

March 2012

## NHS Atlas of Variation in Healthcare for Children and Young People

Reducing unwarranted variation to  
increase value and improve quality



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# The Child Health Atlas has been prepared in partnership with a wide range of organisations:



**The national Child and Maternal Health Observatory (ChiMat)** provides information and intelligence to improve decision-making for high quality, cost effective services. It supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children's, young people's and maternal health. This specialist observatory is part of the Yorkshire and Humber Public Health Observatory (YHPHO) which is part of a network of nine Public Health Observatories in England.

<http://www.chimat.org.uk/>



**Diabetes Health Intelligence** is a strategic programme within the **Yorkshire and Humber Public Health Observatory (YHPHO)**. The YHPHO has a commitment to support the diabetes community by providing timely, quality-assured national diabetes health intelligence. YHPHO is part of a network of nine public health observatories in England.

<http://www.yhpho.org.uk/>



**The National Diabetes Information Service (NDIS)** is a national strategic partnership which provides health commissioners, providers and people with diabetes with the necessary information to aid decision-making and improve services on a local and national level. The five partner organisations are NHS Diabetes, Diabetes UK, Diabetes Health Intelligence, Innove and the NHS Information Centre for health and social care. The service is funded by NHS Diabetes.

<http://www.diabetes-ndis.org/>

## NDAU

Neonatal Data Analysis Unit

**The Neonatal Data Analysis Unit (NDAU)** is an independent academic unit based at the Chelsea & Westminster Hospital campus of Imperial College London. The aim of the NDAU is to support UK neonatal units, neonatal networks, and NHS Trusts to improve not only the quality of care for newborns but also the outcomes for newborns through health services support and research.

<http://www1.imperial.ac.uk/medicine/research/researchthemes/reproscience/paediatrics/neonatalmedicine/ndau/>



### Screening Programmes

Sickle Cell and Thalassaemia



**NHS Sickle Cell and Thalassaemia (SCT) Screening Programme.** The goal of the NHS SCT Screening Programme is to develop a linked programme of high-quality screening and care to support people to make informed choices during pregnancy and before conception, to improve infant health through prompt identification of affected babies, to provide high-quality and accessible care throughout England, and to promote greater understanding and awareness of the disorders and the value of screening.

<http://sct.screening.nhs.uk/>



### Screening Programmes

Newborn Hearing

**NHS Newborn Hearing Screening Programme (NHSP).** The NHS NHSP vision is improving outcomes for every child through a high-quality hearing screening programme, safe and effective assessments and family-centred intervention.

<http://hearing.screening.nhs.uk/>





**The East of England Public Health Observatory (ERPHO)** monitors the health of the population of the East of England and helps the NHS and other organisations ensure that decisions and actions taken to improve health are supported by sound data and information.  
<http://www.erpho.org.uk/>



**Yorkshire and Humber Paediatric Diabetes Network.** The aim of the paediatric diabetes network is to develop a care model for children and young people with diabetes that enables consistent, high-quality access to care no matter where it is delivered across Yorkshire and the Humber. The network brings together clinicians, service users, carers and commissioners across Yorkshire and the Humber to improve services and share good practice.



**NHS Luton** is a primary care trust (PCT) with the responsibility of planning health care for the town of Luton. The PCT's aim is to improve the health of Luton and reduce health inequalities.  
<http://www.luton.nhs.uk/>



**Luton and Dunstable NHS Foundation Trust** is committed to delivering the best patient care, the best clinical knowledge and expertise and the best technology available, with kindness and understanding from all staff.  
<https://www.ldh.nhs.uk/default.htm>



**Cambridgeshire Community Services NHS Trust** aims to provide high-quality, innovative services that improve the lives of the people served. The vision is to transform services, wherever possible providing these in the community closer to people's homes. Services include health and social care services for Cambridgeshire residents, adult and children's services for Luton residents, adult, community dental and unscheduled care for Peterborough residents, and sexual health services for Suffolk residents with Suffolk Integrated Healthcare.  
<http://www.cambscommunityservices.nhs.uk/Home/tabid/286/language/en-GB/Default.aspx>



**Solutions for Public Health (SPH)** is a not-for-profit public health organisation within the NHS dedicated to better health and better healthcare for all. SPH works with decision-makers across the public and third sectors to improve health and reduce health inequalities. SPH brings together a unique synthesis of clinical and public health experience, analytical and research skills and business performance to help customers improve the services they offer and commission.  
<http://www.sph.nhs.uk/>

Right Care continues to pay homage to the inspirational publication, *The Dartmouth Atlas of Health Care 1998*, and the vision and commitment of Professor John Wennberg who first charted this territory.

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## Foreword

The usual response to the question of how to improve the quality of healthcare that children receive is:

“We should spend more money on children’s services.”

However, this approach, in isolation, misses the point. There is much evidence to show that greater resource allocation does not necessarily correlate with improved quality of services or improved health outcomes.

Furthermore, although total NHS spending will be protected for the next few years, there is an imperative to make efficiency savings of £20 billion. Unless children’s health services can demonstrate that available resources are already being maximised, requests for increased investment will seem disingenuous to colleagues working to improve adult health services.

Variations in healthcare exist for many legitimate reasons. Populations and individuals have distinct needs, and some of the variation observed is a reflection of the responsiveness of the service to meeting particular needs. However, the degree of variation demonstrated in the Child Health Atlas cannot be explained solely on that basis. Unwarranted variations are driven not by the needs of the patient but by the limitations of the healthcare system and the healthcare professionals within it.

The indicators selected represent a wide range of child health services provided by the NHS. However, limitations in the data have constrained our capacity to highlight variation in all of the areas we would have wished to cover. Many of the indicators selected are the result of a trade-off between the ideal and the possible.

Despite this necessary pragmatism, the degree of unwarranted variation demonstrated in this Atlas is too great to be explained by shortcomings in data recording or analysis alone. Highlighting the magnitude of variation in these areas should stimulate commissioners and clinicians to analyse the quality of care they provide, not only for a specific indicator but across the service for which that indicator is but one aspect. Identifying and tackling unwarranted variations in healthcare will improve both the quality and efficiency of the care provided, and deliver the best possible health outcomes for all children and young people.

To do this, we must improve the quality and accessibility of data collection systems. We must harness the power of clinical networks, to pool resources and clinical expertise, to improve quality and to optimise health outcomes for children and young people. Above all, we must see the existing magnitude of unwarranted variations in healthcare for children and young people as a platform, from which to inspire commissioners to evaluate the performance of local child health services and to maximise value and improve outcomes for the population of children and young people for which they are responsible.

I would like to record my thanks to Ronny Cheung, whose dedication and hard work have been instrumental in the creation of the Child Health Atlas. I am grateful also to ChiMat for their invaluable expertise during the origination and development of the Atlas, and to Right Care for their support throughout the editorial and production process. Most of all, I would like to thank the many contributing experts who have freely provided their time, insights and support for this important document.



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 February 2012





# Reducing unwarranted variation: right care for children and young people

Total NHS spending on children's healthcare services has been estimated at £6.7 billion.<sup>1</sup> Reducing unwarranted variation in healthcare by eliminating inefficiencies can save commissioning bodies millions of pounds through the redeployment of resources. The NHS Institute for Innovation and Improvement has estimated that if all NHS organisations improved their performance to match the top-performing 25% the NHS could save about £3.6 billion.<sup>2</sup>

As Don Berwick, the doyen of quality management in the USA (who is also a paediatrician), has observed:

*"Variation is a thief. It robs from processes, products and services the qualities that they are intended to have. ... Unintended variation is stealing healthcare blind today."*<sup>3</sup>

However, as highlighted in a recent King's Fund report, the aims of identifying and tackling variations in care are not restricted to maximising the efficient use of limited resources but, more importantly, can be extended to highlighting any inequity in the quality, provision and outcomes of healthcare services.<sup>4</sup>

The aim in publishing the *NHS Atlas of Variation in Healthcare for Children and Young People* is to highlight unwarranted variations in children's healthcare services. It is hoped that the Child Health Atlas will act as a catalyst for commissioners and clinicians to explore whether the performance of services across England shows:

- variation that is warranted or explicable solely by factors outwith their control;
- unwarranted variation, which merits further investigation.

## The concept of unwarranted variation

Variations in children's healthcare services are well known to clinicians and commissioners working in the field, and also to the children and young people and their families. Socio-economic status, health need, ethnicity, and patient and family choice are valid reasons why healthcare provision and outcomes can differ from one geographical area to another.

The prevalence or distribution of some conditions can show major geographical variation, translating into variations in population need. For instance, the rates of sickle cell disease are much higher in urban areas than rural ones. It is relatively easy to account for this when constructing an indicator to map. As an example, the number of emergency hospital admissions for sickle cell disease per individual patient is shown in Map 10.

Variation may be deemed unwarranted where there are concerns about the appropriateness of clinical practice, or inequity in access to care. Professor John Wennberg, founder of *The Dartmouth Atlas of Health Care* and originator of health atlases, defines unwarranted variation as:

*"Variation in the utilization of health care services that cannot be explained by variation in patient illness or patient preferences."*<sup>5</sup>

It is difficult but necessary to distinguish warranted variation, which reflects patient-centredness and clinical responsiveness to local health needs, from unwarranted variation, which may reflect differences in the quality, equity and efficiency of care. Only after this distinction has been made will it be possible to promote the former while reducing the latter.

1 Kennedy I (2010) *Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs*. Department of Health. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_119445](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119445)

2 NHS Institute for Innovation and Improvement (2009) *Converting the potential into reality: 10 steps a commissioner can take to realise the benefits of Better Care Better Value Indicators*. Free to users from NHS England, go to: [http://www.institute.nhs.uk/option\\_com\\_joomcart.html](http://www.institute.nhs.uk/option_com_joomcart.html)

3 Berwick DM (1991) *Controlling variation in health care: a consultation from Walter Shewhart*. *Medical Care* 29:1212–1225.

4 Appleby J, Raleigh V, Frosini F et al (2011) *Variations in Health Care: The good, the bad and the inexplicable*. The King's Fund, London. <http://www.kingsfund.org.uk/publications/>

5 Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Healthcare*. Oxford University Press. Also available at: <http://www.dartmouthatlas.org/>

Every population, and each individual, may have different needs, values and priorities. Imposed uniformity is neither possible nor desirable, but unwarranted variations in quality, efficiency or equity of access require urgent redress if the value of existing NHS resources is to be maximised for the benefit of children and young people.

## Variations in quality and equity of access

Variations in the quality of service and in clinical outcomes persist despite the work on quality improvement that has taken place in the NHS over the last two decades. There are few healthcare professionals who do not understand the value of guidelines, metrics and clinical governance in promoting high-quality care.

Some of the variations in quality and health outcomes may be the result of clinical judgement, based on individual patient needs. Other variations may result from innovations in local service delivery that lead to improvements in care, from which other local services can learn. However, the degree of variation observed for the indicators presented in the Child Health Atlas cannot be attributed to these factors alone, and therefore these indicators highlight clinical areas for improvement.

Where the performance of an intervention is supported by good-quality evidence, any variation from the defined optimal standard can be viewed in simplistic terms as “bad” variation, what Wennberg calls “variation in effective care”.

However, the performance of most clinical interventions is a complex balance of risk and benefit, supply and demand. Variation may be due to:

- Differences in patient and/or clinician choice of therapy (termed by Wennberg as “preference-sensitive care”);
- Variation in the utilisation of services based on the capacity to deliver a particular treatment in that locality (termed by Wennberg as “supply-sensitive care”).

In these circumstances, “quality” is more difficult to define, and the cause(s) of variation much more difficult to unpick.

Variation in these circumstances may be due to individual clinician preference for a particular technique

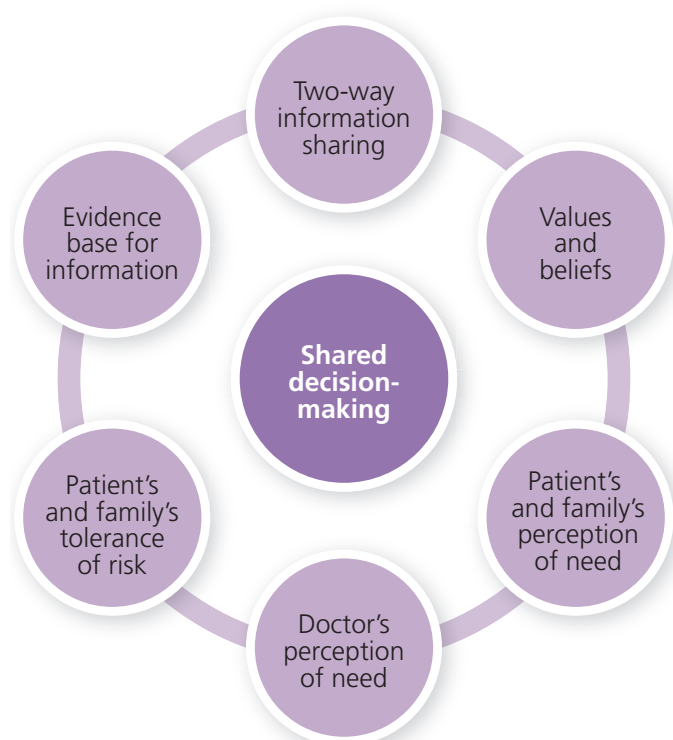
or intervention. Clinicians may also take a decision on their patient’s behalf which assumes the patient’s best interest, but which may well be coloured by their own values and expectations and not those of the patient and/or their family.<sup>6</sup>

To reduce unwarranted variation in these more complex scenarios, shared decision-making between patient/family and clinician is vital. The process must be:

- Grounded in the patient and/or family being well informed;
- Sensitive to the individual’s and/or family’s needs and values (see Figure I.1).

Shared decision-making holds the key to maximising quality and efficiency in these circumstances. The evidence shows that patients and their families, making a choice using patient decision aids and the evidence available, often choose an option that utilises less resources and results in a better patient experience.<sup>6</sup>

**FIGURE I.1: Key components in shared decision-making**



Not all variation arises as a direct result of service design and delivery: equity of access and outcomes in children and young people are also affected by pre-existing health status and socio-economic factors. To promote

6 Wennberg JE, Brownlee S, Fisher E et al. (2008) “An agenda for change: improving quality and curbing health care spending: opportunities for the Congress and the Obama administration”. Dartmouth Atlas of Health Care. [http://www.dartmouthatlas.org/downloads/reports/agenda\\_for\\_change.pdf](http://www.dartmouthatlas.org/downloads/reports/agenda_for_change.pdf)

child health, where the effects and influence of health, education and social services are deeply intertwined, it is vital for the NHS to continue to work in partnership with other professionals, and to approach reducing variation as a multi-professional inter-agency process.

## Variations in efficiency and expenditure

There is an expectation that increasing expenditure on a service improves its quality, but there is little evidence to support such an expectation. For instance, in the provision of childhood diabetes services, there is no clear correlation between increased levels of resource and improved clinical outcomes.<sup>7</sup> The key determinants of quality are:

- how the resource is used;
- the nature of the system that supports and delivers care.

Expenditure is also a function of budgeting decisions, which often reflect historical practices rather than population need. The demonstration of unwarranted variation in both budgeting and actual expenditure, using standardised comparisons with other populations, can enable commissioners to pinpoint and understand where there may be issues of unequal access to healthcare services.

Improving the quality of care can enhance the efficiency of a service. Reducing unnecessary emergency admissions for children with asthma is clinically beneficial for the patients, but also reduces the number of expensive bed-days and the use of other scarce clinical resources (see Map 19). Yet the evidence, both in this country and internationally, suggests that, even where clinicians agree on the optimal quality of a clinical service, variations in children's health services still exist.<sup>8</sup> The influence of supply and demand (of inpatient beds and clinical resource capacity) and the practice preferences of clinicians combine to produce unwarranted variations in the quality and efficiency of services.

Commissioners and clinicians need to triangulate the data on population need, allocated resource and the efficiency of local services to identify the optimal balance required to deliver high-quality care and reduce the

unwarranted variation in child health services that exists in NHS England (see Figure I.2).

**FIGURE I.2: Promoting commissioning for high-quality care: key sources of data required**



However, local child health services are not simply a series of conditions or pathways. Services are an ecological system, individual components of which can be improved and unwarranted variations reduced, as measured by specific indicators. However, any changes in a single component will affect the child health service throughout the local health economy. Commissioners need to take a holistic view towards identifying and tackling unwarranted variation in the child health service, which means considering the entire population for which they are responsible.

## Commissioning for outcomes

The Health and Social Care Bill places the emphasis on outcomes-based commissioning of healthcare services.<sup>9</sup> If providers are to be remunerated on the basis of the outcomes achieved, commissioners need not only to identify what metrics are reliable and valid but also to establish robust systems for data collection.

A network model of delivering healthcare for children

7 Harron KL, McKinney PA, Feltbower RG et al. (2011) Resource and outcome in paediatric diabetes services. *Archives of Disease in Childhood* 2011 doi:10.1136/adc.2010.198275

8 Goodman DC (2009) Unwarranted variations in pediatric medical care. *Pediatric Clinics of North America* 5; 56(4): 745-755.

9 <http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/HealthandSocialCareBill2011/index.htm>

is a powerful means of ensuring the quality of both the clinical service and data collection. In a managed network, one or more specialist centres work in close cooperation with local or community-based providers. Specialist centres are:

- Commissioned to deliver expertise and ongoing training and support for healthcare providers within a network;
- Through audit, education and training, responsible for the quality of care provided to all patients within a network.

The advantage of this model is that it aligns the ongoing education and experience of healthcare professionals with the responsiveness of a service delivered as close to the patient's home as possible. The economies of scale mean that specialist resources can be pooled to enhance efficiency and the overall quality of care for children and their families.

Managed networks can also generate a dataset sufficient to allow comparison among services, and as a result deliver increased patient choice. Children's health services tend to provide care for smaller populations when compared with adult services. If individual providers of healthcare for children confine themselves to the datasets they collect, for many conditions the numbers of patients would be too small for statistically significant comparisons to be made. Pooling comparable data from a network allows statistical robustness in analysis, while facilitating a valid comparison among providers in the same network with regard to population demographics. If commissioners can establish mechanisms to ensure that the data the networks collect are standardised and accessible, it will be possible regularly to analyse unwarranted variation not only among providers within the same network but also among networks. This will confer the capacity, routinely and systematically, to deliver meaningful outcome comparisons among geographical areas and the populations served, in line with the first recommendation of the King's Fund report on variations in healthcare.<sup>4</sup>

## "Above average" – the enemy of variations analysis

The distribution of outcomes based on geographical

and population boundaries is essentially what underlies any study of variations in healthcare. The goal of demonstrating unwarranted variation is to encourage systems redesign to reduce variation, narrowing the range such that there are fewer outliers and the data points are more uniform. Reducing variation means that a healthcare service becomes more equitable, reflecting standardised and reproducible systems of care.

When the lowest-performing outliers are identified, the direction of travel is clear. Work needs to be done to understand the reasons behind certain levels of performance, and it is necessary for commissioners, clinicians and patients and their families to collaborate if the service is to be improved.

Even in commissioning localities where the level of performance can be regarded as that of a leader in the field, it is important to look beyond narrowing the range and reducing variation. It is critical to move the whole distribution towards higher-quality outcomes. International comparisons can often dispel myths about what is possible in terms of quality improvement. For instance, only the top performing 10 PCTs in NHS England can state that 89% or more of children with diabetes in the local population have a glycated haemoglobin level of <10.0% (see Map 11); in Germany, a glycated haemoglobin of <10% is achieved for 90% of all children with diabetes nationwide.<sup>10</sup> By expanding the context within which performance is viewed, it is possible to adjust aspirations for future performance in NHS England.

There is a further reason why high-performing services cannot afford to be satisfied with the status quo. Variations analysis is dependent on an arbitrary denominator – an artificially defined population boundary. In the Child Health Atlas, the information is presented at primary care trust (PCT) level for data and historical reasons. However, within PCT boundaries, there is likely to be unwarranted variation among subsets of each population which also needs to be tackled. It is vital to guard against using "average" values, which distance us as commissioners and clinicians from the service being provided for individual children and young people. If we continually seek to create better systems in order to improve the care provided on an individual basis, improvements in the population average will follow.

## Uncharted waters: the challenge for commissioners

Existing population boundaries will change as new commissioning systems come into being. As the denominator for the data changes, so, too, will the maps presented. However, this does not make the Child Health Atlas obsolete. The analysis of unwarranted variations needs to be understood as a dynamic process, and any atlas of variation in healthcare is a means to make that analysis more accessible. By illustrating the stark nature of existing unwarranted variations, we hope to encourage clinical commissioning groups (CCGs) to ascertain the quality of children's health services within the newly formed population boundaries as a matter of urgency.

With the reforms detailed in the Health and Social Care Bill,<sup>9</sup> the power to change the way in which the care for children is delivered has been shifted towards clinical commissioners. It will be their responsibility to ensure that children receive a first-class service, regardless of where they live. The challenge will be to ensure that the work already being done to measure and reduce unwarranted variation will not be superseded by financial, structural and transitional demands.

However, help is available. Colleagues at the Child and Maternal Health Observatory (<http://www.chimat.org>) have been mapping variations in child health for several years, and have produced practical tools to tackle unwarranted variation, such as the Disease Management Information Toolkit (DMIT) for long-term conditions.<sup>11</sup> During a major transition, it is important not to lose sight of our shared purpose to provide the highest quality of care for each individual child.

The outcomes of healthcare provision for children and young people are not limited to health metrics. Outcomes that lie outside the traditional boundaries of healthcare, such as educational attendance and attainment, or measures of well-being and resilience, are markers of how well a healthcare system supports children. One of the key challenges for clinical commissioners will be whether it is possible to hold providers to account for these wider outcome measures and to reward improved outcomes for children and families, while having the degree of flexibility needed to enable clinicians to innovate within these parameters.

<sup>11</sup> <http://www.chimat.org.uk/default.aspx?QN=CHMTDMIT>





# Map and chart presentation

## Selection of indicators

Experts in clinical child health and in health data analysis, public health observatories and Department of Health policy teams were consulted about the selection and development of the indicators in the Child Health Atlas. Topics were selected to include as wide a range of child health services as possible, and indicators relating to those topics were chosen because they were deemed of particular interest with respect to unwarranted variations in healthcare.

Limitations of data quality and availability have precluded the inclusion of some topics that would benefit from variations analysis. The Child Health Atlas should be viewed as a starting point or stimulus to encourage commissioners and clinicians to investigate health outcomes in local populations.

ChiMat would welcome suggestions from users about indicators of interest that could be included in the range of indicators currently available online (<http://www.chimat.org.uk>).

## Order of appearance

In general, as for Atlas 1.0 and Atlas 2.0, the maps are presented in order of ICD classification, followed by some topics such as “Emergency Care”, that do not fall readily into a single programme budget category (PBC). However, for the Child Health Atlas, we have begun the map section with two non-PBC topics – “Resources” and “Health Promotion and Disease Prevention” – and then the “Conditions of Neonates” PBC has been moved forward to appear next. Thereafter, PBCs are presented in the correct order.

## Data sources

Data for most of the indicators in the Child Health Atlas have been extracted by colleagues at ChiMat from existing national datasets, including:

- › Clinical and Health Outcomes Knowledge Base (NHS Information Centre for health and social care; NHS IC);
- › Department for Education (DfE) statistics;
- › Health Protection Agency (HPA) Centre for Infections;
- › Hospital Episode Statistics (HES);
- › Office for National Statistics (ONS);
- › Integrated Performance Measures Monitoring.<sup>1</sup>

Data for Map 17 were prepared and provided by the NHS Newborn Hearing Screening Programme.

For most of the remaining indicators, data from national audits have been used to generate the maps; provenance of these datasets is given in the relevant commentaries.

In April 2010, 2 PCTs merged, and the number of PCTs changed from 152 to 151; owing to the way in which data have been supplied by the various sources, some of the indicators which include data from 2009/10 present data as 152 PCTs and others present data as 151 PCTs.

## Classification

Data for each of the indicators included in the Child Health Atlas are displayed as both a chart and map to show variation in terms of magnitude and geographical location within England. London is shown as a page inset on all PCT and local authority maps to keep detail that otherwise might be lost.

The charts and maps for all indicators are colour classified into thematic displays, which group the areas (e.g. PCTs) into categories and allow the reader to view and compare areas on the map without having to refer to individual values. A simple method of classification using equal counts of areas was used to display all indicators, regardless of distribution of data within

<sup>1</sup> Previously known as Vital Signs Monitoring Return.

indicators. Five equal counts of areas or 'quintiles' were classified for all indicator data where possible. However, as most of the indicators include a total number of areas that are not divisible by 5 (e.g. 151 or 152 PCTs), in most cases the classifications do not include exactly the same number of areas. The method used to create the classification was to rank order the areas from highest to lowest values, then divide the ranks into 5 equal categories. However, in some cases, indicators included tied ranks (i.e. where some area values were exactly the same) and no areas were split into different categories where the rank was equal; this meant that an equal split was not possible in these cases. For the few indicators where there were many tied ranks of equal data, the split between categories was adjusted to ensure a 'best fit' of equal numbers, without splitting areas with the same values.

The disadvantage with quintiles and equal counts of data is that it does not take into account the distribution of the data, and categories can be created with very different ranges of variation between the highest and lowest values. This should be taken into consideration when comparing areas in different categories within indicators.

The classification is shaded from light purple (lowest value) to dark purple (highest value) on both the charts and maps. The ranges and their shading do not indicate whether a high or low value for an area represents either good or poor performance.

The charts have been originally produced in Microsoft Excel 2007 and the maps originally created using MapInfo Professional 10.5.

## Standardisation

Standardisation allows like to be compared with like, by making sure that differences in the number of events (e.g. deaths or infections) observed in two or more populations are not due to differences in the age and sex profile between the different populations. (For example, suppose population A has a higher death rate than population B. However, if population A also has a higher proportion of older people, then we would expect there to be more deaths and it would be misleading to infer that people are dying at a faster rate in population A than population B.) The two main methods of standardisation are directly standardised rates (DSRs) and indirectly standardised rates.

Directly standardised rates adjust for differences in age

and sex distribution by applying the observed rates (e.g. of death or infection) for each age-band in the study population to a standard population structure to obtain a weighted average rate.

Indirectly standardised rates adjust for the differences in age and sex distribution by applying the observed rates (e.g. of death or infection) for each age-band in a standard population (e.g. England) to the population of the same age-groups in the study area.

The directly standardised rate is the method that has been used to standardise data in the Child Health Atlas, and the data have been standardised by age alone.

In Atlas 1.0 and Atlas 2.0, some of the indicators were weighted for need using the Hospital & Community Health Services (HCHS) and Person Based Resource Allocation (PBRA) methodology. This allows the data illustrations to account for the "need variables" of local health economies, using factors such as age distribution, sex, deprivation, distance to health service and Disability Living Allowance. However, these models are built on overall populations (i.e. adults and children combined), and there are no comparable models that have the capacity to weight for populations of children only.

For Maps 1, 5, 6, 13, 14, 20, 21 and 26, it has been possible to investigate correlations between the data and socio-economic deprivation; these are presented as separate visualisations (Figure 21.1 is available only on the Atlas website). Values from the Index of Multiple Deprivation (IMD) 2010 have been used. The IMD is a composite rating of seven markers of social deprivation: income, employment, health and disability, education and skills, housing and services, living environment, and crime.

## Confidence intervals

All of the indicators have error terms associated with them to give an indication of the level of uncertainty of the calculation, referred to as confidence intervals. Statistical uncertainties usually arise because the indicators are based on a random sample of finite size from a population of interest. Confidence intervals are used to assess what would happen if we were to repeat the same study, over and over, using different samples each time. The precise statistical definition of a 95% confidence interval states that, on repeated sampling, 95 times out of 100 the true population value would be within the calculated confidence interval range and for 5 times out of 100 the true value would be either higher



or lower than the range. For all of the indicators, the confidence intervals have been calculated and displayed on the charts as a series of vertical lines intersecting the top of each column. The smaller the confidence interval, the more stable the indicator; a larger number of events leads to a smaller interval.

## Exclusions

For each of the indicators mapped to a PCT or upper-tier local authority geography, the calculation of the full range of variation is given in the accompanying commentaries; in addition, the range has then been calculated from which the highest five values and the lowest five values have been excluded. This is because “outliers” could be the result of errors in data management, e.g. some data may not have been returned or events may have been recorded twice. This exclusion was originally suggested by Professor Sir Mike Richards for Atlas 1.0, and Right Care has continued to use the “Richards heuristic” in Atlas 2.0 and the Child Health Atlas.

For some indicators, where a local indicator value is created from less than five events, then these values are removed from the map and associated chart. (For example, where the indicator value is the rate of elective admissions to hospital per population, the events are the number of admissions to hospital). The indicator values are removed for two reasons:

- they are not considered sufficiently reliable, where chance could have too much influence over the value;
- they are considered potentially disclosive of individuals in the local area.

Reported indicator values of zero are displayed on the column charts for each indicator where relevant as per all other values; values of zero appear as an “absence”, with the x axis extended proportionately to show the number of values that are zero.

## Domains in the NHS Outcomes Framework

Underneath the title for each indicator, the domain or domains in the NHS Outcomes Framework 2011/12 relevant to the indicator have been listed. The five domains are as follows:

- Domain 1 Preventing people from dying prematurely
- Domain 2 Enhancing quality of life for people with long-term conditions
- Domain 3 Helping people to recover from episodes of ill health or following injury
- 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

**Table S.1: Summary of indicators in the Child Health Atlas showing the range and magnitude of variation before and after exclusions;<sup>1</sup> each indicator has been assigned to one of the following categories – activity, cost, equity, outcome, quality (performance as compared against a standard), and safety**

Map no.	Title	Range	Fold difference	Range after exclusions	Fold difference after exclusions	Category of indicator
1	Rate of expenditure (£) on child community health services per head of population aged 0–17 years by PCT 2008/09	1.0–343.4	354	28.6–223.8	8	Cost
2	Percentage of immunisation completion for routine vaccinations against diphtheria, tetanus, pertussis, polio and <i>Haemophilus influenzae</i> type b (DTaP/IPV/Hib) at 2 years by PCT 2009/10	85.3–99.2	1.2	87.6–98.5	1.1	Activity (prevention)
3	Percentage of immunisation completion for routine vaccinations against pneumococcal disease (PCV) at 2 years by PCT 2009/10	63.9–97.4	1.5	71.5–95.0	1.3	Activity (prevention)
4	Percentage of immunisation coverage for routine vaccinations against measles, mumps and rubella (MMR) at 2 years by PCT 2009/10	73.0–96.7	1.3	78.5–94.3	1.2	Activity (prevention)
5	Percentage of infants who are totally or partially breastfeeding at 6–8 weeks by PCT 2010/11	19.2–83.1	4.3	23.1–74.6	3.2	Outcome
6	Rate of perinatal mortality per 1000 births by PCT 2007–2009	3.5–12.6	3.6	5.0–11.0	2.2	Outcome Equity (of access)
7	Proportion (%) of eligible premature babies tested for retinopathy of prematurity (ROP) within the recommended timeframe by PCT 2009/10	14.3–80.0	6	19.2–64.7	3.4	Quality
8	Full-term (≥37 weeks' gestational age at birth) admissions as a proportion (%) of all babies admitted to specialist neonatal care by PCT 2010	24.7–100.0	4	34.7–69.2	2	Outcome
9	Emergency admissions of home births and re-admissions to hospital of babies within 14 days of being born per 1000 live births by PCT 2009/10	15.8–98.3	6	21.5–77.5	3.6	Quality
10	Number of emergency hospital admissions for sickle cell disease (SCD) per individual patient aged 0–17 years by PCT 2007/08–2009/10	1.2–5.8	5	1.7–4.5	2.6	Quality
11	Percentage of children aged 0–15 years in the National Diabetes Audit (NDA) with diabetes whose most recent HbA1c measurement was 10% (86 mmol/mol) or less by PCT 1 January 2009 to 31 March 2010	41.7–100.0	2.4	61.3–92.2	1.5	Outcome
12	Percentage of children aged 0–15 years with previously diagnosed diabetes in the National Diabetes Audit (NDA) admitted to hospital for diabetic ketoacidosis five years prior to the end of the audit period by PCT 1 January 2009 to 31 March 2010	6.4–46.7	7	14.5–37.3	2.6	Outcome

<sup>1</sup> For PCTs and upper-tier local authorities, the five highest values and the five lowest values have been excluded.

