

### Why is this issue important?

End of life care services support those with advanced, progressive, incurable illness to live as well as possible until they die. They also enable people to choose their preferred place of death. The provision of end of life care services has become increasingly complex as people are living longer with multiple conditions.

Surveys of the public have shown that the first preference for most people in the UK (56-74 %) would be to die at home, although as people become sicker and approach death this proportion may decline, as they want access to more extensive support, such as hospice care.<sup>1</sup>

The Department of Health *End of Life Care Strategy* (2008) has been refreshed. In the *Action for End of Life Care 2014* NHS England sets out a five year vision for improvements in end of life care. Including adopting a long term conditions care model to engage and inform individuals and carers; make health and social care committed to partnership working; developing supportive organisational processes; commissioning to improve end of life care. This has been developed further with NHS England's *Ambitions for Palliative and End of Life Care: A national framework for local action. 2015-2020* this sets out six ambitions:

- Each person to be seen as an individual
- Each person to get fair access to care
- Maximising comfort and Wellbeing
- Care is co-ordinated
- All staff are prepared to care
- Each community is prepared to help

### Key outcomes

- ***Bereaved carers' views on the quality of care in the last 3 months of life (NHS Outcomes Framework)***

The National Dementia Strategy 2009 has a related objective of improving end of life care for people with dementia (see dementia section).

<sup>1</sup> Department of Health. End of life care strategy. 2<sup>nd</sup> annual report. 2010.

### Impact in Brighton & Hove

The quality and outcomes framework for general practice includes two indicators for palliative care:

- Establish and maintain a register of all patients in need of palliative care/support irrespective of age
- Regular (at least three monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed.

As at March 2015 there were 679 patients on palliative care registers in Brighton & Hove, 0.2% of patients. This ranged from no patients to 94 per practice (from 0% to 2.15% of patients). Across England 0.3% of patients are on a palliative care register. 89% of practices had regular multidisciplinary case review meetings where all patients on the palliative care register are discussed.<sup>2</sup>

The NHS Brighton and Hove Clinical Commissioning Group (CCG) financial spend in 2013/14 on end of life care services was £3.31 million. That equates to £1.18 million per 100,000 people<sup>3</sup>

In 2015 there were 2,123 deaths (all ages) in Brighton & Hove. Of these, 41% occurred in hospital, whilst 23% occurred in the usual place of residence and 22% in care homes (Table 1). Brighton & Hove performs better than England for deaths in hospital (47% of deaths in England were in hospital) and has the third lowest percentage of deaths in hospital of the 17 comparator Clinical Commissioning Groups (CCG).<sup>4</sup>

Brighton & Hove is similar to England for the percentage of deaths in usual place of residence and has the 2<sup>nd</sup> lowest percentage of people dying in hospitals of its comparator group of 17 CCGs.

<sup>2</sup> Health and Social Care Information Centre. Quality and Outcomes Framework (QOF) 2014/15. 2015. Available at <http://digital.nhs.uk/qof> [Accessed 16/08/2016]

<sup>3</sup> NHS England. 2013/14 CCG Programme Budgeting Benchmarking Tool. Available at: <https://www.england.nhs.uk/resources/resources-for-cgcs/prog-budgeting/> [Accessed 16/08/2016]

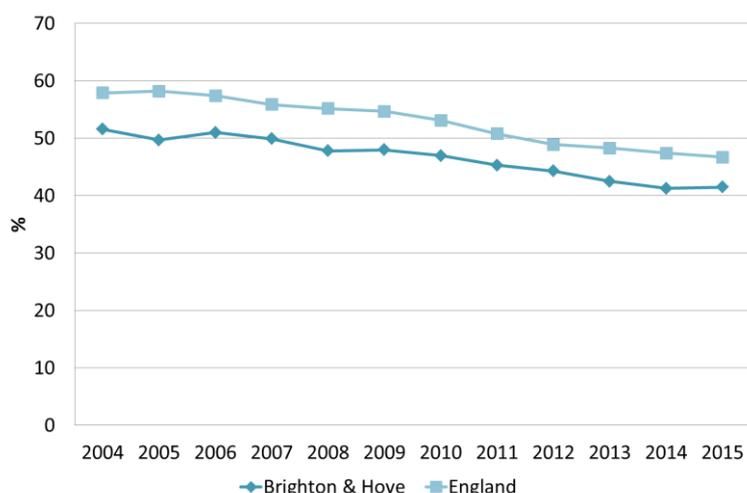
<sup>4</sup> National end of life care Intelligence Network. National End of Life Care Profiles for Local Authorities. Available at: <http://fingertips.phe.org.uk/profile/end-of-life> [Accessed 02/11/2016]

