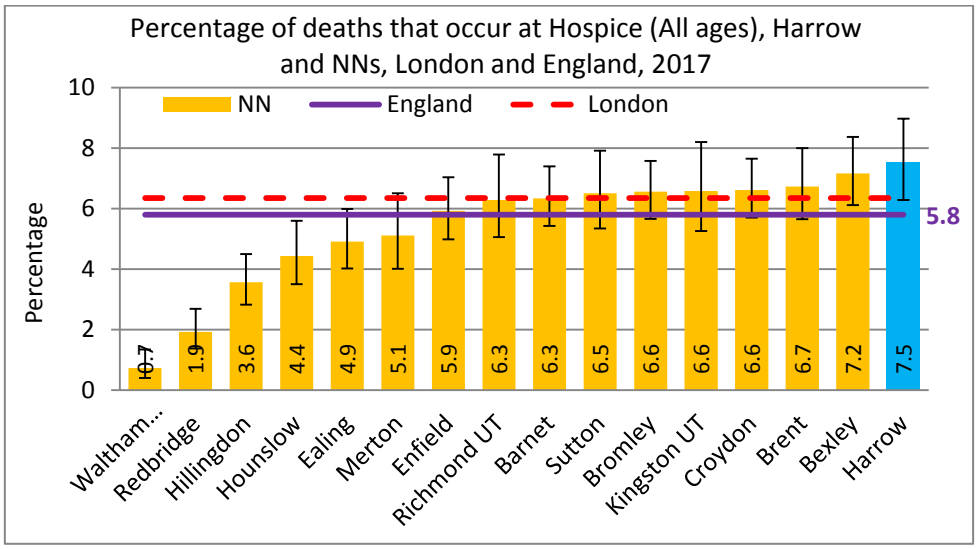
Fig 3 Percentage of deaths that occured at home (All ages), Harrow and NNs, London and England, 2017



Source: PHOF

Death at Hospice: The total number of death in Harrow that occurred at 'Hospice' During 2017 was 112 (7.5% of the total death)from which 70 (62%) were 65 years old and over and 42 (38%) were under 65 years old. In 2017, Harrow had the highest rate of deaths occurred at hspice between NNs, it was similar to London (6.3%) but significantly higher than the England average rate of 5.8% (Fig 4).

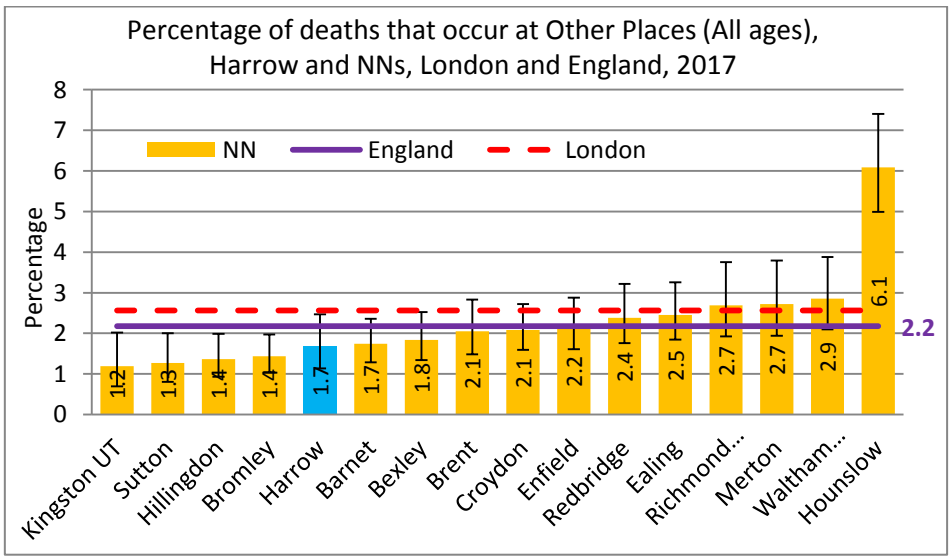
Fig 4 Percentage of deaths that occured at hospice (All ages), Harrow and NNs, London and England, 2017



Source: PHOF

Other places: The total number of death in Harrow that occurred at 'Other Place' During 2017 was 25 (1.7% of the total death) from which 6 (24%) were 65 years old and over and 19 (76%) were under 65 years old. In 2017, Harrow had the 5th lawest rate of deaths occurred at hspice between NNs, significanlty lower than London (6.3%) but similar to the England average rate of 2.2% (Fig 5).

