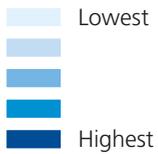


END-OF-LIFE CARE

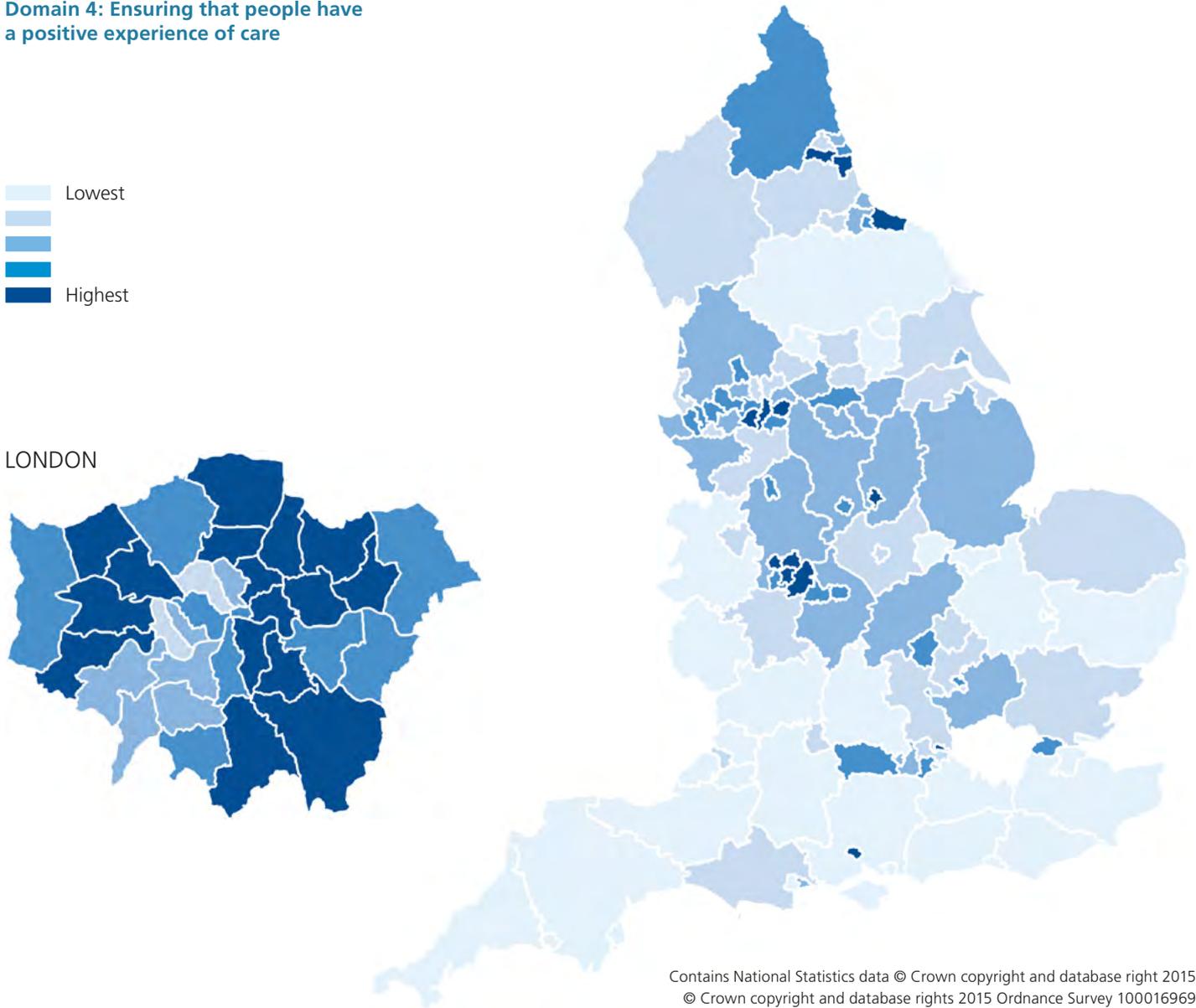
Map 66: Percentage of all deaths in an area that occurred in hospital by upper-tier local authority