**Table 1: Place of death, Brighton & Hove, South East and England, 2015**

	No of deaths in Brighton & Hove	Brighton & Hove %	South East %	England %
<b>Hospital</b>	881	41%	43%	47%
<b>Home</b>	495	23%	26%	23%
<b>Care home</b>	496	22%	25%	22%
<b>Hospice</b>	173	8%	8%	6%
<b>Other place</b>	78	4%	2%	2%
<b>Total</b>	2,123			

Source: Public Health England. End of life care profiles.<sup>4</sup>

**Figure 1: Percentage of all deaths where the place of death was a hospital, Brighton & Hove CCG and England, 2004 to 2015**



Source: Public Health England. End of life care profiles.<sup>4</sup>

The percentage of deaths occurring in hospital has fallen in the city over the past decade, from 52% in 2004 to 41% in 2015. The equivalent fall for England was from 58% in 2004 to 47% in 2015 (Figure 1).<sup>4</sup>

Information on bereaved carers' views on the quality of care in the last three months of life is only available for the whole of England. It shows that in 2015, 70% of bereaved carers' felt that overall the care their loved one received was outstanding, excellent or good. Of those whose loved one: received home care in the last three months of life, 80% said it was excellent or good; were admitted to hospital, 76% said their care from doctors was excellent or good (74% for nurses); were cared for in a hospice 92% said their care was

excellent or good (91% for the last three months of life).<sup>5</sup>

Of the 496 patients who died in the care of the Specialist Palliative Community Service (part of the Martlets Hospice and Sussex Community NHS Foundation Trust's Palliative Care Partnership) in 2015/16, 41% died at home, 21% in the hospice, 19% in the acute hospital, and 18% in a care home.<sup>6</sup>

Between April and May 2016 over 75% of Palliative Care Partnership patients had died in their preferred place of death.<sup>7</sup>

### Where we are doing well

The End of Life Care Profile for Brighton & Hove (Table 1) shows that a statistically significantly lower proportion of people are dying in hospital in Brighton & Hove (41% in 2015) compared with England (47%).<sup>4</sup>

Brighton & Hove Clinical Commissioning Group (CCG) has distributed a folder of prescribing guidelines for palliative care to all GP Practices. In response to service user feedback it has also issued a leaflet to residents on the different roles of staff within the End of Life Care Team. The My Life Brighton & Hove website also includes information and links to support people.<sup>8</sup>

A two year e-learning project for end of life care in care homes and nursing homes has also been launched in the city. The End of Life Care Home Training Project will directly address the current variation in practice by introducing and promoting best practice around end of life through supporting homes to roll out e-learning programme for their staff. The project will work with each home, supporting the workforce to undertake e-learning, ensuring a tailored approach across all the available modules and encouraging and supporting

<sup>5</sup> Health and Social Care Information Centre. From the National Survey of Bereaved People (VOICES - Views of Informal Carers - Evaluation of Services) provided by the Office for National Statistics (ONS) – Official Statistic. Available at <https://indicators.hscic.gov.uk/webview/index.jsp?v=2&submode=ddi&study=https%3A%2F%2F192.168.228.51%3A443%2Fobj%2FStudy%2FP01784&mode=documentation&top=yes> [Accessed 16/08/2016]

<sup>6</sup> The National Council for Palliative Care. Minimum Data Set 2014/15

<sup>7</sup> Brighton & Hove Performance Monitoring Report. June 2016.

<sup>8</sup> My Life Brighton & Hove. Website available at: <http://www.mylifebh.org.uk/support-groups-charities/end-of-life-support-information/> [Accessed 16/08/2016]

## 9. End of life care

homes to embed the modules as part of their organisational training programmes.

A professional network for end of life care and learning disabilities launched in Brighton & Hove in 2013. This network meets twice a year, to share good practice, resources and promote collaborative working. In addition, the network supports the delivery of an annual study day for professionals and carers across Sussex, in partnership with similar end of life and learning disability networks in East & West Sussex.

