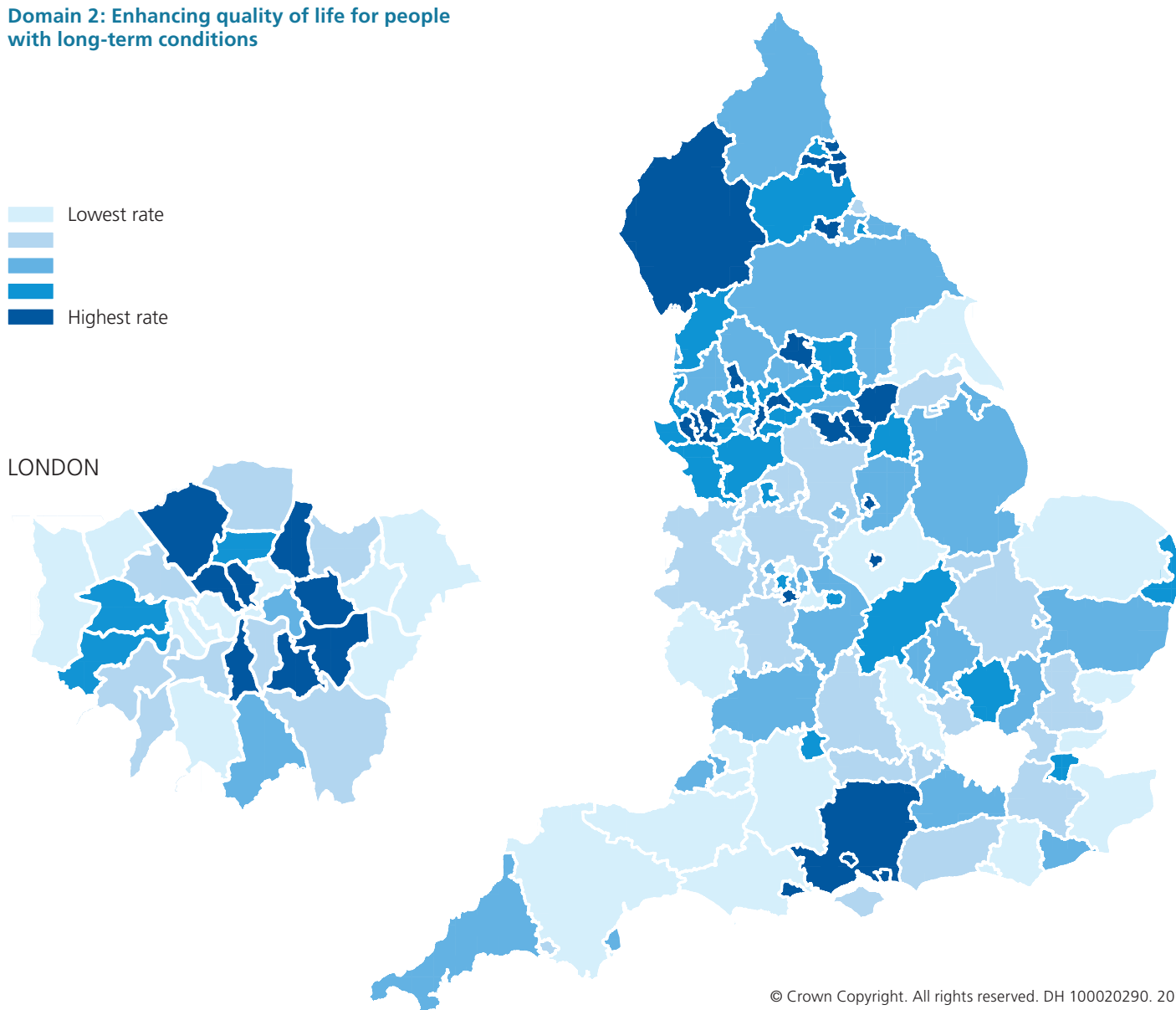


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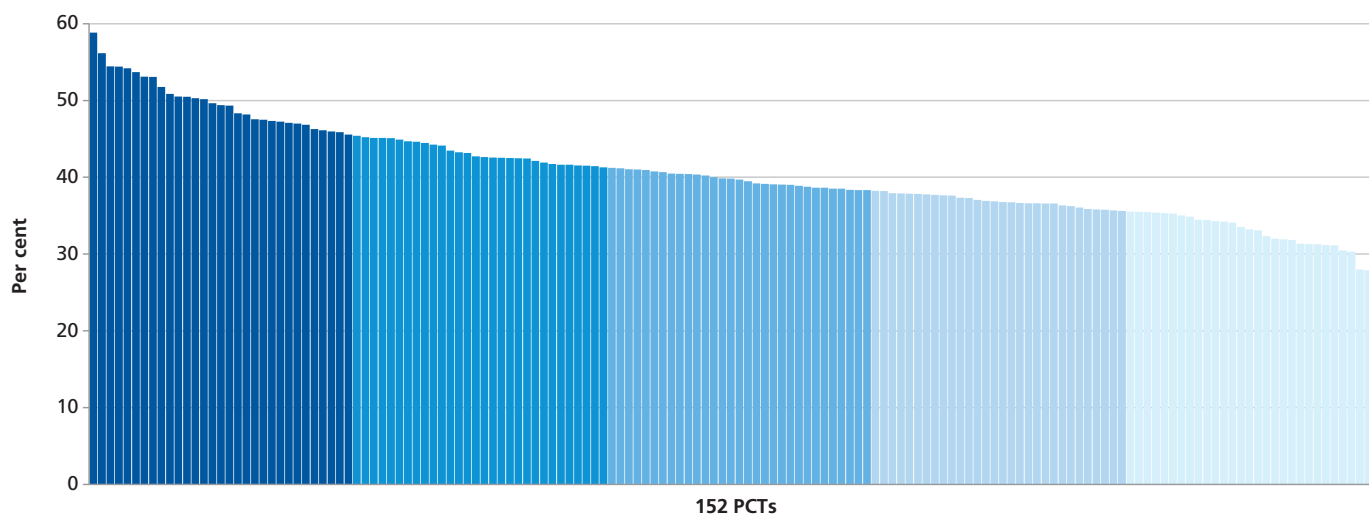
Map 13: Reported numbers of dementia on GP registers as a percentage of estimated prevalence by PCT

2009/10

Domain 2: Enhancing quality of life for people with long-term conditions



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Context

Dementia currently affects about 750,000 people in the UK. It is a syndrome, i.e. a group of related symptoms, associated with increased age, in which there is a decline in brain function, especially memory. There are four main types:

- › Alzheimer's disease, the most common;
- › Vascular dementia, as a result of stroke or a series of transient ischaemic attacks;
- › Dementia with Lewy bodies;
- › Frontotemporal dementia, much rarer, usually occurring in people under 65 years.