Fig 5 Percentage of deaths that occured at hospice (All ages), Harrow and NNs, London and England, 2017

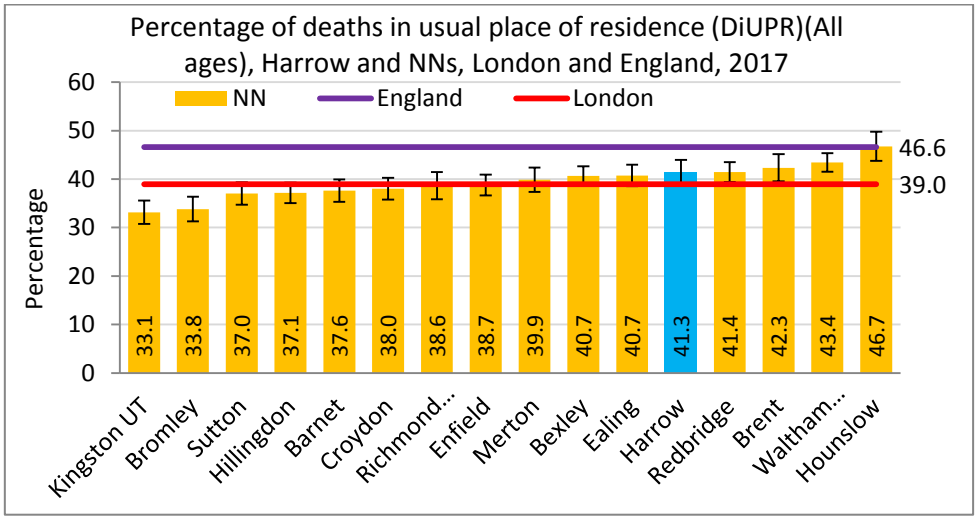


Source: PHOF

Death in Usual Place of Residence (DiUPR) by underlying cause of death

All causes: From the total number of recorded deaths in 2017 in Harrow at UPR, 578 (87.4%) were aged 65 and over and 73 (12.6%) were under 65 years old. The percentage of death in Harrow that occurred in UPR in 2017 was 41.3%, the fifth highest between NNs, significantly higher than London average of 39% but lower than the England average of 46.6% (Fig 6).

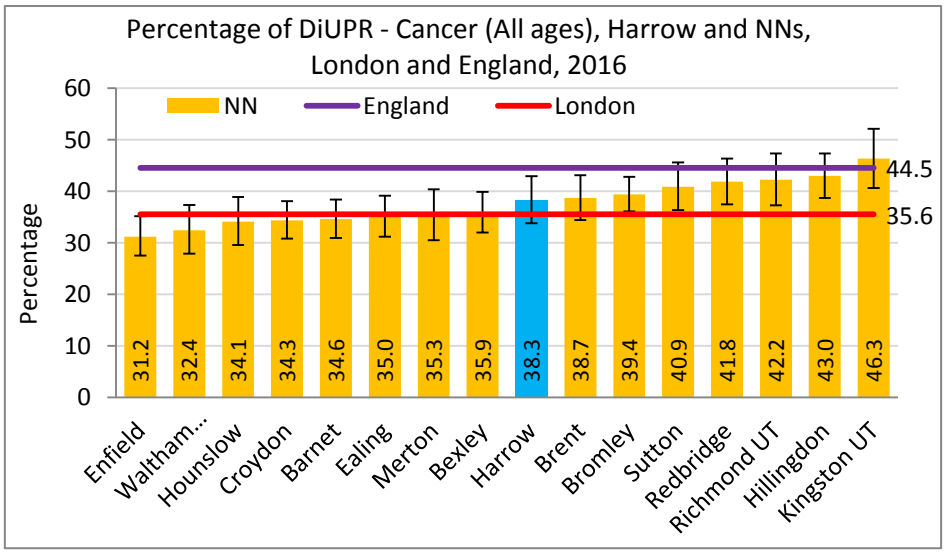
Fig 6 Percentage of deaths in usual place of residence (DiUPR)(All ages), Harrow and NNs, London and England, 2017



Source: PHOF

Cancer: From 426 recorded number of cancer deaths in 2017 in Harrow, 163 (38.3%) occured in their UPR. Harrow's rate was similar to the London average but significantely lower than England average of 44.5% (Fig 7).

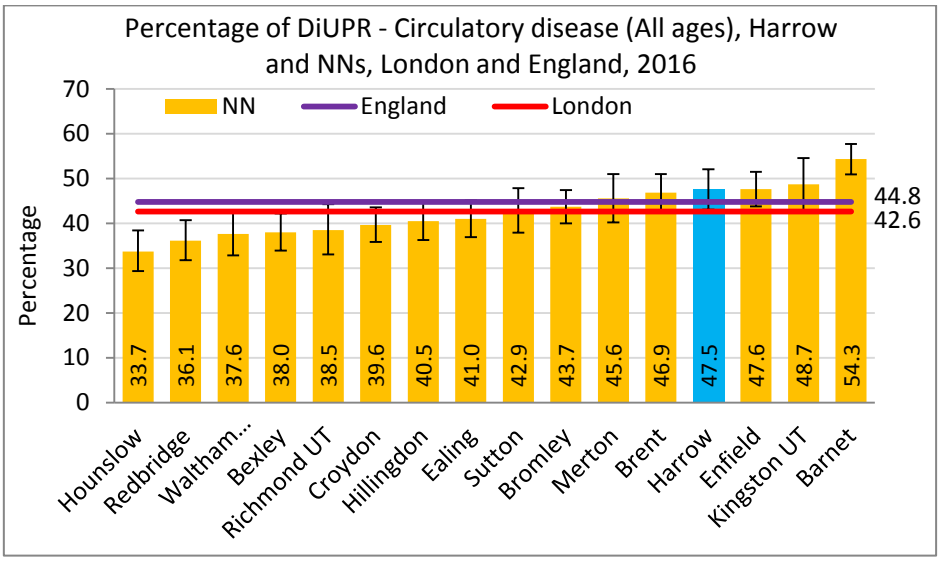
Fig 7 Percentage of cancer deaths in UPR (all ages), Harrow and NNs, London and England, 2017



Source: PHOF

Circulatory Disease: From 469 recorded number of circulatory disease deaths in 2017 in Harrow, 223 (47.5%) occured in their UPR. Harrow's rate of 47.5% was the 4th highest between NNs and similar to the average rate of London and England 42.6% and 44.8% respectively (Fig 8).