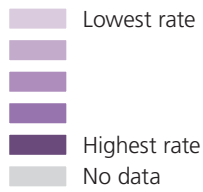
Map no.	Title	Range	Fold difference	Range after exclusions	Fold difference after exclusions	Category of indicator
13	Rate of inpatient admissions >3 days' duration in children per 100,000 population aged 0–17 years for mental health disorders by PCT 2007/08–2009/10	3.4–166.1	49	4.4–30.3	7	Activity
14	Percentage of primary school children in state-funded schools with a statement of special educational needs (SEN) by local authority at January 2011	0.3–2.9	11	0.4–2.3	6	Activity
15	Emergency admission rate for children with epilepsy per 100,000 population aged 0–17 years by PCT 2007/08–2009/10	19.1–181.2	9	30.8–133.7	4.3	Quality
16	Mean length of emergency inpatient stay (days) for children with epilepsy aged 0–17 years by PCT 2007/08–2009/10	0.4–4.1	9	0.8–2.8	3.5	Cost
17	Mean time (days) from referral to assessment for hearing tests in newborns by PCT 2010	10.5–57.2	5	13.3–43.6	3.3	Quality
18	Rate of aural ventilation tube (grommet) insertion in children per 100,000 population aged 0–17 years by PCT 2007/08–2009/10	62.1–495.1	8	91.6–424.0	4.6	Activity
19	Emergency admission rate for children with asthma per 100,000 population aged 0–17 years by PCT 2009/10	25.9–641.9	25	97.6–468.5	4.8	Quality
20	Rate of admissions for bronchiolitis in children per 100,000 population aged under 2 years by PCT 2007/08–2009/10	351–5140	15	689–3826	6	Activity
21	Mean length of stay (days) for bronchiolitis in children aged under 2 years by PCT 2007/08–2009/10	0.7–4.1	6	1.3–3.3	2.6	Cost
22	Rate of elective tonsillectomy in children per 100,000 population aged 0–17 years by PCT 2007/08–2009/10	83.1–500.4	6	145.1–423.7	2.9	Activity
23	Admission rate for children for upper and/or lower gastro-intestinal endoscopy per 100,000 population aged 0–17 years by PCT 2007/08–2009/10	39.9–226.3	6	62.5–168.4	2.7	Activity
24	Emergency admission rate for inflammatory bowel disease (IBD) in children per 100,000 population aged 0–17 years by PCT 2007/08–2009/10	53.9–535.7	10	75.8–401.3	5	Quality
25	Proportion (%) of elective orchidopexy procedures performed before the age of 2 years by PCT 2007/08–2009/10	9.7–51.2	5	13.0–46.8	3.6	Quality
26	Rate of accident and emergency (A&E) attendances per 1000 population aged under 5 years by PCT 2009/10	34.3–1232.6	36	231.1–805.4	3.5	Activity
27	Percentage of all deaths in children aged 0–17 years with life-limiting conditions that occur in hospital by PCT 2005–2009	47.4–100.0	2.1	56.3–93.3	1.7	Outcome

**RESOURCES**

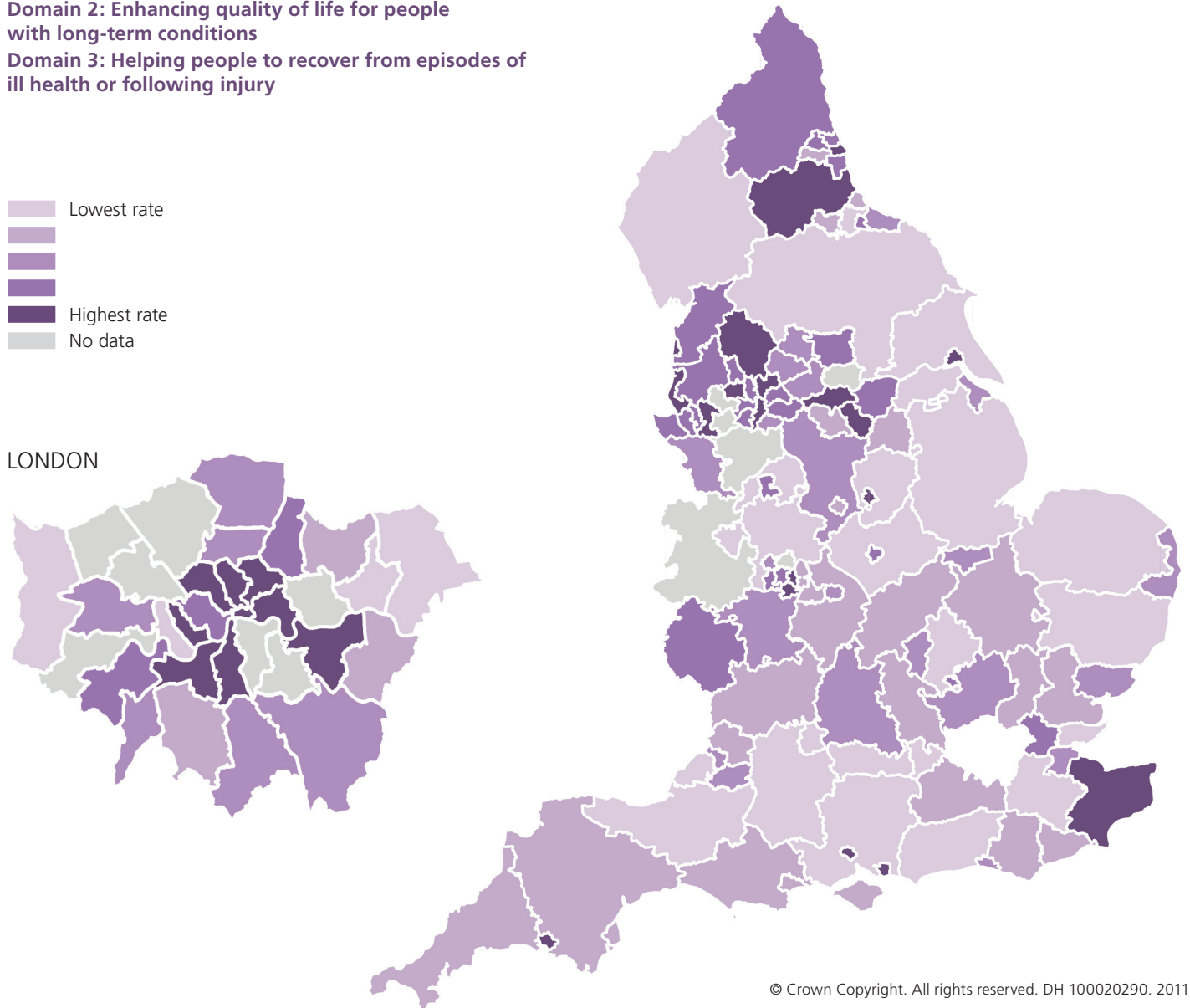
**Map 1:** Rate of expenditure on community child health services per head of population aged 0–17 years by PCT

2008/09

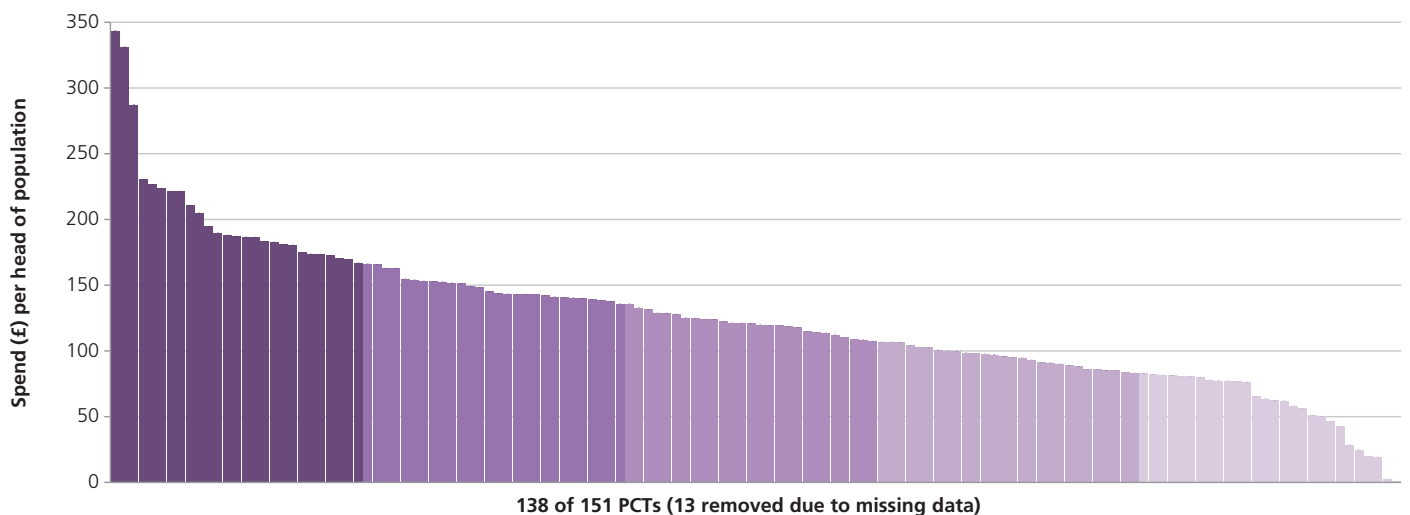
Domain 2: Enhancing quality of life for people with long-term conditions  
 Domain 3: Helping people to recover from episodes of ill health or following injury



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## Context

Community child health provides a range of services to children and young people, including those with long-term conditions: mental health, neurodisability, safeguarding, immunisation and learning disability. Community child health coordinates health, education and social care for children and their families.

Several factors have increased demand on community child health services:

- Medical technology, through prolonging the survival of many children and young people with previously fatal diseases and disabilities, while enabling more children with long-term conditions to be cared for at home;
- Increasingly mobile populations;
- Patchy distribution of migrant populations with complex needs.

Policy drivers making community child health an investment priority for commissioners are:

- Provision of health services safely and closer to home in a structured, coordinated manner;
- Health promotion and targeted intervention in early years, especially as health inequalities in early years have a disproportionate effect on health and social outcomes into adulthood.<sup>1</sup>

Increased investment does not guarantee better outcomes. When interpreting the results, consider this indicator in conjunction with indicators relating to outcomes from community child health services, such as Maps 2–4, 14 and 17.

Data are voluntary submissions from individual PCTs to the Children’s Service Mapping exercise.<sup>2</sup>

## Magnitude of variation

For PCTs in England, the rate of expenditure on community child health services per head of population aged 0–17 years ranged from £1.0 to £343.4 (354-fold variation).<sup>3</sup> When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is £28.6–£223.8 per head of population aged 0–17 years, and the variation is eightfold.

Some variation may result from:

- Voluntary data submission;
- Reporting bias – each PCT selects the scope of the services it includes in the submission;
- Different funding models for community child health, with different providers and PCTs sharing differing proportions of the overall cost.

Although caution is necessary when interpreting the data, it is unlikely these factors alone account for the degree of variation observed.

Community child health expenditure is related to the level of social and healthcare need. There is a positive correlation between total expenditure and socio-economic deprivation (see Figure 1.1).

However, as expenditure in the 10 most-deprived PCTs varies threefold and that in the 10 least-deprived varies sixfold (see Figure 1.2, page 74), deprivation or “social need” cannot be solely responsible for the degree of variation observed.

## Options for action

Improvements in the organisation, provision and reach of community child health services could reduce the demand for more expensive secondary care services. Investment in ambulatory and community-based services for targeted populations may bring economic and clinical benefits.

Commissioners need to evaluate local services and policies continuously to ensure expenditure per capita matches population needs.

Child health commissioners and practitioners and education and local government need to work in partnership. This requires a greater degree of data sharing, at the individual and population level, to safeguard clinical quality, promote research and improve outcomes in child health.

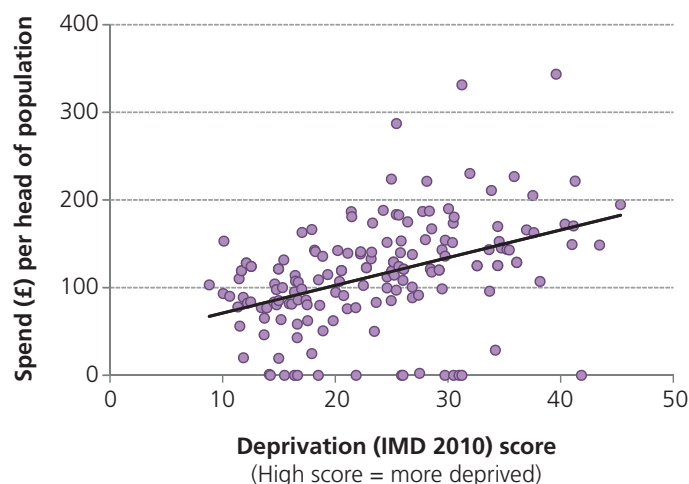
Data submission and collection needs to be standardised to ensure valid comparisons of outcome and expenditure. Improved data linkage among health, education and social care would strengthen appropriate resource allocation locally and performance management.

Commissioners could link investment in community child health services to a requirement for clinical audit of local services. Clinically meaningful indicators need to be agreed locally to identify high-priority community child health outcome measures and allow benchmarking against national comparators.

## RESOURCES

- British Association for Community Child Health (<http://www.bacch.org.uk>): information and guidance for clinicians and commissioners about improving the effectiveness and efficiency of community child health services.

**Figure 1.1: Correlation between rate of expenditure on community child health services per head of population aged 0–17 years by PCT 2008/09 and deprivation**



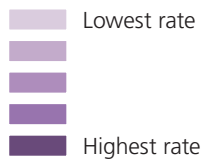
1 Institute of Health Equity (2010) *Fair Society, Healthy Lives. The Marmot Review. Strategic Review of Health Inequalities in England post-2010.* <http://www.instituteoftheequity.org/projects/fair-society-healthy-lives-the-marmot-review>  
 2 Archive website; funding discontinued in July 2010. <http://www.childrensmapping.org.uk>  
 3 13 PCTs did not submit any data.

HEALTH PROMOTION AND DISEASE PREVENTION

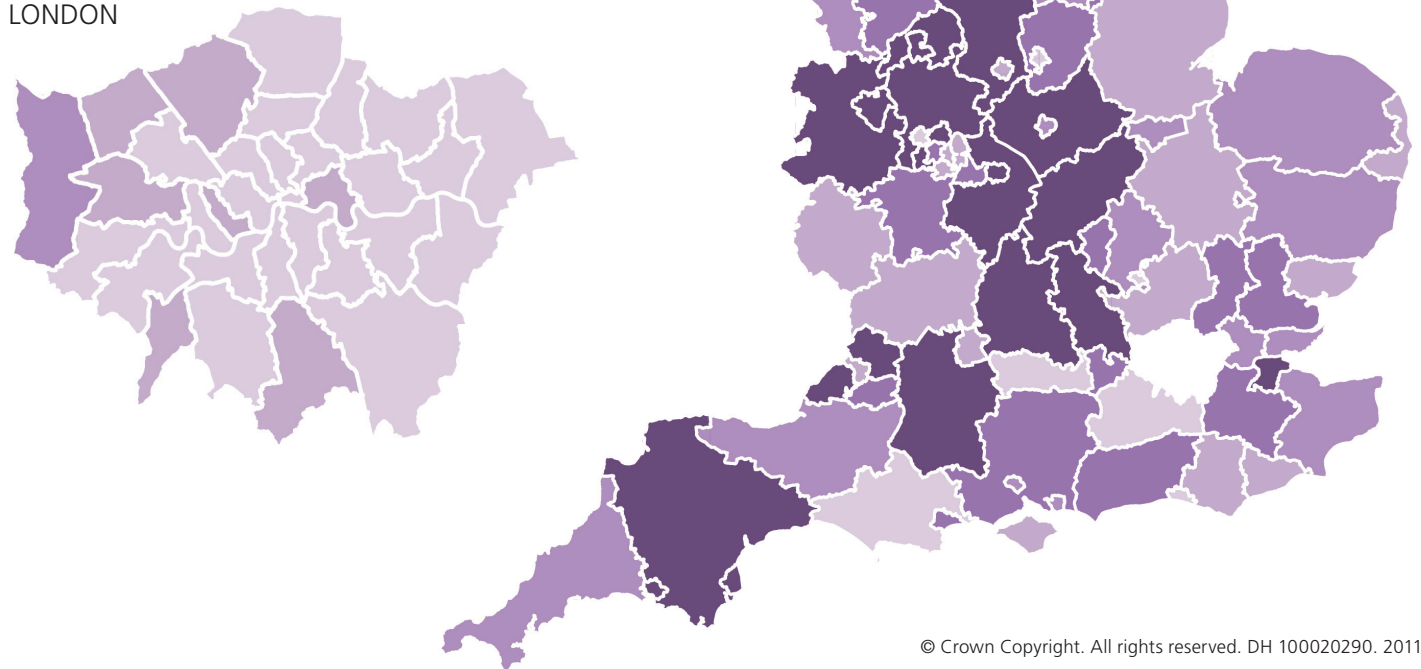
**Map 2:** Percentage of immunisation completion for routine vaccinations against diphtheria, tetanus, pertussis, polio and *Haemophilus influenzae* type b (DTaP/IPV/Hib) at 2 years by PCT

2009/10

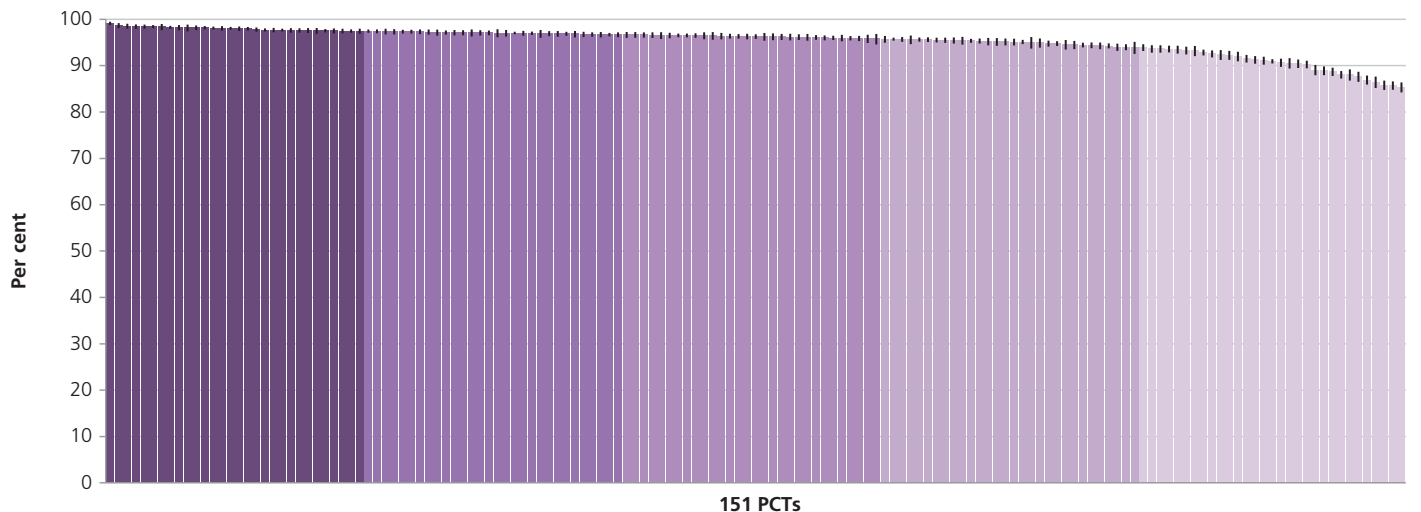
Domain 1: Preventing people from dying prematurely  
 Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



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## Context

“Vaccination has greatly reduced the burden of infectious diseases. Only clean water, also considered to be a basic human right, performs better.”<sup>1</sup>

Childhood immunisations have transformed the health of children worldwide. For individuals, they may:

- prevent infection;
- reduce deaths and morbidity from common, and often serious, infections;
- reduce rates of related illnesses, such as certain cancers or secondary infections.

High rates of population immunity to some infectious diseases may protect those who are not immunised, known as “herd immunity”.

Vaccines are cost-effective. The Health Protection Agency has demonstrated the economic benefits of vaccines currently included in the routine childhood immunisation schedule.<sup>2</sup>

Despite concerted efforts to promote uptake, opportunities for immunisation are missed.<sup>3,4</sup> Investment (e.g. in Sure Start programmes) does not guarantee:

- improvement in overall rates;<sup>5</sup>
- reduction of socio-economic inequalities in uptake.<sup>6</sup>

In the UK, infants at 2 years of age should have received doses of vaccination against diphtheria, tetanus, pertussis, polio, *Haemophilus influenzae* type b, meningococcal meningitis type C, pneumococcus, measles, mumps and rubella (German measles).<sup>7</sup>

The pattern and magnitude of variation in the uptake of each vaccination is similar at 2 years of age. Three vaccinations have been selected for visualisation:

- Combined 5-in-1 vaccine for diphtheria, tetanus, pertussis, polio and *Haemophilus influenzae* type b (DTaP/IPV/Hib);
- Pneumococcal conjugate vaccine (PCV);
- Measles, mumps and rubella (MMR) vaccine.

## Magnitude of variation

### MAP 2: COMBINED 5-IN-1 DTaP/IPV/Hib VACCINE

For PCTs in England, the percentage of immunisation completion for routine vaccinations against diphtheria, tetanus, pertussis, polio and *Haemophilus influenzae* type b ranged from 85.3% to 99.2% (1.2-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 87.6–98.5%, and the variation is 1.1-fold. However, the percentage of children who did **not** receive the full course of DTaP/IPV/Hib vaccination ranged from 0.8% to 14.7% (18-fold variation), and when the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded the range is 1.5–12.4%, and the variation is eightfold.

1 Andre FE, Booy R, Bock HL et al. (2008) Vaccination greatly reduces disease, disability, death and inequity worldwide. *Bulletin of the World Health Organization* 86; 81-160. <http://www.who.int/bulletin/volumes/86/2/07-040089/en/>

2 Health Protection Agency (2005) Protecting the health of the Nation's children: the benefit of vaccines: 2005. <http://www.hpa.org.uk/Publications/InfectiousDiseases/InfectionControl/0505Childrenhealthvaccinereport/>

3 Conway SP (1999) Opportunistic immunisation in hospital. *Archives of Disease in Childhood* 81:422 doi:10.1136/adc.81.5.422

4 Walton S, Elliman D and Bedford H (2007) Missed opportunities to vaccinate children admitted to a paediatric tertiary hospital. *Archives of Disease in Childhood* 92:620 doi:10.1136/adc.2006.104778

5 Melhuish E, Belsky J, Leyland AH et al. (2008) Effects of fully-established Sure Start Local Programmes on 3-year-old children and their families living in England: a quasi-experimental observational study. *Lancet* 372:1641.

6 Reading R, Colver A, Openshaw S et al. (1994) Do interventions that improve immunisation uptake also reduce social inequalities in uptake? *British Medical Journal* 308:1142.

7 Department of Health (2010) Routine childhood immunisation from November 2010.

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_122404](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122404)

8 Samad L, Tate AR, Dezateux C et al. (2006) Differences in risk factors for partial and no immunisation in the first year of life: prospective cohort study. *British Medical Journal* 332:1312.

### MAP 3: PCV (page 26)

For PCTs in England, the percentage of immunisation completion for routine vaccinations against pneumococcal disease ranged from 63.9% to 97.4% (1.5-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 71.5–95.0%, and the variation 1.3-fold. However, the percentage of children who did **not** receive the full course of PCV ranged from 2.6% to 36.1% (14-fold variation), and when the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded the range is 5.0–28.5%, and the variation is sixfold.

### MAP 4: MMR VACCINE (page 27)

For PCTs in England, the percentage of immunisation coverage for routine vaccinations against MMR ranged from 73.0% to 96.7% (1.3-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 78.5–94.3%, and the variation 1.2-fold. However, the percentage of children who did **not** receive the first dose of MMR vaccine ranged from 3.3% to 27.0% (8-fold variation), and when the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded the range is 5.7–21.5%, and the variation is 3.8-fold.

## Options for action

Clinical leadership among public health, primary care and secondary care health professionals is needed to maximise immunisation rates.

NICE recommends that commissioners ensure their information and data collection systems can identify children who have missed immunisations, and offer them the opportunity to receive them in a timely manner.

Commissioners need to increase immunisation rates for at-risk groups, particularly children:

- who have missed previous immunisations;
- not registered with a GP;
- from certain ethnic minority groups or non-English-speaking families;
- who are vulnerable, such as children with disabilities or a chronic illness, looked-after children, children who are homeless and children who are asylum seekers.

The reasons for partial immunisation may be different from those given by people who refuse immunisation for their children; this should be taken into account when working to increase uptake rates.<sup>8</sup>

## RESOURCES

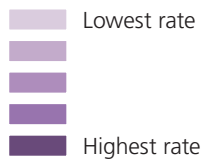
- NICE Guidance (2009) Guidance on differences in the uptake of immunisations (including targeted vaccines) in people younger than 19 years. Public health guidance, PH21. <http://www.nice.org.uk/PH21>

HEALTH PROMOTION AND DISEASE PREVENTION

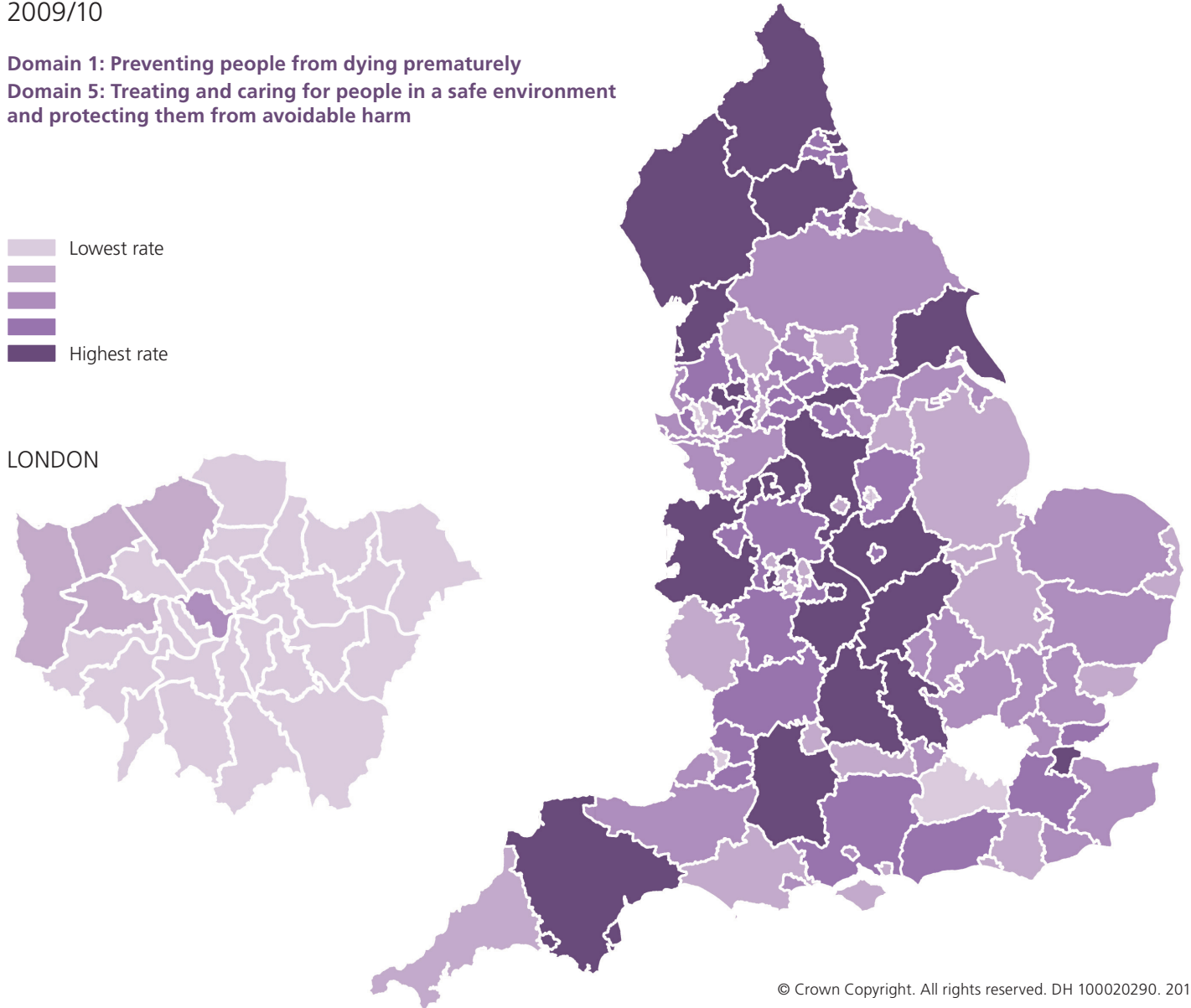
# Map 3: Percentage of immunisation completion for routine vaccinations against pneumococcal disease (PCV) at 2 years by PCT

2009/10

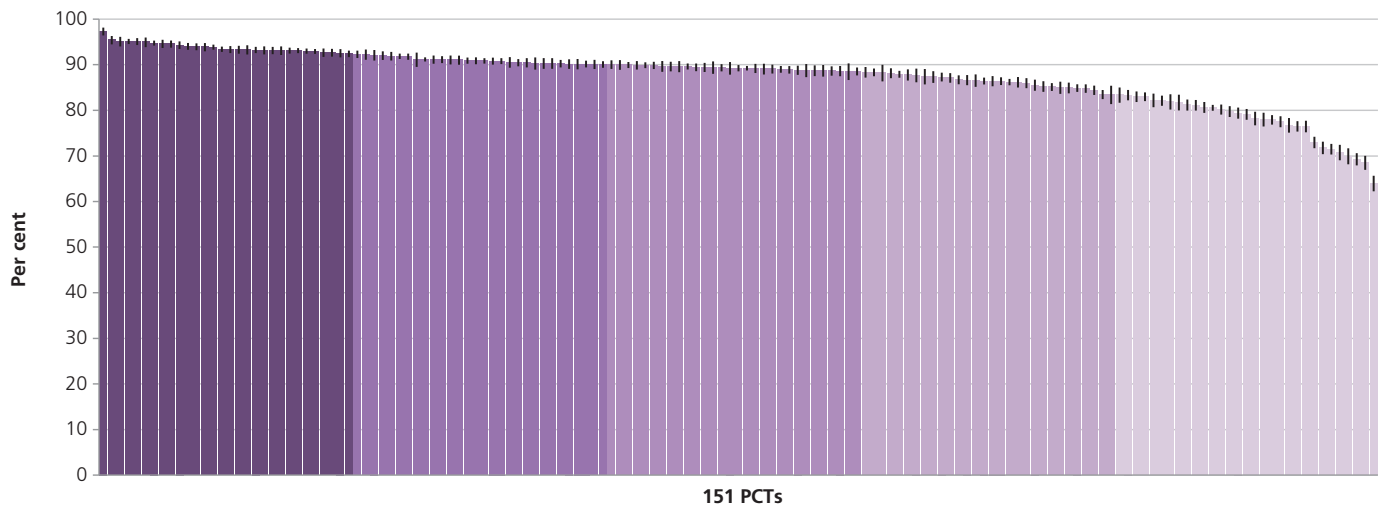
Domain 1: Preventing people from dying prematurely  
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



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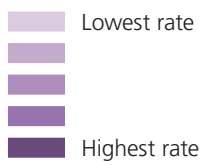