Sometimes, a person may have more than one type. There is no cure, and symptoms deteriorate over time. However, there are treatments that can improve the quality of life for people with dementia and their carers.

Early diagnosis is vital to ensure that:

- › Patients are started on the correct care pathway (see "Resources");
- › Patients receive better care, especially early on in the course of dementia while they still have the capacity to discuss and decide upon treatment options;
- › The needs of carers can be taken into account, and carers supported if they so wish.

Identification of people with dementia depends on awareness not only of the types of dementia and the symptoms but also of mild cognitive impairment (MCI), in which a person's memory loss (cognitive decline) is greater than that expected for their age and level of education but does not interfere with daily living. People with MCI are 10–15 times more likely to develop dementia.

People with suspected dementia should be referred to a memory assessment service specialising in the diagnosis and initial management of dementia (NICE Dementia quality standards, see "Resources"). In a recent survey of PCTs, investment in memory assessment services had increased.¹

At least 40% of people thought to have dementia have not been diagnosed; in some areas, this proportion is much higher.

Magnitude of variation

For PCTs in England, the reported numbers of dementia on GP registers as a percentage of estimated prevalence ranged from 26.8% to 58.8% (2.2-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 31.1–53.7%, and the variation is 1.7-fold.

Dementia has been stigmatised. Some people assume nothing can be done and may not seek help, and GPs may not refer them for specialist assessment.

Possible reasons for unwarranted variation include differences in:

- › Awareness in primary care;
- › Access to memory assessment services;
- › Systems in secondary care to identify and refer people with dementia;
- › Access to mental health, primary care or community geriatric input in residential and nursing homes.

Options for action

Commissioners should review:

- › level of access to memory assessment services, and whether it matches estimated prevalence of dementia locally;
- › local plans in response to the National Dementia Strategy and NICE guidance (see "Resources").

Commissioners and primary and secondary care providers should review the training available for healthcare professionals to improve early identification and diagnosis of dementia.

GPs need to consider:

- › referring people who complain of memory problems to memory assessment services;
- › the possibility of dementia, especially in people with vascular risk factors for the condition – high blood pressure, obesity, atrial fibrillation, raised cholesterol, diabetes, and excessive alcohol consumption.

RESOURCES

- › Department of Health (2009) Living well with dementia: A National Dementia Strategy. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058
- › NICE Guidance. CG42 Dementia: NICE guideline. <http://guidance.nice.org.uk/CG42/NiceGuidance/pdf/English>
- › NICE Dementia quality standard. <http://www.nice.org.uk/aboutnice/qualitystandards/dementia/dementiaqualitystandard.jsp>
- › NICE Pathway on dementia. <http://pathways.nice.org.uk/pathways/dementia>