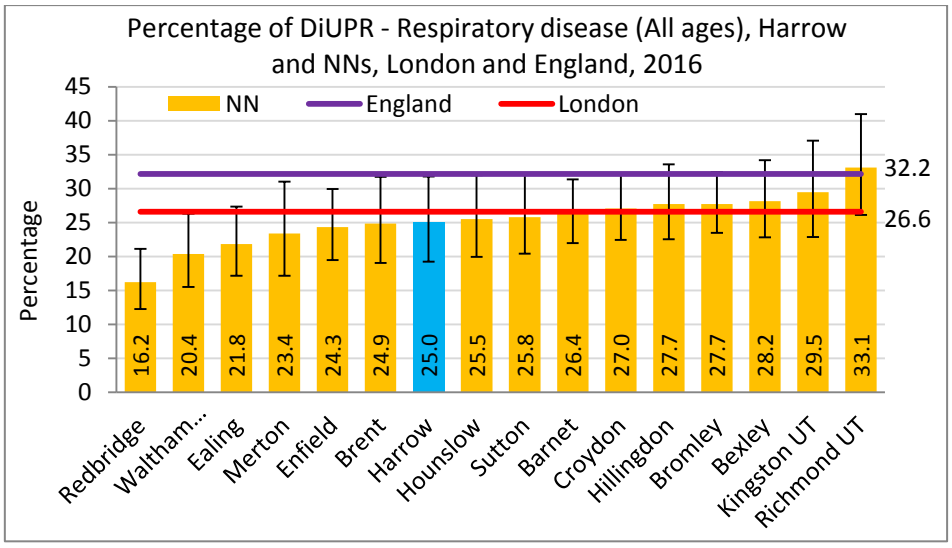
Fig 8 Percentage of circulatory disease deaths in UPR (all ages), Harrow and NNs, London and England, 2017



Source: PHOF

Respiratory Disease: From 180 recorded number of respiratory disease deaths in 2017 in Harrow, 45 (25%) occured in their UPR. Harrow's rate was not significantly different from average rate of London and England (26.6% and 32.2% respectively) (Fig 9).

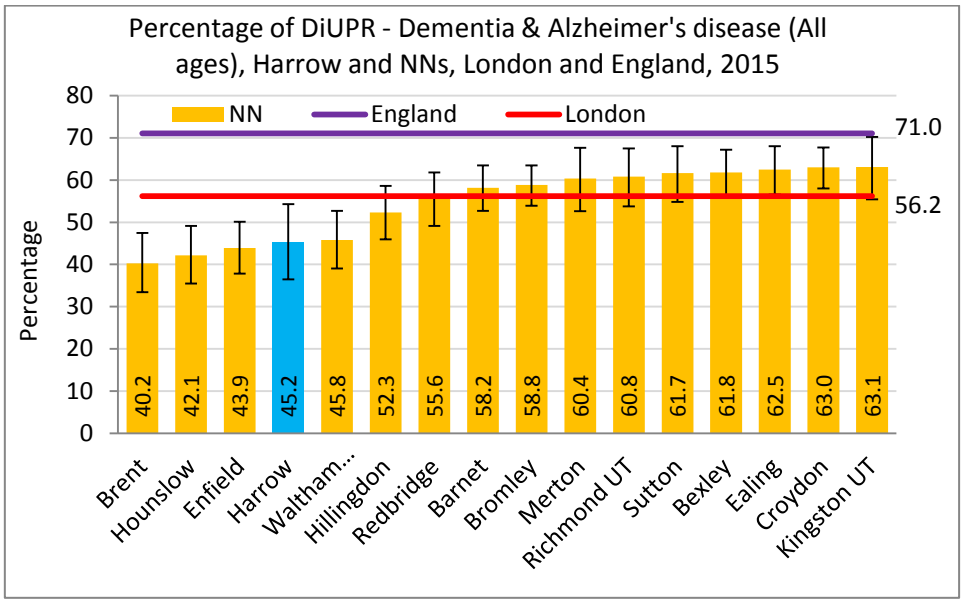
Fig 9 Percentage of respiratory disease deaths in UPR (all ages), Harrow and NNs, London and England, 2017



Source: PHOF

Dementia and Alzheimer's Disease: From 115 recorded number of deaths with underlysing causes of dementia and alzheimer's disease in 2017 in Harrow, 52 (45.2%) occured in their UPR. Harrow's rate was the 4th lowest between NNs, also significantly lower than the average rate of London and England (56.2% and 71% respectively) (Fig 10).