HEALTH PROMOTION AND DISEASE PREVENTION

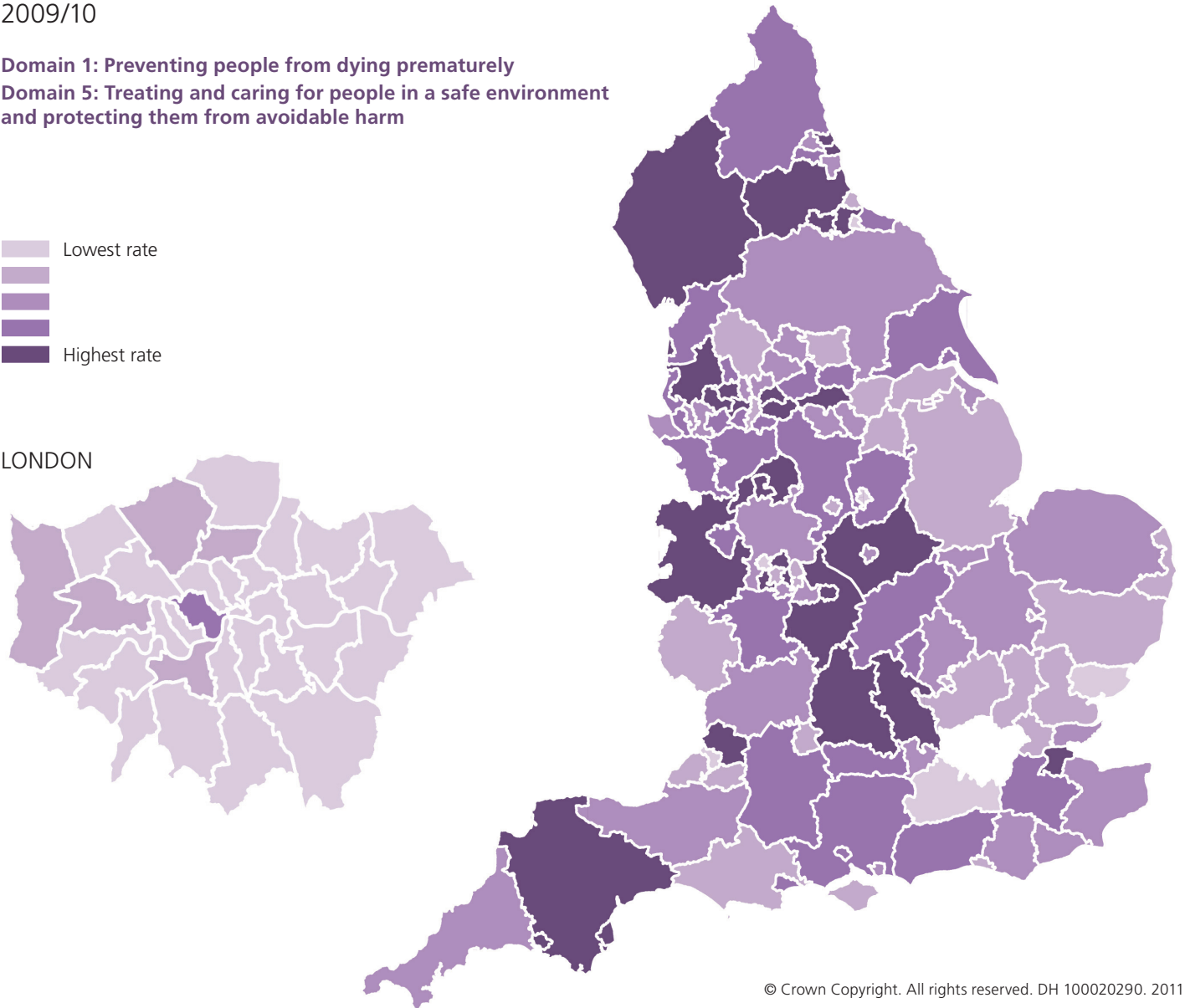
**Map 4:** Percentage of immunisation coverage for routine vaccinations against measles, mumps and rubella (MMR) at 2 years by PCT

2009/10

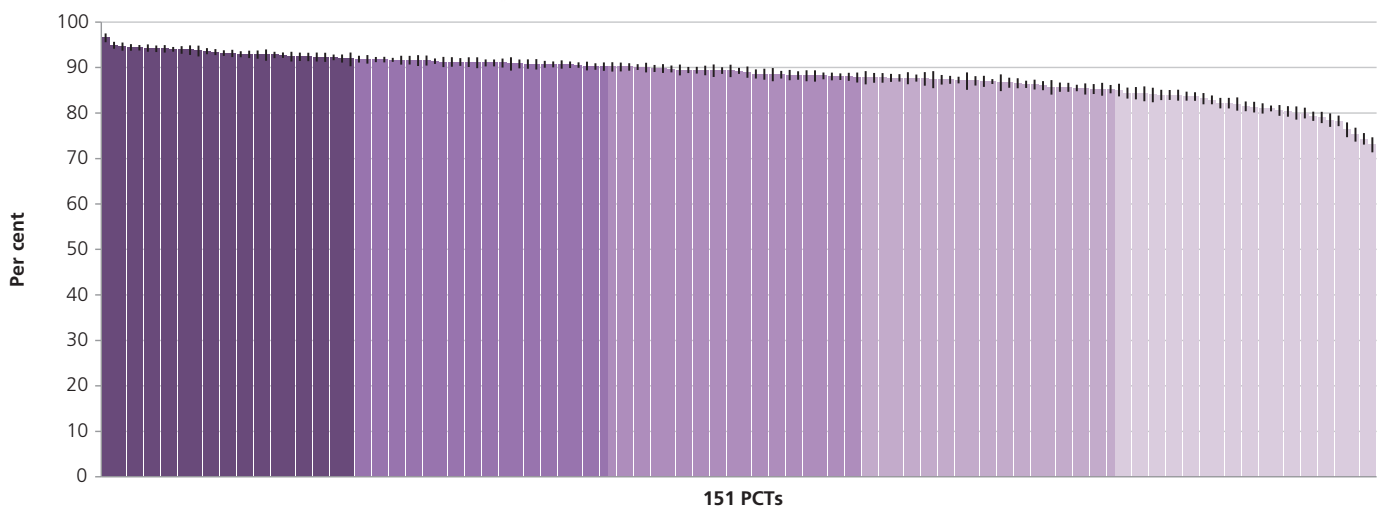
Domain 1: Preventing people from dying prematurely  
 Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



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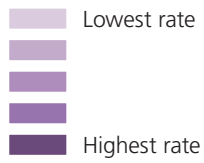


HEALTH PROMOTION AND DISEASE PREVENTION

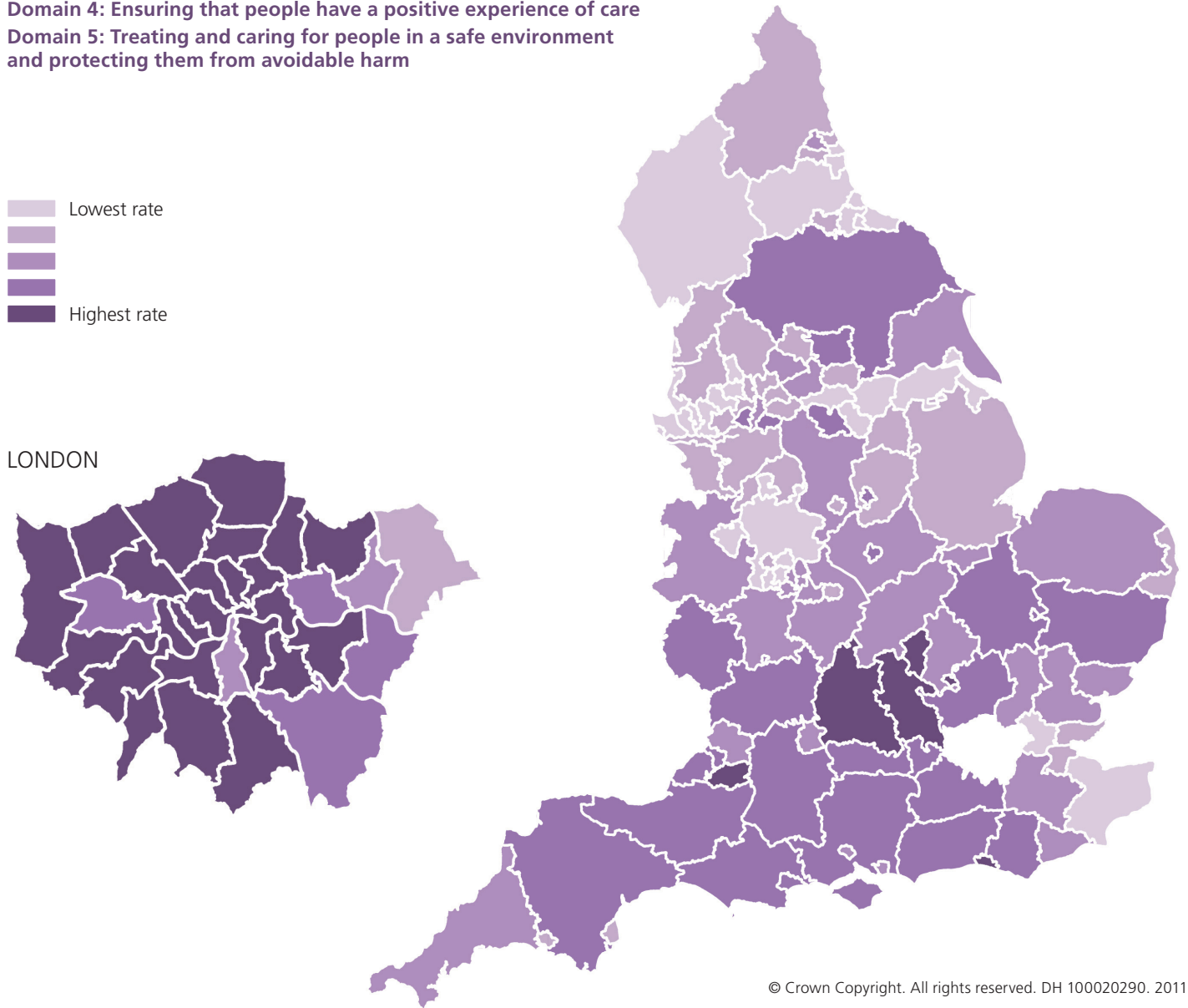
# Map 5: Percentage of infants who are totally or partially breastfeeding at 6–8 weeks by PCT

2010/11

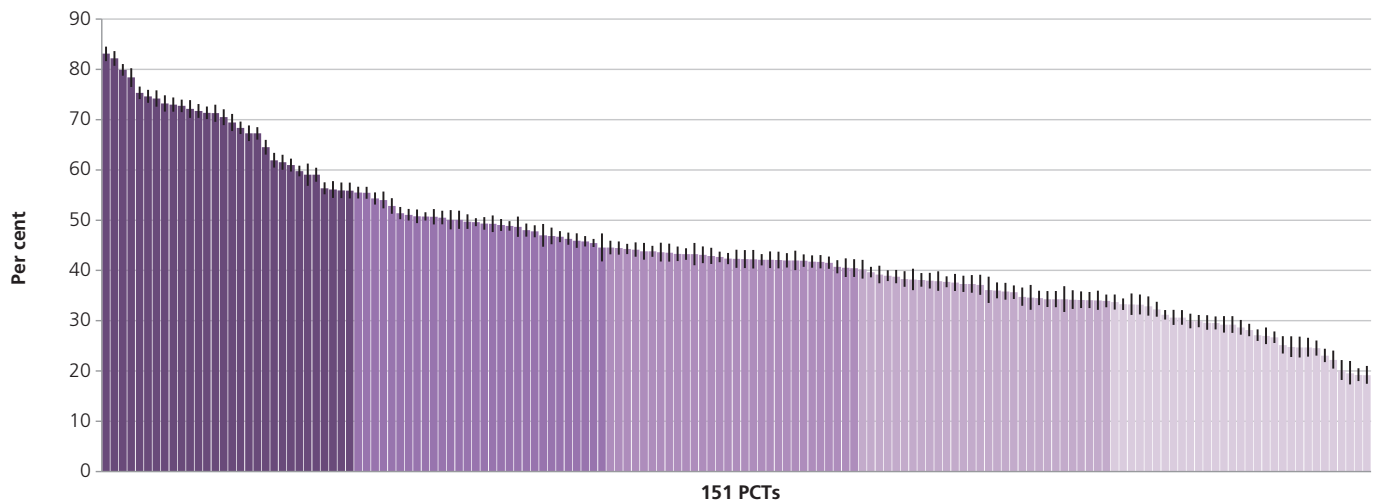
Domain 4: Ensuring that people have a positive experience of care  
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



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## Context

The World Health Organization and the Department of Health recommend exclusive breastfeeding of infants up to the age of six months. Although a minority of infants cannot be breastfed due to maternal health or other reasons, the benefits of breastfeeding are well established:

- reduced hospital admissions of infants for diarrhoea and vomiting and respiratory infections;
- reduced risk of sudden infant death;
- reduced lifetime risk of obesity and diabetes.

In addition, women who breastfeed have a reduced risk of ovarian and of breast cancer.

In economic studies, increasing rates of breastfeeding in infants have been found to have an overall cost benefit for families, health services and the wider society (see "Resources": NICE, Costing report for CG37).

## Magnitude of variation

For PCTs in England, the percentage of infants who are totally or partially breastfeeding at 6–8 weeks ranged from 19.2% to 83.1% (4.3-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 23.1–74.6%, and the variation is 3.2-fold.

The proportion of infants being breastfed is influenced by socio-economic factors, and deprivation is associated with lower levels of breastfeeding. However, breastfeeding is a complex issue, and deprivation is only one of several influencing factors. A comparison of breastfeeding among the 10 most-deprived PCTs shows a fourfold variation, and among the 10 least-deprived PCTs shows a 1.75-fold variation (Figure 5.1), which suggests that considerable unwarranted variation exists.

Many new mothers require support to initiate and sustain breastfeeding, starting from confirmation of conception. Differences in the provision of local community midwifery and health visitor services and perinatal care will affect the rates of breastfeeding observed among PCTs.

## Options for action

Commissioners and clinicians need to review the proportion of infants being breastfed in the local population, and share good practice particularly among localities that have a similar socio-economic and ethnic profile.

Commissioners and health professionals need:

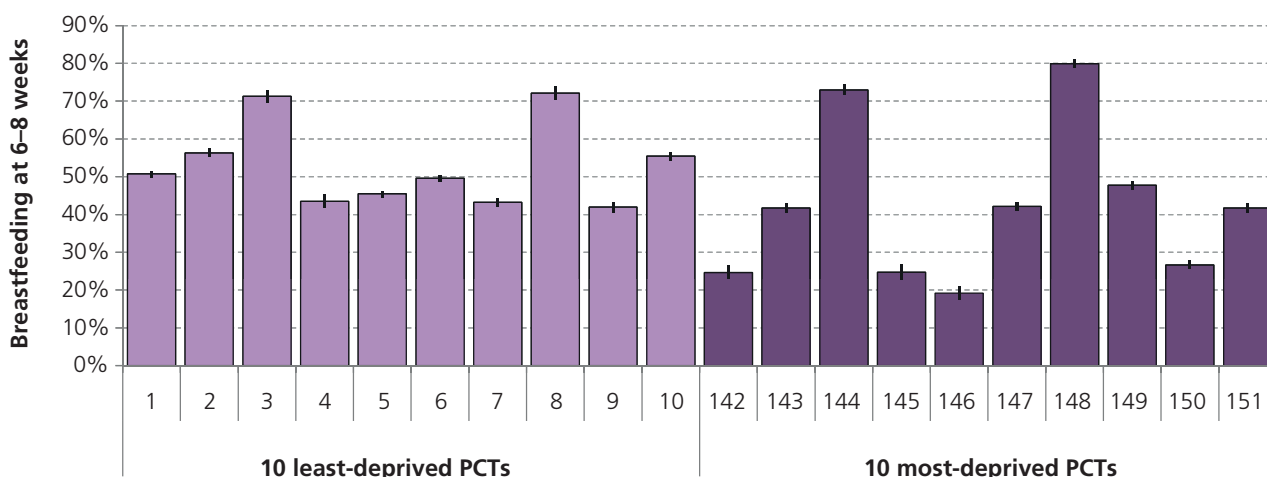
- to assess whether performance locally compares favourably with that in localities which have a similar population profile;
- to identify whether there are any unwarranted variations among social, ethnic or other groups in the local population, to understand the reasons for low rates and to target any relevant interventions.

Commissioners need to ensure there is adequate support for mothers and families not only to establish breastfeeding but also to prolong its duration, including education (both antenatal and postnatal) and the dissemination of public health messages, particularly aimed at groups where rates are found to be especially low.

## RESOURCES

- Dyson L, Renfrew M, McFadden A et al. (2006) Promotion of breastfeeding initiation and duration. Evidence into practice briefing. NICE. [http://www.nice.org.uk/niceMedia/pdf/EAB\\_Breastfeeding\\_final\\_version.pdf](http://www.nice.org.uk/niceMedia/pdf/EAB_Breastfeeding_final_version.pdf)
- NICE Guidance (2008) Guidance for midwives, health visitors, pharmacists and other primary care services to improve the nutrition of pregnant and breastfeeding mothers and children in low income households. Public health guidance, PH11. <http://guidance.nice.org.uk/PH11>
- NICE Guidance (2006) Postnatal care: Routine postnatal care of women and their babies. Clinical guidelines, CG37. <http://www.nice.org.uk/CG037>
- NICE Guidance (2006) Postnatal care: Routine postnatal care of women and their babies. Costing report. Implementing NICE guidance in England. NICE clinical guideline no. 37. <http://guidance.nice.org.uk/CG37/CostingReport/doc/English>
- NICE (2008) A peer-support programme for women who breastfeed. Commissioning guide. Implementing NICE guidance. <http://www.nice.org.uk/media/63D/7B/BreastfeedingCommissioningGuide.pdf>

**Figure 5.1: Percentage of infants who are totally or partially breastfeeding at 6–8 weeks 2010/11 among the 10 least-deprived and 10 most-deprived PCTs (IMD 2010)**

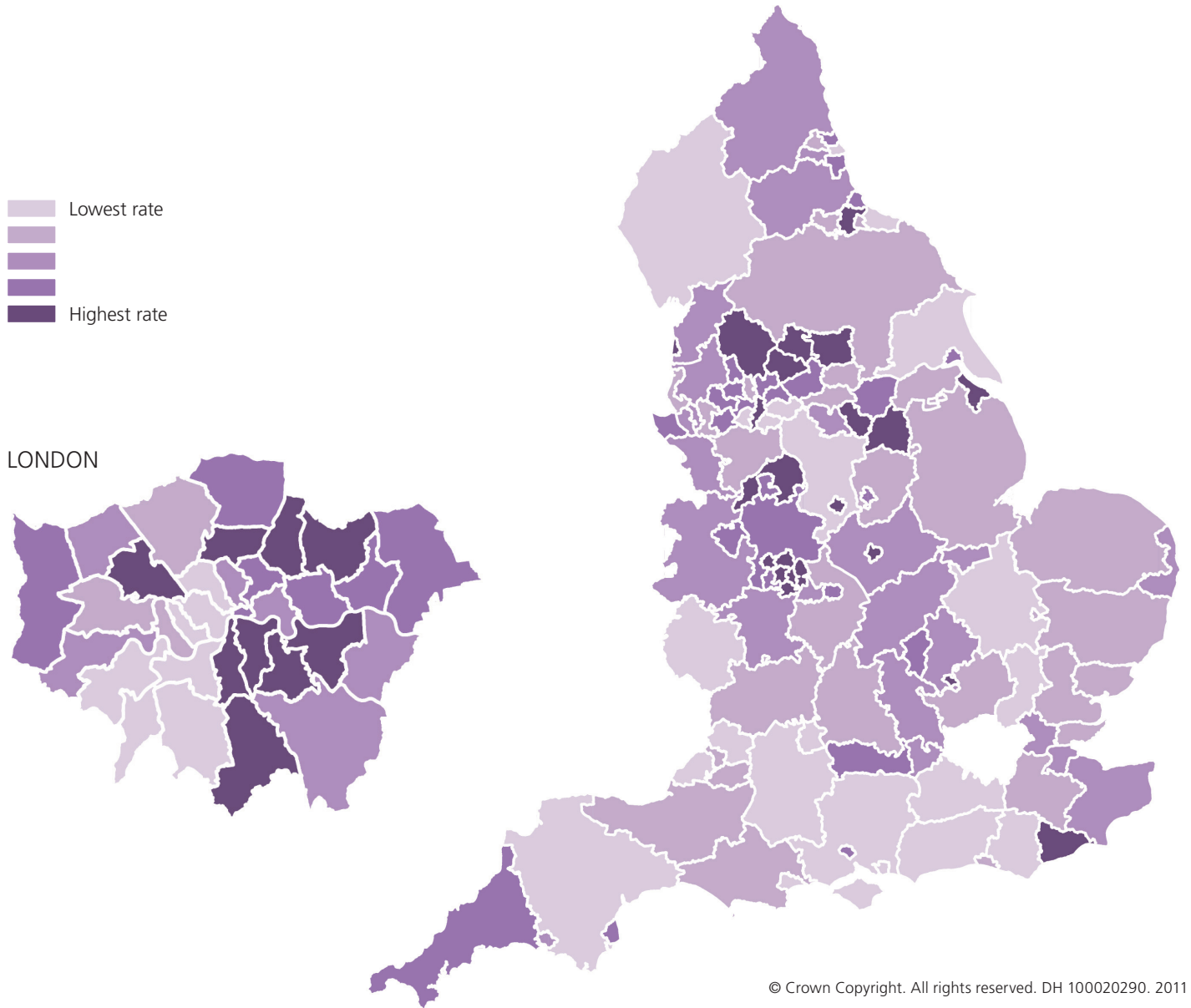


CONDITIONS OF NEONATES

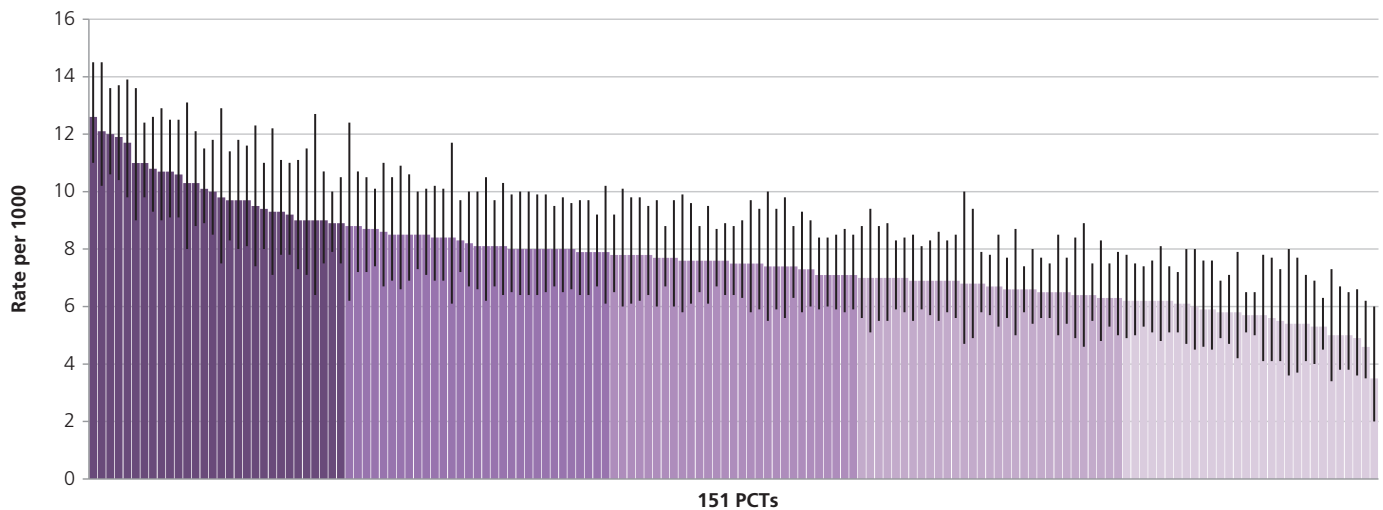
# Map 6: Rate of perinatal mortality per all births by PCT

2007–2009

Domain 1: Preventing people from dying prematurely



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## Context

Perinatal mortality comprises all stillbirths (babies born dead after 24 weeks' gestation) and babies born alive but who die within 7 days of birth expressed as a rate per 1000 births. Perinatal mortality is an indicator that highlights the state of maternal health and nutrition, as well as healthcare in the antenatal, obstetric and neonatal period.

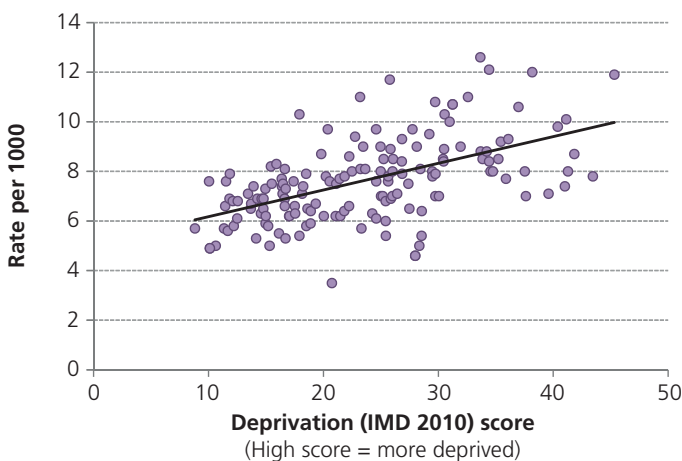
This indicator is one of the national quality indicators in Domain 1 of the NHS Outcomes Framework 2011/12.

## Magnitude of variation

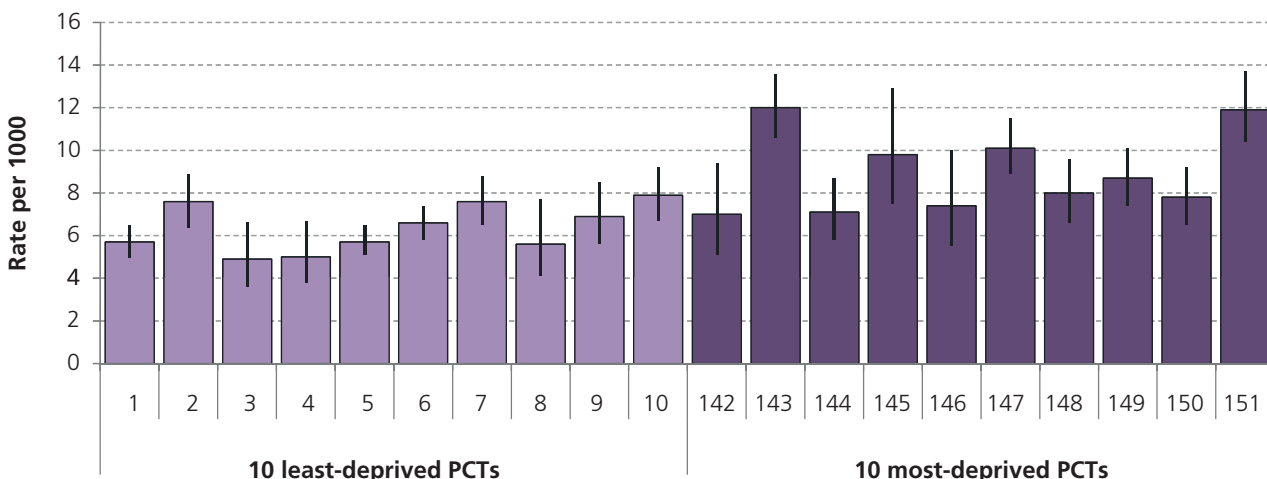
For PCTs in England, the rate of perinatal mortality per 1000 births ranged from 3.5 to 12.6 (3.6-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 5.0–11.0 per 1000 births, and the variation is 2.2-fold.

There is an association between higher perinatal mortality and socio-economic deprivation (see Figure 6.1). However, deprivation cannot be the sole reason for the variation

**Figure 6.1: Correlation between rate of perinatal mortality per 1000 births by PCT 2007–2009 and deprivation**



**Figure 6.2: Rate of perinatal mortality per 1000 births 2007–2009 among the 10 least-deprived and 10 most-deprived PCTs (IMD 2010)**



observed at PCT level: among the 10 most-deprived PCTs, there is a 1.7-fold variation in perinatal mortality rates, and among the 10 least-deprived PCTs the degree of variation is 1.6-fold (see Figure 6.2).

Many public health and social risk factors, such as obesity, smoking, ethnic background, the prevalence of inherited disorders and teenage pregnancy, can influence the rates of stillbirth and pre-term birth; some pre-term babies will die before 7 days of age. However, differences in the quality of and access to antenatal and perinatal care could account for unwarranted variation in perinatal mortality.

## Options for action

Commissioners need to ensure that the quality of pre-pregnancy, antenatal, intrapartum and neonatal care is high by:

- Studying local variations in perinatal mortality, down to clinician-level, to identify whether variations in outcomes are warranted or unwarranted;
- Ensuring there is adequate capacity and training of community- and hospital-based health professionals to deliver a high-quality antenatal and perinatal service for mothers and babies, including nutritional and other preventative health advice.