 **See what Right Care is doing about dementia on page 32**

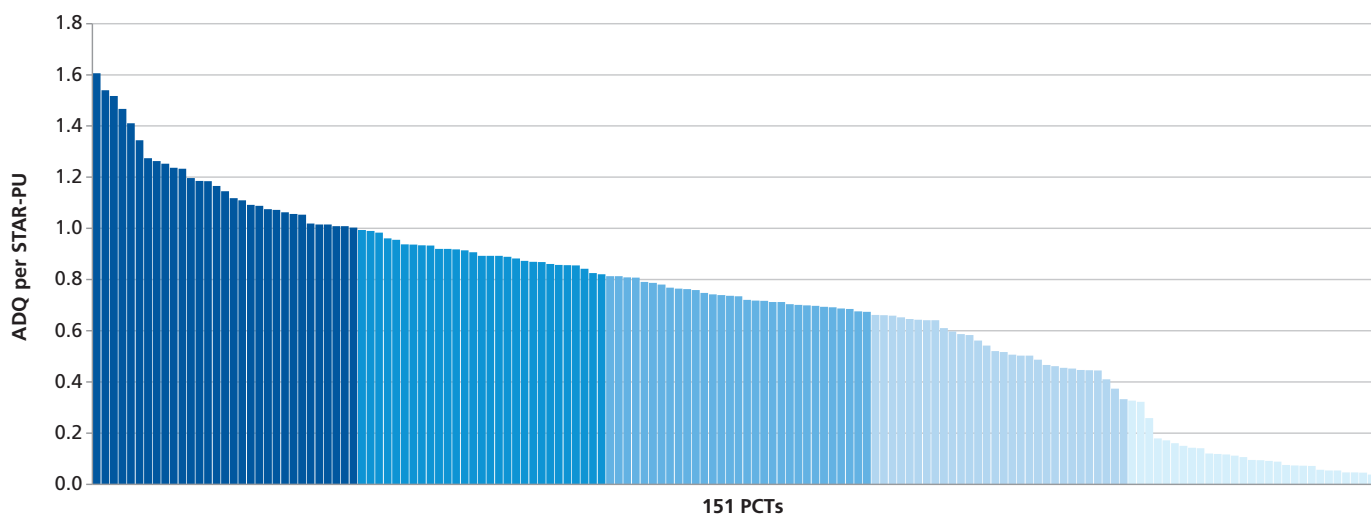
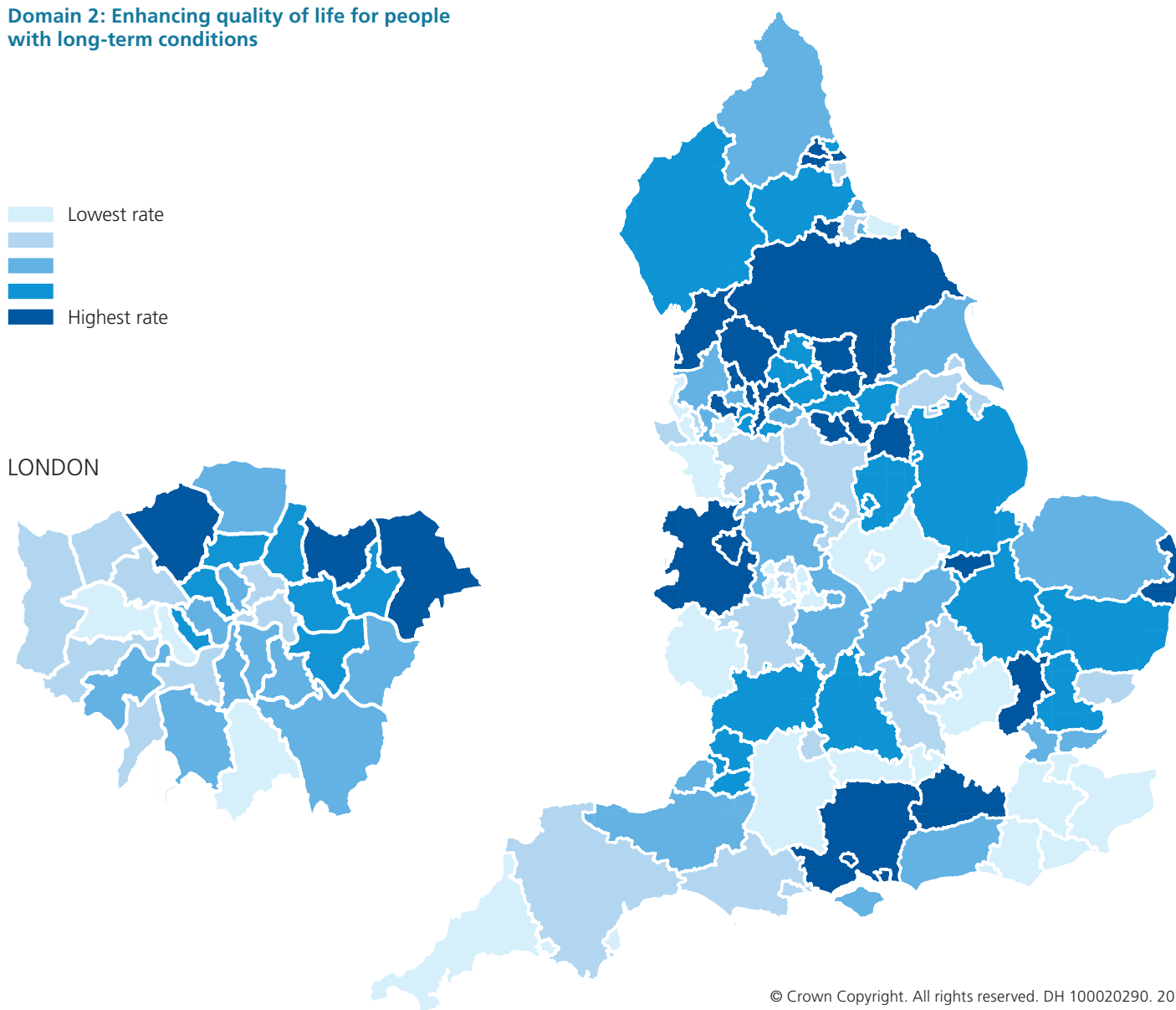
¹ NHS Information Centre (2011) Establishment of Memory Services – Provisional results of a survey of Primary Care Trusts, 2011. http://www.ic.nhs.uk/webfiles/publications/005_Mental_Health/Establishment_memory_services/Establishment_of_Memory_Services_Provisional_results_of_a_survey_of_PCTs_2011v2.pdf

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Map 14: Anti-dementia drug items prescribed per weighted population (STAR-PU) in primary care by PCT

Average daily quantity (ADQ) per STAR-PU 2009/10

Domain 2: Enhancing quality of life for people with long-term conditions



Context

There are two main types of drug used to treat Alzheimer's disease, the commonest form of dementia: cholinesterase inhibitors, and NMDA receptor antagonists. Three cholinesterase inhibitors are used in the treatment of mild to moderate Alzheimer's disease:

- Donepezil (Aricept);
- Galantamine (Reminyl);
- Rivastigmine (Exelon).

Cholinesterase inhibitors prevent the enzyme acetylcholinesterase from breaking down acetylcholine in the brain, which acts as a neurotransmitter. Higher levels of the chemical are then available to act as a messenger between brain cells, which may temporarily improve or stabilise symptoms for 6–12 months for between 40% and 70% of patients with Alzheimer's disease.

Only one NMDA receptor antagonist, memantine (Ebixa), is recommended in the treatment of severe Alzheimer's disease, and for patients with moderate disease who cannot take a cholinesterase inhibitor. It blocks the chemical glutamate, which is released in excessive amounts when brain cells are damaged in Alzheimer's disease, and causes further damage to the cells. Memantine temporarily slows down the progression of symptoms for people in the middle and later stages of the disease.

In NICE guidance, drug treatment should be started by a clinician who specialises in the care of people with dementia. Usually, patients are started on a low dose, which will be increased for greater effectiveness up to a level that the patient can tolerate. Drug treatment should be reviewed regularly, usually by a specialist team, and continued for as long as the benefits to the patient outweigh the side-effects. NICE also recommends that the views of the carer on the patient's condition are discussed at the start of drug treatment, and at any subsequent check-up.

Magnitude of variation

For PCTs in England, the anti-dementia drug items prescribed per weighted population (STAR-PU) in primary care ranged from 0.03 to 1.6 (52-fold variation). When the five PCTs with the highest number of items and the five PCTs with the lowest number of items are excluded, the range is 0.1–1.3, and the variation is 25-fold.

Although this indicator has been weighted for age, sex and temporary residents within a practice, it cannot account for other practice demographic issues, such as different morbidity patterns, or service differences, such as prescription duration.

However, as the degree of variation is large, it is likely there is unwarranted variation in this aspect of care for people with dementia. One possible reason for unwarranted variation in the number of anti-dementia drug items prescribed is variation in the diagnosis of dementia (see Map 13), which could reflect one or more of the following:

- Levels of awareness in primary care;
- Availability of training and skills development for primary care providers in the identification and diagnosis of dementia, including Alzheimer's disease;
- Access to, and capacity of, memory assessment services;
- Case-finding;
- Local protocols.

Options for action

Clinicians should review the treatment regimens in place for all patients with Alzheimer's disease and ensure that they comply with the most recent guidance from NICE (23 March 2011; see "Resources").