Brighton & Hove CCG has a Locally Commissioned Service (LCS) for palliative care. The five key outcomes for each GP practice offering this LCS in 2016 are:

- A percentage increase in the proportion of patients on the palliative care register, who also have a electronic record and/or out of hours form
- Percentage increase in after death reviews with findings disseminated to cluster GPs
- GP attendance at annual End of Life Care educational event and cascading information
- A practice staff member to attend at least one Gold Standards Framework meeting
- Each practice to have a GP palliative care lead

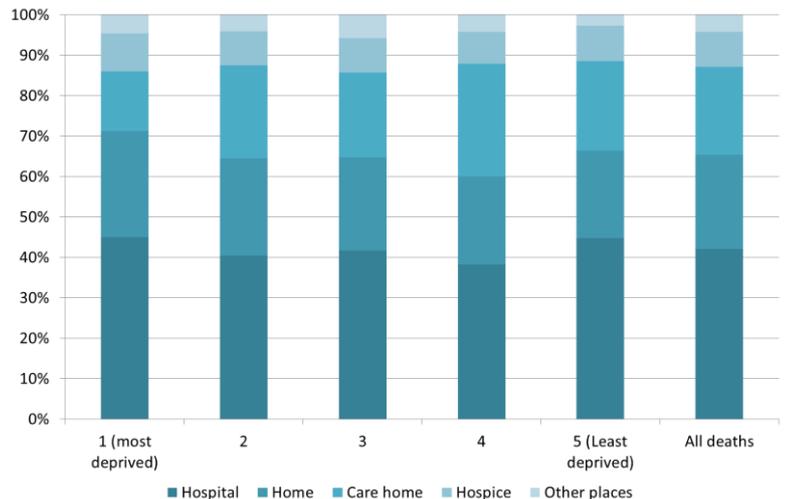
### Local inequalities

Socio-economic deprivation is a major determinant of where, when and how people die. Nationally people living in the most deprived quintile (the poorest 20% of areas) are more likely to die in hospital (61%) than any other quintile (54-58%). People living in the most deprived quintile (11%) are less likely to die in care or nursing homes than any other quintile (16-20%).<sup>9</sup>

However, in Brighton & Hove, between 2013 and 2015, there was little difference in place of death by deprivation quintile (Figure 2) with the exception of deaths in care homes. This followed

the national pattern with a lower percentage of residents who died in the most deprived quintile, dying in a care home (15% compared with 22% of all deaths).

**Figure 2: Place of death by Brighton & Hove by**

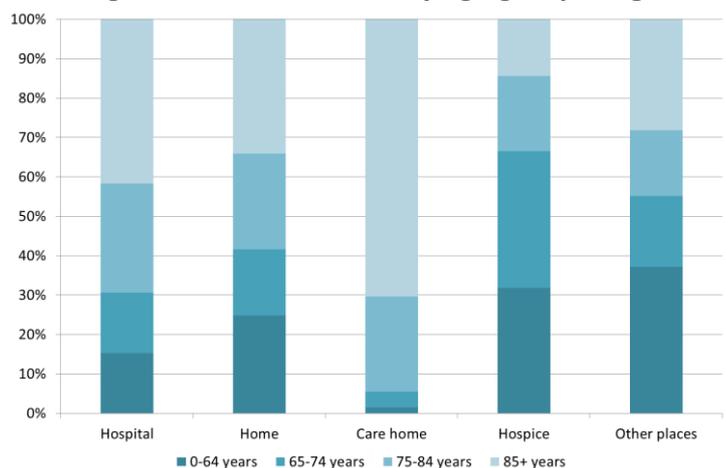


### deprivation quintile, 2013-2015

Source: Primary Care Mortality Database. NHS Digital. Produced by the Public Health Intelligence team.

