i The 2nd Atlas of variation in risk factors and healthcare for respiratory disease in England

## Quick user guide



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<sup>1</sup> Title shows indicator details including: value type, geography and year.

<sup>2</sup> The y-axis plots the value and gives details of the value type e.g. rate / proportion and the unit e.g. per 100,000 population.

<sup>3</sup> The x-axis shows the geography and the number of areas on chart.

The line

shows the

England

average.

Variation in rate of emergency admissions to hospital for respiratory disease per population by CCG (2017/18) 3,000 2,500 2 2,000 \$ 1.500 1,000 195 CC Gr 3.000 2,500 2.000 2013/14 2014/15 2015/16 2016/17 2017/18 Example Max-Min No significa ohange (Range) 96th-6th WDENING Significant pe roen til No significan change 76th-26th 496.6 pe roen ti k INCREASING Significant Median

<sup>5</sup> Each bar represents an area (e.g. a CCG). The height of the bar is relative to the value for that area. Collectively, the bars show the spread of values across England.

The colour of the bar represents how significant the area's value is in relation to England based on the area's confidence interval. Areas utilise the same colours and categories as the maps.

Areas that are significantly higher than England at a 99.8% or 95% level are shown as darker bars whereas those with lower significance to England, at a 99.8% or 95% level, are lighter. The colour in the middle represents areas that are not significantly different from England.

Where the significance bar chart shows little variation across the CCGs. the equal interval map colours have been used.

Context An emergency adm unschedul Magnitude of variation Map R14: Variation in percentage of admissions to wital for respiratory disease that were re-admitted as within 30 days of discharge by CCG **Options for action** period Respiratory admission rates ter minimise the impact of Public Health England. Health profile for England (2017) England. Chapter 2: major causes of death and how they have changed [Accessed 21 January 2019] World Health Organization The ICD-10 Classification of

<sup>6</sup> For each indicator, data is presented visually in a time series of box and whisker plots. The box plots show the distribution of data.

The line inside each box shows the median (the mid-point, so if the 195 CCGs were sorted in order of value, the value halfway between the CCGs in the 97th and 98th position would give the median). The bottom and top of the teal box represents the values which 25% and 75% of the areas fall below. 50% of the areas have a value within this range.

The whiskers mark the values at which 5% and 95% of areas fall below. The median and maximum values are also shown.

The time series allows us to see how the median has changed over time, but also whether the gap between the extreme values has changed.

The table accompanying the box and whisker plots shows whether there has been any statistically significant change in the median, or in the degree of variation over time.

## Sections in the chapter

Context - provides an overview of why the indicator is of public health interest

Magnitude of variation - provides commentary in relation to the chart, box plot and table

Option for action - gives suggestions for best practice

**Resources** – gives links to useful documents

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## How were the categories calculated?





Confidence intervals give an estimated range in which the true CCG value lies.

Where the CCG's confidence interval does not overlap with the England value, the CCG is classed as being *significantly higher* or *lower than England at a 99.8% level.* 

If the England value lies between the 99.8% and 95% CI, this value is classed as being *significantly higher* or *lower* than England at a 95% level.

Where the England value is between the upper and lower 95% CI, the CCG is classed as *not being significantly different from England*.

D 0		
ROX &	whisker	plot

### Whiskers

Show the extreme values in the dataset.

### Box

50% of the data values lie between the 25<sup>th</sup> and 75<sup>th</sup> percentile. The distance between these is known as the inter-quartile range (IQR). **Maximum** The value of the area with the highest value. 95<sup>th</sup> percentile 95% of areas have values below this.

75<sup>th</sup> percentile 75% of areas have values below this.

Median (50<sup>th</sup> percentile) The median is the middle value of an ordered dataset. Half of the observations are below it and half above.

25<sup>th</sup> percentile 25% of areas have values below this.

5<sup>th</sup> percentile 5% of areas have a value below this. **Minimum** The value of the area with the lowest value.

Box plotCCG rank positionpercentile(195 CCGs in 2018)	
Max	195
- 95%	Mid value between values of CCGs in ranks 185 and 186
75%	Mid value between values of CCGs in ranks 146 and 147
50% - Median	Mid value between values of CCGs in ranks 97 and 98
25%	Mid value between values of CCGs in ranks 48 and 49
5%	Mid value between values of CCGs in ranks 9 and 10
Min	1

### End of life care

## Deaths from respiratory diseases: variation in place of death

### Context

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.<sup>1,2,3</sup> 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.<sup>4,5</sup> The benefits of palliative care are very well recognised for patients with advanced lung cancer,<sup>6</sup> with improvements in quality of life and even increases in survival when introduced early in the disease trajectory.<sup>7</sup> There is also a strong body of evidence on the benefits of palliative care for patients with COPD and ILD,<sup>2,8</sup> including a possible survival benefit,<sup>9</sup> although this is less widely known.