## RESOURCES

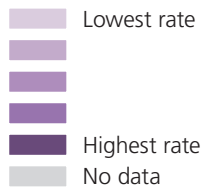
- NICE Guidance (2008) Guidance for midwives, health visitors, pharmacists and other primary care services to improve the nutrition of pregnant and breastfeeding mothers and children in low income households. Public health guidance, PH11. <http://guidance.nice.org.uk/PH11>
- NICE Guidance (2006) Postnatal care: Routine postnatal care of women and their babies. Clinical guidelines, CG37. <http://www.nice.org.uk/CG037>
- NICE Topic. Gynaecology, pregnancy and birth. <http://guidance.nice.org.uk/Topic/GynaecologyPregnancyBirth>
- NICE (2010) Specialist neonatal care quality standard. <http://www.nice.org.uk/guidance/qualitystandards/specialistneonatalcare/specialistneonatalcarequalitystandard.jsp>

**CONDITIONS OF NEONATES**

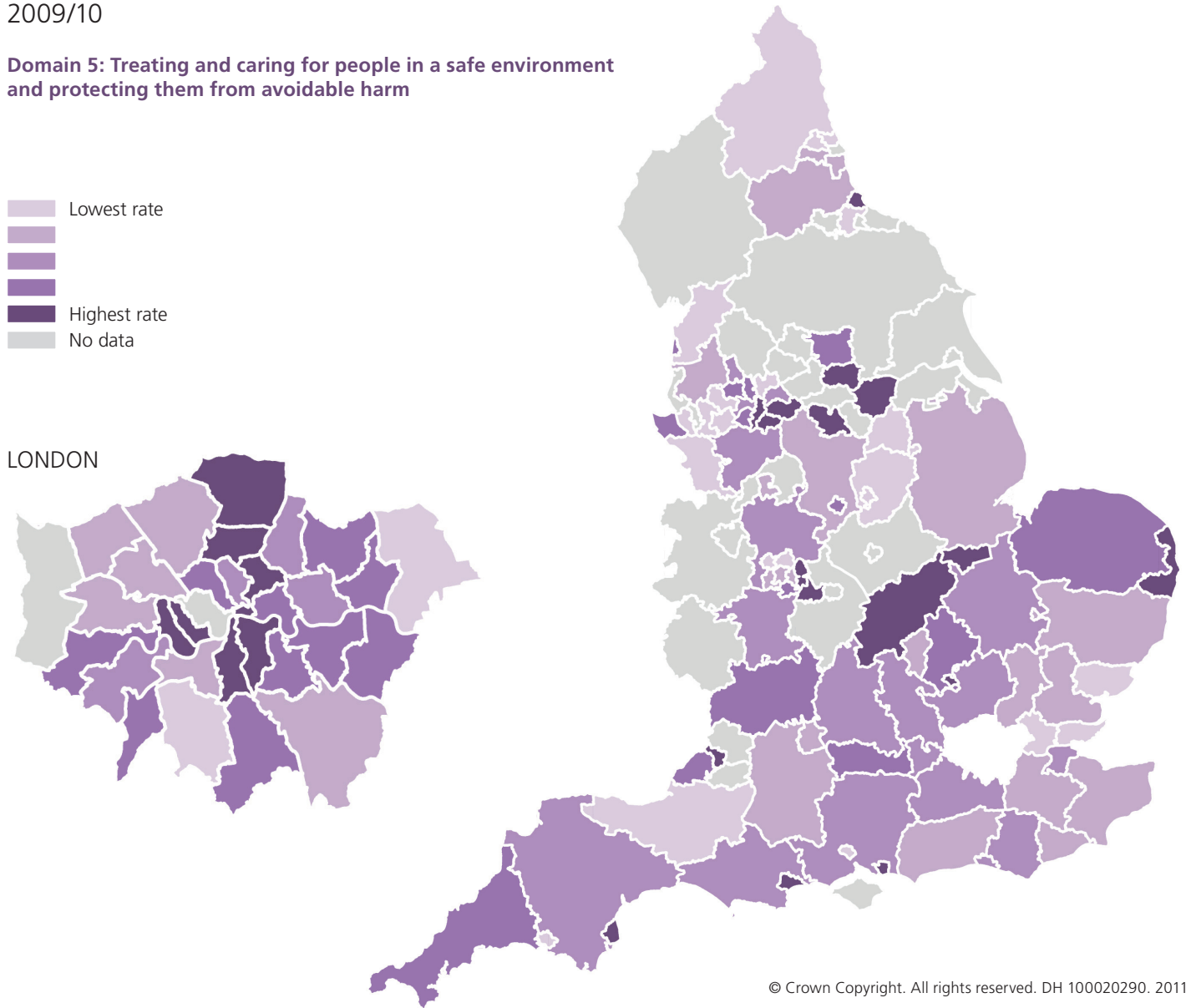
**Map 7:** Proportion (%) of eligible premature babies tested for retinopathy of prematurity (ROP) within the recommended timeframe by PCT

2009/10

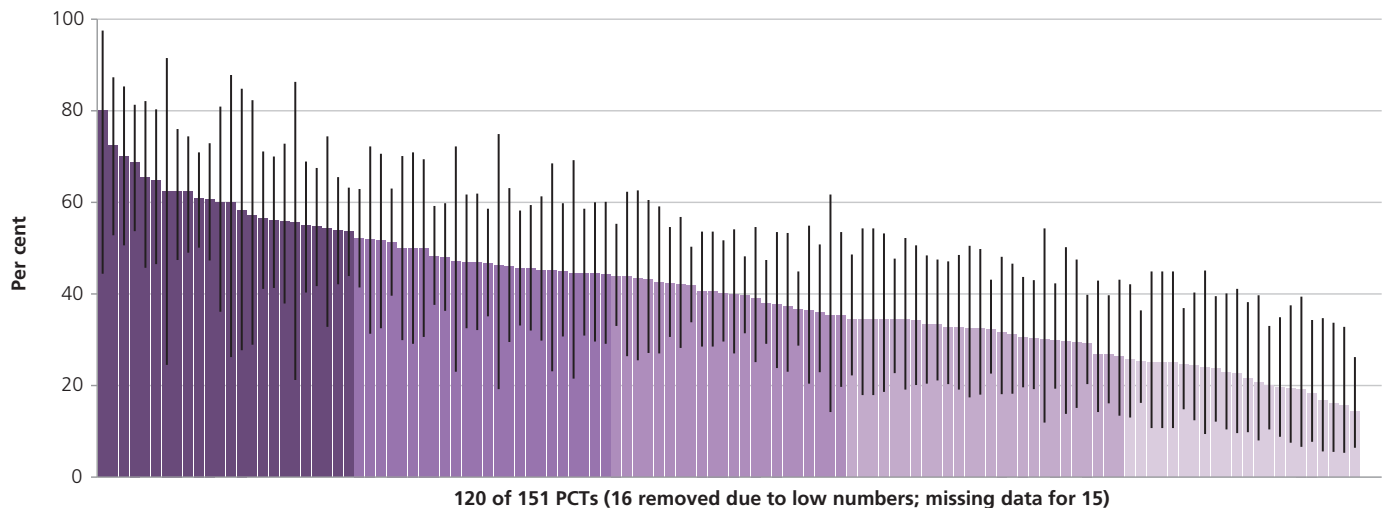
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



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## Context

Premature babies are at risk of retinopathy of prematurity (ROP), a disease that threatens the development of vision. If detected early enough, ROP is largely amenable to treatment. Delay in or failure of testing of eligible at-risk babies can lead to increased risk of irreversible vision loss.

National guidelines define the eligibility criteria for ROP testing, and contain recommendations about implementing best practice (see “Resources”). Testing relies on:

- › adequate resourcing of the service;
- › a multidisciplinary approach;
- › clear communication between neonatal and ophthalmology teams.

The Neonatal Data Analysis Unit (NDAU) extracted patient data from the National Neonatal Research Database (NNRD) covering neonatal units in England. Data were used from 135 of 171 neonatal units (79%) which had complete data for 2009/10. To derive PCT-level data, records for all babies who fulfilled the eligibility criteria were analysed according to mother’s usual place of residence.

Data are expressed as the ratio of the number of infants **recorded** as receiving ROP testing within the recommended timeframe to the total number of infants eligible. Data deemed ineligible for inclusion covered:

- › infants who may have had ROP testing outwith the recommended timeframe;
- › eligible infants with incomplete records of ROP testing.

## Magnitude of variation

For PCTs in England, the proportion of eligible premature babies tested for ROP within the recommended timeframe ranged from 14.3% to 80% (6-fold variation).<sup>1</sup> When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 19.2–64.7%, and the variation is 3.4-fold.

The existence of variation for this indicator is of concern. Even for the five PCTs with the best performance, the percentage of eligible babies tested within the timeframe ranges from 65.5% to 80%. As national clinical guidance is available for ROP testing, this degree of variation highlights the case for not only narrowing the range but

shifting the entire distribution towards 100% (see page 14; see also Atlas 2.0, pages 36–37).

Work is underway to improve data quality for ROP testing in the NNRD. The degree of variation observed could reflect the accuracy of local data recording or differences in clinical processes, both of which are factors that commissioners can influence.

## Options for action

Commissioners and neonatal units need to review the workforce requirements for providing a timely ROP testing service appropriate for the local population of at-risk babies, including:

- › staff training and recruitment;
- › resource allocation;
- › appropriate skill mix;
- › job planning.

Using the neonatal network model to deliver neonatal ophthalmology care can be beneficial through pooling resources and maximising efficiencies of scale. Data can be analysed and benchmarked against:

- › those from other units within each network;
- › those from other networks;
- › appropriate international data.

Coordination and leadership at a supra-local level ensures adequate workforce skill mix and maintenance of minimum standards of practice.

Strong clinical leadership is required to deliver a coherent system that minimises variation in practice and outcome for ROP testing. The multidisciplinary approach adopted in the Greater Manchester Neonatal Network is an example of how such a system can be achieved through partnership working and high-quality inter-professional communication.

The NNRD is a successful clinically driven database for research and quality improvement. However, there is a need not only to improve data coverage of ROP practices but also to refine the data collection system to obtain data that are more accurate and more granular.

## RESOURCES

- › Royal College of Ophthalmologists and Royal College of Paediatrics and Child Health (2008) Guideline for the Screening and Treatment of Retinopathy of Prematurity. <http://www.rcpch.ac.uk/sites/default/files/ROP%20Guideline%20-%20Jul08%20final.pdf>

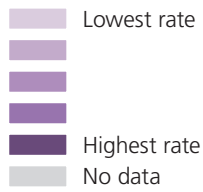
<sup>1</sup> Data were not submitted for 15 PCTs; data have been removed for 16 PCTs.

CONDITIONS OF NEONATES

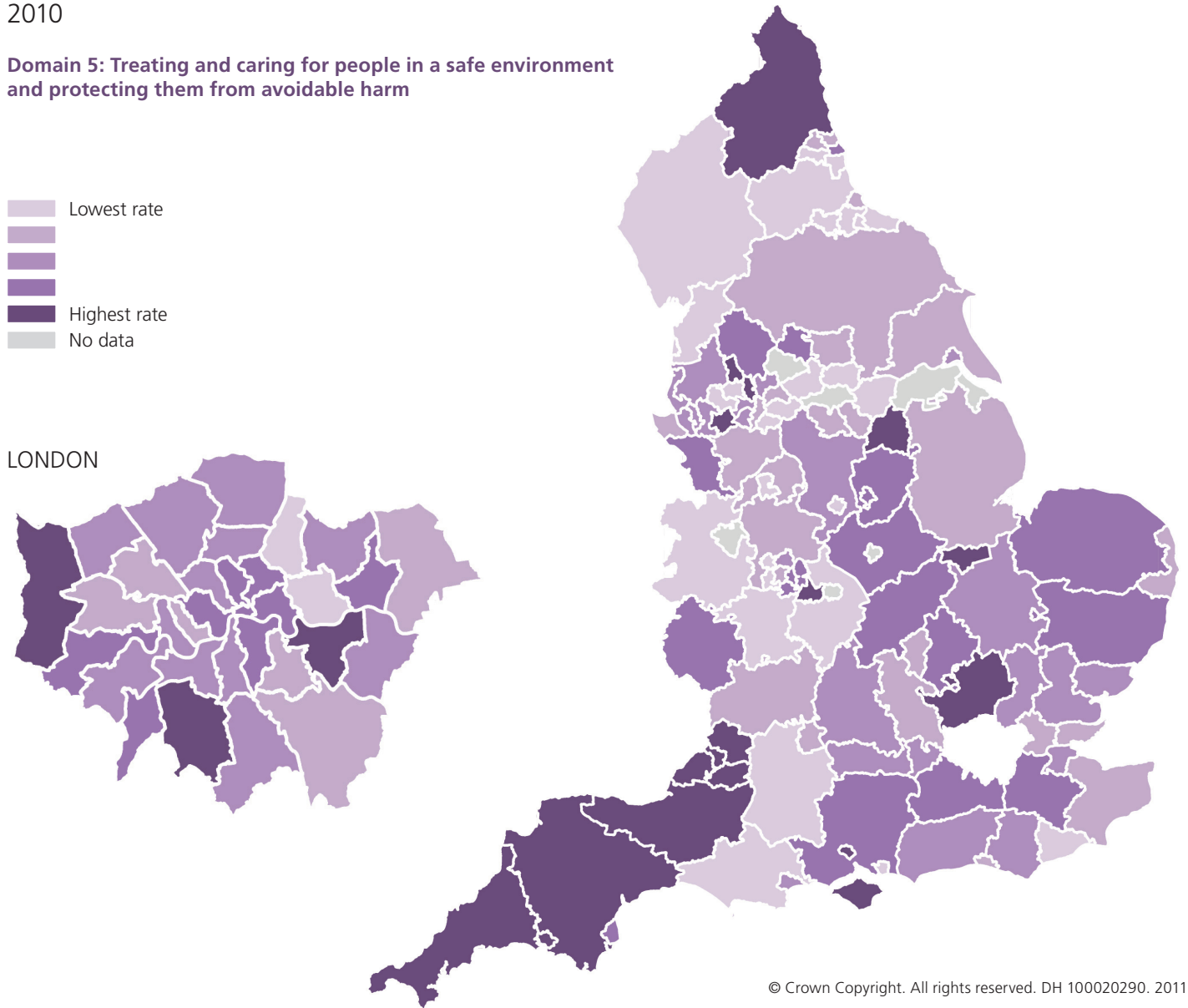
**Map 8:** Full-term ( $\geq 37$  weeks' gestational age at birth) admissions as a proportion (%) of all babies admitted to specialist neonatal care by PCT

2010

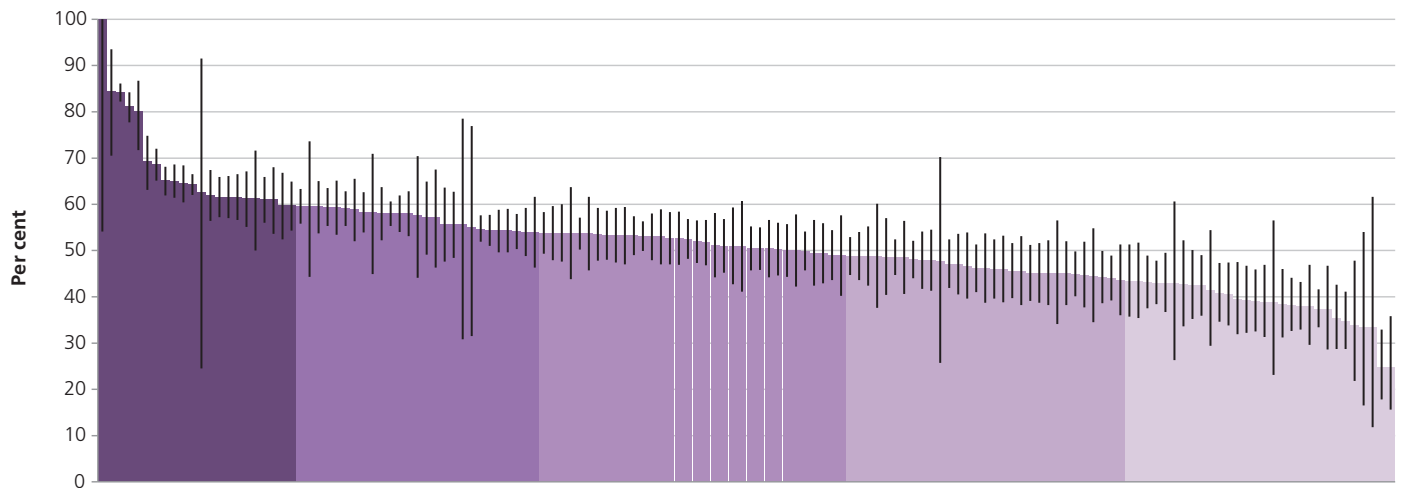
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



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144 of 151 PCTs (7 removed due to low numbers)



## Context

In the NHS Outcomes Framework 2011/12, this is a national quality indicator.

Most neonatal care in hospital arises from managing premature babies. The number of premature babies is determined by local demography and socio-economic deprivation, and is not amenable to change through commissioning. However, sick babies of any gestation may be admitted for several reasons amenable to intervention.

The health of newborn babies can be affected by maternal health, including:

- Smoking habit and alcohol consumption;
- Conditions such as diabetes.

Newborn babies can have respiratory distress syndrome as a complication of birth by Caesarean section. Often the baby needs to be admitted for treatment.

Reducing the admissions of full-term babies to specialist neonatal care could save substantial costs and allow resource reallocation.

The Neonatal Data Analysis Unit (NDAU) extracted patient data from the National Neonatal Research Database (NNRD) covering neonatal units in England. Data were used from 135 of 171 neonatal units (79%) which had complete data for 2009/10. To derive PCT-level data, records were analysed according to mother's usual place of residence.

## Magnitude of variation

For PCTs in England, full-term ( $\geq 37$  weeks' gestational age at birth) admissions as a percentage of all babies admitted to specialist neonatal care ranged from 24.7% to 100% (4-fold variation).<sup>1</sup> When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 34.7–69.2%, and the variation is twofold.

Although socio-economic deprivation affects neonatal mortality and morbidity, it has a greater impact on premature births and cannot explain the variation observed because the indicator includes all births.

Possible reasons for variation are differences in:

- Coding;
- Maternal health;
- Access to antenatal care;
- Clinical practice in perinatal care or neonatal team clinical decision-making;
- Number of skilled midwives on postnatal wards;

- Admission criteria to neonatal units, special care baby units and transitional care within individual hospitals;
- Data submission within some PCTs.

There are parallels with variations analysis of adult intensive care units where bed capacity has an independent effect on the level of medical intervention irrespective of clinical need. The decision to admit a full-term baby to specialist neonatal care is influenced by:

- the baby's clinical condition;
- availability of cots.

Some variation may arise from different levels of provision, exemplifying what Wennberg termed a supply-side cause of unwarranted variation.

In total, 25,420 full-term babies were admitted to 135 reporting neonatal units. The number of live births in England in 2009/10 was 687,007 (ONS, 2010): assuming rates of premature births of 7% (ONS, 2008), this indicates an average of 4% of all babies  $\geq 37$  weeks' gestation were admitted in 2010. As there were data for only 79% of units, this percentage could be higher.

## Options for action

Each neonatal network needs to develop guidelines for clinical admission criteria, and all neonatal units need to implement them.

To reduce complications to newborn babies, commissioners and providers could review:

- interventions to reduce alcohol and smoking during pregnancy;
- access to antenatal care and screening;
- local Caesarean section rates in conjunction with admissions of full-term babies to specialist neonatal care.

Performance data could be analysed and benchmarked to enable comparisons:

- among units in each network;
- among networks in England;
- with other developed countries.

## RESOURCES

- NICE Topic. Gynaecology, pregnancy and birth. <http://guidance.nice.org.uk/Topic/GynaecologyPregnancyBirth>
- NICE Guidance (2006) Postnatal care: Routine postnatal care of women and their babies. Clinical guidelines, CG37. <http://www.nice.org.uk/CG037>
- NICE (2010) Specialist neonatal care quality standard. <http://www.nice.org.uk/guidance/qualitystandards/specialistneonatalcare/specialistneonatalcarequalitystandard.jsp>

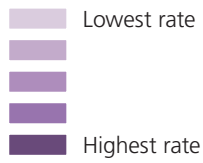
<sup>1</sup> Data from seven PCTs have been removed.

CONDITIONS OF NEONATES

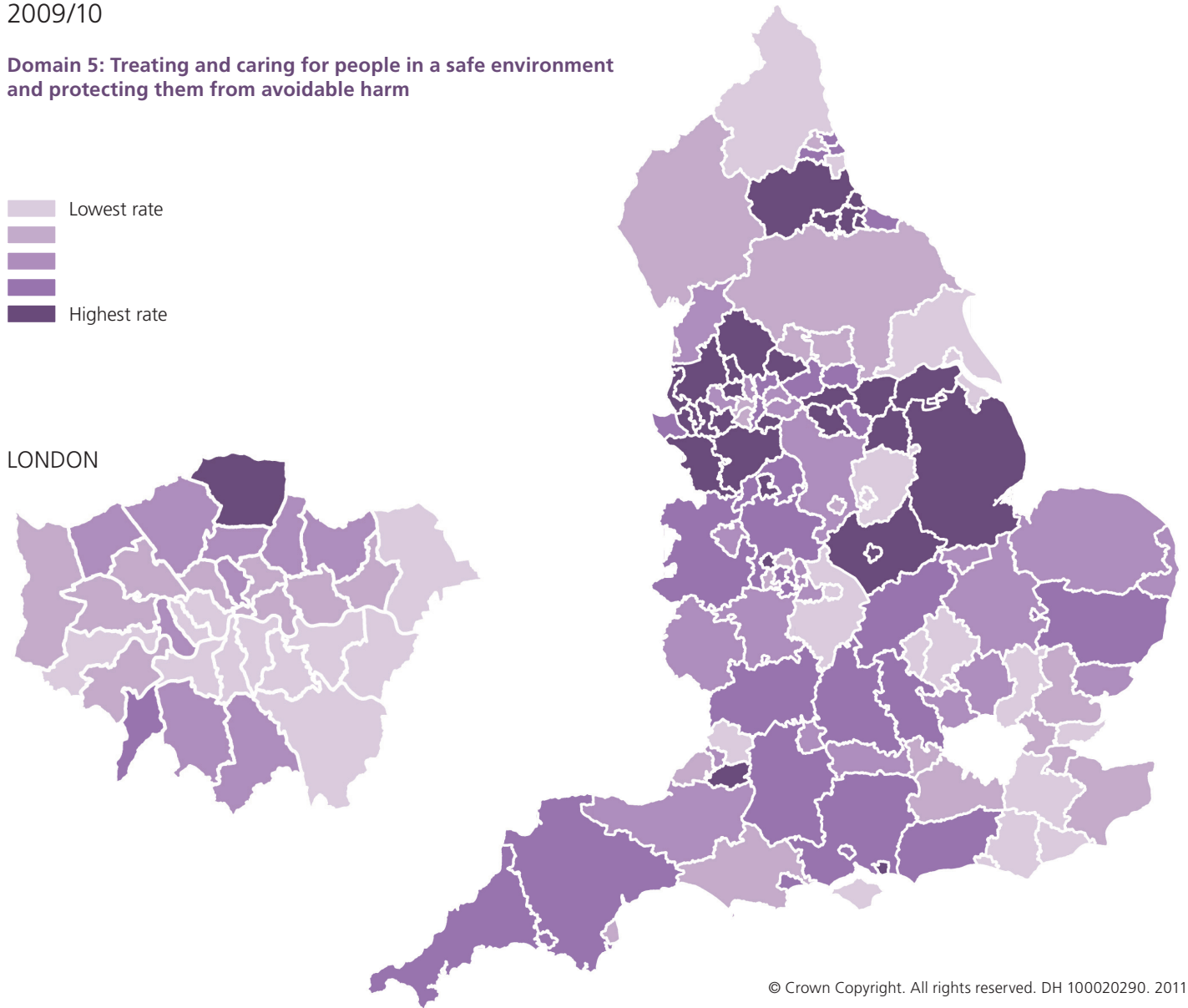
# Map 9: Emergency admissions of home births and re-admissions to hospital of babies within 14 days of being born per all live births by PCT

2009/10

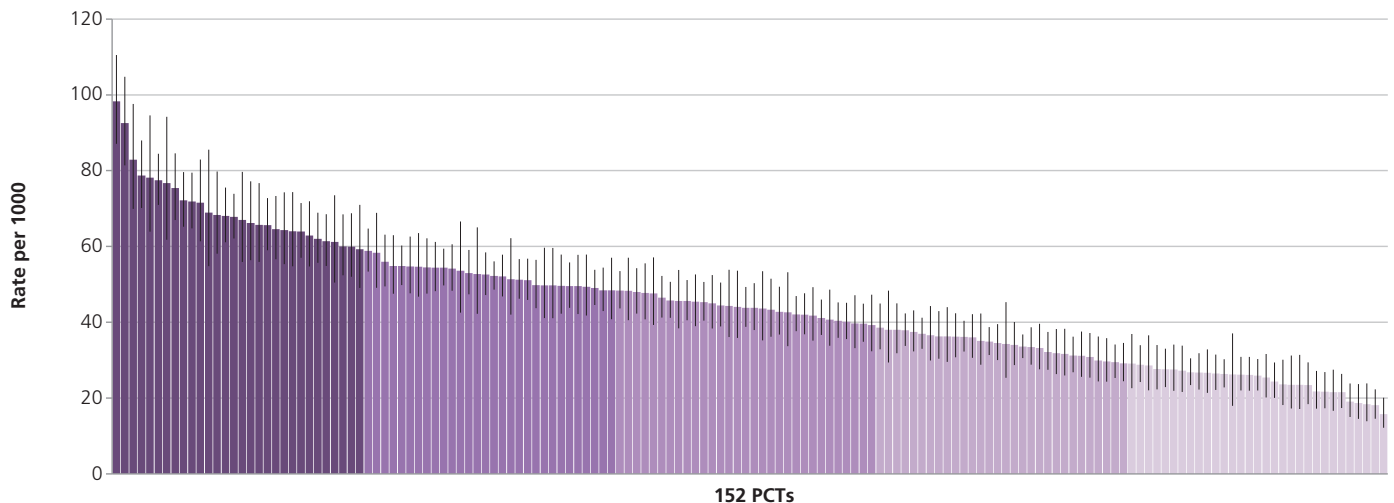
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



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## Context

The Healthcare Commission report *Towards better births: A review of maternity services in England* drew attention to the problem of re-admission of mothers and babies.

*“High levels of re-admissions of either mother or babies can suggest problems with either the timing or quality of health assessments before the initial transfer or with the postnatal care once the mother is home. Dehydration and jaundice are two common reasons for re-admission of babies and are often linked to problems with feeding. Half of the trusts had an admission rate of eight per 1,000 babies or greater for these conditions two or more days after birth.”*

Postnatal care provision crosses acute and primary healthcare sectors, with the majority of care taking place in the woman’s home. Care is likely to include:

- routine clinical examination and observation of the woman and her baby;
- routine infant screening to detect potential disorders;
- support for infant feeding;
- ongoing provision of information and support.

Helping mothers to know what signs and symptoms indicate something serious and what is normal gives them reassurance and confidence.

Giving babies the best start in life through good-quality postnatal care means they are less likely to have health problems during childhood and into adulthood.

## Magnitude of variation

For PCTs in England, the emergency admissions of home births and re-admissions to hospital of babies within 14 days of being born per 1000 live births ranged from 15.8 to 98.3 (6-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 21.5–77.5 per 1000 live births, and the variation is 3.6-fold.

## Options for action

Commissioners and providers need to ensure that improved antenatal education and information is provided to parents. At each postnatal contact, parents should be offered information and advice to enable them:

- to assess their baby’s general condition;
- to identify signs and symptoms of common health problems in babies;
- to contact a healthcare professional or emergency service if required.

Commissioners should ensure implementation of NICE guidelines on postnatal care (see “Resources”), and in particular that:

- examination of the newborn is undertaken by suitably qualified healthcare professionals;
- each woman has her own personalised care plan which takes into account not only her needs but also her baby’s.

As a minimum standard, all maternity care providers could implement an externally evaluated structured programme that encourages breastfeeding, such as the Baby Friendly Initiative (see “Resources”).

Healthcare professionals should care for newborn babies according to NICE guidance on routine postnatal care and on neonatal jaundice (see “Resources”).

## RESOURCES

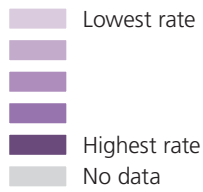
- NICE Guidance (2006) Postnatal care: Routine postnatal care of women and their babies. Clinical guidelines, CG37. <http://www.nice.org.uk/CG037>
- NICE Guidance (2010) Neonatal jaundice: Recognition and treatment of neonatal jaundice. Clinical Guidelines, CG98. <http://guidance.nice.org.uk/CG98>
- Baby Friendly Initiative. <http://www.babyfriendly.org.uk>
- Royal College of Obstetricians and Gynaecologists (RCOG) (2008) Standards for Maternity Care. <http://www.rcog.org.uk/womens-health/clinical-guidance/standards-maternity-care>

**DISORDERS OF THE BLOOD**

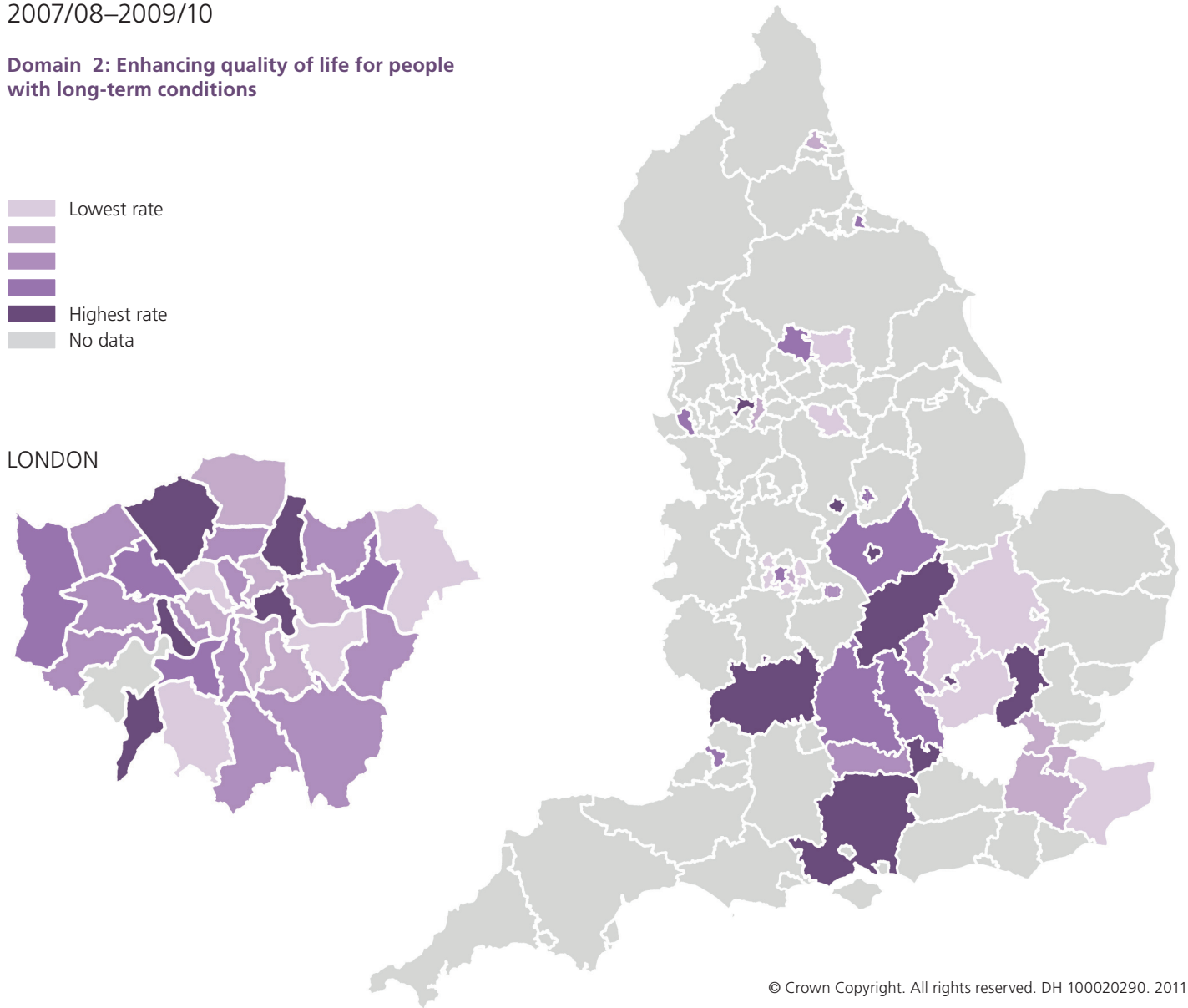
**Map 10:** Number of emergency hospital admissions for sickle cell disease (SCD) per individual patient aged 0–17 years by PCT

2007/08–2009/10

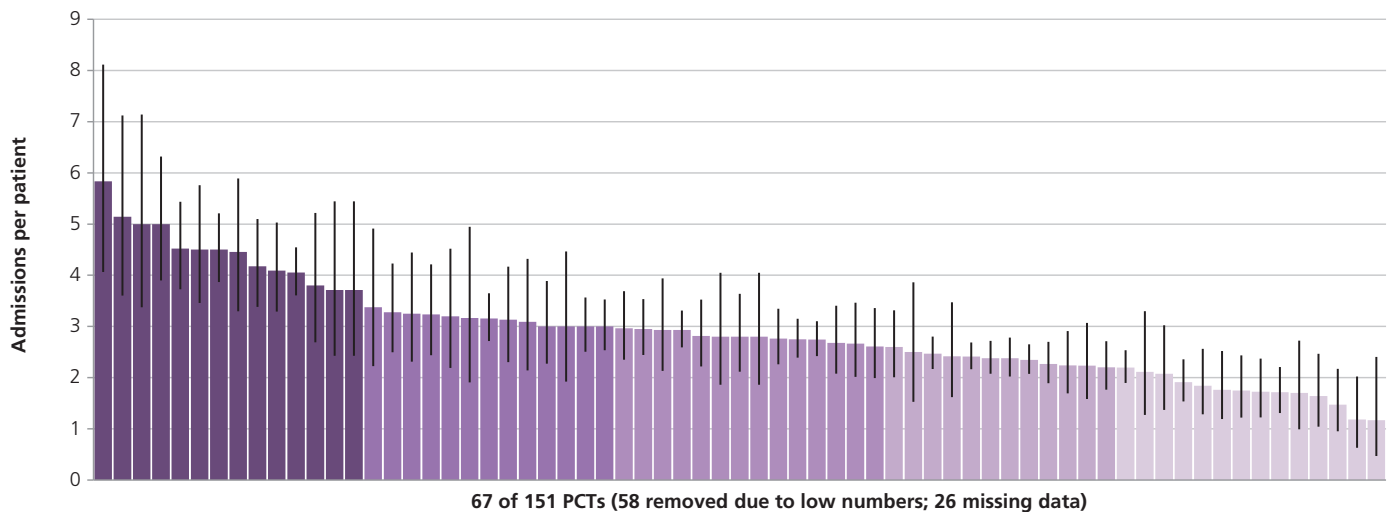
Domain 2: Enhancing quality of life for people with long-term conditions



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## Context

Sickle cell disease (SCD) is an inherited blood disorder, which intermittently causes red blood cells to deform and break down leading to blocked blood vessels. Complications include episodes of severe pain, stroke and respiratory collapse, as well as anaemia and susceptibility to infections. People affected by SCD have a reduced life-expectancy.