2013

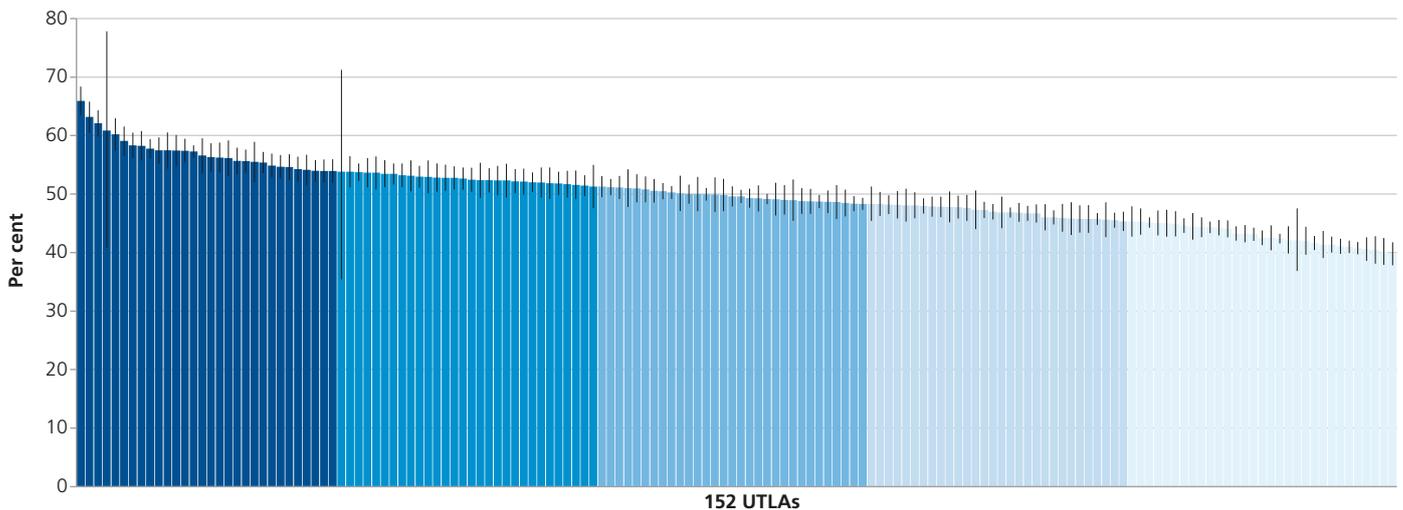
Domain 4: Ensuring that people have a positive experience of care



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Context

Over 450,000 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"), 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. Hospitalisation should not be used as the default setting for care when it is clear that admission is medically unnecessary and contrary to someone's expressed wishes, and where alternative care arrangements can be made.

The NICE Quality Standard for End of Life Care (see "Resources") covers all settings and services in which care is provided by health and social care to all adults approaching the end of life. It includes a quality statement on the timely identification of people in the last days of life, and the coordination and delivery of care in accordance with their personalised care plan.

Current models of unplanned care are expensive. Emerging good practice shows that effective community teams working with clearly identified patients who have a personalised care plan can improve people's experiences at end of life, and the experience of their families, while reducing, or at least not increasing, cost to the local system.

Care of the dying is provided by a range of agencies including the NHS, local authority social services, charities, and hospices.

Magnitude of variation

Map 66: Deaths in hospital

For upper-tier local authorities (UTLAs) in England, the percentage of all deaths in an area that occurred in hospital ranged from 39.8% to 65.9% (1.7-fold variation), a 26.2% difference. When the five UTLAs with the highest percentages and the five UTLAs with the lowest percentages are excluded, the range is 41.0–59.1%, and the variation is 1.4-fold, an 18.1% difference.¹

In 2013 in just over half of all UTLAs (80 out of 152), the percentage of all deaths that occurred in hospital was below 50%.

Map 67: Deaths in usual place of residence

For CCGs in England, the percentage of all deaths in an area that occurred in usual place of residence ranged from 24.6% to 56.5% (2.3-fold variation), a 31.9% difference. When the seven CCGs with the highest percentages and the seven CCGs with the lowest percentages are excluded, the range is 32.8–52.5%, and the variation is 1.6-fold, a 19.6% difference.²

For both indicators, possible reasons for the degree of variation observed include differences in:

- the proportion of people older than 65 years in local populations, i.e. people most likely to be in a residential care home;
- the number of residential care home places per head of population aged older than 65 years;
- personal factors – age, marital status, and level of deprivation³;
- proximity to a hospital;
- availability of 24-hour telephone and other community support;
- existence of a clear care plan for the last days of life;
- whether the person lives alone or whether there are family or friends who are able to provide care and support;
- professional and family understanding that a person is likely to die in the next few weeks, days or hours, and communication about this between professionals and people close to the patient.

1 For 2006–2008 data by local authority, see Atlas 1.0, Map 29, pages 82–83.

2 For 2010 data by PCT, see Atlas 2.0, Map 66, pages 198–199.

3 Gao W, Ho YK, Verne J et al on behalf of the GUIDE_Care project (2013) Changing Patterns in Place of Cancer Death in England: A Population-Based Study. *PLoS Med* 10(3): e1001410. doi: 10.1371/journal.pmed.1001410 <http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001410>

Options for action

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:

- 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.