RESOURCES

- NICE Guidance. Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease. <http://www.nice.org.uk/guidance/TA217>
- Department of Health (2009) Living well with dementia: A National Dementia Strategy. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058
- NICE Guidance. CG42 Dementia: NICE guideline. <http://guidance.nice.org.uk/CG42/NiceGuidance/pdf/English>
- NICE Dementia quality standard. <http://www.nice.org.uk/aboutnice/qualitystandards/dementia/dementiaqualitystandard.jsp>
- NICE Pathway on dementia. <http://pathways.nice.org.uk/pathways/dementia>

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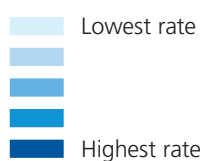
Map 15: Rate of admissions to hospital for patients >74 years with a secondary diagnosis of dementia by PCT

Age-specific rate 2009/10

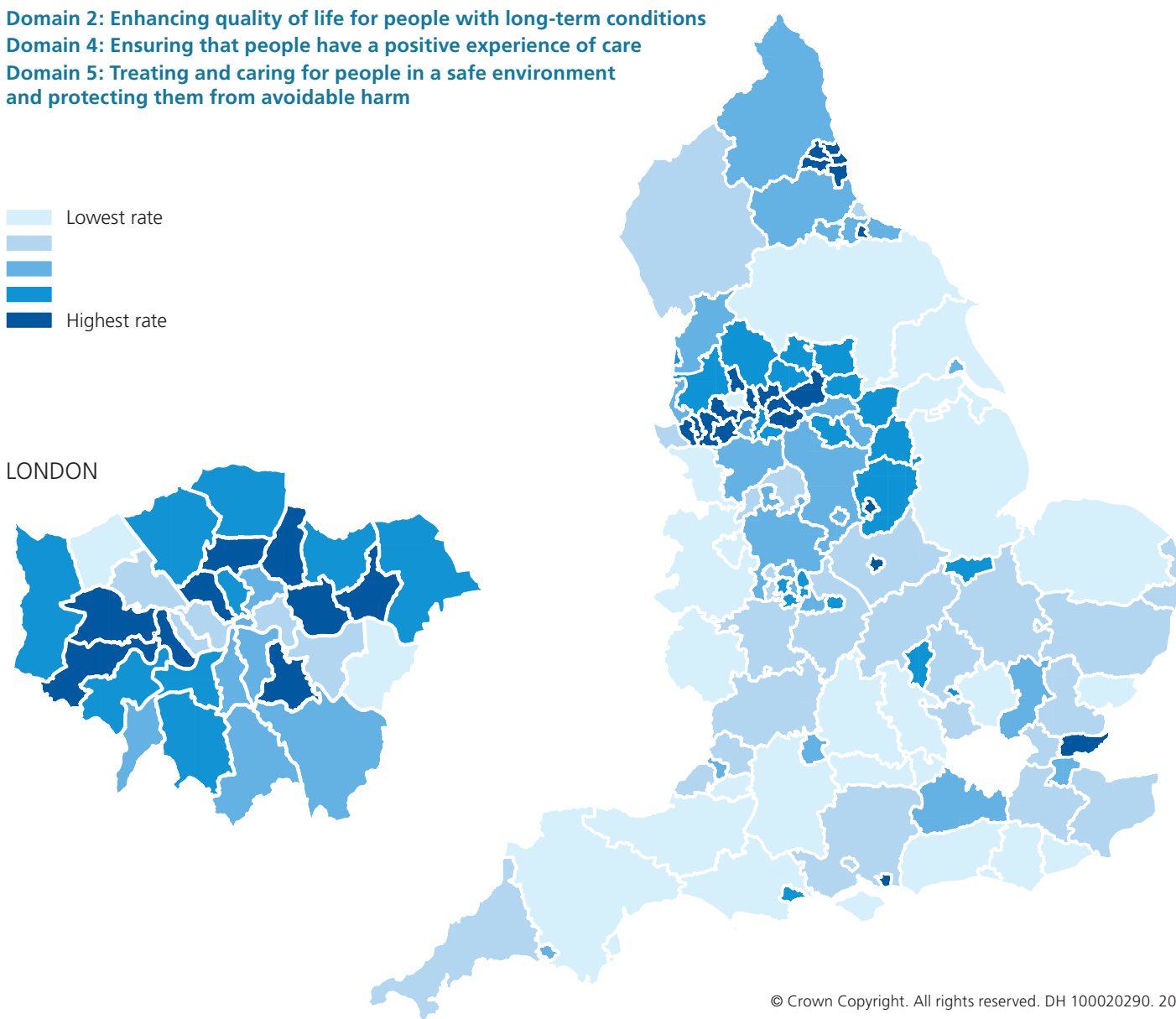
Domain 2: Enhancing quality of life for people with long-term conditions

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

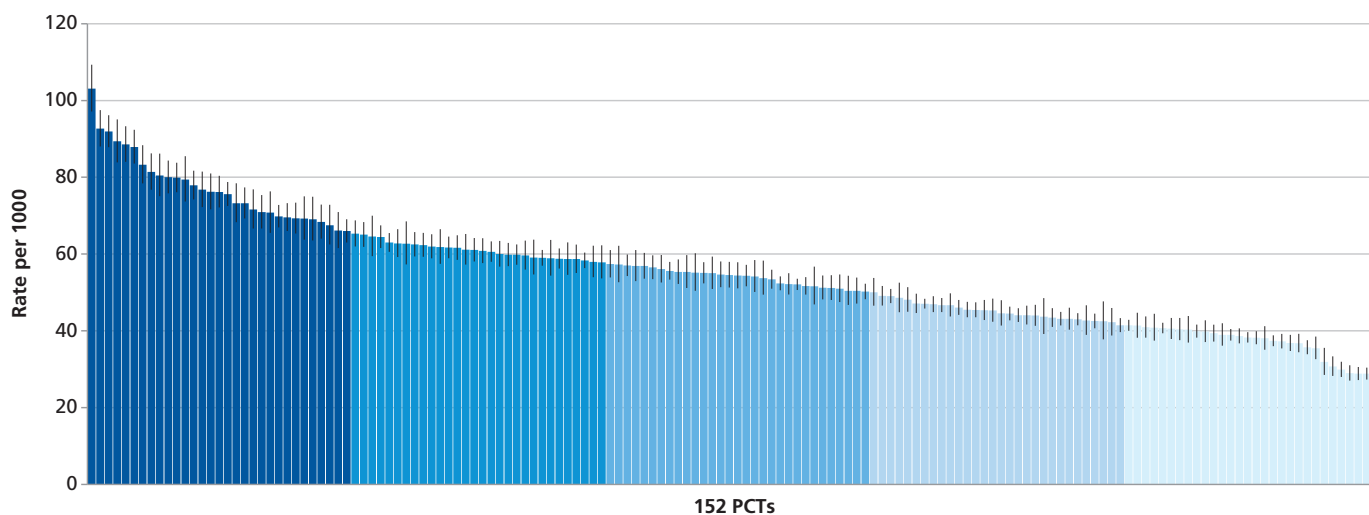
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



LONDON



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Context

People with dementia have complex needs, and in the later stages they can have high levels of dependency and morbidity.