# Table 32.1: Number of deaths by recorded main cause of mortality by place of death, England,2015-2017

Respiratory condition	Hospital	Home	Care Home	Hospice	Total Deaths
COPD	49,073	18,815	10,314	1,315	80,253
ILD	10,696	3,668	1,410	692	16,616
Lung Cancer	31,624	28,137	10,473	13,568	85,336

# Table 32.2: Percentage of deaths by recorded main cause of mortality by place of death, England, 2015-2017

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%

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,<sup>10</sup> with evidence that with good advanced care planning patients are more likely to die in their preferred place.<sup>11</sup> Although place of death is only one factor of importance to patients and their families, and not necessarily the most important one,<sup>12,13</sup> the fact that it is routinely recorded for all deaths provides useful insights into variations in end of life care.

General surveys have found that home is the preferred place of death for most people,<sup>14</sup> 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,<sup>15</sup> home or hospice were the most common 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 Tables 32.1 and 32.2, 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. 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.<sup>16</sup> 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.<sup>4</sup> 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,<sup>8,17</sup> patients with COPD and ILD have much poorer access to palliative care.<sup>2,18,19</sup>

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, including issues of refractory fatigue and breathlessness and psychological coping mechanisms, and will require appropriate community resources to support patients who prefer to die at home.

## **Options for action**

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 areas of deprivation

## Resources

British Lung Foundation <u>End of life</u> Resources to support people with a lung condition [Accessed 29 July 2019]

British Lung Foundation and Marie Curie (2017) <u>Caring for</u> <u>someone with long-term lung conditions at end of life</u> Resources to support healthcare professionals [Accessed 29 July 2019]

National Institute for Health and Care Excellence (2015) Care of dying adults in the last days of life (NICE guideline [NG31]) [Accessed 29 July 2019]

National Institute for Health and Care Excellence (2017) Care of dying adults in the last days of life (NICE quality standard [QS144]) [Accessed 29 July 2019]

National Institute for Health and Care Excellence (2018) <u>Chronic obstructive pulmonary disease in over 16s:</u> <u>diagnosis and management (NICE guideline [NG115])</u> [Accessed 29 July 2019]

National Institute for Health and Care Excellence (2016) <u>Palliative care – dyspnoea (NICE Clinical Knowledge</u> <u>Summary</u>) [Accessed 29 July 2019]

National Institute for Health and Care Excellence (2011) End of life care for adults (NICE quality standard [QS13]) [Accessed 29 July 2019]

National Institute for Health and Care Excellence (2019) End of life care for adults in the last year of life: service delivery (In development [GIDCGWAVE0799]) [Accessed 29 July 2019]

National Institute for Health and Care Excellence (2019) Lung cancer: diagnosis and management (NICE guideline [NG122]) [Accessed 29 July 2019]

## **Geographical analysis**

This atlas of variation shows the number and percentages of deaths for COPD, ILD and lung cancer for all CCGs within England. Data from 2006 to 2008 up to 2015 to 2017 for all CCGs, including significance comparisons to the England average, are included in the available data sheet and online interactive tools.

Tables 32.1 and 32.2 and Tables 32.3, 32.4, 32.5 show the England averages over these time periods for all 3 respiratory diagnoses and places of death.

The following pages then present the CCG statistical significance maps for lung cancer deaths for all places of death, and for COPD deaths for home and hospital deaths only.

## Magnitude of variation summary

### **COPD deaths:**

There were significant changes in the percentage of COPD deaths occurring in hospital and home between the periods 2006 to 2008 and 2015 to 2017. The CCG median percentage of deaths occurring at home increased significantly from 19.4 in 2006 to 2008 to 23.1 in 2015 to 2017. The CCG median percentage of deaths occurring in hospital decreased significantly from 67.9 in 2006 to 2008 to 61.5 in 2015 to 2017.

There was no significant change in the CCG median percentage of deaths occurring in care homes or hospices.

### Interstitial lung disease deaths:

The CCG median percentage of Interstitial lung disease deaths occurring in hospital decreased significantly from 71.2 in 2006 to 2008 to 66.7 in 2015 to 2017. There was no significant change in the CCG median percentage of deaths occurring at home, at 21.3 in 2015 to 2017.

The trend analysis for ILD deaths in hospice and care homes is not robust as too many CCGs were suppressed due to low numbers. The CCG median percentage of deaths for those areas not suppressed was 5.8 for hospices and 8.7 for care homes in 2015 to 2017.