In England, SCD occurs in 1 in 2000 live births, being most common in people of Black African or Caribbean origin.

Health services for SCD have developed mainly in urban areas where susceptible populations tend to live.<sup>1</sup> Overall hospital admissions for children with SCD have more than halved over the past 30 years,<sup>2</sup> but the patchy geographical distribution of affected populations makes unwarranted variation in the care and well-being of children with SCD more likely.

There is clinical and service guidance for the management of SCD in childhood;<sup>3,4</sup> a guideline on the management of an acute painful sickle cell episode in hospital is currently being developed.<sup>5</sup>

Absolute admission rates vary widely by prevalence of SCD. To control for prevalence, data show the number of emergency admissions to hospital per child admitted with SCD in England during 2007/08–2009/10.

## Magnitude of variation

For PCTs in England, the number of emergency admissions for SCD per individual patient aged 0–17 years ranged from 1.2 to 5.8 (5-fold variation).<sup>6</sup> When the five PCTs with the highest number of emergency admissions and the five PCTs with the lowest number of emergency admissions are excluded, the range is 1.7–4.5 per individual patient, and the variation is 2.6-fold.

Repeated emergency admissions for children and young people with SCD may reflect differences in:

- the quality of ongoing clinical care in the community and of care in the emergency department;
- admission criteria;
- the extent of support and education for families to manage common complications in the community.

## Options for action

Local and specialist commissioners need to analyse the efficiency and quality of the SCD service provided locally and across the clinical network. A clinical network model, as recommended by the National Haemoglobinopathies Project,<sup>4</sup> can help keep care as close to home as possible, while providing expertise to support local services especially in areas of low prevalence.

Care is best delivered by a specialist multidisciplinary team, led by a paediatrician or paediatric haematologist with expertise in SCD, and comprising nurse specialists, psychologists, play therapists, social workers and pharmacists.

All emergency and paediatric departments providing care for children with SCD should use evidence-based management guidelines and clear criteria for admission to hospital.

Peer review of services can reduce unwarranted variations across the country.<sup>7</sup>

Inadequate knowledge of SCD among clinical staff can lead to poor ongoing and acute pain management and has been a contributory factor in the deaths of patients with SCD.<sup>8</sup> In-service training and specific educational programmes are vital for all staff caring for children with SCD.

Targeted education programmes for children and families are pivotal to preventing sickle crises and complications, and give families the confidence to manage safely more episodes at home.

Adolescence can be challenging for children with SCD and their families. Commissioners need to include in the service specification for all networks and providers the active management of the transition of care into adult services.

## RESOURCES

- NHS Sickle Cell and Thalassaemia Screening Programme has produced standards and guidelines for a range of SCD-related services, including:
  - Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care
  - TCD (Transcranial Doppler) Scanning for Children with Sickle Cell Disease<http://sct.screening.nhs.uk/standardsandguidelines>

1 Streetly A, Latinovic R, Henthorn J (2010) Positive screening and carrier results for the England-wide universal newborn sickle cell screening programme by ethnicity and area for 2005-7. *Journal of Clinical Pathology* 63: 626-629. doi: 10.1136/jcp.2010.077560

2 Day TG et al. (2011) Changing Pattern of Hospital Admissions of Children with Sickle Cell Disease Over the Last 50 Years. *Journal of Pediatric Hematology and Oncology* 33: 491-495.

3 NHS Sickle Cell and Thalassaemia Screening Programme (2010) Sickle Cell Disease in Childhood: Standards and Guidelines for Clinical Care, 2nd edition. <http://sct.screening.nhs.uk/standardsandguidelines>

4 National Haemoglobinopathies Project (2011) "Model Service Specification for Community Haemoglobinopathy Care" and "Model Service Specification for Specialised/Tertiary (Acute) Haemoglobinopathy Services". East Midlands Specialised Commissioning Group. <http://www.emscg.nhs.uk>

5 NICE clinical guideline. Sickle cell acute painful episode: management of an acute painful sickle cell episode in hospital. Scheduled for publication June 2012. <http://guidance.nice.org.uk/CG/Wave24/6>

6 Data from 84 PCTs are not included: 58 PCTs had low numbers of admissions; data were missing for 26 PCTs.

7 West Midlands Quality Review Service (2011) Services for Children and Young People with Haemoglobin Disorders. Peer Review Programme 2010-11: Overview Report. <http://www.wmqi.westmidlands.nhs.uk/wmqrs/publications/for-review-programme/52>

8 NCEPOD (2008) *A Sickle Crisis? A report of the National Confidential Enquiry into Patient Outcome and Death* (2008). <http://www.ncepod.org.uk/2008sc.htm>

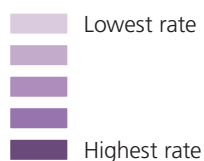


**ENDOCRINE, NUTRITIONAL AND METABOLIC PROBLEMS**

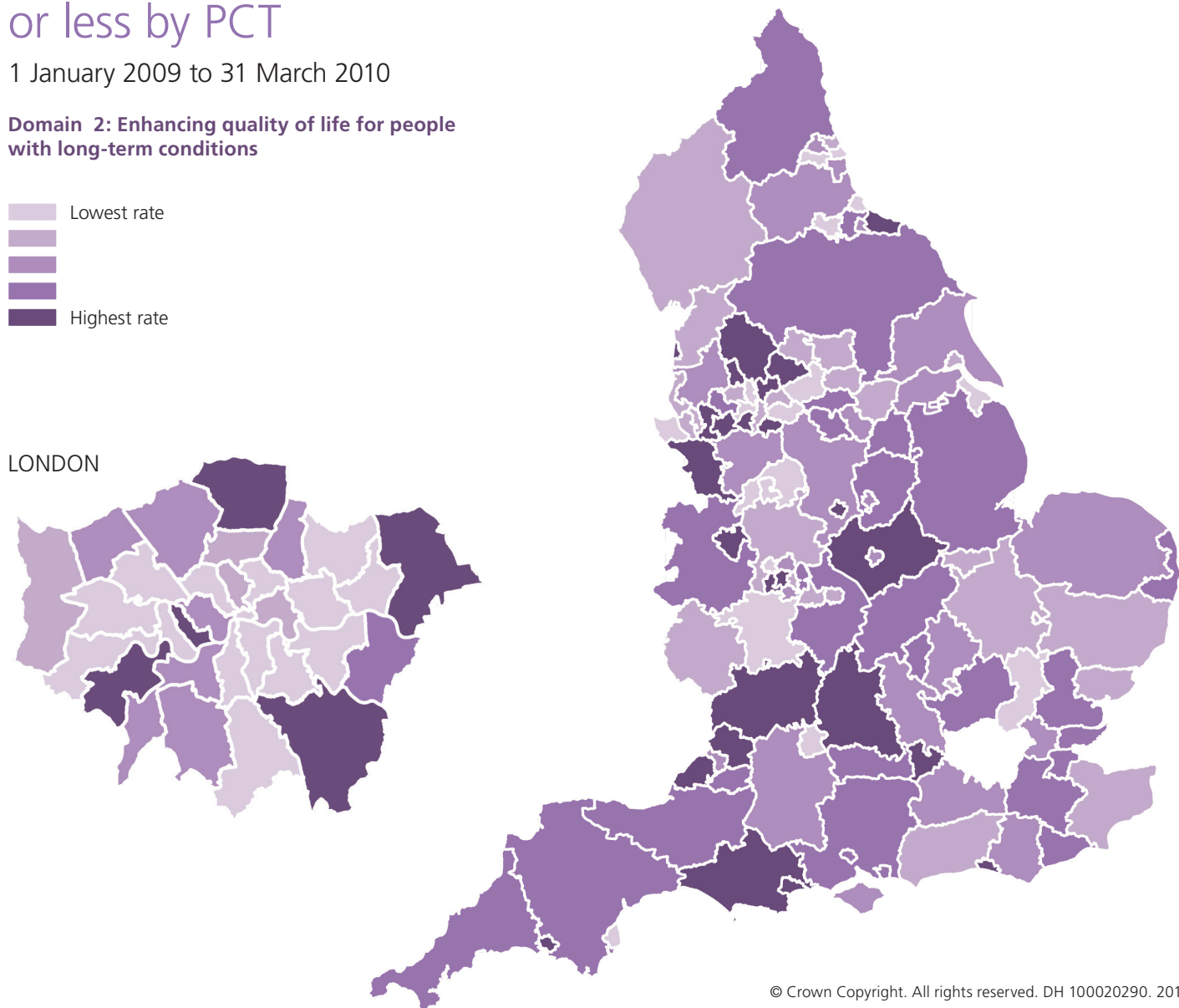
**Map 11:** Percentage of children aged 0–15 years in the National Diabetes Audit (NDA) with diabetes whose most recent HbA1c measurement was 10% (86 mmol/mol) or less by PCT

1 January 2009 to 31 March 2010

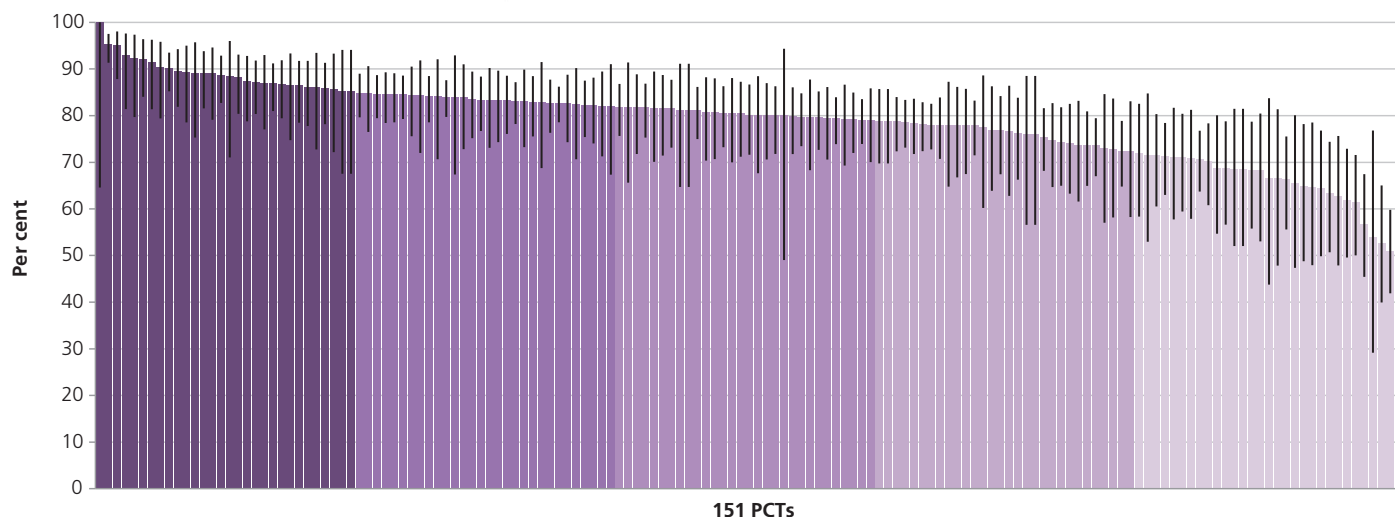
**Domain 2: Enhancing quality of life for people with long-term conditions**



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## Context

Good blood glucose control reduces the risk of developing diabetic complications in the longer term. Glycated haemoglobin (HbA1c) is an indicator of average blood glucose levels over the previous 8–12 weeks. In national and international guidance, an HbA1c of value 7.5% (58 mmol/mol) or lower is recommended for children with diabetes.<sup>1,2</sup>

In 2009/10, the National Diabetes Audit (NDA) revealed that 85.5% of children and young people with diabetes in England had an HbA1c value greater than the recommended target level of <7.5%,<sup>3</sup> whereas only 45–50% of children and young people with diabetes in Germany and Austria had an HbA1c level >7.5%.<sup>4</sup> These children are at increased risk of developing complications.

Given the small number of children whose HbA1c level meets the current recommended target of <7.5%, data have been presented for children and young people whose most recent HbA1c measurement was 10% (86 mmol/mol) or less.

NDA demographic categories are limited to children below the age of 16 years.

## Magnitude of variation

For PCTs in England, the percentage of children aged 0–15 years in the NDA with diabetes whose most recent HbA1c measurement was 10% or less ranged from 41.7% to 100.0% (2.4-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 61.3–92.2%, and the variation is 1.5-fold

In England, the mean is 80% for children with an HbA1c measurement of <10%, whereas in Sweden in 2002 it was 96%,<sup>5</sup> a figure that only one PCT in England can match currently.

There is no statistically significant correlation between this indicator and deprivation at PCT level: one possibility is that the variation is “provider-side”, and could be the result of how individual NHS organisations deliver care and education to children and young people and their families, rather than individual patient behaviour alone.

The magnitude of variation in glycaemic control of children and young people with diabetes is high nationally and internationally.<sup>4–7</sup>

## Options for action

Improvement in glycaemic control for children and young people at a population level requires a multifaceted approach, facilitated by managed clinical networks working in tandem with commissioners.

Commissioners and providers need to ensure complete data submission to the Paediatric NDA, with comparisons of outcomes data across networks nationally and internationally.

Commissioners need to review minimum service specifications to ensure they are in line with current NICE guidance<sup>1</sup> and Department of Health policy on service configuration.<sup>8</sup> Local, regional and national peer review of services can promote best practice, and help to assess performance and improve outcomes.

Providers need to ensure that services are staffed by skilled, experienced paediatric multidisciplinary teams, under clear clinical leadership.

Where clinically indicated, providers should give patients access to appropriate technologies (e.g. insulin pumps and continuous glucose monitoring) in accordance with NICE guidance.<sup>9</sup>

To improve outcomes for children and young people with diabetes, education is pivotal. Commissioners and providers need to collaborate to deliver standardised self-management education programmes individually tailored for each child, their family and school. Standardised specialist training needs to be provided for all healthcare professionals involved in the care of children and young people with diabetes.

See also page 75, Case-study 1.

## RESOURCES

- ▶ SWEET project e.V (<http://www.sweet-project.eu>): an international collaboration of paediatric diabetes services working to improve care through benchmarking clinical outcomes, comparing services and best practice, and sharing standards, guidance and research.
- ▶ NICE Guidance (2008) Continuous subcutaneous insulin infusion for the treatment of diabetes (review). Technology appraisals, TA151. <http://guidance.nice.org.uk/TA151>
- ▶ NICE (2009) Insulin pump therapy service. Commissioning guide. Implementing NICE guidance. <http://www.nice.org.uk/media/87F/E2/InsulinPumpsToolDevelopmentUpdate.pdf>

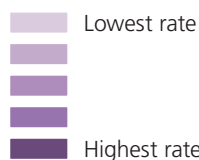
- 
- 1 NICE (2004) Diagnosis and management of type 1 diabetes in children, young people and adults (CG15). [Update currently being scheduled] <http://guidance.nice.org.uk/CG15>
  - 2 ISPAD (2009) ISPAD Clinical Practice Consensus Guidelines. *Pediatric Diabetes* 10: Suppl 12. <http://www.ispad.org/FileCenter.html?CategoryID=5>
  - 3 NHS Information Centre (2011) National Diabetes Paediatric Audit Report 2009/10. [http://www.ic.nhs.uk/webfiles/Services/NCASP/Diabetes/200910%20annual%20report%20documents/NHSIC\\_National\\_Diabetes\\_Paediatric\\_Audit\\_Report\\_2009\\_2010.pdf](http://www.ic.nhs.uk/webfiles/Services/NCASP/Diabetes/200910%20annual%20report%20documents/NHSIC_National_Diabetes_Paediatric_Audit_Report_2009_2010.pdf)
  - 4 DPV-Wiss database. [http://buster.zibmt.uni-ulm.de/dpv/dpv\\_wiss.php?lang=en](http://buster.zibmt.uni-ulm.de/dpv/dpv_wiss.php?lang=en)
  - 5 Hanberger L, Samuelsson U, Lindblad B et al. (2008) A1C in children and adolescents with diabetes in relation to certain clinical parameters: the Swedish Childhood Diabetes Registry SWEDIABKIDS. *Diabetes Care* 31: 927-929. <http://www.hvideogroup.org>
  - 7 <http://www.sweet-project.eu>
  - 8 Department of Health (2007) *Making every young person with diabetes matter*. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_073674](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073674)
  - 9 NICE (2008) Continuous subcutaneous insulin infusion for the treatment of diabetes (review). Technology appraisals, TA151. <http://guidance.nice.org.uk/TA151>

**ENDOCRINE, NUTRITIONAL AND METABOLIC PROBLEMS**

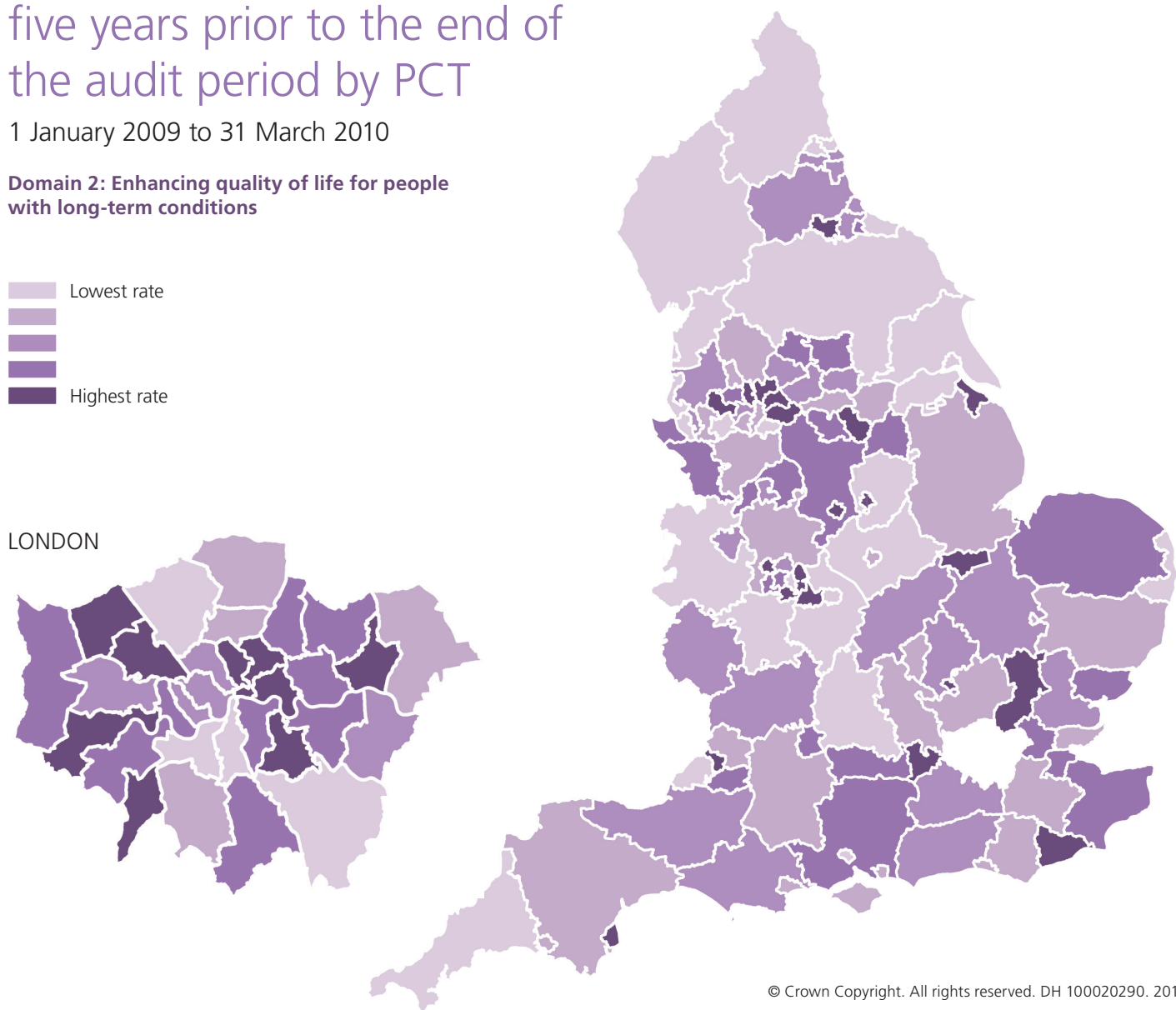
**Map 12:** Percentage of children aged 0–15 years with previously diagnosed diabetes in the National Diabetes Audit (NDA) admitted to hospital for diabetic ketoacidosis five years prior to the end of the audit period by PCT

1 January 2009 to 31 March 2010

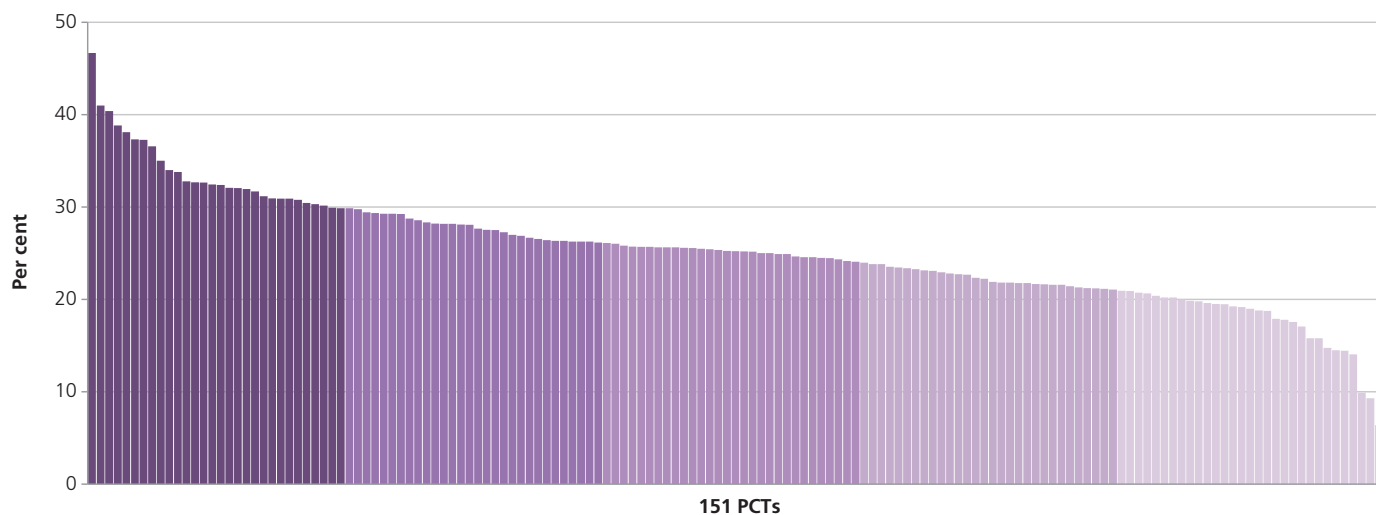
Domain 2: Enhancing quality of life for people with long-term conditions



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## Context

Diabetic ketoacidosis (DKA) is a preventable cause of mortality and morbidity for children and young people with diabetes. It occurs when blood glucose levels are very high. It is a dangerous condition, and fatal if left untreated. A key management goal of good diabetes care is the prevention of episodes of DKA.

“Unplanned hospitalisations for diabetes in the under 19s” is a national quality indicator in Domain 2 of the NHS Outcomes Framework 2011/12.

In 2009/10, 9% of children and young people aged 0–17 years with diabetes in England and Wales experienced at least one episode of DKA.<sup>1</sup>

Many attendances to hospital for DKA involve children for whom it is the first, diagnostic, episode. These cases need to be discounted when using the DKA rate as an outcome measure in the management of children with established diabetes, therefore, this indicator excludes children who were diagnosed with diabetes between 1 January 2009 and 31 March 2010.

Demographic categories used by the National Diabetes Audit (NDA) limit data analysis to children below the age of 16 years only. [The paediatric component of the NDA is now being managed by the Royal College of Paediatrics and Child Health (RCPCH; see “Resources”).]

## Magnitude of variation

For PCTs in England, the percentage of children aged 0–15 years with previously diagnosed diabetes in the NDA admitted to hospital for DKA five years prior to the end of the audit period ranged from 6.4% to 46.7% (7-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 14.5–37.3%, and the variation is 2.6-fold.

## Options for action

Service providers and commissioners need to work in close collaboration to ensure that the clinical services provided to children and their families are in accordance with NICE guidance (see “Resources”) and International Society for Pediatric and Adolescent Diabetes (ISPAD) consensus guidelines (see “Resources”).

Any commissioned diabetes service needs to provide a continuum of care from hospital to the community delivered by a specialist paediatric multidisciplinary team (MDT), including consultant paediatricians with expertise in children and young people with diabetes, paediatric diabetes specialist nurses, paediatric dietitians, psychologists with an interest in diabetes, social workers, pharmacists and play therapists.

National standards of training for healthcare professionals involved in the care of children and young people with diabetes need to be developed urgently.

The key to preventing and treating DKA in children is to have adequate numbers of highly trained staff with the knowledge and skills to provide 24-hour expert advice on the management of diabetes, using written management guidelines and local pathways. A network model of diabetic care can help to make this process more efficient and effective than individual providers working independently. A clinical network providing services for children and young people with diabetes can deliver the broader coordinated approach necessary to ensure a standardised approach to the prevention of DKA.

Early detection of symptoms, appropriate management at home, and better understanding of the diabetes disease processes can reduce the rates of DKA in children.<sup>2</sup> Commissioners need to ensure that age- and maturity-appropriate, structured and standardised self-management education is an integral part of the diabetes service in order to help prevent DKA.

Programmes of re-education need to be targeted at children who are at particularly high risk of DKA, such as adolescents, looked-after children, children from non-English-speaking families, and children known to have poor glycaemic control.

See also page 75, *Case-study 1*.

## RESOURCES

- NICE Guidance (2004) Diagnosis and management of type 1 diabetes in children, young people and adults (CG15). [Update currently being scheduled] <http://guidance.nice.org.uk/CG15>
- International Society for Pediatric and Adolescent Diabetes (ISPAD) (2009) ISPAD clinical practice consensus guidelines. <http://www.ispad.org/FileCenter.html?CategoryID=5>
- National Paediatric Diabetes Audit (NPDA). <http://www.rcpch.ac.uk/npda>

1 NHS Information Centre (2011) National Diabetes Paediatric Audit Report 2009/10. [http://www.ic.nhs.uk/webfiles/Services/NCASP/Diabetes/200910%20annual%20report%20documents/NHSIC\\_National\\_Diabetes\\_Paediatric\\_Audit\\_Report\\_2009\\_2010.pdf](http://www.ic.nhs.uk/webfiles/Services/NCASP/Diabetes/200910%20annual%20report%20documents/NHSIC_National_Diabetes_Paediatric_Audit_Report_2009_2010.pdf)

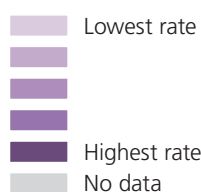
2 Bismuth E, Laffel L (2007) Can we prevent diabetic ketoacidosis in children? *Pediatric Diabetes* 8; 24-33.

**MENTAL DISORDERS**

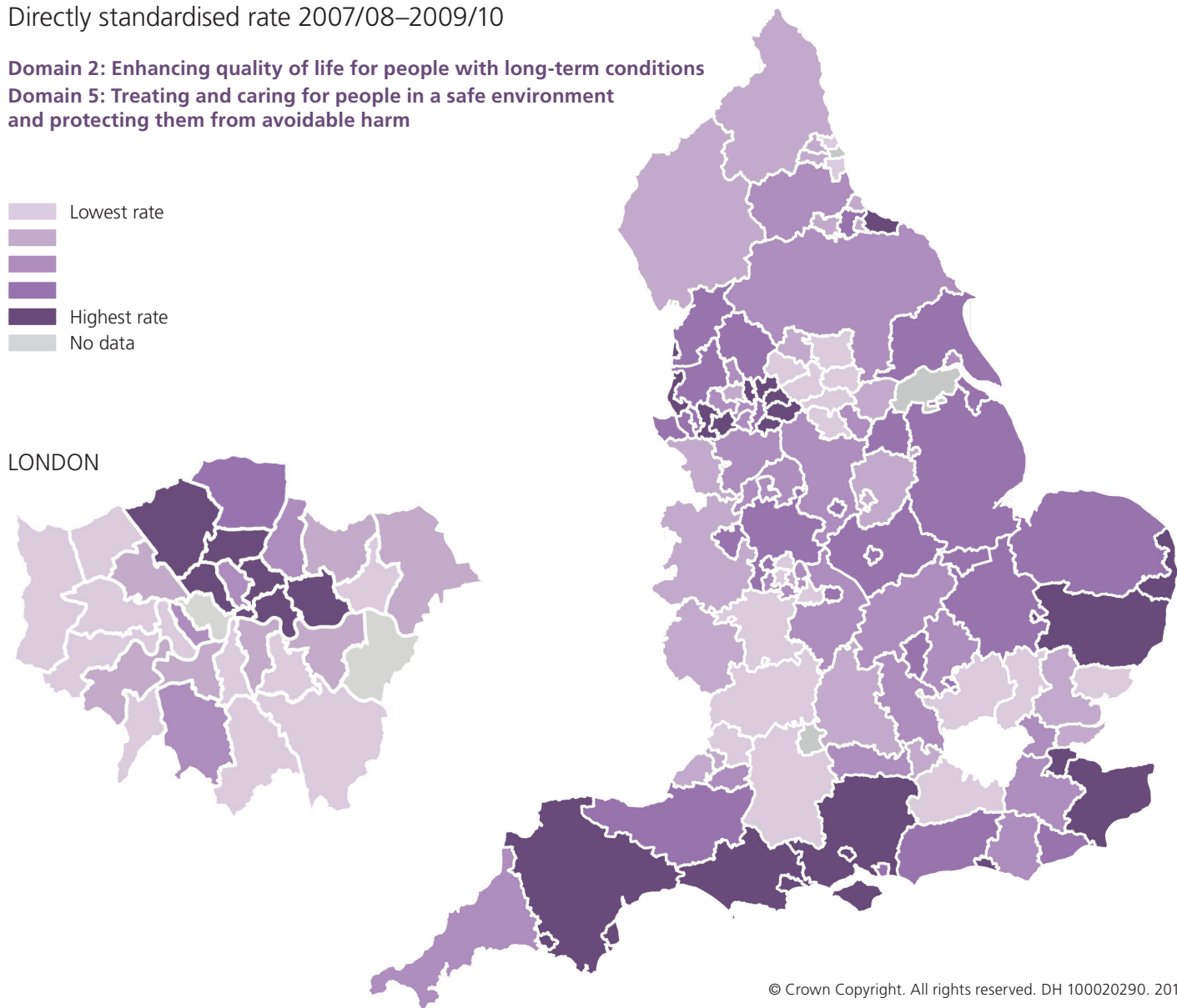
**Map 13:** Rate of inpatient admissions >3 days' duration in children per population aged 0–17 years for mental health disorders by PCT

Directly standardised rate 2007/08–2009/10

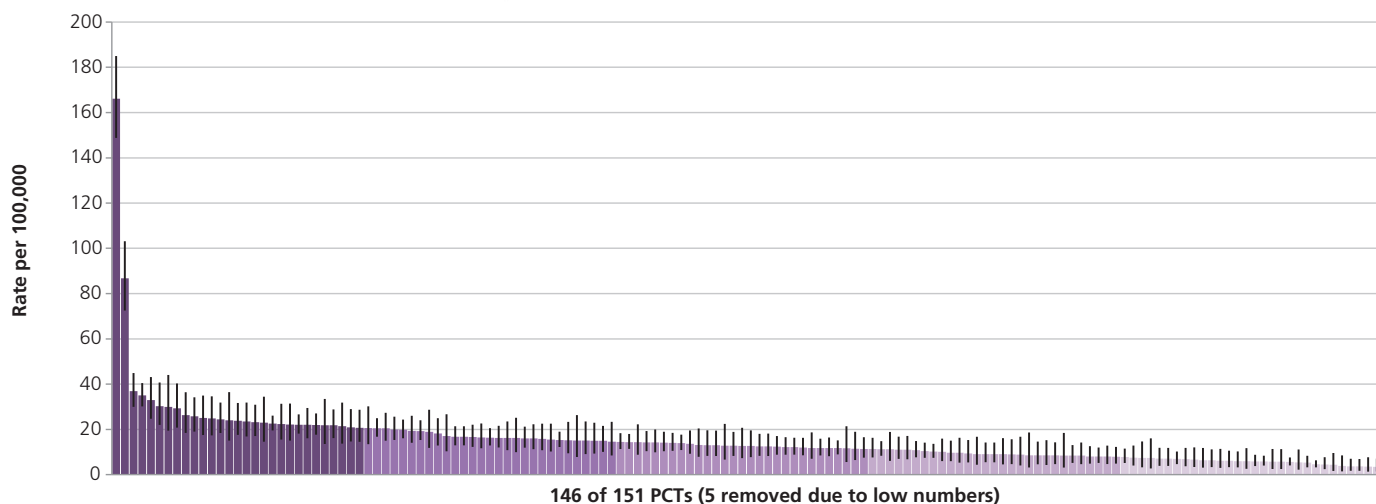
Domain 2: Enhancing quality of life for people with long-term conditions  
 Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



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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.<sup>1</sup>

The societal cost of mental ill health is estimated at £105 billion,<sup>2</sup> 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 when 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).<sup>3</sup> 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.<sup>4</sup> However, when the 2007/08–2009/10 admission rates are plotted against deprivation indices, there is no statistical correlation (see Figure 13.1).