With population ageing, patients admitted to hospital tend to be older, and dementia increases in prevalence with age. Results of observational studies suggest that one in four admissions to general hospital is a patient with co-morbid dementia, although dementia is rarely the primary reason for admission. However, co-morbid dementia can be poorly identified, or poorly coded on identification. Moreover, many people in hospital with co-morbid dementia have never received a diagnosis.

Admission to hospital can adversely affect patients with dementia. Strategies to improve the care of patients with dementia at risk of hospital admission include:

- Preventing unnecessary admission;
- Improving the quality of care for patients with dementia who are in hospital for any reason.

Sometimes, a person may have more than one type. NICE Dementia quality standard (number 8) states that people with suspected or known dementia admitted to an acute or general hospital setting should:

*"... have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health."*¹

Magnitude of variation

For PCTs in England, the rate of admissions to hospital for patients >74 years with a secondary diagnosis of dementia ranged from 24.9 to 103.1 per 1000 population (4.1-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 30.7–87.9 per 1000 population, and the variation is 2.9-fold.

Variation could be due to:

- under-reporting of dementia as a co-morbidity;
- dementia not being coded as a secondary diagnosis;
- lower or higher rates of true dementia prevalence.

Reasons for unwarranted variation include:

- low rates of diagnosis (see Map 13);
- in the absence of diagnosis, poor identification of dementia as a co-morbidity.

Options for action

Commissioners and providers can prevent unnecessary admission to hospital by:

- Ensuring access to memory assessment services in relation to local population needs;
- Establishing mechanisms to increase the early diagnosis of dementia;
- Ensuring that, once diagnosed, patients and their carers are given written and verbal information about the condition, and treatment and support options in the local area (NICE Dementia standard number 3);¹
- Actively managing people with dementia, including early intervention that could enable patients to stay at home, such as housing telecare and support for carers.

The impact of incentivising hospitals to improve identification and diagnosis of dementia needs to be explored.

Commissioners and secondary care providers should be alert to undiagnosed dementia as a possible co-morbidity in older patients, and ensure there are protocols for case-finding and referral to appropriate services.

Commissioners and secondary care providers should provide good-quality care for patients in hospital with co-morbid dementia that:

- Is person-centred;
- Involves the patient's carer(s);
- Is delivered by trained staff;
- Includes specific protocols for nutrition, hydration, end-of-life care, and discharge planning.

RESOURCES

- Royal College of Psychiatrists (2005) Who Cares Wins. Improving the outcome for older people admitted to the general hospital: Guidelines for the development of Liaison Mental Health Services for older people. <http://www.rcpsych.ac.uk/PDF/WhoCaresWins.pdf>
- Royal College of Psychiatrists' Centre for Quality Improvement (2010) National Audit of Dementia (Care in General Hospitals). Preliminary Findings of the Core Audit. <http://www.rcpsych.ac.uk/pdf/The%20Interim%20Report2.pdf>
- National Audit Office (2007) Improving services and support for people with dementia. http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx
- NHS Confederation (2010) Acute awareness: improving hospital care for people with dementia. <http://www.nhsconfed.org/Publications/reports/Pages/Dementia-report-Acute-awareness.aspx>

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¹ NICE Dementia quality standard. <http://www.nice.org.uk/aboutnice/qualitystandards/dementia/dementiaqualitystandard.jsp>

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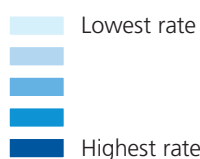
Map 16: Total bed-days in hospital per population for patients >74 years with a secondary diagnosis of dementia by PCT

Age-specific rate 2009/10

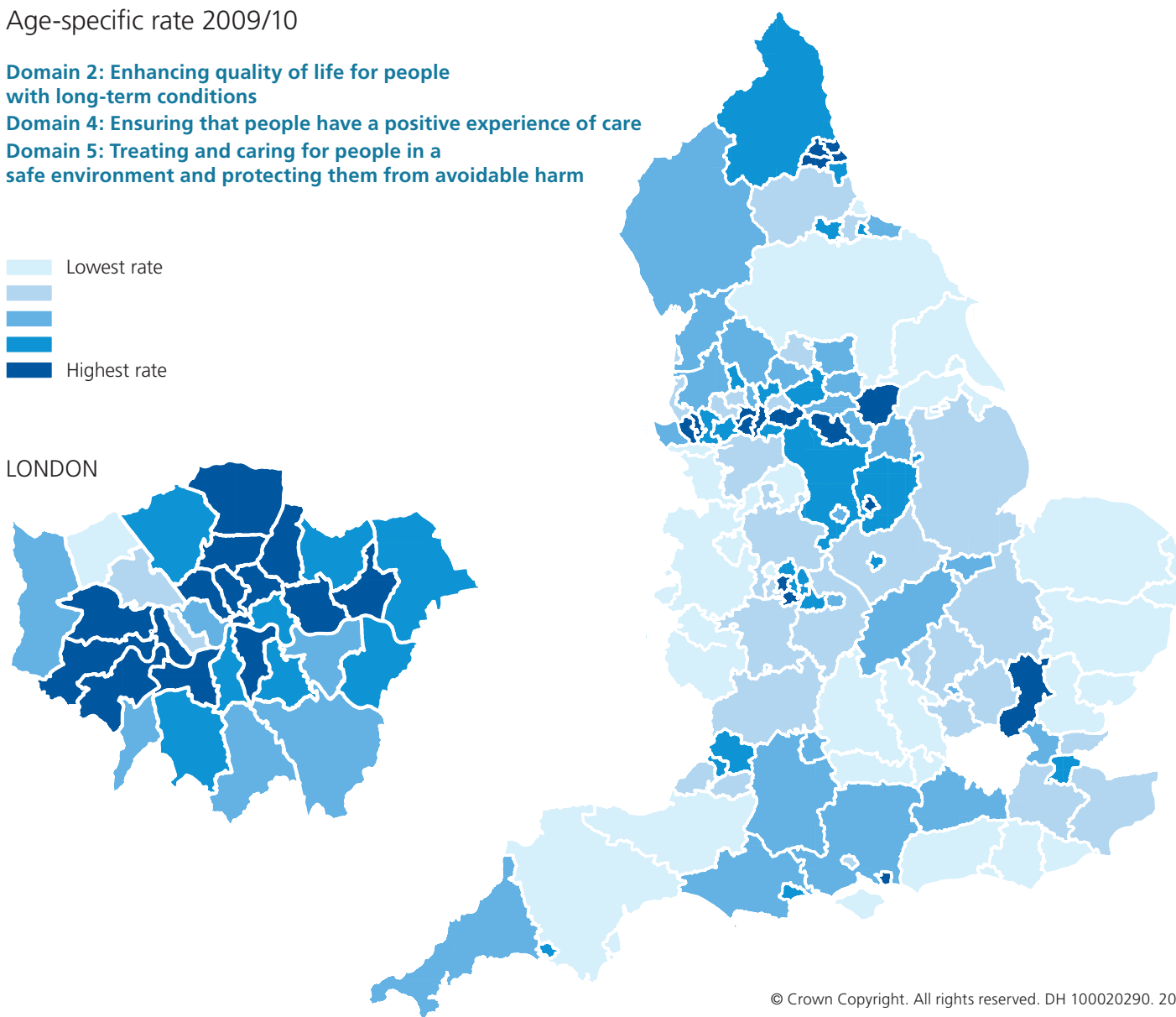
Domain 2: Enhancing quality of life for people with long-term conditions