### Lung cancer deaths:

There were significant changes in the percentage of lung cancer deaths occurring in hospital, home and care homes between the periods 2006 to 2008 and 2015 to 2017. The CCG median percentage of deaths occurring in homes and care homes both increased significantly; for deaths at home the CCG median increased from 27.2 in 2006 2008 to 32.1 in 2015 to 2017 and in care homes the CCG median increased from 8.2 in 2006 to 2008 to 12.2 in 2015-17. For deaths occurring in hospital, the CCG median significantly decreased from 45.9 in 2006 to 2008 to 36.7 in 2015 to 2017.

There was no significant change in the CCG median percentage of deaths occurring in a hospice, remaining constant at 16.5 in 2015 to 2017.

Where do people with COPD die?



# Where do people with ILD die?



# Where do people with Lung Cancer die?



### Table 32.3: Place of death for COPD deaths 2006-2008 to 2015-2017 (%)

	Hospital	Home	Care Home	Hospice
2006-2008	67.65	19.47	11.15	0.79
2009-2011	65.63	20.37	12.08	1.10
2012-2014	62.36	21.80	13.52	1.39
2015-2017	61.15	23.44	12.85	1.64

# Table 32.4: Place of death for ILD deaths 2006-2008 to 2015-2017 (%)

	Hospital	Home	Care Home	Hospice
2006-2008	70.35	18.59	7.38	2.86
2009-2011	69.15	19.28	7.36	3.51
2012-2014	66.33	20.97	8.55	3.57
2015-2017	64.37	22.08	8.49	4.16

# Table 32.5: Place of death for lung cancer deaths 2006-2008 to 2015-2017 (%)

	Hospital	Home	Care Home	Hospice
2006-2008	46.26	27.35	9.09	15.73
2009-2011	42.52	29.87	10.35	15.64
2012-2014	38.36	32.36	11.79	15.69
2015-2017	37.06	32.97	12.27	15.90

### End of life care – COPD

# **Map 32a:** Variation in percentage of deaths from COPD that occurred in hospital by CCG (2015-2017)





#### Variation in percentage of deaths from COPD that occurred in hospital by CCG (2015-2017)

188 out of 195 CCGs (7 missing due to small numbers)

The map and column chart display the latest period (2015 to 2017), during which CCG values ranged from 48.3% to 74.1% which is a 1.5-fold difference between CCGs.

The England value for 2015 to 2017 was 61.1%.

#### End of life care – COPD

# **Map 32b:** Variation in percentage of deaths from COPD that occurred at home by CCG (2015-2017)



# **Map 32c:** Variation in percentage of deaths from lung cancer that occurred in hospital by CCG (2015-2017)





Variation in percentage of deaths from lung cancer that occurred in hospital by CCG (2015-2017)

184 out of 195 CCGs (11 missing due to small numbers)

The map and column chart display the latest period (2015 to 2017), during which CCG values ranged from 21.9% to 59.9% which is a 2.7-fold difference between CCGs.

The England value for 2015 to 2017 was 37.1%.

# **Map 32d:** Variation in percentage of deaths from lung cancer that occurred at home by CCG (2015-2017)





Variation in percentage of deaths from lung cancer that occurred at home by CCG (2015-2017)

187 out of 195 CCGs (8 missing due to small numbers)

The map and column chart display the latest period (2015 to 2017), during which CCG values ranged from 19.2% to 50% which is a 2.6-fold difference between CCGs.

The England value for 2015 to 2017 was 33%.

# **Map 32e:** Variation in percentage of deaths from lung cancer that occurred in a care home by CCG (2015-2017)



#### Variation in percentage of deaths from lung cancer that occurred in a care home by CCG (2015-2017)

# **Map 32f:** Variation in percentage of deaths from lung cancer that occurred in a hospice by CCG (2015-2017)





Variation in percentage of deaths from lung cancer that occurred in a hospice by CCG (2015-2017)

The map and column chart display the latest period (2015 to 2017), during which CCG values ranged from 1.1% to 40.4%

172 out of 195 CCGs (23 missing due to small numbers)

which is a 38.1-fold difference between CCGs. The England value for 2015 to 2017 was 15.9%. <sup>3</sup> Henoch I, Bergman B, Gustafsson M and others (2007) The Impact of Symptoms, Coping Capacity, and Social Support on Quality of Life Experience Over Time in Patients with Lung Cancer J Pain Symptom Manage 34(4):370-379 doi: 10.1016/j.jpainsymman.2006.12.005 [Accessed 29 July 2019]