In 2015, 43% of hospital deaths are of those aged 75-84 years and 42% are aged 85 or over (Figure 3). The majority of people dying in care homes are aged 85 years or over (70%). Around a third of those dying in a hospice are under 65 years (32%)

**Figure 3: Place of death by age group, Brighton &**



### Hove Clinical Commissioning Group, 2015

Source: End of life care profile. Public Health England

A higher proportion of men die at home (27%) than women (21%) and slightly more men die in hospital (45% men and 43% of women). A higher proportion of women die in a care or nursing home (25%) than

<sup>9</sup> Public Health England National end of life care intelligence network. Deprivation and death: Variation in place and cause of death. February 2012. Available at: [http://www.endoflifecare-intelligence.org.uk/resources/publications/deprivation\\_and\\_death](http://www.endoflifecare-intelligence.org.uk/resources/publications/deprivation_and_death)

## 9. End of life care

men (13%).<sup>10</sup> This is likely to be a result of women living longer than men.

Between 2013 and 2015 a higher proportion of people with respiratory conditions died in hospital than with other conditions (Table 2). A similar proportion of cancer patients died their own home (26%) as in a hospice (27%), with 29% dying in hospital.

**Table 2: Place of death for selected causes of death, average per year 2013-2015**

	Cancer	Cardio-vascular disease	Respiratory disease
<b>Hospital</b>	171 (29%)	257 (48%)	158 (61%)
<b>Own residence</b>	156 (26%)	149 (28%)	46 (18%)
<b>Care home</b>	93 (16%)	110 (20%)	49 (19%)
<b>Hospice</b>	159 (27%)	*	*
<b>Other places</b>	13 (2%)	*	*
<b>Total</b>	591	541	261

**Source:** Primary Care Mortality Database. NHS Digital. Produced by the Public Health Intelligence team. \*Suppressed due to potential for disclosure.

### Predicted future need

It is projected that the number of deaths per year will be around 1,900 in 2020 and around 2,000 deaths in 2030.<sup>11</sup>

### What we don't know

We do not know what the preferred place of death is for some Brighton & Hove residents.

Deaths registration data does not record sexual orientation, ethnicity, gender reassignment or other protected characteristic groups. The End of Life Palliative Care Partnership is now focusing on

<sup>10</sup> Public Health England. EoL Profiles: Place of death Brighton & Hove CCG. Instant Atlas Report. Annual average for 2011-2013. Available at: [http://www.endoflifecare-intelligence.org.uk/profiles/CCGs/Place\\_of\\_Death/atlas.html](http://www.endoflifecare-intelligence.org.uk/profiles/CCGs/Place_of_Death/atlas.html) [Accessed 16/09/2016]

<sup>11</sup> Office for National Statistics (ONS). Subnational population projections: 2014-based projections. 2016. Available at: <https://www.ons.gov.uk/releases/subnationalpopulationprojections2014basedprojections> [Accessed 16/08/2016]

the collection of protected characteristics and postcode data.

### Key evidence and policy

Key evidence and policy can be found in the Department of Health National End of Life Care Strategy 2008.

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/136431/End\\_of\\_life\\_strategy.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf)

Action for End of Life Care 2014 NHS England. Outlines NHS England's vision of action for end of life care

<https://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>

Ambitions for Palliative and End of Life Care: A national framework for local action. 2015-2020. NHS England.

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

Care of dying adults in the last days of life. NICE guideline NG 31. December 2015. This guideline includes recommendations on: recognising when people are entering the last days of life; communicating and share decision making; clinically assisted hydration; medicine to manage pain, breathlessness, nausea and vomiting, anxiety, agitation, delirium, and noisy respiratory secretions and anticipatory prescribing.

<https://www.nice.org.uk/guidance/ng31>

Sixteen NICE Quality Statements set out the standard of care to be provided in end of life care for adults.

<https://www.nice.org.uk/guidance/qs13>

Further NICE Quality Standards are being produced for the last days of life due to be published in March 2017 and service delivery guidelines due in 2018. NICE guidance on end of life care for infants, children and young people is also being developed.

### Recommended future local priorities

1. Redesign interventions to improve end of life care within Care Homes and Nursing Homes.
2. Continue to support developments and progress around electronic information sharing

## 9. End of life care

and coordination between health and social care.

3. Implement robust equalities monitoring across the end of life care pathway.

### Key links to other sections

- Adults with physical disabilities or sensory impairments
- Adults with learning disabilities
- Carers
- Older people – Social care
- Coronary heart disease
- Respiratory disease
- Cancer
- Stroke
- Dementia

### Further information

End of Life Care Network

<http://www.endoflifecare-intelligence.org.uk/home.aspx>

### Last updated

November 2016