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

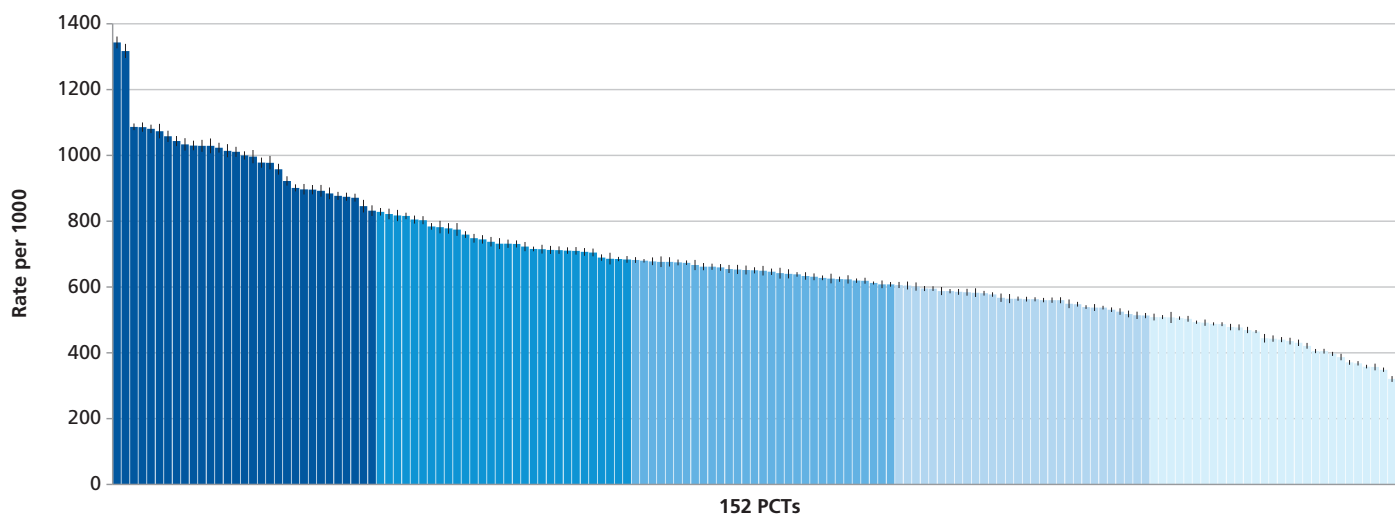
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



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Context

People with dementia have complex needs, and in later stages they can have high levels of dependency and morbidity.

With population ageing, patients admitted to hospital tend to be older, and dementia increases in prevalence with age. Results of observational studies suggest that one in four admissions to general hospital is a patient with co-morbid dementia, although dementia is rarely the primary reason for admission. However, co-morbid dementia can be poorly identified, or poorly coded on identification.

Hospital admission can adversely affect the health of patients with dementia. The National Audit Office estimated that co-morbid dementia can add an average of seven days to a patient's length of stay.¹ It is important:

- To identify inpatients with co-morbid dementia which is as yet undiagnosed;
- To improve quality of care for all patients with dementia in hospital for whatever reason.

NICE Dementia quality standard (number 8) states that once people with dementia are inpatients in an acute or general hospital setting they should:

"... have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health."²

Magnitude of variation

For PCTs in England, the total bed-days in hospital per population for patients >74 years with a secondary diagnosis of dementia ranged from 281.5–1343.0 per 1000 population (4.8-fold variation). When the five PCTs with the highest number of bed-days and the five PCTs with the lowest number of bed-days are excluded, the range is 367.9–1073.4 per 1000 population, and the variation is 2.9-fold.

Variation may be due to different service models for the management of care of the elderly, such as local care units or early rehabilitation services for patients, where bed-days may not be recorded in hospital statistics

Possible reasons for unwarranted variation are differences in:

- the diagnosis of dementia (see Map 13);
- identification of co-morbid dementia when patients with undiagnosed dementia are admitted to hospital for another reason;

- access to services specialising in dementia diagnosis and management;
- use of comprehensive geriatric assessment, management of co-morbidities and discharge planning;
- integration of community health, social care and long-term care services, and the priority in the local health economy for reducing delayed transfers of care.

Options for action

To prevent unnecessary hospital admission, commissioners and providers should:

- Ensure access to memory assessment services in relation to local population needs;
- Establish mechanisms to improve early diagnosis of dementia;
- Ensure that, once diagnosed, patients and their carers are given written and verbal information about the condition, and treatment and support options in the local area (NICE Dementia standard number 3);²
- Actively manage people with dementia, including early intervention to enable patients to stay at home, e.g. housing telecare and support for carers.