Fig 10 Percentage of respiratory disease deaths in UPR (all ages), Harrow and NNs, London and England, 2017 52 out of 115

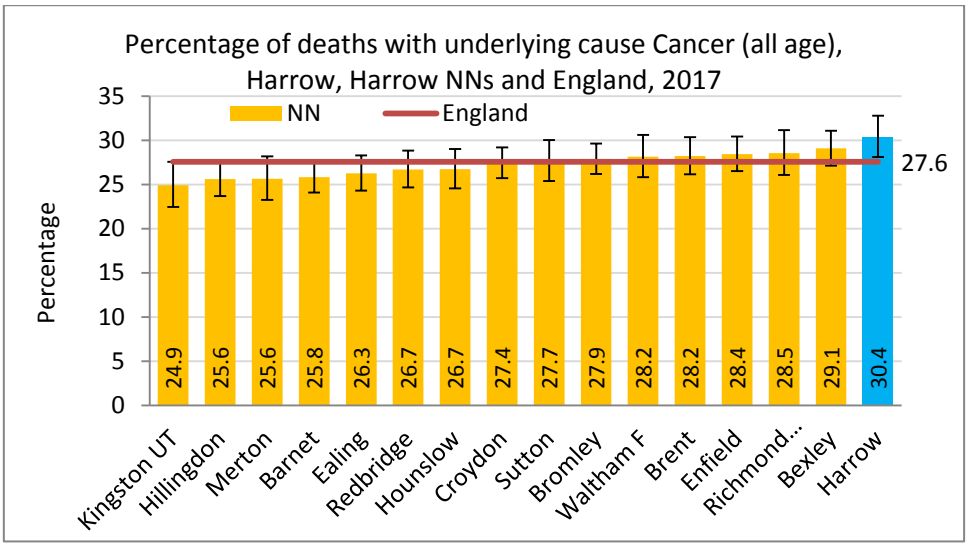


Source: PHOF

Underlying cause of death

Cancer: In 2017 the number of death in Harrow with underlying cause of cancer was 453 (30.4% of the total death). Harrow had the highest rate between all NNs and significantly higher than the England average rate of 27.6% (Fig 11).

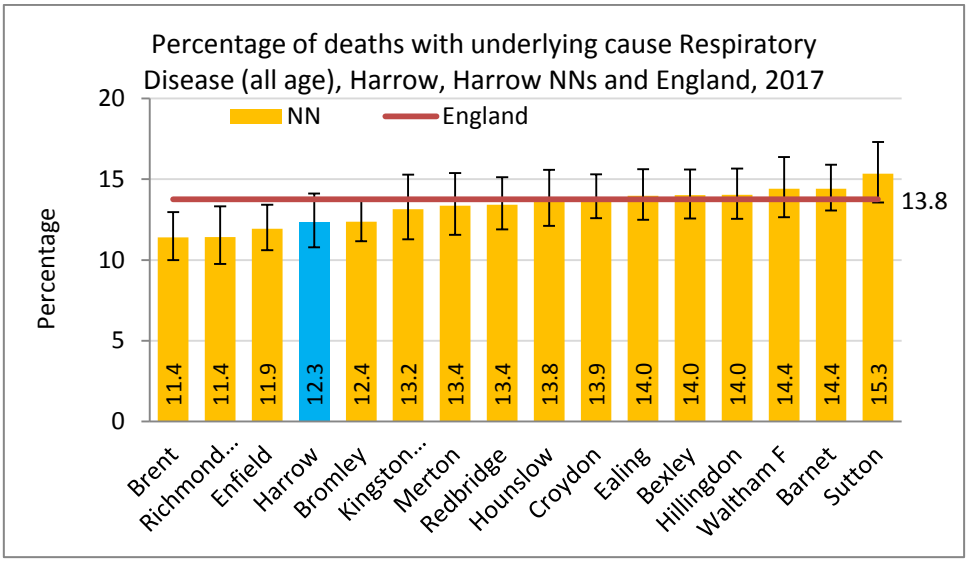
Fig 11 Percentage of deaths with underlying cause of cancer (all age), Harrow, NNs and England, 2017



Source: PHOF

Respiratory Desease: In 2017 the number of death in Harrow with underlying cause of respiratory disease was 184 (12.3% of the total death). Harrow had the 4th lowest rate between all NNs, also not significantly different to the England averagerate of 13.8% (Fig 12).

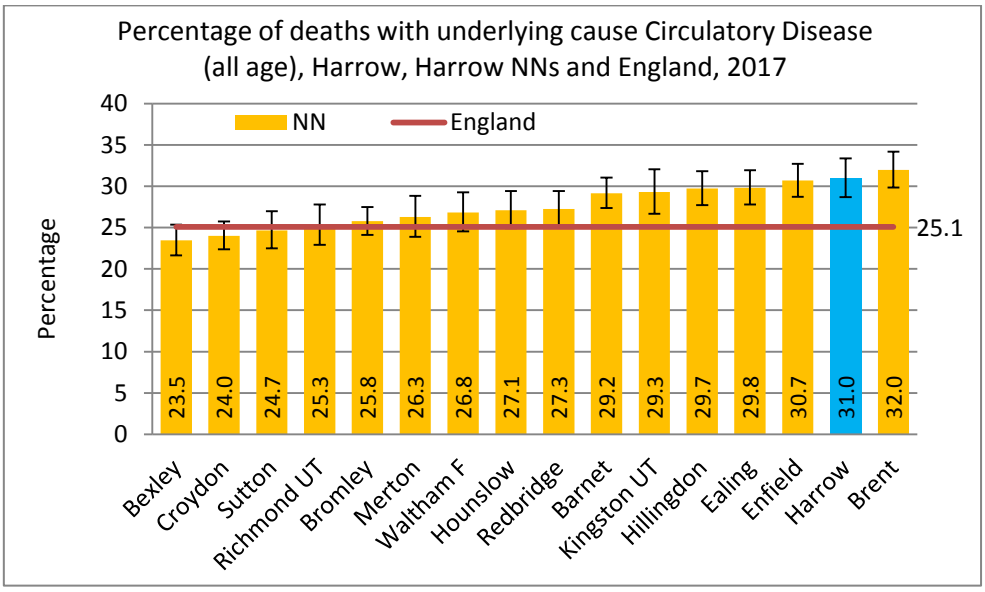
Fig 12 Percentage of deaths with underlying cause of respiratory disease (all age), Harrow, NNs and England, 2017