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.

1 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>

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](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](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4019358)

## 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.

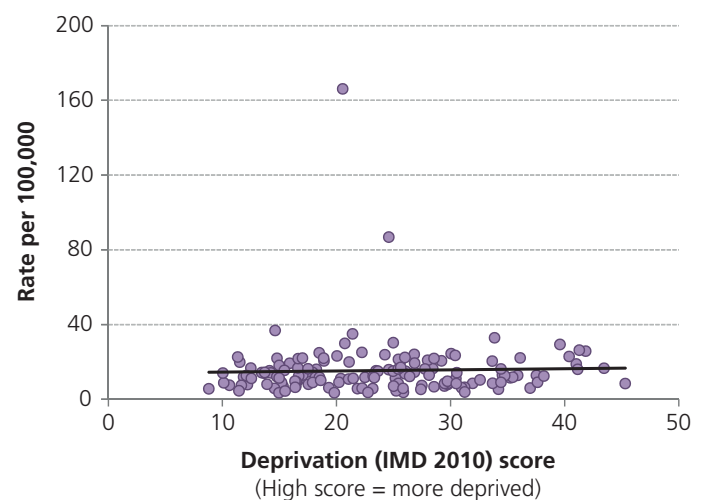
Partnership working with social care can influence admission rates and lengths of stay.

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 need to 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>

**Figure 13.1: Correlation between rate of inpatient admissions >3 days' duration in children per 100,000 population aged 0–17 years for mental health disorders by PCT 2007/08–2009/10 and deprivation**



1 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>

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](http://www.centreformentalhealth.org.uk/pdfs/Economic_and_social_costs_2010.pdf)

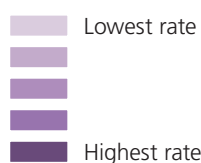
3 Data from five PCTs have been removed.

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](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4019358)

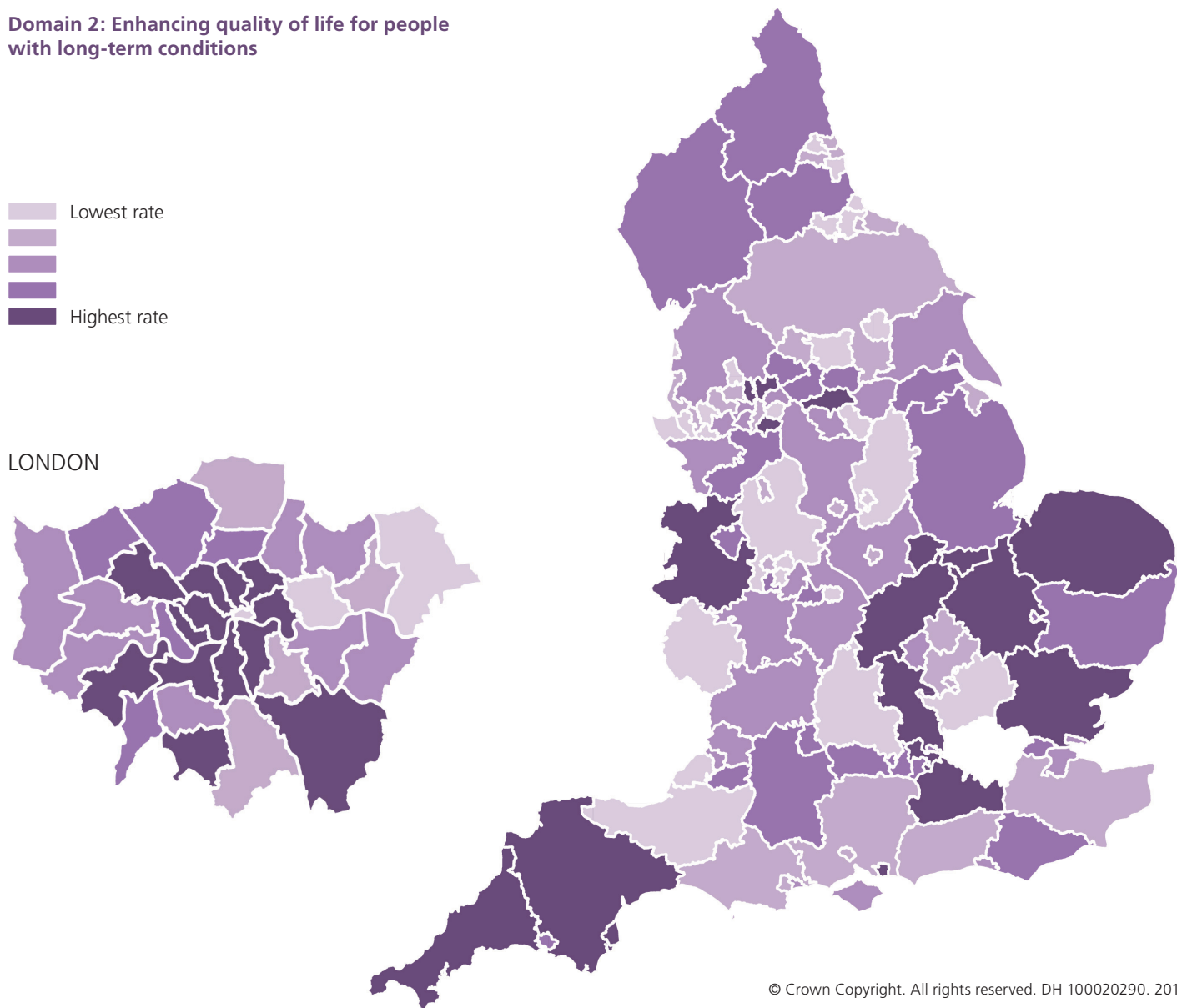
**PROBLEMS OF LEARNING DISABILITY**

**Map 14:** Percentage of primary school children in state-funded schools with a statement of special educational needs (SEN) by local authority at January 2011

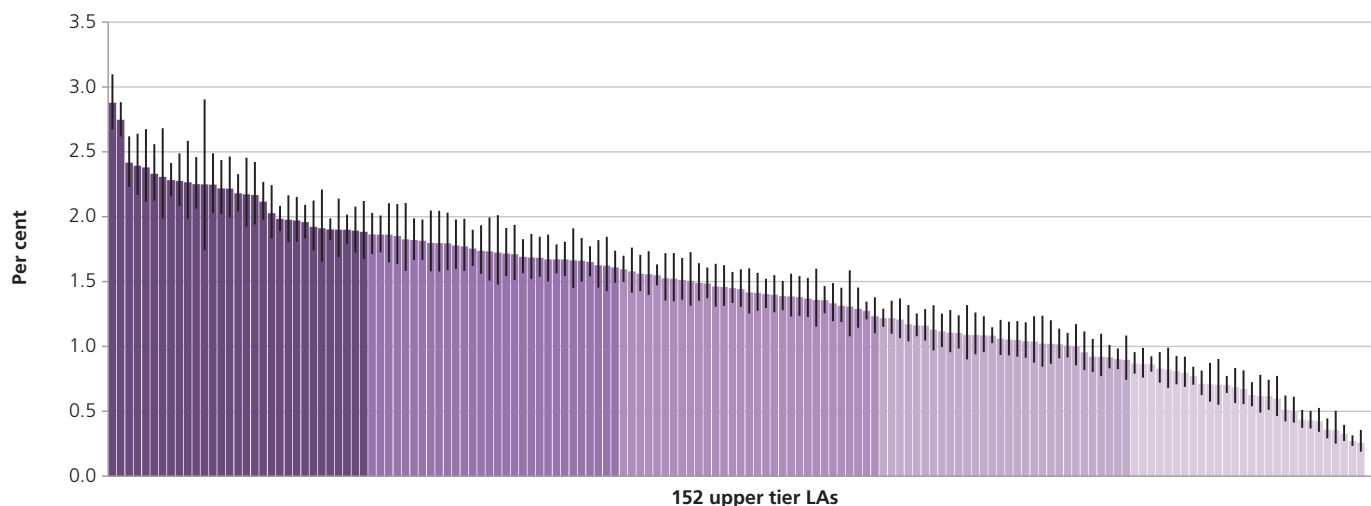
Domain 2: Enhancing quality of life for people with long-term conditions



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## Context

Children with special educational needs (SEN) have a learning difficulty that requires special educational provision. A learning difficulty means the child has:

- Significantly greater difficulty learning than the majority of children in the same age-group;
- A disability preventing or hindering them from using general educational facilities provided in the local authority (LA) for children of the same age-group.

There are four levels of special educational provision: usual support, School Action, School Action Plus, and a statement of SEN. Children with a statement of SEN are either not making progress under School Action or School Action Plus or they require considerable additional support due to severe and complex needs. Children in special schools have a statement of SEN.

The statement has six parts:

- General information about the child;
- Description of the child’s needs following assessment;
- Help to be given to meet the child’s needs;
- Type of school the child should attend, and arrangements for out of school hours or off school premises;
- The child’s non-educational needs;
- Help the child will get to meet non-educational needs.<sup>1</sup>

The local authority reviews the statement at least once a year.

## Magnitude of variation

For upper-tier local authorities in England, the percentage of primary school children in state-funded schools with a statement of SEN ranged from 0.3% to 2.9% (11-fold variation). When the five upper-tier LAs with the highest percentages and the five upper-tier LAs with the lowest percentages are excluded, the range is 0.4–2.3%, and the variation is approaching sixfold.

Possible reasons for variation are differences in:

- the prevalence of complex medical conditions, although it is unlikely to account for the degree of variation observed;
- deprivation levels in different areas (see Figure 14.1);
- child health service spending (SEN data, collected by local authority, and community health spend, collected by PCT, cannot be correlated).

The most plausible explanation is the lack of set criteria governing different levels of support in school, leading to variation in interpretation among, and within, localities during decision-making about writing a statement of SEN. However, this factor is most amenable to intervention by commissioners.

## Options for action

All levels of identified need for support in school and the proposed measures of early development in the Tickell Report (see “Resources”) together with measures in the Early Years Foundation Stage Profile (statutory assessment requirement for children reaching the end of the Foundation Stage; see

“Resources”) could be analysed in relation to:

- child health service spending;
- availability of nursery places;
- availability of staff, such as speech therapists.

Such timely identification of potential future needs, emphasising early years identification and risk assessment, would enable commissioners and health and education professionals to create bespoke funding and resource allocation plans for supporting children with additional needs in each local population. This will deliver higher-quality services through:

- Greater flexibility and responsiveness to local needs;
- Evidence-based modelling of future workload to inform workforce planning;
- Allowing redeployment of resources to prevention/early intervention through better and earlier identification of at-risk children;
- More efficient use of educational and community health resources.

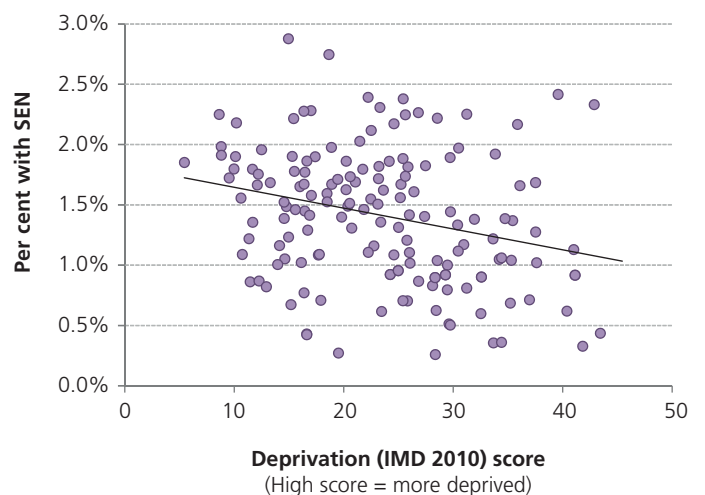
Commissioners in agencies caring for children with additional needs could:

- share information on performance;
- collaborate to standardise the assessment process.

## RESOURCES

- Tickell C (2011) The Early Years: Foundations for life, health and learning. An Independent Report on the Early Years Foundation Stage to Her Majesty’s Government. <http://media.education.gov.uk/MediaFiles/B/1/5/7BB15EFF0D-A4DF-4294-93A1-1E1B88C13F68%7DTickell%20review.pdf>
- Early Years Foundation Stage Profile Data. <http://data.gov.uk/dataset/early-years-foundation-stage-profile-results-england-2010>
- Early Years Foundation Stage Profile – assessment scales reference sheet. [http://www.qcda.gov.uk/resources/assets/poster\\_v8\\_aw.pdf](http://www.qcda.gov.uk/resources/assets/poster_v8_aw.pdf)

**Figure 14.1: Correlation between percentage of primary school children in state-funded schools with a statement of SEN by local authority at January 2011 and deprivation**



1 [http://www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/SpecialEducationalNeeds/DG\\_4000870](http://www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/SpecialEducationalNeeds/DG_4000870)

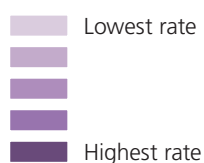


### NEUROLOGICAL PROBLEMS

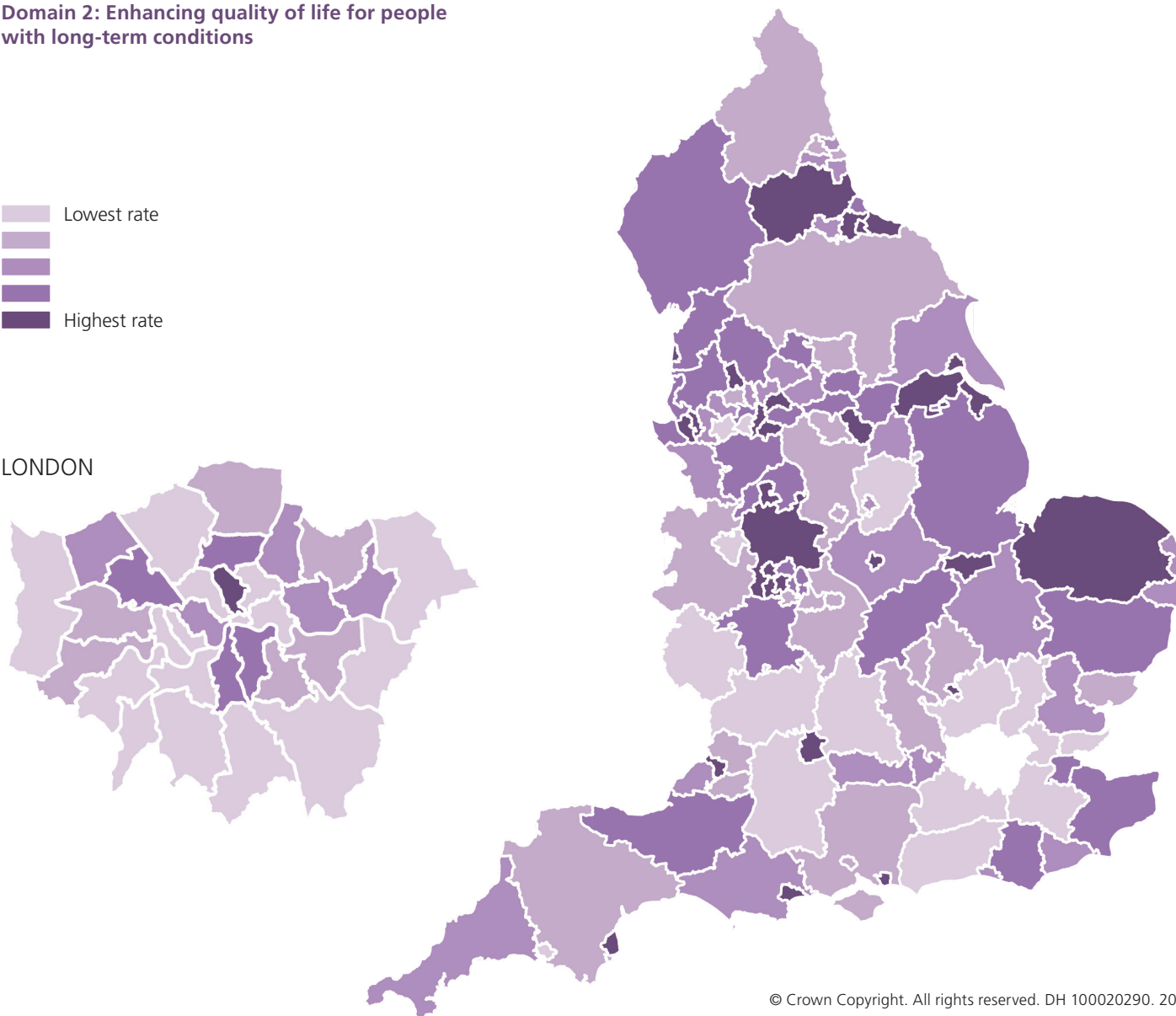
## Map 15: Emergency admission rate for children with epilepsy per population aged 0–17 years by PCT

Directly standardised rate 2007/08–2009/10

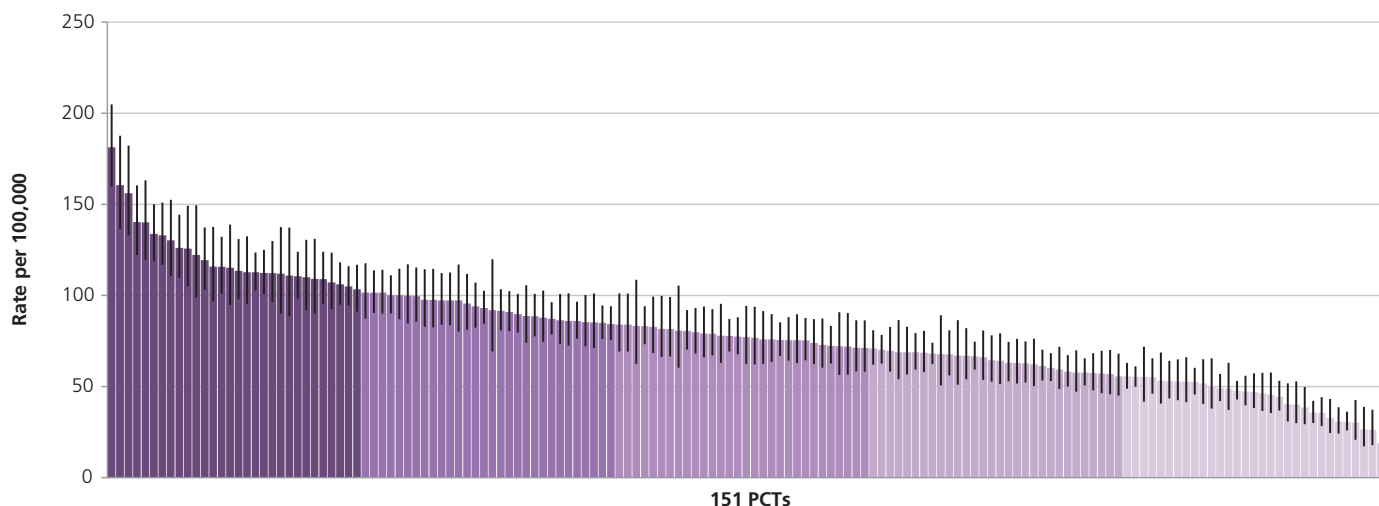
Domain 2: Enhancing quality of life for people with long-term conditions



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## Context

Epilepsy is common in children, affecting approximately 48,000 in England.<sup>1</sup> Childhood epilepsy encompasses a range of disorders of varying complexity and diagnostic difficulty. Complex co-morbidities are more common in childhood than in adult epilepsy. Unplanned hospitalisation for asthma, diabetes and epilepsy in children and young people under 19 years is a national quality indicator in the NHS Outcomes Framework 2011/12.

## Magnitude of variation

For PCTs in England, the emergency admission rate for children with epilepsy per 100,000 population aged 0–17 years ranged from 19.1 to 181.2 (9-fold variation). When the five PCTs with the highest emergency admission rates and the five PCTs with the lowest emergency admission rates are excluded, the range is 30.8–133.7 per 100,000 population aged 0–17 years, and the variation is 4.3-fold.

Epilepsy is more common in deprived populations. However, as the higher prevalence rate in socio-economically deprived populations is only about one-quarter greater than the mean rate, deprivation alone cannot explain this degree of variation.

Variations in emergency admission rates for children with epilepsy can reflect differences in:

- Emergency management of acute seizures;
- Availability of community-based support, such as specialist epilepsy nursing services;
- Effectiveness of ongoing seizure control;
- Thresholds for seeking admission;
- Admission criteria of local departments;
- Thresholds for deciding to admit a child.

The occurrence of seizures in childhood epilepsy can be unpredictable. For a few children, long-term seizure control can be very difficult. These children could influence the number of emergency admissions in certain PCTs. However, as the numbers are so small, it is unlikely to account for the degree of variation observed, particularly as the data are aggregated over three years.

Variation is also seen in the prevalence of epilepsy, and the proportion of children diagnosed with epilepsy who do not have the disease. Epilepsy can be difficult to

diagnose in children. In the absence of referral guidance and specialist expertise within a managed network setting, children with equivocal clinical presentations can often be wrongly diagnosed.<sup>2</sup>

## Options for action

Commissioners need to consider the benefits of commissioning the following interventions for children with epilepsy.

- First seizure services to streamline investigation and diagnosis where possible.
- Integrated care pathways, including the development of personal management plans for children and their families.
- Specialist nurses in the epilepsy service, whose roles could include coordination of care pathway, family support, population education, and liaison with primary care and education services.
- Enhanced links with social care and education, including medication policies in schools.
- Specific services to aid the transition of children with epilepsy from paediatric to adult epilepsy services.

A managed network model of delivering epilepsy care will help to improve seizure control in many children with epilepsy and rationalise clinical decision-making about the need for admission.

See also page 77, Case-study 2.

## RESOURCES

- NICE Guidance (2012) The epilepsies. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. Clinical guidelines, CG137. <http://guidance.nice.org.uk/CG137>
- British Paediatric Neurology Association (BPNA) runs courses in the UK for health professionals involved in the management of children with epilepsy. These courses help to ensure a consistent clinical approach to the diagnosis and management of epilepsy in children. <http://www.bpna.org.uk/pet/>
- Epilepsy 12 is a national audit of childhood epilepsy, monitoring performance of units against 12 key quality standards: 99% of eligible units have signed up. Outputs will be valuable for commissioners when assessing the performance of local providers. <http://www.rcpch.ac.uk/epilepsy12>
- Patient education and support is available from national and local services. <http://www.epilepsy.org.uk/info>

1 Epilepsy Action (2009) Epilepsy in England: time for change. <http://www.epilepsy.org.uk/campaigns/timeforchange>

2 Uldall P, Alving J, Hansen LK, Kibæk, Buchholt J (2006) The misdiagnosis of epilepsy in children admitted to a tertiary epilepsy centre with paroxysmal events. *Archives of Disease in Childhood* 91: 219-221.

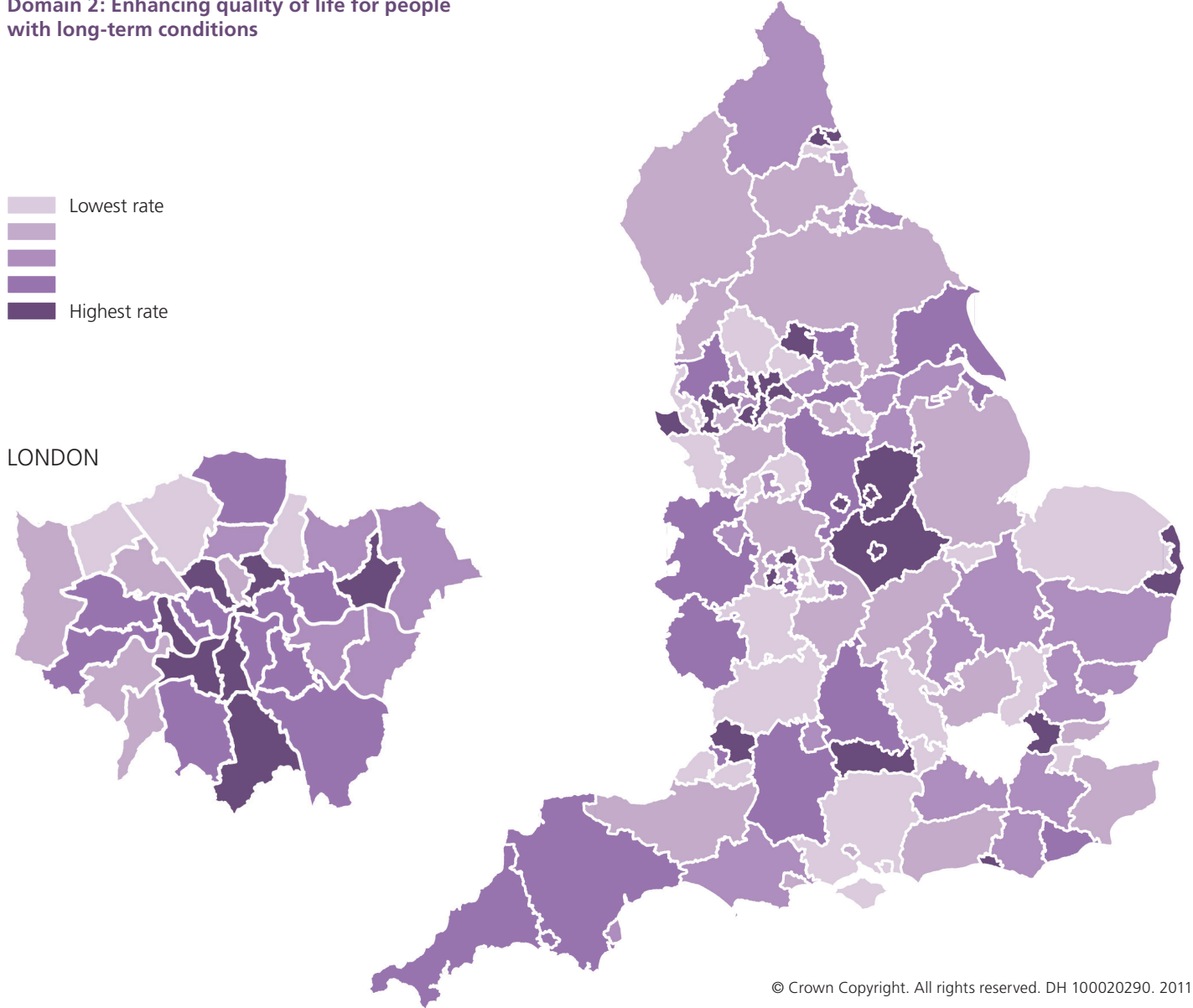


### NEUROLOGICAL PROBLEMS

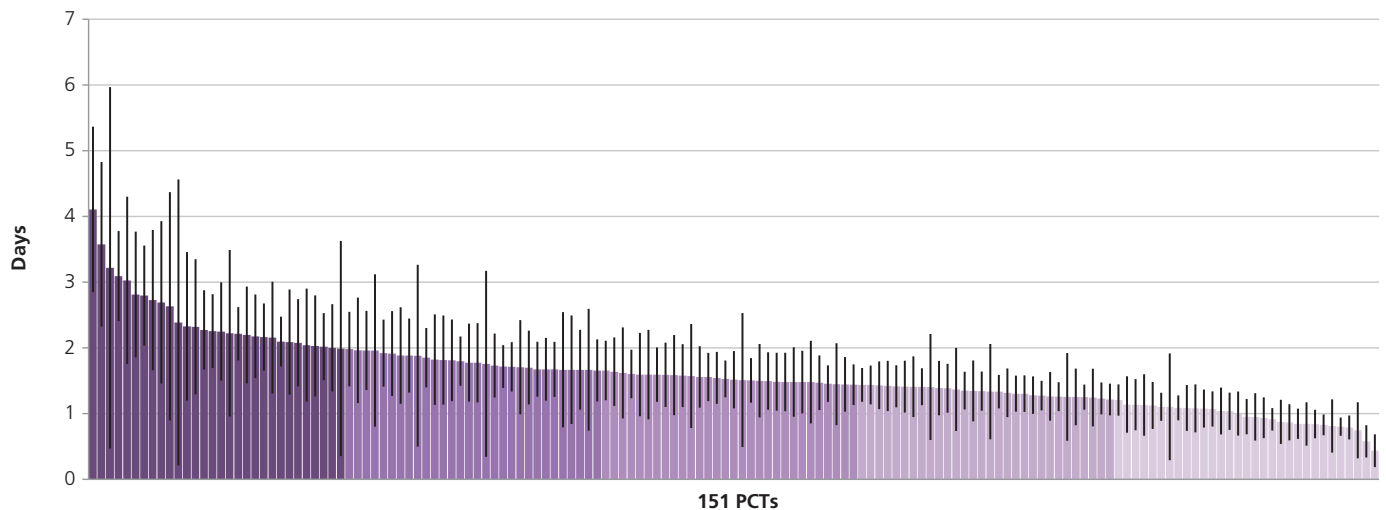
## Map 16: Mean length of emergency inpatient stay (days) for children with epilepsy aged 0–17 years by PCT

2007/08–2009/10

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



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## Context

Frequent or prolonged hospital admissions for children with epilepsy disrupt their education and family life, thereby affecting the well-being of children and their families.

In a review of health economic analyses of the cost of care in childhood epilepsy, unnecessary hospital admission was one of the most expensive aspects of epilepsy care.<sup>1</sup> The cost of caring for children in whom the control of epilepsy is poor is greater than twice that involved in caring for children in whom seizure control is good. The increased expenditure is due to greater costs for both medication and hospital admissions.

## Magnitude of variation

For PCTs in England, the mean length of emergency inpatient stay for children with epilepsy aged 0–17 years ranged from 0.4 to 4.1 days (9-fold variation). When the five PCTs with the highest mean lengths of stay and the five PCTs with the lowest mean lengths of stay are excluded, the range is 0.8–2.8 days for children with epilepsy aged 0–17 years, and the variation is 3.5-fold.

Some degree of variation is warranted because many children with epilepsy have other neurodevelopmental problems and physical disability, which may prolong their stay in hospital once admitted.

However, there is likely to be some degree of unwarranted variation given the magnitude of variation observed and the fact that the data have been aggregated over three years. Some of the reasons for unwarranted variation could be generic to hospital patient-flow processes, and therefore experienced in common with many other conditions, for example:

- delays in investigations;
- availability of health professionals for inpatient consultations;
- suboptimal discharge processes.

Differences in the level of community-based support, in particular, specialist epilepsy nursing services, may also contribute to a delay in discharge, affecting the confidence of both families and clinicians to discharge the child at an appropriate time.

Differences in clinical practice may also exist.

## Options for action

Commissioners need to ensure local providers have clear guidelines for the management and investigation of first seizures and of epilepsy.

In areas where individual providers have a prolonged duration of admission, commissioners and providers need to investigate hospital processes and patient flows.

To maximise efficiency and quality of care, individual departments need to determine whether there are differences in clinical practice among individual clinicians.