Commissioners and secondary care providers should be alert to undiagnosed dementia as a possible co-morbidity in older patients, and ensure there are protocols for case-finding and referral to appropriate services.

Commissioners and secondary care providers should provide good-quality person-centred care for hospital patients with co-morbid dementia which:

- Involves the patient's carer(s);
- Is delivered by trained staff;
- Includes protocols for nutrition, hydration, end-of-life care, and discharge planning.

RESOURCES

- Royal College of Psychiatrists' Centre for Quality Improvement (2010) National Audit of Dementia (Care in General Hospitals). Preliminary Findings of the Core Audit. <http://www.rcpsych.ac.uk/pdf/The%20Interim%20Report2.pdf>
- NHS Confederation (2010) Acute awareness: improving hospital care for people with dementia. <http://www.nhsconfed.org/Publications/reports/Pages/Dementia-report-Acute-awareness.aspx>
- Department of Health (2009) Use of resources in adult social care: A guide for local authorities. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_107596

¹ National Audit Office (2007) Improving services and support for people with dementia. http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx

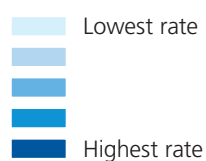
² NICE Dementia quality standard. <http://www.nice.org.uk/aboutnice/qualitystandards/dementia/dementiaqualitystandard.jsp>

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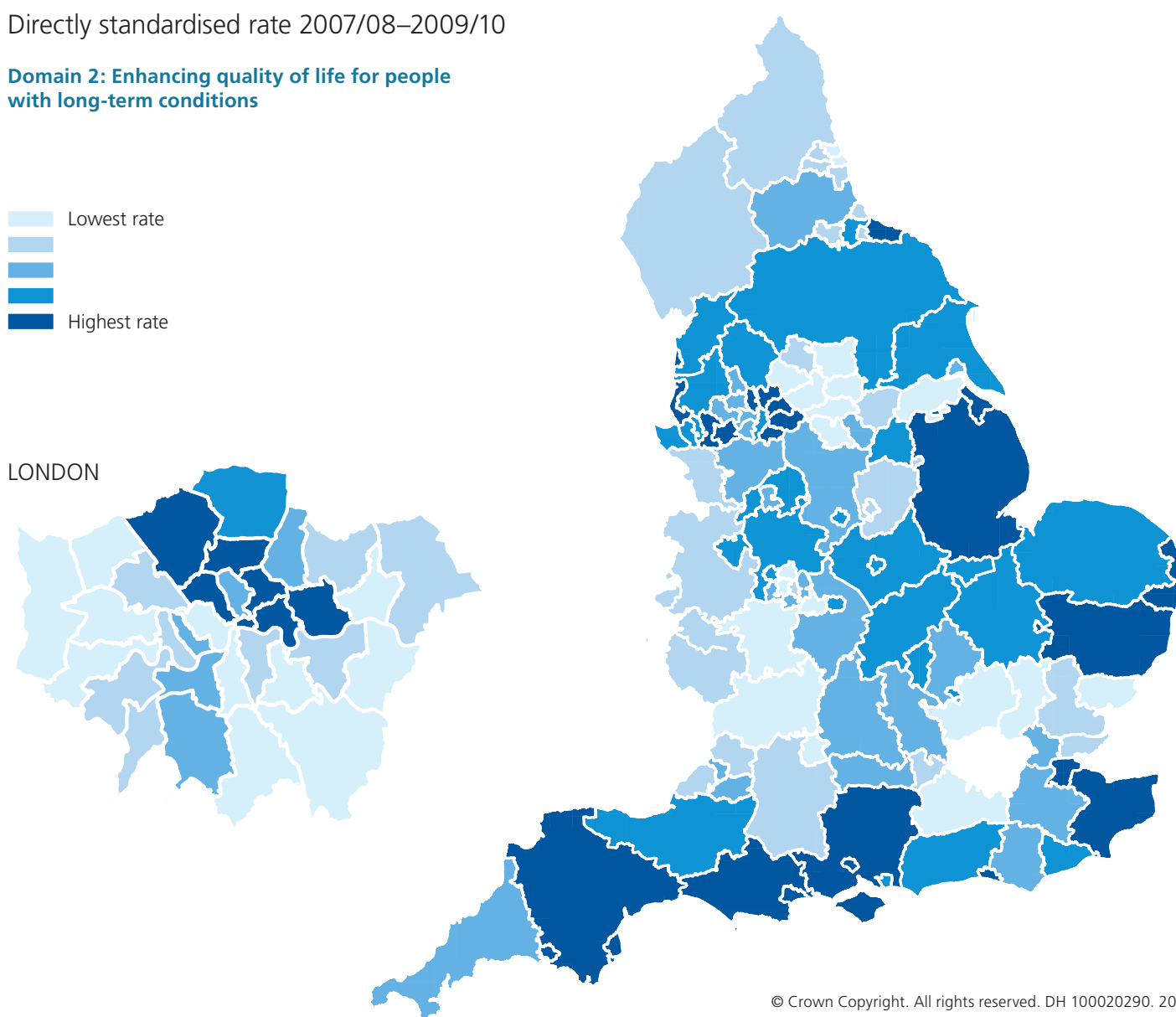
Map 17: Rate of inpatient admissions >3 days' duration in children per population aged 0–17 years for mental health disorders by PCT