Source: PHOF

Circulatory Disease: In 2017 the number of death in Harrow with underlying cause of circulatory disease was 462 (31% of the total death). Harrow had the 2nd highest rate between all NNs, also significantly higher than the England average rate of 25.1% (Fig 13).

Fig 13 Percentage of deaths with underlying cause of circulatory disease (all age), Harrow, NNs and England, 2017



Source: PHOF

Options for action[13]

Commissioners and providers should review these maps and underlying data in combination with local data on the incidence of lung cancer, the prevalence of COPD and ILD, and quality metrics for patients with these conditions, with particular emphasis on the availability of:

• early access to palliative care services for all patients with advanced respiratory diseases, including fatigue and breathlessness services

• integrated respiratory disease/palliative care services for patients with COPD and ILD

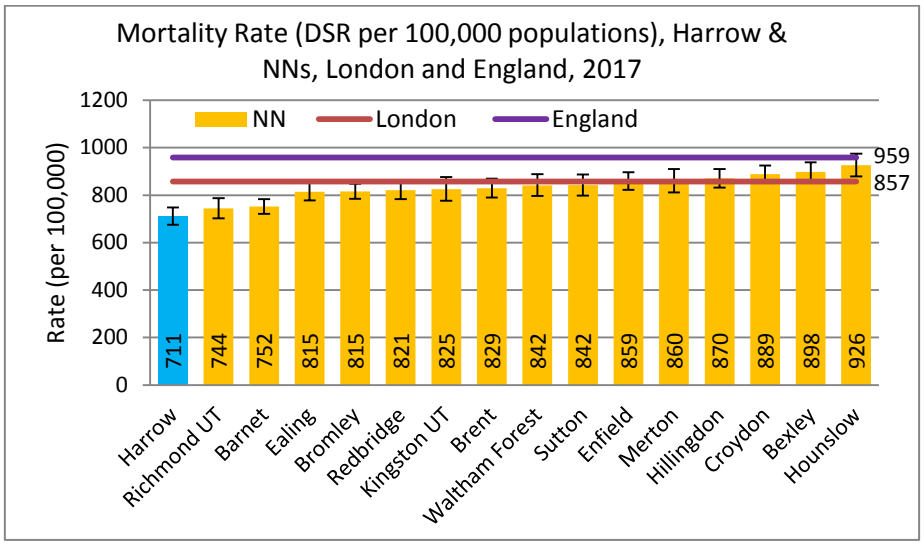
• access to end of life care services, including hospices

• services for those at highest risk of poor access, especially those with co-morbidities and living in and living in areas of deprivation

Mortality: Harrow directly standarised mortality rate per 100,000 of population in 2017 was 711, the lowest rate between all NNs and significantly lower than the London average of 857 also England average of 959 (Fig 14).

[13] PHE, 2019, The 2nd Atlas of variation in risk factors and healthcare for respiratory disease in England

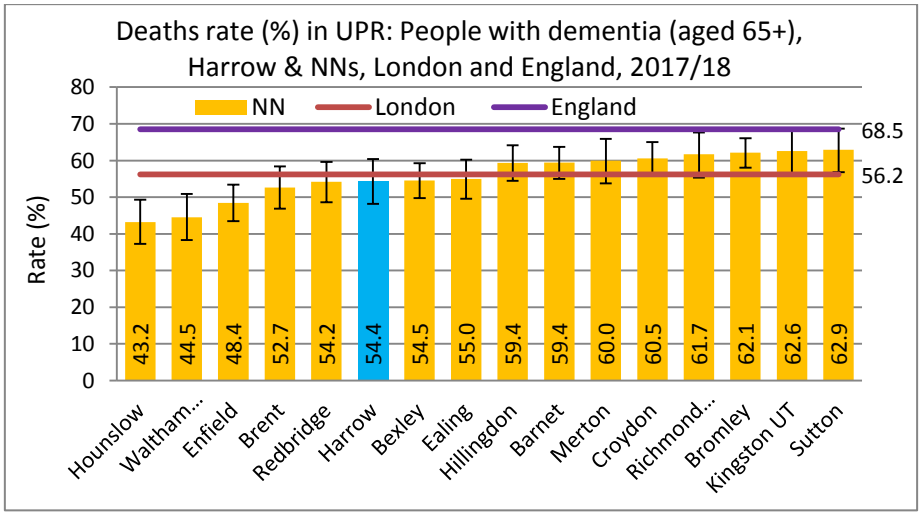
Fig 14 Mortality Rate (DSR per 100,000 populations), Harrow & NNs, London and England, 2017



Source: PHOF

Dementia: Recorded prevalence of DiUPR, people with dementia (aged 65 years and over) for Harrow, Nearest neighbours, London and England in 2017/18 is presented in Fig 15. Graph shows the rate of people with dementia who died in UPR during 2017/18 was 54.4%, slightly (not significantly) lower than London average of 56.2% but significantly lower than the England average of 68.5% (Fig 15).