Commissioners and providers need to ensure that:

- Each child has an individual care plan agreed between the clinician and the child and his/her family;
- All children with epilepsy have access to community-based support services, including access to a community specialist epilepsy nurse as recommended in NICE guidance (see “Resources”).

A clinical network model is the optimal design not only for the delivery of services including the above options for action, but also to ensure that the care provided is affordable and that provider organisations are accountable.

See also page 77, Case-study 2.

## RESOURCES

- NICE Guidance (2012) The epilepsies. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. Clinical guidelines, CG137. <http://guidance.nice.org.uk/CG137>
- British Paediatric Neurology Association (BPNA) runs courses in the UK for health professionals involved in the management of children with epilepsy. These courses help to ensure a consistent clinical approach to the diagnosis and management of epilepsy in children. <http://www.bpna.org.uk/pet/>
- Epilepsy 12 is a national audit of childhood epilepsy, monitoring performance of units against 12 key quality standards: 99% of eligible units have signed up. Outputs will be valuable for commissioners when assessing the performance of local providers. <http://www.rcpch.ac.uk/epilepsy12>
- Patient education and support is available from local and national services. <http://www.epilepsy.org.uk/info>

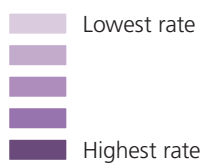
1 Beghi E et al. (2005) A review of the costs of managing childhood epilepsy. *Pharmacoeconomics* 23: 27-45.

### PROBLEMS OF HEARING

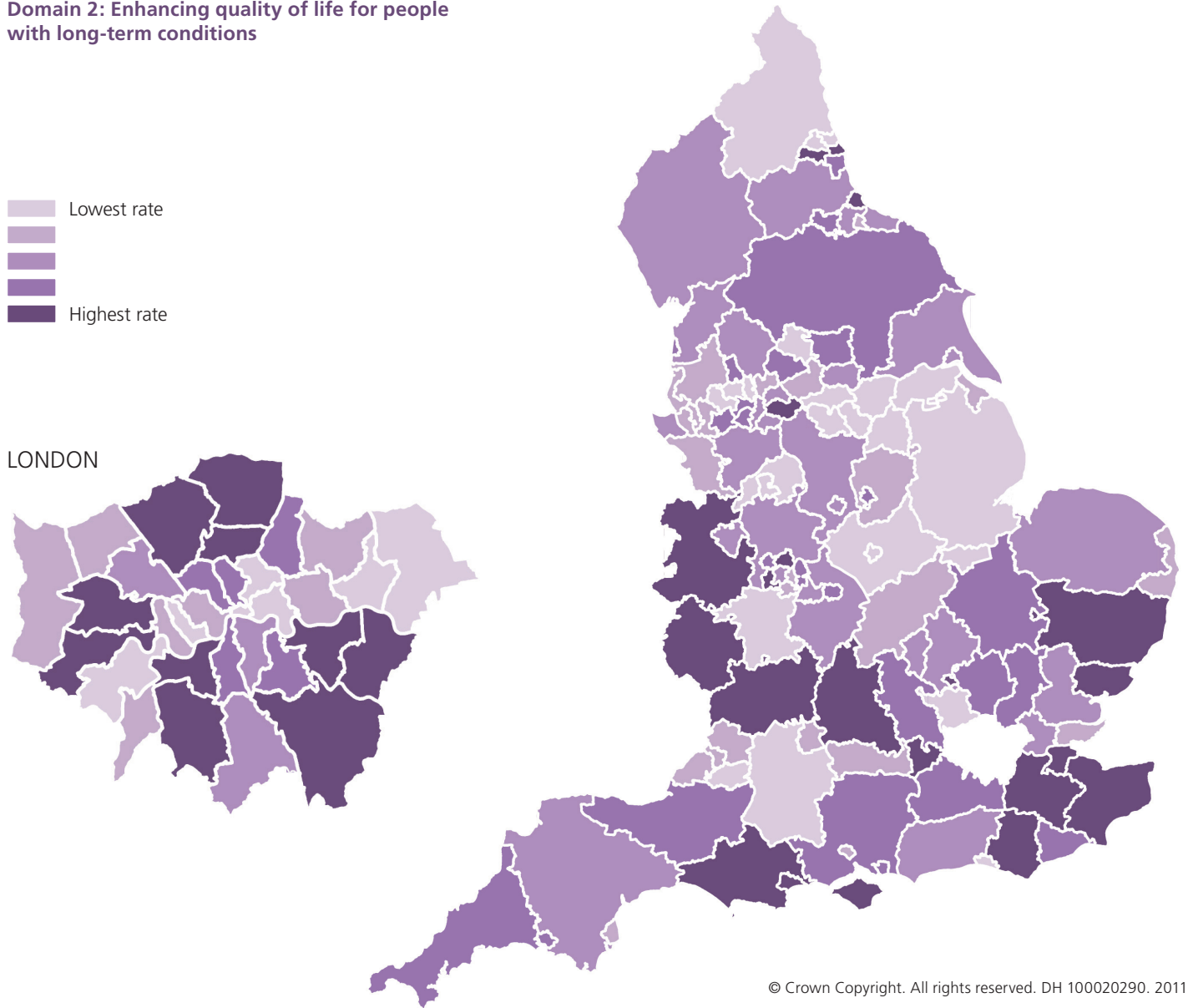
# Map 17: Mean time from referral to assessment for hearing tests in newborns by PCT

2010

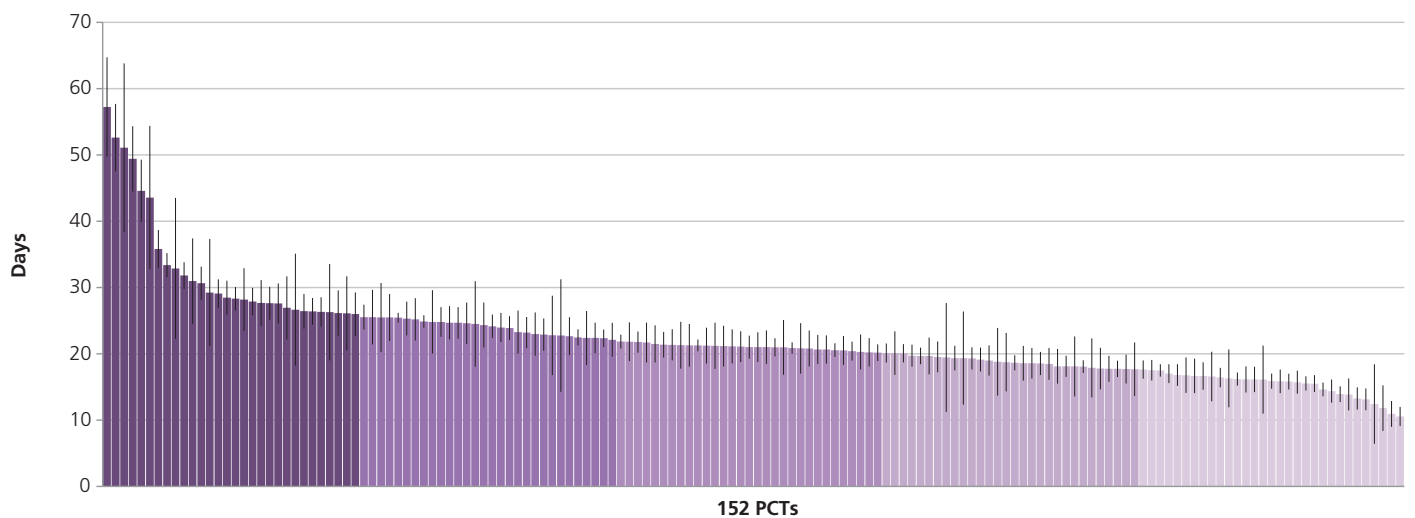
Domain 2: Enhancing quality of life for people with long-term conditions



LONDON



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## Context

Congenital deafness (moderate, severe or profound hearing loss) has a major impact on child development. There are 20,000 permanently deaf children in England, who receive services from the NHS, including genetic services because deafness has major genetic aetiologies, social services, and education services. About £250 million is spent on paediatric audiology and related services for families and their children in a year. Early identification by the NHS Newborn Hearing Screening Programme (NHSP) greatly reduces this impact.

Through the NHS NHSP, children are referred to paediatric diagnostic audiology services if they have a poor response in either one ear or both ears at screening. The average referral rate to paediatric diagnostic audiology services is 2%: for about 0.5% of these referrals, this is because babies do not have a clear response in both ears, and for 1.5% of referrals it is because there is not a clear response in one ear.

Between 13,000 and 14,000 children are referred each year in England. As a result of audiological assessment, children are diagnosed as permanently deaf, in need of further diagnostics, or hearing within normal limits. Of the 1000 children identified as deaf by the NHS NHSP in a year, 660 will have bilateral deafness, and, of those, 170 will be profoundly deaf.

The NHSP has a set of quality standards and service specifications (see “Resources”). The key performance indicator relating to referral for audiological assessment is:

*“All parents of babies that refer from the screen and wish to continue should be offered an appointment that is within 4 weeks of screen completion.”*

This indicator focuses on the interface between the NHSP and paediatric audiology services. The data show mean time to confirmatory assessment after referral from the NHSP.

Reducing the degree of variation in the mean time from referral to assessment for hearing tests across England will reduce the level of inequity for newborns and their parents offered hearing screening.

## Magnitude of variation

For PCTs in England, the mean time from referral to assessment for hearing tests in newborns ranged from

10.5 to 57.2 days (5-fold variation). When the five PCTs with the highest mean times and the five PCTs with the lowest mean times are excluded, the range is 13.3–43.6 days, and the variation is 3.3-fold.

Reasons for warranted variation include differences in the levels of risk and genetic aetiologies in different areas.

Possible reasons for unwarranted variation include differences in:

- › Capacity;
- › Prioritisation of services;
- › Arrangements for cover;
- › Availability of education services staff with whom to work;
- › Quality of management of audiology assessment services.

## Options for action

Commissioners and providers in areas where the mean time from referral to assessment for hearing tests is 25 days or greater need to explore why the times are longer than those in the middle part of the distribution (see column chart), including looking at the interface between local screening services, paediatric audiology services and education services.

The UK National Screening Committee (NSC) has been working with the Map of Medicine® to produce pathways for all the English non-cancer screening programmes for which it has responsibility. The Map of Medicine care pathways for newborn hearing screening (including diagnostic assessment and habilitation) have now been completed, and can be localised by commissioners and providers in order to help promote standards in newborn hearing screening, including improving the time from referral to assessment (see “Resources”).

## RESOURCES

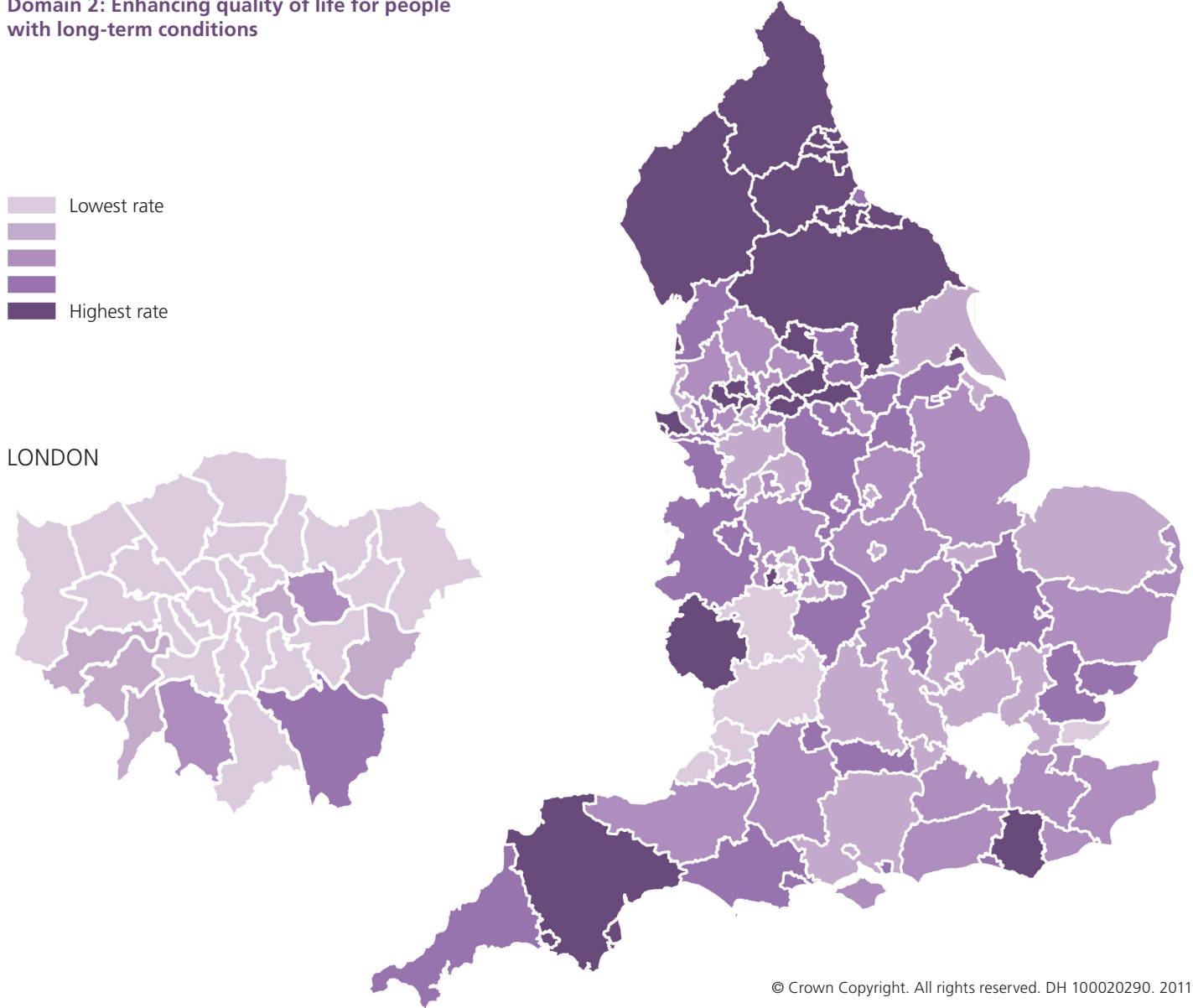
- › NHS Newborn Hearing Screening Programme (NHSP). Standards and Protocols. <http://hearing.screening.nhs.uk/standardsandprotocols>
- › NHS Newborn Hearing Screening Programme (NHSP). NHSP Map of Medicine care pathways. <http://hearing.screening.nhs.uk/cms.php?folder=3788>

### PROBLEMS OF HEARING

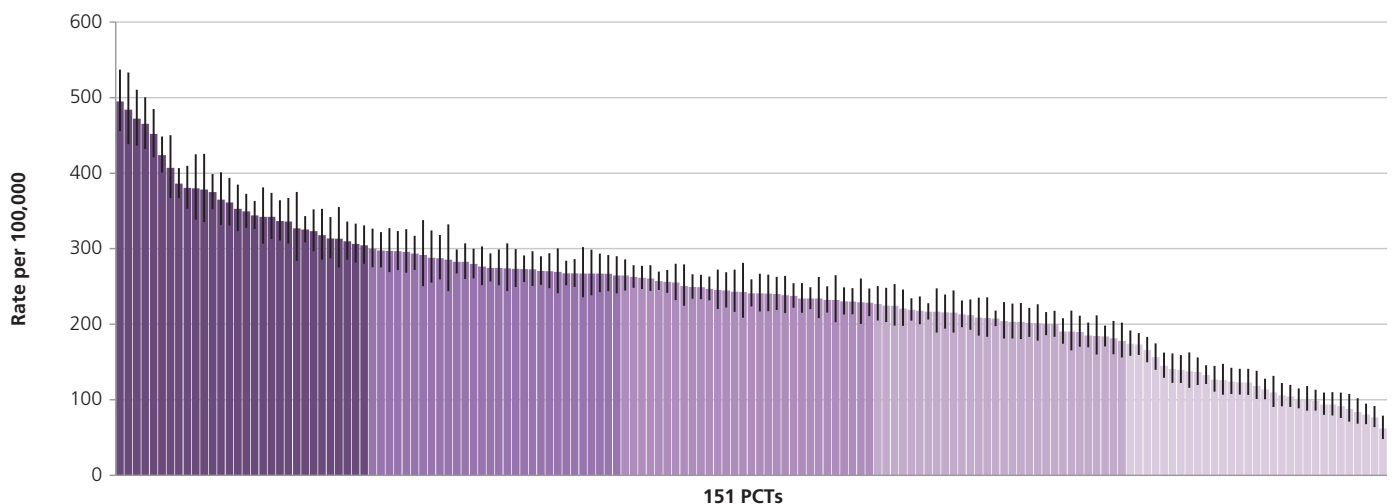
## Map 18: Rate of aural ventilation tube (grommet) insertion in children per population aged 0–17 years by PCT

Directly standardised rate 2007/08–2009/10

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



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## Context

Otitis media with effusion (OME) is a build-up of fluid in the middle ear resulting in hearing loss. Approximately 80% of children suffer an episode before the age of 5 years. The majority of cases are self-limiting, with recovery of hearing loss. No treatment other than active monitoring has proved effective during the early stages of the condition.

For children in whom there is no resolution over a three-month period, surgical treatment by inserting an aural ventilation tube (grommet) is effective. The aural ventilation tube equalises pressure in the middle ear and reduces the inflammatory changes that cause an effusion.

In the NICE guideline on the surgical management of OME (see “Resources”), surgical treatment is recommended for children with bilateral OME, documented over a three-month period, who have a specified level of hearing impairment.

## Magnitude of variation

For PCTs in England, the rate of aural ventilation tube insertion in children per 100,000 population aged 0–17 years ranged from 62.1 to 495.1 (8-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 91.6–424.0 per 100,000 population aged 0–17 years, and the variation is 4.6-fold.

The degree of variation observed shows much work still needs to be done to ensure quality and value are maximised for this intervention. Over the past decade, emphasis has been placed on the clinical and financial sequelae of unnecessary surgical intervention for OME, often justifiably so. However, the consequences of failing to intervene in a child with persistent OME are:

- › prolonged hearing impairment;
- › social, developmental and language delays;
- › harmful effects on educational progress.

## Options for action

The application of NICE guidance (see “Resources”) offers commissioners and clinicians clarity in the appropriateness of the service delivered. Commissioners need to follow NICE guidelines when commissioning services to ensure equity of access for clinically justified interventions, while reducing unnecessary interventions that divert resource from those who fulfill clinical criteria.

As children aged four years and under are generally unable to comply with pure-tone audiometry testing, it is difficult to document a definitive level of hearing impairment. It is vital that access should not be denied to these children; in this age-group, behavioural testing combined with objective tympanometry is suitable as an alternative. Commissioners need to work in close collaboration with clinicians to design local services that optimise access, quality and value.

Clinical leadership is essential to ensure the commissioning process reflects the health needs of the local population, and the constraints on the clinical service.

*See also Atlas 2.0, page 58, Figure TT.5 for time trend from 2001/02 to 2009/10.*

## RESOURCES

- › NICE Guidance (2008) Surgical management of children with otitis media with effusion (OME). Clinical guidelines, CG60. <http://guidance.nice.org.uk/CG60>

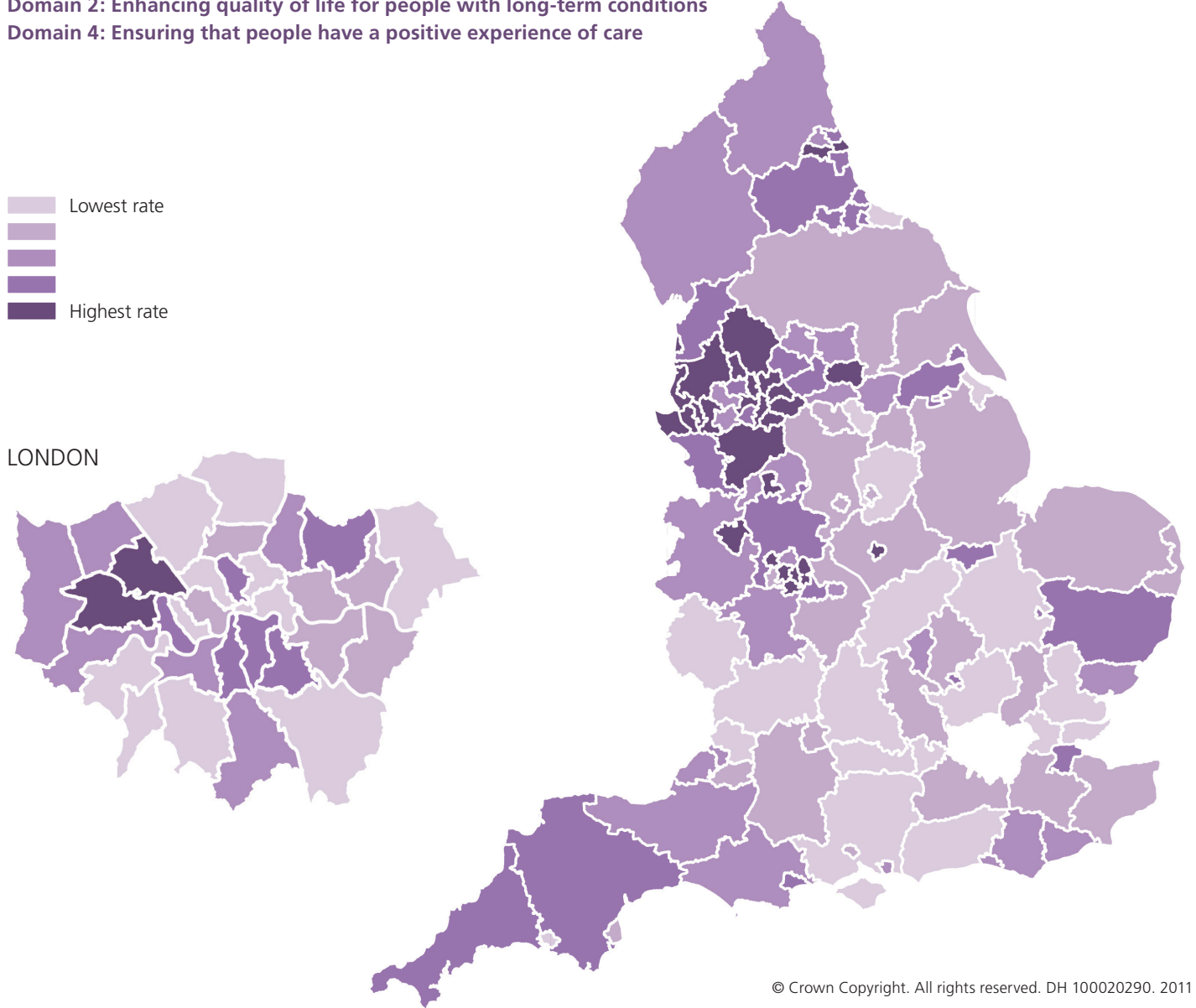


**PROBLEMS OF THE RESPIRATORY SYSTEM**

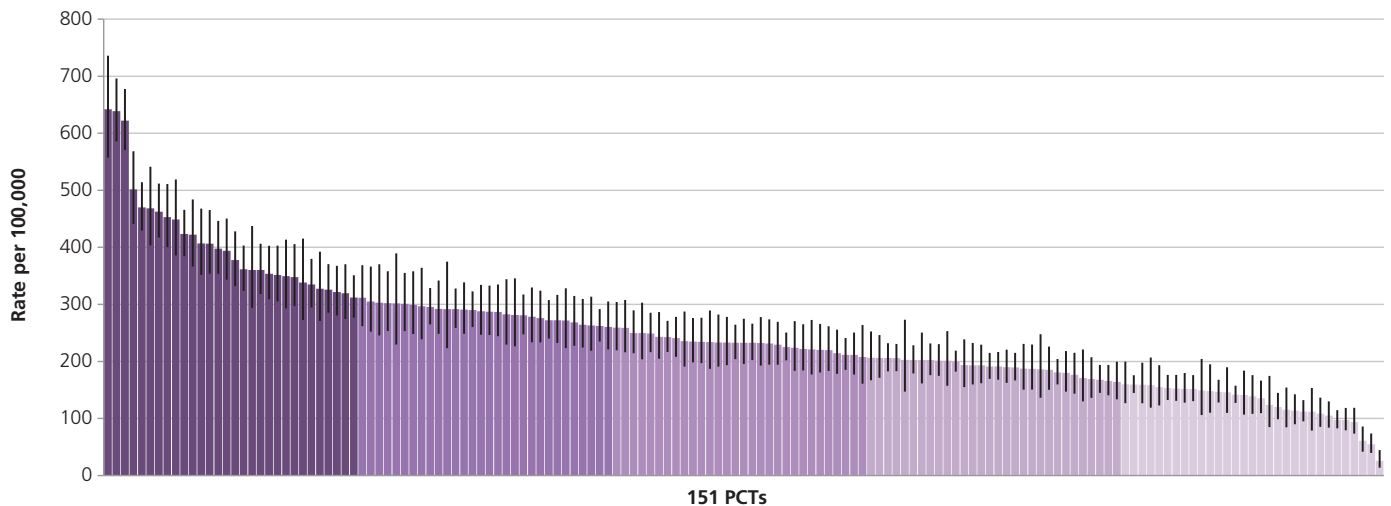
# Map 19: Emergency admission rate for children with asthma per population aged 0–17 years by PCT

Directly standardised 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



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## Context

Asthma is the commonest long-term medical condition in childhood. Emergency admissions should be avoided whenever possible.

Unplanned hospitalisation for asthma, diabetes and epilepsy in children and young people under 19 years is a national quality indicator in the NHS Outcomes Framework 2011/12.

## Magnitude of variation

For PCTs in England, the emergency admission rate for children with asthma per 100,000 population aged 0–17 years ranged from 25.9 to 641.9 (25-fold variation). When the five PCTs with the highest emergency admission rates and the five PCTs with the lowest emergency admission rates are excluded, the range is 97.6–468.5 per 100,000 population aged 0–17 years, and the variation is 4.8-fold.

In 2008/09, the variation was sixfold, and after exclusions it was almost fourfold (see Map 17, Atlas 1.0). The increase in the magnitude of variation may not necessarily represent an overall deterioration in care. The greater magnitude of variation may reflect improvements in care in the best-performing PCTs, rather than deterioration in the worst.

However, it does highlight an increasing inequity in the management of asthma services, which requires urgent redress.

Variation in the rate of emergency admissions may be due to a variety of reasons:

- › suboptimal symptom management and secondary prevention in the community;
- › suboptimal emergency care in the accident and emergency (A&E) department;
- › differences in admission criteria among paediatric clinicians.

## Options for action

Commissioners can use the ChiMat Disease Management Information Toolkit (DMIT; see “Resources”) to identify unwarranted variation in the local management of long-term conditions such as asthma.

A management pathway for asthma would help to reduce unwarranted variation.

Every child with asthma should have an Asthma Care Plan according to the British Thoracic Society/Scottish Intercollegiate Guidelines Network (BTS/SIGN) guideline on management of asthma (see “Resources”).

Commissioners need to ensure that the BTS/SIGN guidelines form the basis of local clinical asthma pathways for which they are responsible.

As the causes of asthma are multifactorial, action to reduce emergency admissions requires a whole pathway approach, including public health, and primary and secondary care. Parental education and school medication management are also vital aspects of the overall care of the child with asthma.

## RESOURCES

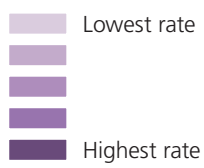
- › ChiMat Disease Management Information Toolkit (DMIT). <http://atlas.chimat.org.uk/IAS/dmit>
- › British Thoracic Society/Scottish Intercollegiate Guidelines Network (BTS/SIGN) British Guideline on the Management of Asthma. May 2008; revised May 2011. <http://www.brit-thoracic.org.uk/guidelines/asthma-guidelines.aspx>

PROBLEMS OF THE RESPIRATORY SYSTEM

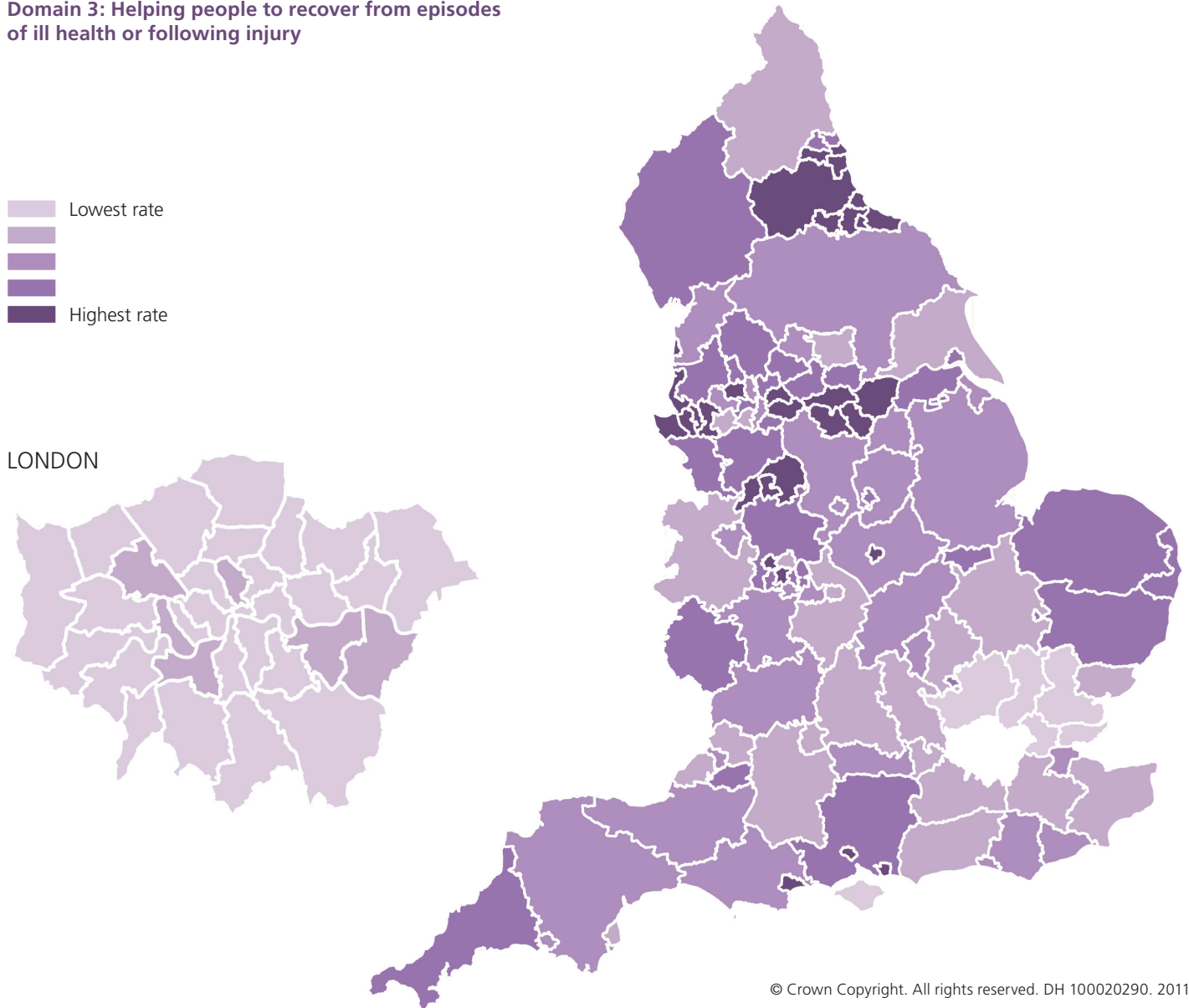
# Map 20: Rate of admissions for bronchiolitis in children per population aged under 2 years by PCT

Directly standardised rate 2007/08–2009/10

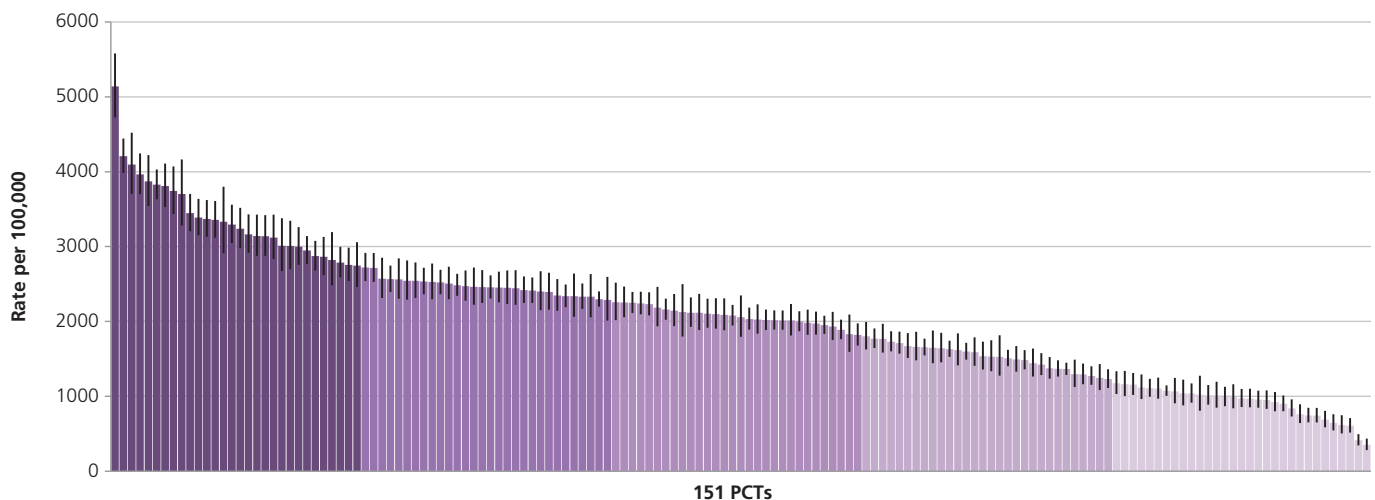
Domain 3: Helping people to recover from episodes of ill health or following injury



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## Context

Bronchiolitis is a viral respiratory infection of the lower airways, predominantly affecting infants under the age of 1 year but occasionally infants up to the age of 2 years. In industrialised countries, 1–3% of all infants are admitted to hospital as a result of bronchiolitis.<sup>1</sup> Human respiratory syncytial virus (RSV) is the most common cause of bronchiolitis in infants, and RSV is the single most common cause of hospital admissions in infancy.<sup>2</sup> Globally RSV is the most common cause of childhood acute and severe lower respiratory tract infections and a cause of substantial mortality.<sup>3</sup>

The incidence of bronchiolitis tends to be seasonal: most cases in England occur in the winter. Although the majority of children with bronchiolitis do not require admission to hospital, those that do will often require feeding therapy and/or supplemental oxygen therapy. Seasonal preventative treatment with monthly injections of monoclonal antibody for a selected population of at-risk children (such as those with pre-existing lung disease or significant congenital heart disease) is clinically beneficial and cost-effective.<sup>4</sup>

There is clinical best-practice guidance covering admission criteria for and subsequent inpatient management of children with bronchiolitis.<sup>4</sup>

## Magnitude of variation

For PCTs in England, the rate of admissions for bronchiolitis in children per 100,000 population aged under 2 years ranged from 351 to 5140 (15-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 689–3826 per 100,000 population aged under 2 years, and the variation is sixfold.