RESOURCES

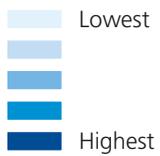
- National Palliative and End of Life Care Partnership. *Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020*. <http://www.endoflifecareambitions.org.uk>
- National Palliative and End of Life Care Partnership. *Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020*. A slide-deck. <http://www.endoflifecareambitions.org.uk>
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END-OF-LIFE CARE

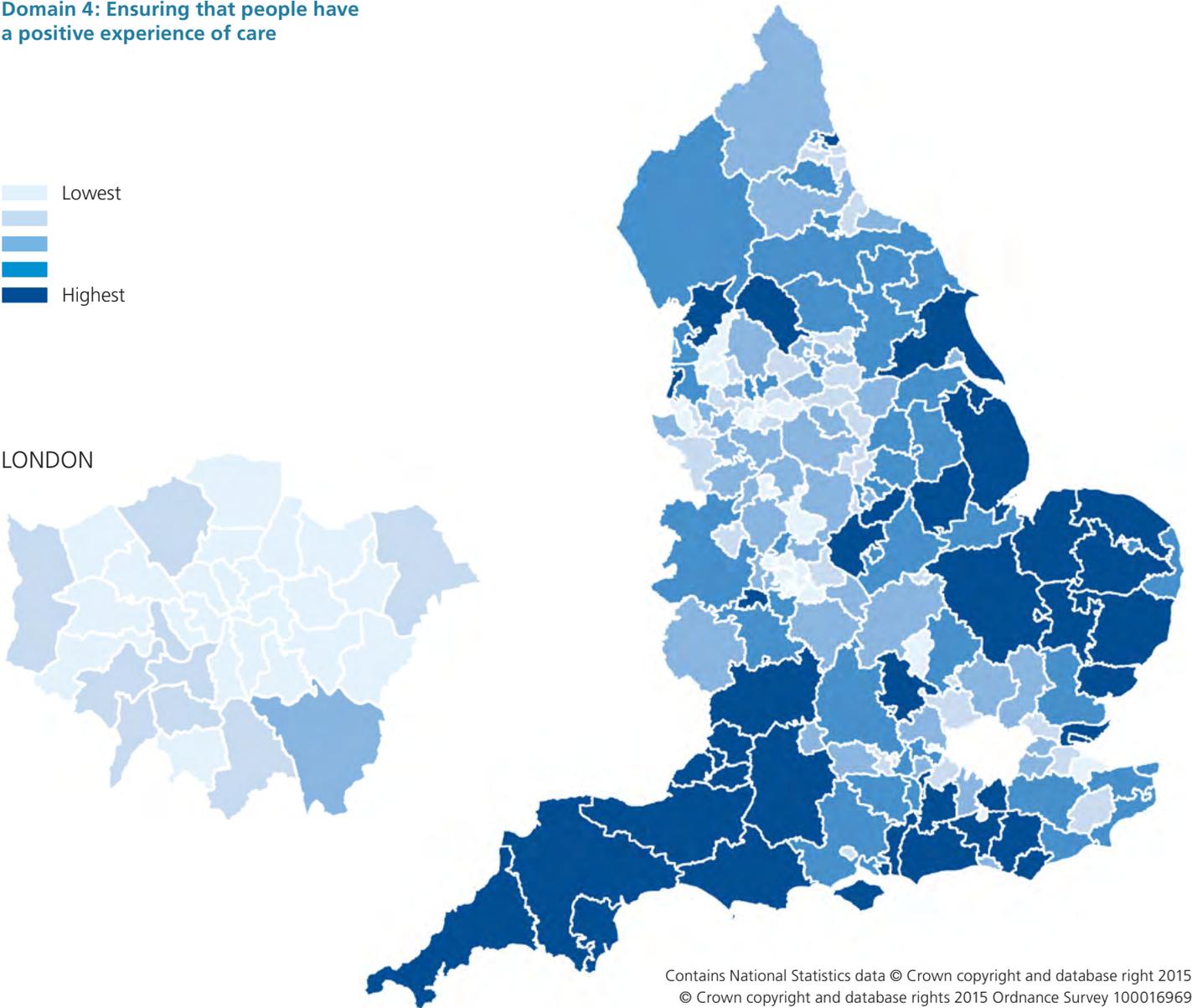
Map 67: Percentage of all deaths in an area that occurred in usual place of residence by CCG

2013

Domain 4: Ensuring that people have a positive experience of care



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