Fig 15 Deaths in Usual Place of Residence: People with dementia (aged 65 +), Harrow, 2 NNs, London and England, 2017/18

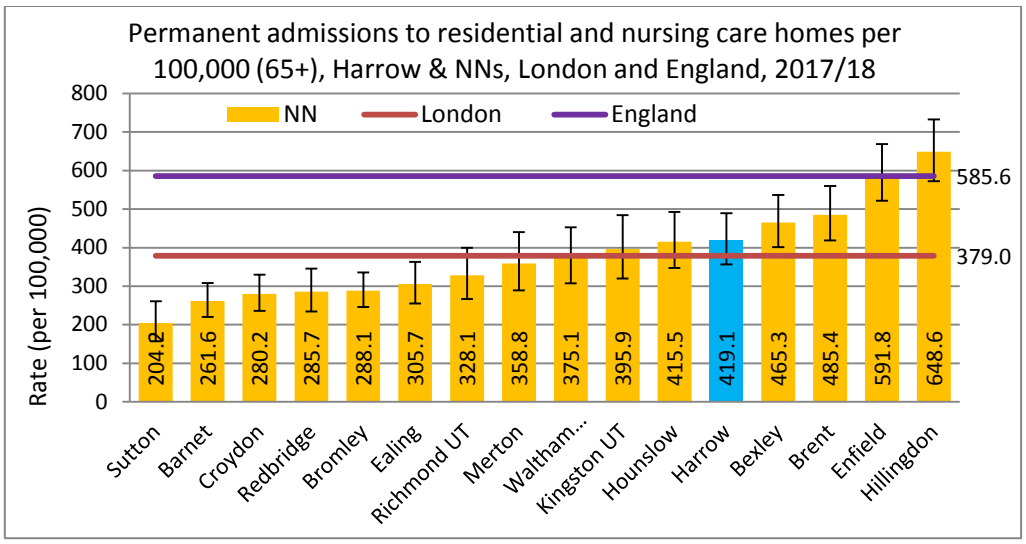


Source: PHOF

Permanent admissions to Care Homes: Permanent admissions to residential and nursing care homes per 100,000 aged 65+ during 2017/18 is illustrated in Fig 16. The graph below shows Harrow had the fifth highest rate of admissions (419.1 persons per 100,000 populations, accounts for 331

people) between all NNs, it was similar to London average but significantly lower than the England average of 585.6 per 100,000 populations.

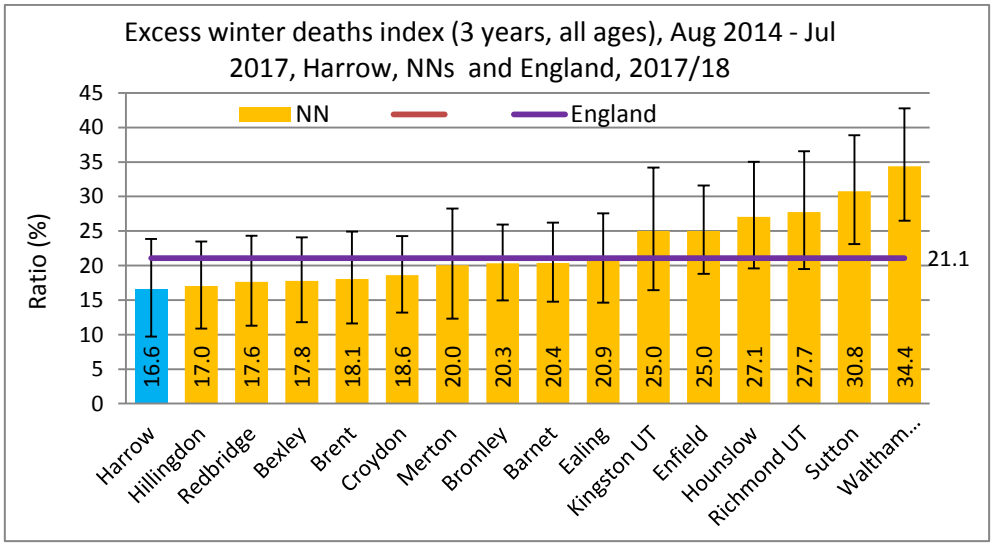
Fig 16 Permanent admissions to residential and nursing care homes rate, 65+, 2017/18



Source: PHOF

Excess Winter Deaths: Excess Winter Deaths Index (EWD Index) is the excess winter deaths measured as the ratio of extra deaths from all causes that occur in the winter months compared with the expected number of deaths, based on the average of the number of non-winter deaths. Harrow with 236 excess deaths (acounted for 16.6% extra death) had the lowest percentage of deaths between all NNs but not signifcantly lower than the England rate of 21.1% (Fig 17).