<sup>4</sup> Claessens M, Lynn J, Zhong Z and others (2000) Dying with lung cancer or chronic obstructive pulmonary disease: Insights from SUPPORT J Am Geriatr Soc 48:S146-S153 doi: 10.1111/j.1532-5415.2000.tb03124.x [Accessed 29 July 2019]

<sup>5</sup> Habraken J, ter Riet G, Gore J and others (2009) <u>Health-Related Quality of Life in End-Stage COPD and Lung Cancer Patients</u> J Pain Symptom Management 37(6):973-981 doi: 10.1016/j.jpainsymman.2008.07.010 [Accessed 29 July 2019]

<sup>6</sup> National Institute for Health and Care Excellence (2019) Lung cancer: diagnosis and management. (NICE guideline [NG122]) [Accessed 29 July 2019]

<sup>7</sup> Temel J, Greer J, Muzikansky A and others (2010) Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer N Engl J Med 363:733-742 doi: 10.1056/NEJMoa1000678 [Accessed 29 July 2019]

<sup>8</sup> Kreuter M, Bendstrup E, Russell A and others (2017) Palliative care in interstitial lung disease: living well The Lancet Respiratory Medicine 5(12):968-980 doi: 10.1016/S2213-2600(17)30383-1 [Accessed 29 July 2019]

<sup>9</sup> Higginson I, Bausewein C, Reilly C and others (2014) <u>An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: A randomised controlled trial Lancet Respir Med 2(12):979-987 10.1016/S2213-2600(14)70226-7 [Accessed 29 July 2019]</u>

<sup>10</sup> Public Health England End of Life care profiles [Accessed 29 July 2019]

- <sup>11</sup> Dixon J, King D and Knapp M (2016) <u>Advance care planning in England: Is there an association with place of death? Secondary analysis of data from the National Survey of Bereaved People BMJ Support Palliat Care 0:1-10 doi: 10.1136/bmjspcare-2015-000971 [Accessed 29 July 2019]</u>
- <sup>12</sup> Steinhauser K, Christakis N, Clipp E and others (2000) Factors considered important at the end of life by patients, family, physicians, and other care providers J Am Med Assoc 284(19):2476-2482 doi: 10.1001/jama.284.19.2476 [Accessed 29 July 2019]
- <sup>13</sup> Waghorn M, Young H and Davies A (2011) Opinions of patients with cancer on the relative importance of place of death in the context of a 'good death' BMJ Support Palliat Care 1:310-314 doi: 10.1136/bmjspcare-2011-000041 [Accessed 29 July 2019]

<sup>14</sup> Gomes B, Calanzani N and Higginson I (2011) Local preferences and place of death in regions within England 2010 [Accessed 29 July 2019]

<sup>15</sup> Skorstengaard M, Neergaard M, Andreassen P and others (2017) <u>Preferred Place of Care and Death in Terminally III Patients with Lung and Heart Disease Compared to Cancer Patients</u> J Palliat Med 20(11) doi: 10.1089/jpm.2017.0082 [Accessed 29 July 2019]

<sup>16</sup> Cohen J, Beernaert K, Van den Block L and others (2017) Differences in place of death between lung cancer and COPD patients: A 14-country study using death certificate data npj Prim Care Respir Med 27(14) doi: 10.1038/s41533-017-0017-y [Accessed 29 July 2019]

<sup>17</sup> National Institute for Health and Care Excellence (2018) Chronic obstructive pulmonary disease in over 16s: diagnosis and management (NICE guideline [NG115]) [Accessed 29 July 2019]

<sup>18</sup> Elkington H, White P, Addington-Hall J and others (2005) The healthcare needs of Chronic obstructive pulmonary disease patients in the last year of life Palliat Med 19:485-491 doi:

10.1191/0269216305pm1056oa [Accessed 30 July 2019]

<sup>19</sup> Gore J, Brophy C and Greenstone M (2000) How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer Thorax 55:1000-1006 doi: 10.1136/thorax.55.12.1000 [Accessed 30 July 2019]

<sup>&</sup>lt;sup>1</sup> Elkington H, White P, Addington-Hall J and others (2004) The last year of life of COPD: A qualitative study of symptoms and services Respiratory Medicine 98:439-445 doi: 10.1016/j.rmed.2003.11.006 [Accessed 29 July 2019]

<sup>&</sup>lt;sup>2</sup> Gardiner C, Gott M, Payne S and others (2010) Exploring the care needs of patients with advanced COPD: An overview of the literature Respiratory Medicine 104:159-165 doi: 10.1016/j.rmed.2009.09.007 [Accessed 29 July 2019]