Directly standardised rate 2007/08–2009/10

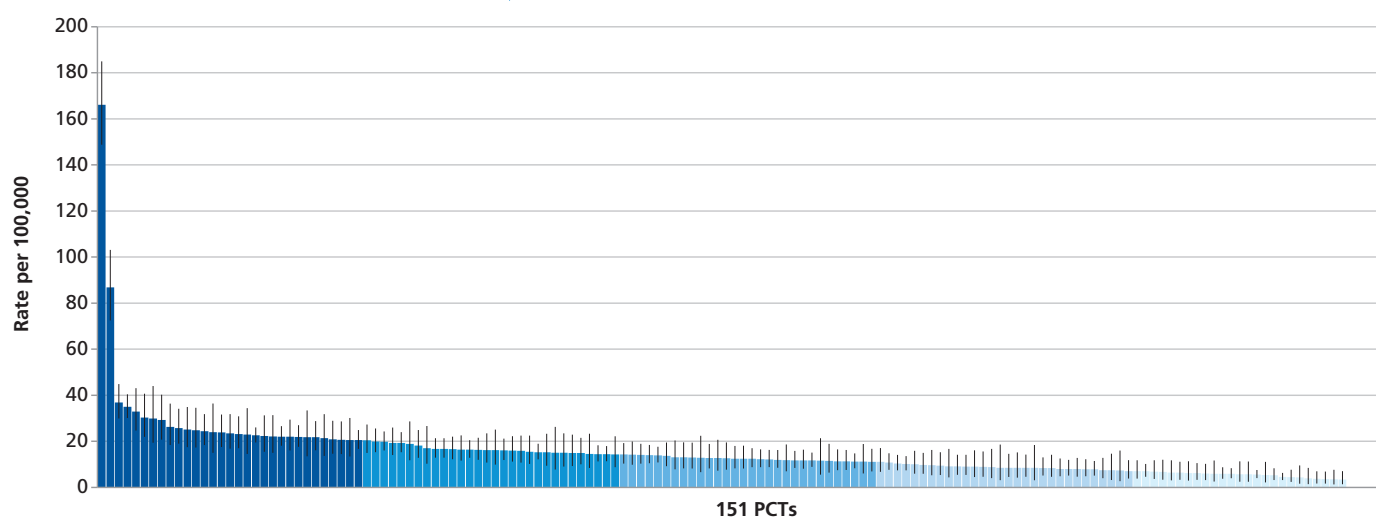
Domain 2: Enhancing quality of life for people with long-term conditions



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Context

Approximately 10% of 5- to 16-year-olds have a mental health disorder diagnosed at some point during childhood (ONS, 2004). This figure rises steeply in adulthood, to 23% suffering mental ill-health at some point in their lives (ONS 2009). Half of the adults diagnosed with mental illness will have shown symptoms by 14 years of age, and three-quarters by 20 years of age.¹

The societal cost of mental ill health is estimated at £105 billion,² and predicted to increase. Much of this cost is the consequence of early onset disorders which are recurrent or persistent. There are clinical and financial reasons to provide this patient group with the most effective intervention in as timely a way as possible.

Hospital admissions for inpatient psychiatric care represent a small but important subset of healthcare services for children and young people. They incur considerable expenditure compared with the cost of ambulatory out-of-hospital care. In selected patients, such admissions can be crucial, conferring benefit on children most in need. Evidence-based management of this limited resource is critical.

This indicator focuses on children and young people who require more than three days' admission to hospital for psychiatric treatment. The three-day threshold excludes the large proportion of children and young people admitted overnight in general hospital settings following deliberate self-harm (a different patient population with regard to care), of whom only a minority will be admitted to dedicated psychiatric units.

Magnitude of variation

For PCTs in England, the rate of inpatient admissions >3 days' duration in children per 100,000 population aged 0–17 years for mental health disorders ranged from 3.4 to 166.1 (49-fold variation).³ When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 4.4–30.3 per 100,000 population aged 0–17 years, and the variation is sevenfold.

Many mental health disorders are strongly associated with deprivation.⁴ However, when the 2007/08–2009/10 admission rates are plotted against deprivation indices, there is no statistical correlation (see Figure 17.1).

Although the reasons for this variation have not been investigated in research studies, a magnitude of sevenfold variation in a disorder for which the diagnostic criteria can be subjective probably represents unwarranted variation due to differences in the level of provision of important facilities for different populations, what Wennberg termed a "supply side" cause of unwarranted variation.

Options for action

Specialist ambulatory care services perform a gate-keeping role for inpatient care. The organisation, level of provision and

extent of local services will affect admission rates. Intensive ambulatory or outreach services for vulnerable groups may be clinically and cost effective. However, appropriate admission can play a key role.

Partnership working with social care can influence admission rates and lengths of stay.

From 2012, the child and adolescent mental health (CAMHS) national dataset (see "Resources") will enable commissioners to investigate a range of indicators measuring the performance of local services. Commissioners and clinicians should review local data for case-mix, duration of treatment, and outcomes, and plan inpatient and ambulatory services accordingly.

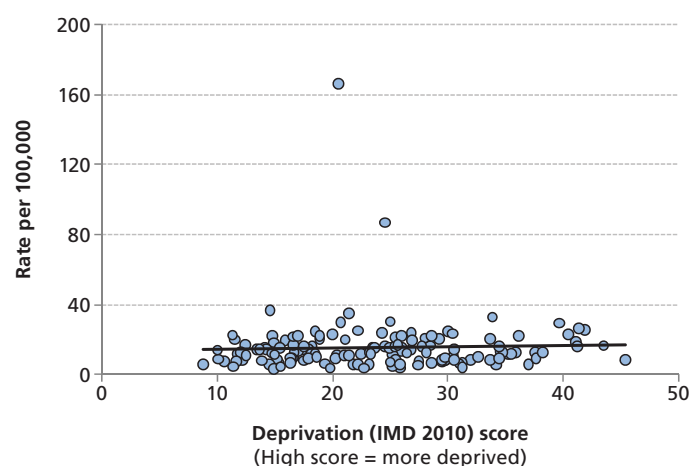
RESOURCES

- › Department of Health (2011) No health without mental health: a cross-Government mental health outcomes strategy for people of all ages. <http://www.dh.gov.uk/en/Healthcare/Mentalhealth/MentalHealthStrategy/index.htm>
- › The Children and Young Persons Improving Access to Psychological Therapies (CYP IAPT) programme, tracking the care and outcomes of patients in CYP IAPT services in England. <http://www.iapt.nhs.uk/children-and-young-peoples-iapt/>
- › CAMHS dataset. <http://www.ic.nhs.uk/services/maternity-and-childrens-data-set/child-and-adolescent-mental-health-services-camhs-secondary-uses-data-set>

This indicator is from the Child Health Themed Atlas

Figure 17.1: Relationship between rate of inpatient admissions >3 days' duration in children per population aged 0–17 years for mental health disorders and Index of Multiple Deprivation (IMD) 2010 by PCT

Directly standardised rate 2007/08–2009/10



1 Department of Health (2011) No health without mental health: a cross-Government mental health outcomes strategy for people of all ages.

2 Centre for Mental Health (2010) The economic and social costs of mental health problems in 2009/10. http://www.centreformentalhealth.org.uk/pdfs/Economic_and_social_costs_2010.pdf

3 Data from five PCTs have been removed.

4 Meltzer H, Gatward R, Goodman R, Ford T (2000) The Mental Health of Children and Adolescents in Great Britain. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4019358