Fig 17 Excess winter deaths index (3 years, all ages), Aug 2014 - Jul 2017

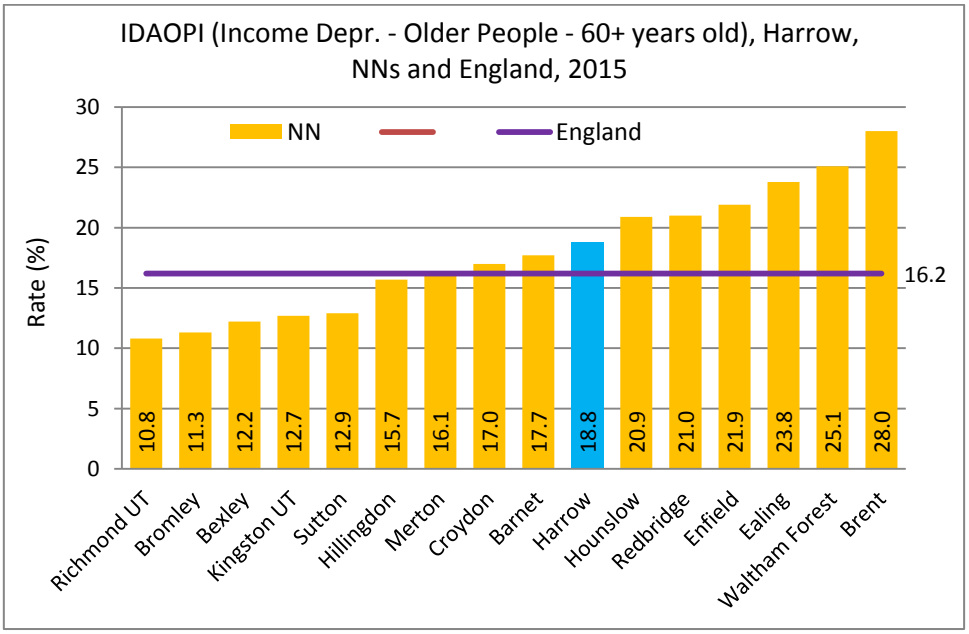


Source: PHOF

Income deprivation, Older People: Income Deprivation Affecting Older People Index (IDAOPI) is a subset of the English Indices of Deprivation using the Income Deprivation Domain. IDAOPI is based

on the percentage of the population aged 60 and over who receive income support, income based job seekers allowance, pension credit or child tax credit claimants aged 60 and over and their partners (if also aged 60 or over). Fig 18 shows the percentage of older people affected by income deprivation in Harrow, it's nearest neigbours and Engalnd according to the indices of Deprivation 2015. The graph below shows 18.8% of older people in Harrow were affected by income deprivation which is higher than average of England (16.2%).

Fig 18 IDAOPI (Income Depr. - Older People - 60+ years old), Harrow, NNs and England, 2015



Source: PHOF

Options for action[14]

Commissioners need to consider how end-of-life care is best coordinated and managed among the range of local service providers, including the NHS, local authority social services, charities, and hospices. The recent publication, Ambitions for Palliative and End of Life Care:

A national framework for local action 2015–2020 (see "Resources"), will be helpful in this respect.

Commissioners need to collaborate with:

- Local authority social services to adopt and implement the fast-track continuing healthcare assessment process for all people identified as at end of life;
- Health and social care statutory and third-sector service providers to ensure high-quality care is provided quickly, responsively and reliably to enable a person to remain in their usual place of residence. Commissioners need to specify that all service providers work towards achieving the NICE quality standard for adult end-of-life care (QS13; see "Resources").

Commissioners together with service providers need to consider the level of support required by older people with multiple morbidities outside a hospital setting. A variety of places may constitute home for an elderly person, not only their own house but also settings such as a residential care home or nursing care home.

Commissioners need to specify that primary care providers:

- Assess, where possible, which people may be in the last year of life and, if it accords with a person's wishes, undertake collaborative care planning through primary care registration, communication and management;
- Share, once consent has been obtained, care-planning information through an electronic palliative care coordinating system (EPaCCS) or equivalent, such that a person's care plan and status are visible to relevant agencies, including community services, ambulance services, accident and emergency services, and personal care services.

All service providers, but particularly GPs, need to assess which people may be approaching the last months or weeks of life, and offer to discuss what matters most, including their preferences for care, place of care, and place of death, while respecting people's wishes if they do not wish to engage in care planning. For those people willing to discuss end-of-life care needs and preferences, a personalised care plan needs to be developed in partnership with the person concerned (unless they prefer not to be involved). A person's family, carers and other people important to them should be involved in these discussions to the extent agreed by the individual concerned. The care plan needs to be:

- Documented and made available to all the relevant agencies, including primary care services, social care services, ambulance services, and local hospitals;

›› regularly reviewed and revised to match changing views and circumstances. Commissioners need to review investment:

[14] PHE, End of Life Care, Atlas of Variation, Online available from: https://fingertips.phe.org.uk › documents › Atlas_2015_EndofLife [Last accessed: 29/10/2019]

- to assess whether additional resources are necessary to support home care for people who are dying

– unnecessary acute hospital admissions entail considerable expenditure, and better value for individuals and for the population could be obtained by adequate investment in home-based care;

- To ensure 24/7 resilience and response in community services, including specialist palliative care, to support people at the end of life and their carers, including after the individual's death.

In Summary:

The biggest weakness in Harrow is that there is not a named CCG clinical director or LA Director responsible for oversight of end of life care nor a joint planning and monitoring group with shared responsibility across local authority, NHS commissioners and providers (a recommendation of the NACEL report)[15].

Gaps in provision as identified in NHS London report are Lack of commissioned 24 hour access to specialist palliative care telephone advice and 7 day hospital and community specialist palliative care (SPC).

[15] National Audit of Care at the End of Life, First round of the audit (2018/19) report England and Wales, online available from: https://www.hqip.org.uk/wp-content/uploads/2019/07/National-Audit-of-Care-at-the-End-of-Life-National-Report-2018-FINAL.pdf [Last accessed: 27/11/2019]

Appendix 1 Population Projection[16]

Table 1 shows number of Harrow population 65+ growth from 2019 to 2015 by age group, Fig 1 compares percentage of population (persons) growth in Harrow with London and England from 2020 to 2035 and Fig 2 illustrates it by sex.

Table 1 Harrow population aged 65 and over, projected to 2035 by age group

Age group	2019	2020	2025	2030	2035
People aged 65-69	11,100	11,400	12,900	13,900	14,100
People aged 70-74	9,700	10,000	10,400	11,800	12,800
People aged 75-79	7,200	7,300	8,900	9,300	10,600
People aged 80-84	5,800	5,900	6,100	7,500	7,900
People aged 85-89	3,600	3,700	4,200	4,400	5,500
People aged 90 and over	2,200	2,300	2,700	3,300	3,800
Total population 65 and over	**39,600**	**40,600**	**45,200**	**50,200**	**54,700**

Fig 1 Percentage of population growth aged 65 and over, projected to 2035 by age group

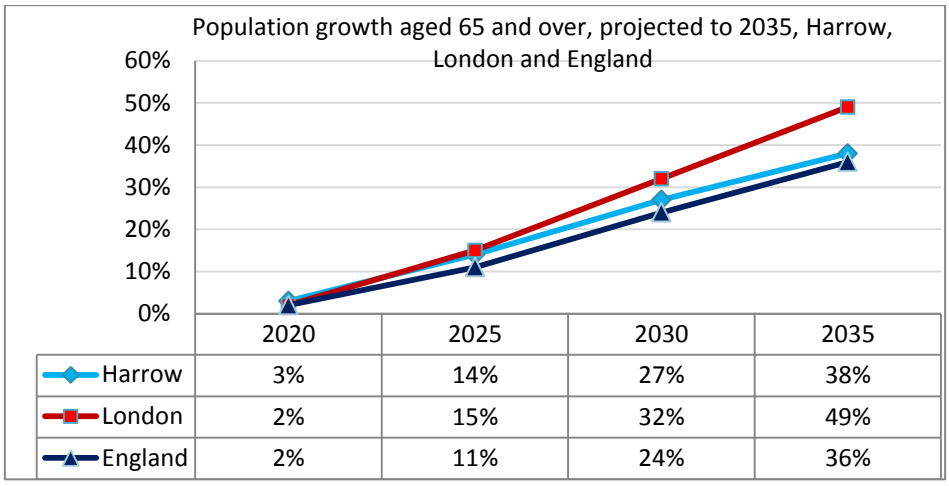
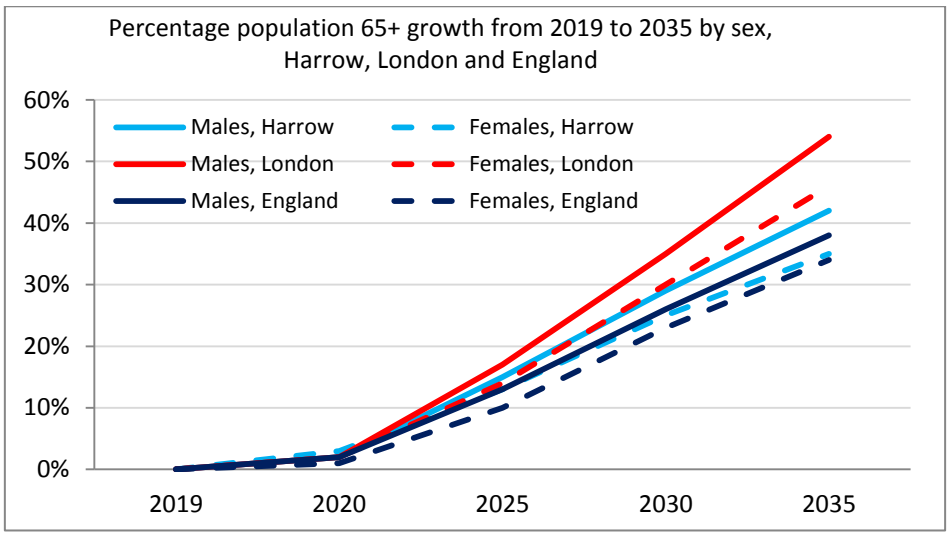


Fig 2 Population growth (%) aged 65 and over by sex, projected to 2035 by age group



[16] *Source: POPPI*