Variations in admissions for children with bronchiolitis may reflect epidemiological factors, including socio-economic deprivation, maternal tobacco smoking during pregnancy and household tobacco-smoking status.<sup>5</sup> In Figure 20.1, there is a positive correlation between the rate of admissions for bronchiolitis and deprivation. However, this cannot be the sole explanation for the degree of variation observed: among the 10 most-deprived PCTs, there is a greater than 10-fold variation in rates of admission for bronchiolitis, and among the 10 least-deprived PCTs there is a greater than twofold variation (see Figure 20.2, page 74).

Reasons for unwarranted variation could be differences in:

- the management and assessment of children with bronchiolitis in the emergency department;
- clinical admission criteria.

Providing supported discharge, and clear “safety-net” advice, to reduce length of stay alleviates the overall burden of bronchiolitis admissions on hospitals but at the cost of an expected increase in re-admissions. Thus, any variation in

admission rates needs to be interpreted taking into account the effect of length of stay (see Map 21, page 60).

## Options for action

Local clinicians, in particular, emergency department practitioners and paediatricians, need to apply:

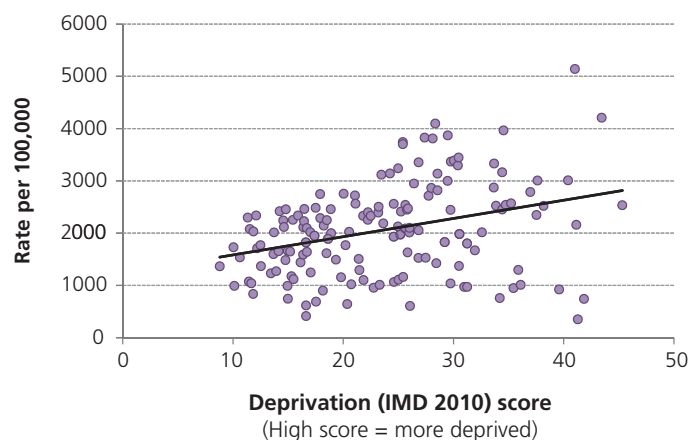
- evidence-based guidance for the assessment of children with respiratory illness;
- clear admission criteria for children presenting with bronchiolitis, based on national evidence-based guidelines supplemented by frequent reviews of the most recent literature.

Clinicians, supported by commissioners, need to ensure that all at-risk children receive prophylaxis against RSV in accordance with Department of Health guidance (see “Resources”). Mechanisms are required not only to deliver treatment to those who present themselves to healthcare services, but also to identify and contact pro-actively the families of at-risk children to ensure the children are protected.

## RESOURCES

- Scottish Intercollegiate Guidelines Network (SIGN) (2006) Bronchiolitis in children. A national clinical guideline. <http://www.sign.ac.uk/pdf/sign91.pdf>
- Joint Committee on Vaccination and Immunisation (JCVI) (23 July 2010) Statement on immunisation for Respiratory Syncytial Virus. [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@ab/documents/digitalasset/dh\\_120395.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@ab/documents/digitalasset/dh_120395.pdf) Amended paragraphs 12 and 13 (15 December 2010) [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@ab/documents/digitalasset/dh\\_122751.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@ab/documents/digitalasset/dh_122751.pdf)
- Department of Health (2006; updated 2011) Immunisations against infectious diseases (“Green Book”). Chapter 27a – Respiratory Syncytial Virus.

**Figure 20.1: Correlation between rate of admissions for bronchiolitis in children per 100,000 population aged under 2 years by PCT 2007/08–2009/10 and deprivation**



1 Leader S, Kohlhasse K (2002) Respiratory syncytial virus-coded pediatric hospitalizations, 1997 to 1999. *Pediatric Infectious Disease Journal* 21: 629–632.

2 Deshpande SA, Northern V (2003) The clinical and health economic burden of respiratory syncytial virus disease among children under 2 years of age in a defined geographical area. *Archives of Disease in Childhood* 88:1065–1069.

3 Nair H et al. (2010) Global burden of acute lower respiratory infections due to respiratory syncytial virus in young children: a systematic review and meta-analysis. *Lancet* 375:1545–1555.

4 Scottish Intercollegiate Guidelines Network (SIGN) (2006) Bronchiolitis in children. A national clinical guideline. <http://www.sign.ac.uk/pdf/sign91.pdf>

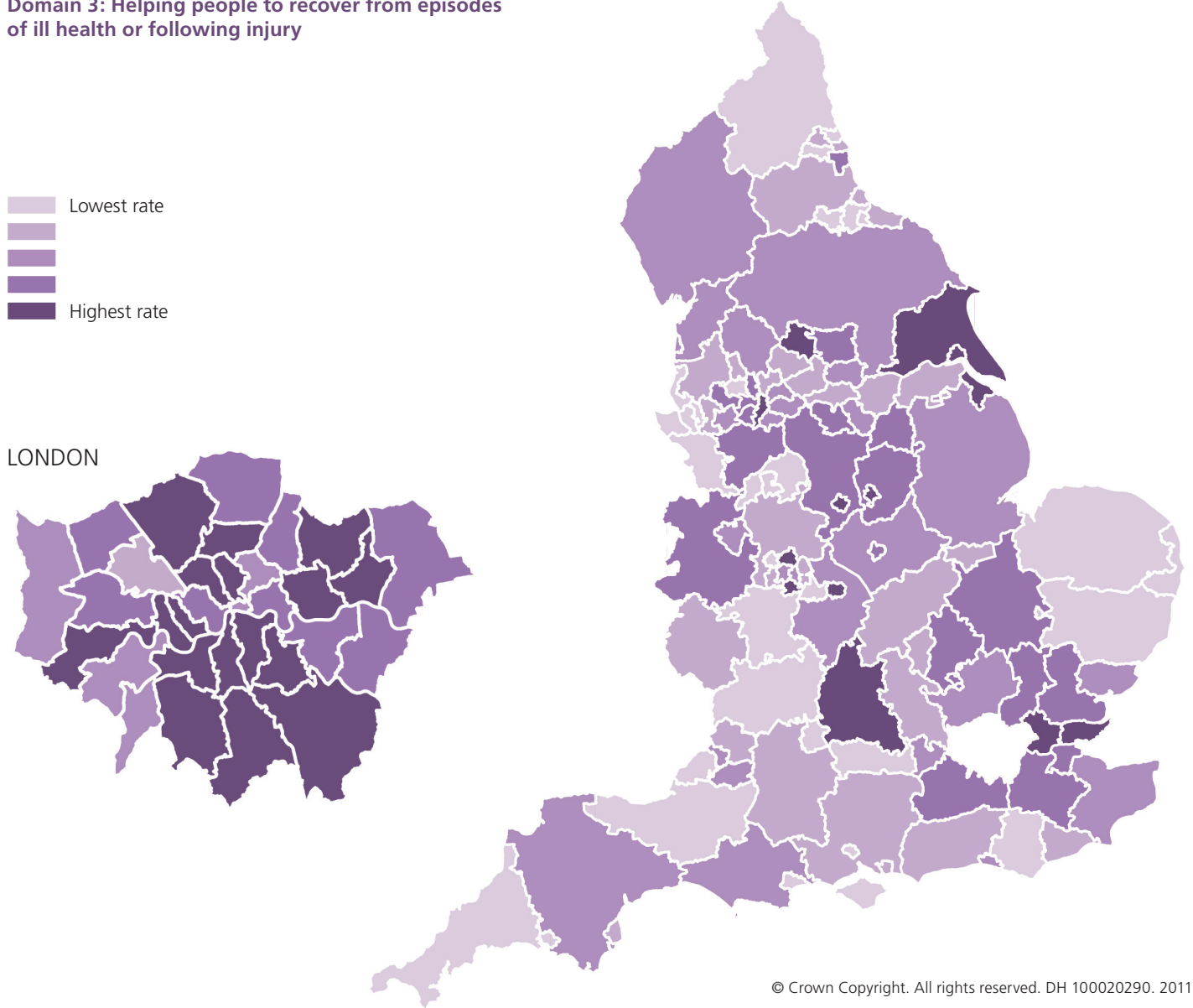
5 Semple MG, Taylor-Robinson DC, Lane S, Smyth RL (2011) Household Tobacco Smoke and Admission Weight Predict Severe Bronchiolitis in Infants Independent of Deprivation: Prospective Cohort Study. *PLoS ONE* 2011; 6(7): e22425. doi:10.1371/journal.pone.0022425

PROBLEMS OF THE RESPIRATORY SYSTEM

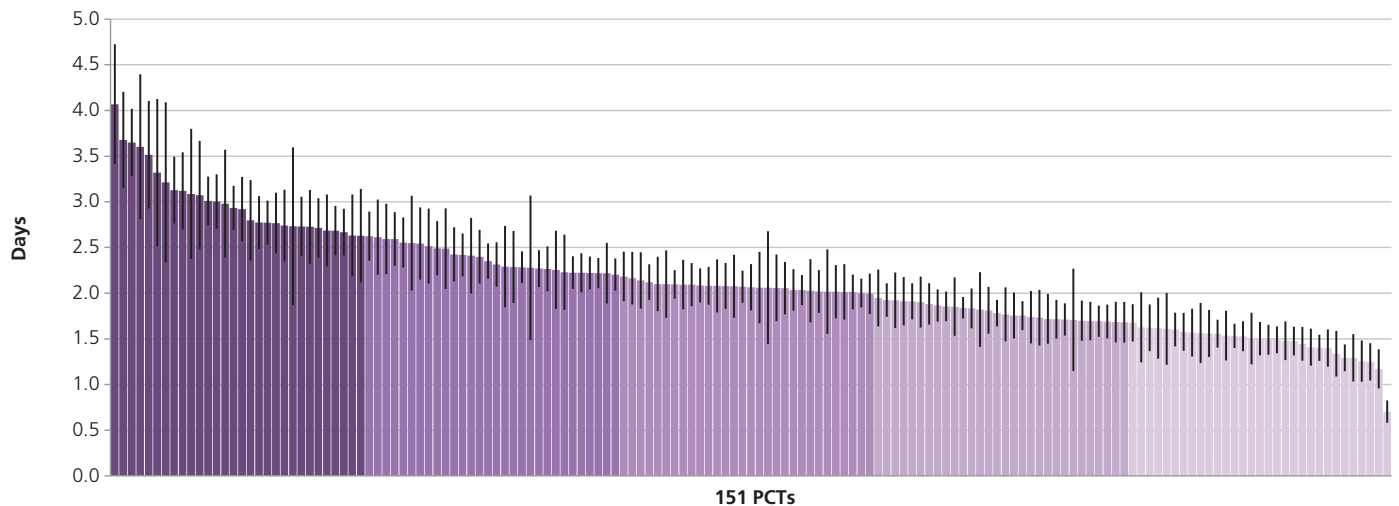
# Map 21: Mean length of stay (days) for bronchiolitis in children aged under 2 years by PCT

2007/08–2009/10

Domain 3: Helping people to recover from episodes of ill health or following injury



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## Context

Bronchiolitis is the most common cause of hospital admission of infants during winter in industrialised countries.<sup>1,2</sup>

Duration of admission is partly a function of the severity of illness; it could also be related to differences in:

- clinical management;
- thresholds for discharge from hospital;
- quality of primary, community and social care support available to families during the infant's recovery period.

Prolonged hospital admission of young children disrupts family life, and affects the well-being of the child and their family, including the financial impact of time off work. The seasonal epidemic nature of bronchiolitis admissions means that unnecessarily prolonged inpatient stays increase demand on resources at a time of year when hospital services already experience high levels of demand.

## Magnitude of variation

For PCTs in England, the mean length of stay for bronchiolitis in children aged under 2 years ranged from 0.7 to 4.1 days (6-fold variation). When the five PCTs with the highest mean lengths of stay and the five PCTs with the lowest mean lengths of stay are excluded, the range is 1.3–3.3 days, and the variation is 2.6-fold.

There does not appear to be a simple relationship between socio-economic deprivation and mean length of stay (see Figure 21.1, <http://www.rightcare.nhs.uk/atlas/>), an observation supported by findings in the published literature with respect to socio-economic deprivation, severity of illness and duration of admission.<sup>3,4</sup> The degree of variation observed cannot be attributed predominantly to variation in socio-economic deprivation. Differences in local practice are likely to account for a considerable proportion of the variation in the lengths of inpatient stay.

Therapies for bronchiolitis are mainly supportive, involving:

- nasogastric tube feeding;
- supplemental oxygen;
- in severe cases, mechanical ventilator support.

There may be differences in local guidelines, particularly the criteria for starting and stopping supplemental oxygen, as well as variation in the clinical criteria for discharge of children with bronchiolitis.<sup>5</sup>

Differences in discharge criteria could also reflect:

- discharge processes for all children in the local department, hospital or provider unit;
- level of support available in the local community.

A family's capacity to care for a recovering infant at home may influence a clinician's decision whether to discharge a child with bronchiolitis. The level of support available locally from the extended family, and community health and social services may account for some of the variation observed.

## Options for action

All departments that admit children with bronchiolitis need:

- To use evidence-based guidelines for inpatient management;
- To have clear thresholds of discharge for children with bronchiolitis, based on existing evidence-based guidelines (e.g. Scottish Intercollegiate Guidelines Network – see "Resources"), that are regularly reviewed to take account of up-to-date evidence on effective treatments to reduce length of stay (e.g. nebulised hypertonic 3% saline<sup>6</sup>).

To identify factors responsible for variations in the duration of admission for bronchiolitis in the local population, commissioners and providers need to investigate differences in:

- clinical management of bronchiolitis;
- wider hospital processes and patient flows.

Introduction of a clinical care pathway has been shown to reduce variation in treatment of bronchiolitis, and significantly reduce duration of admission.<sup>7</sup>

Commissioners need to ensure that vulnerable children and families have access to adequate community-based support regarding recovery after discharge.

## RESOURCES

- Scottish Intercollegiate Guidelines Network (SIGN) (2006) Bronchiolitis in children. A national clinical guideline. <http://www.sign.ac.uk/pdf/sign91.pdf>

- 1 Leader S, Kohlhase K (2002) Respiratory syncytial virus-coded pediatric hospitalizations, 1997 to 1999. *Pediatric Infectious Disease Journal* 21: 629–632.
- 2 Deshpande SA, Northern V (2003) The clinical and health economic burden of respiratory syncytial virus disease among children under 2 years of age in a defined geographical area. *Archives of Disease in Childhood* 88:1065-1069.
- 3 De Debrasi D, Pannuti F, Antonelli F et al. (2010) Therapeutic approach to bronchiolitis: why pediatricians continue to overprescribe drugs. *Italian Journal of Pediatrics* 36: 67.
- 4 Semple MG, Taylor-Robinson DC, Lane S, Smyth RL (2011) Household tobacco smoke and admission weight predict severe bronchiolitis independent of deprivation: prospective cohort study. *PLoS ONE* 2011; 6(7): e22425. doi:10.1371/journal.pone.0022425
- 5 Cunningham S, McMurray A (2011) Observational study of two oxygen saturation targets for discharge in bronchiolitis. *Archives of Disease in Childhood*. doi:10.1136/adc.2010.205211
- 6 Zhang, L., Mendoza-Sassi RA, Wainwright C et al. (2008) Nebulized hypertonic saline solution for acute bronchiolitis in infants. *Cochrane Database of Systematic Reviews*, 2008 (Issue 4).
- 7 Walker C, Danby S, Turner S (2011) Impact of a bronchiolitis clinical care pathway on treatment and hospital stay. *European Journal of Paediatrics* doi: 10.1007/s00431-011-1653-9

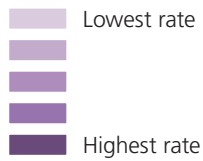


PROBLEMS OF THE RESPIRATORY SYSTEM

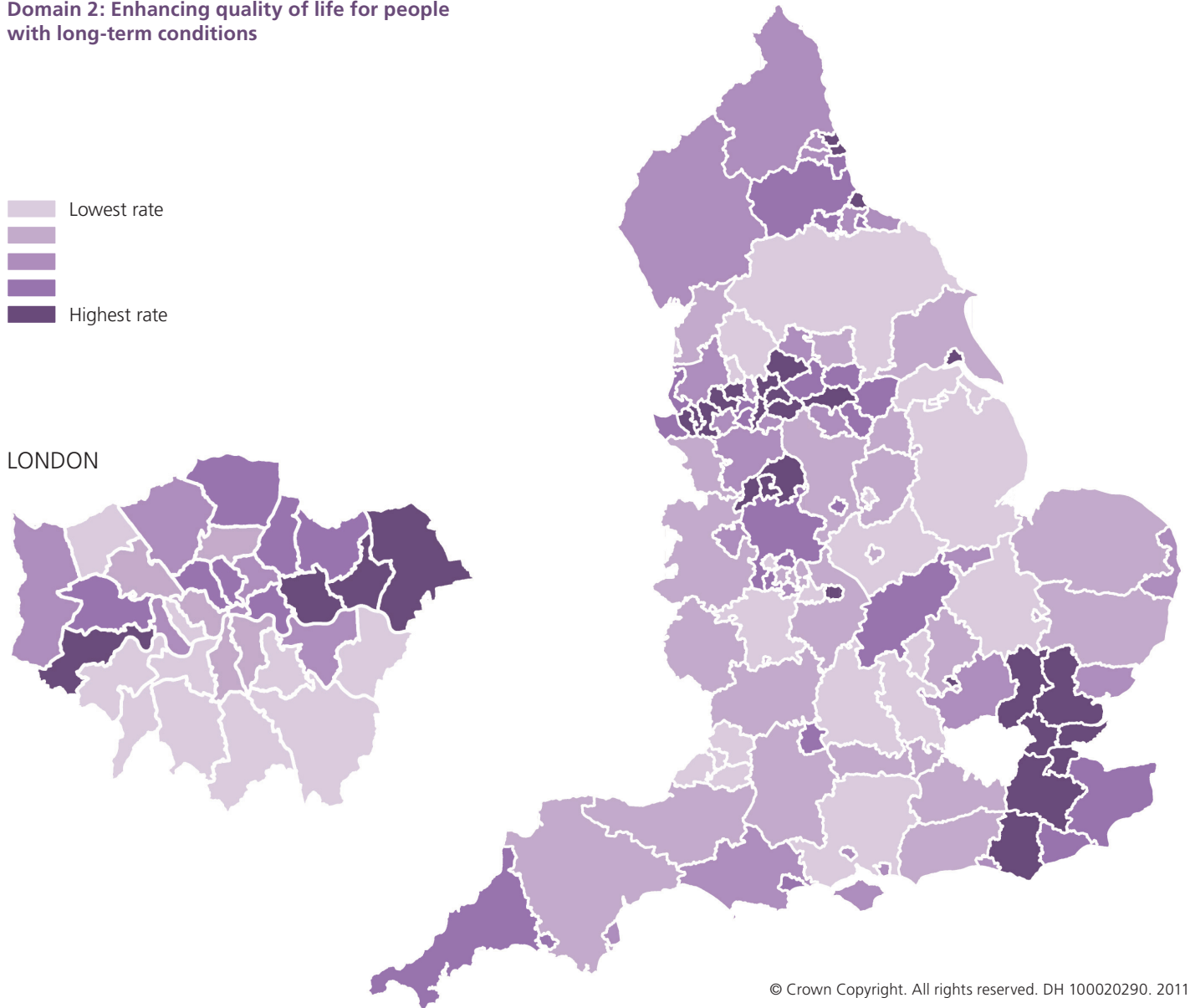
# Map 22: Rate of elective tonsillectomy in children per population aged 0–17 years by PCT

Directly standardised rate 2007/08–2009/10

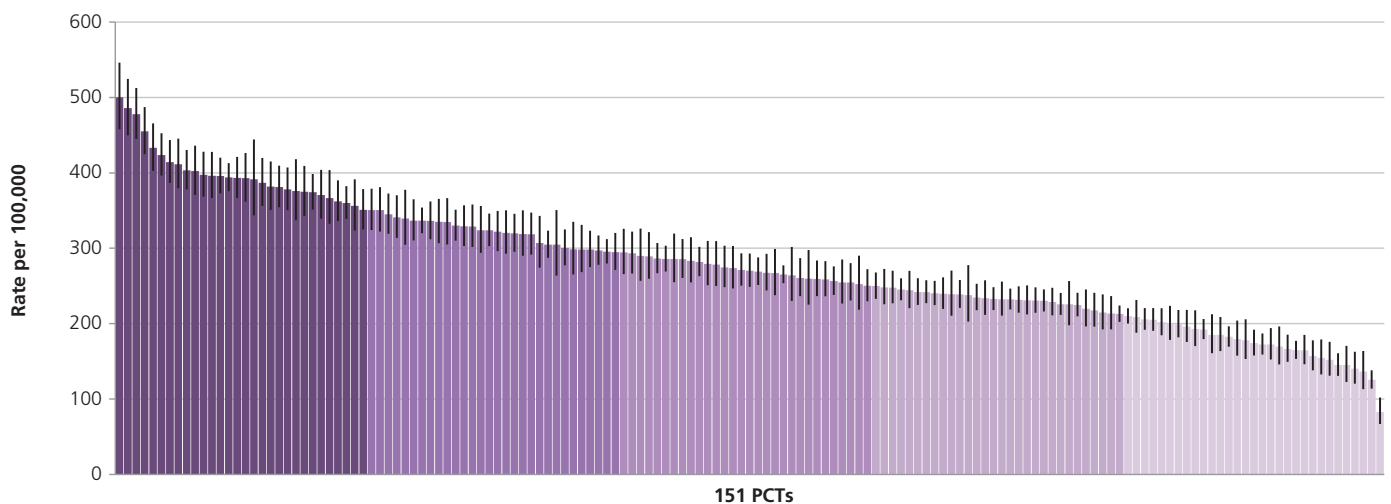
Domain 2: Enhancing quality of life for people with long-term conditions



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## Context

The commonest indications for childhood tonsillectomy are recurrent tonsillitis and sleep-related breathing disorders (SRBD), including obstructive sleep apnoea (OSA).

The Scottish Intercollegiate Guidelines Network (SIGN) have published evidence-based indications for tonsillectomy for the treatment of recurrent tonsillitis (see "Resources"). Over-use of tonsillectomy places increased demand on limited resources, and can lead to unnecessary complications for those children in whom active monitoring might be a more appropriate strategy. However, failure to intervene for children who fulfill the treatment criteria may be just as harmful, affecting the quality of life of the child and their family, as well as incurring increased costs from repeat attendances, antibiotic prescriptions, and hospital admissions, as well as a loss of parental income.

Treatment for SRBD accounts for about 25% of tonsillectomies (combined with adenoidectomy) for children in England. SRBD and OSA form a spectrum of conditions in which upper airway obstruction during sleep produces poor sleep quality, daytime fatigue, poor school performance and, in severe cases, serious disorders of cardiopulmonary function. However, there is currently a lack of robust evidence to inform the appropriate threshold for surgical intervention.

## Magnitude of variation

For PCTs in England, the rate of elective tonsillectomy in children per 100,000 population aged 0–17 years ranged from 83.1 to 500.4 (6-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 145.1–423.7 per 100,000 population aged 0–17 years, and the variation is 2.9-fold.

In contrast to the historical view that childhood tonsillectomy is an operation undertaken on "middle-class" children, some of the most deprived areas have the highest rates.

It is not possible to say with any certainty what the "optimal rate" for tonsillectomy in children might be. The historical overuse of tonsillectomy in children has

had a high profile, however, there is a danger that this trend has been reversed in some areas to the extent that children who may benefit from the procedure are now unable to obtain access to it. The SIGN guidance is clear: there are clinically proven benefits for selected children, and, barring exceptional individual cases, it would be equally inappropriate to withhold treatment as it is to provide it unnecessarily.

There is an urgent need to define evidence-based clinical and functional thresholds for surgical intervention in OSA based on high-quality research.

## Options for action

Commissioners need to investigate what proportion of the activity in local rates of tonsillectomy is attributable to recurrent tonsillitis and OSA in order to identify whether there is inappropriate over- or under-activity for each of the indications, and thereby enable interventions to be targeted accordingly.

Commissioners and clinicians need to apply the SIGN guidance on tonsillectomy for recurrent tonsillitis in service planning, ensuring equity of access for clinically justified interventions, while reducing unnecessary interventions that divert resources from children who fulfill clinical criteria.

Although no national guidance on indications for tonsillectomy for the treatment of SRBD currently exists, commissioners and clinicians need to agree local criteria to fund tonsillectomy for SRBD symptoms, which should be:

- ▶ based on best available evidence;
- ▶ outcome- as well as process-based;
- ▶ benchmarked against the agreements made with other local commissioners to ensure equity of access and high-quality outcomes.

See also *Atlas 2.0*, page 59, Figure TT.8 for time trend from 2001/02 to 2009/10.

## RESOURCES

- ▶ Scottish Intercollegiate Guidelines Network (SIGN) (2010) Management of sore throat and indications for tonsillectomy. A national clinical guideline. <http://www.sign.ac.uk/guidelines/fulltext/117/index.html>

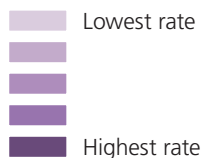


PROBLEMS OF THE GASTRO-INTESTINAL SYSTEM

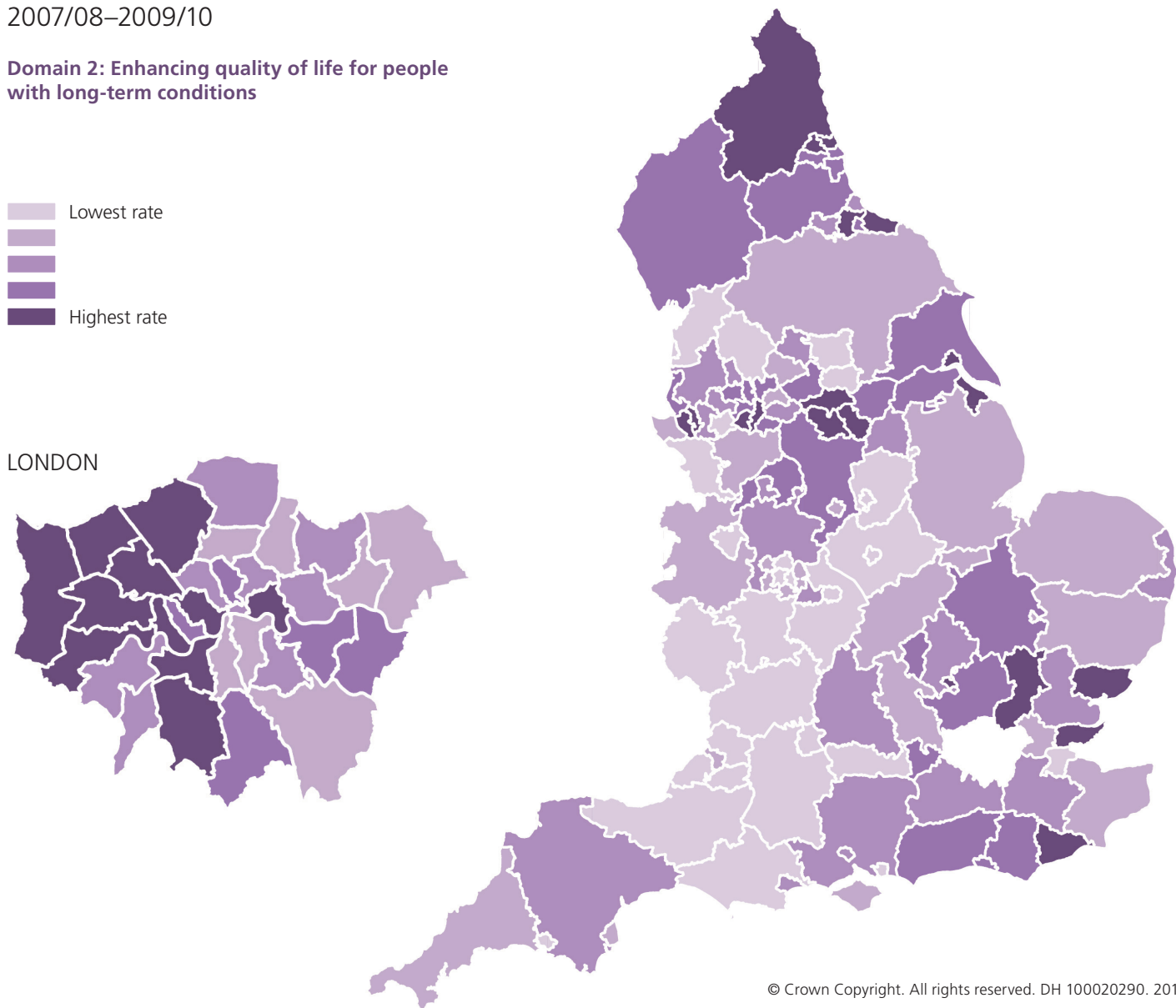
# Map 23: Admission rate for children for upper and/or lower gastro-intestinal endoscopy per population aged 0–17 years by PCT

2007/08–2009/10

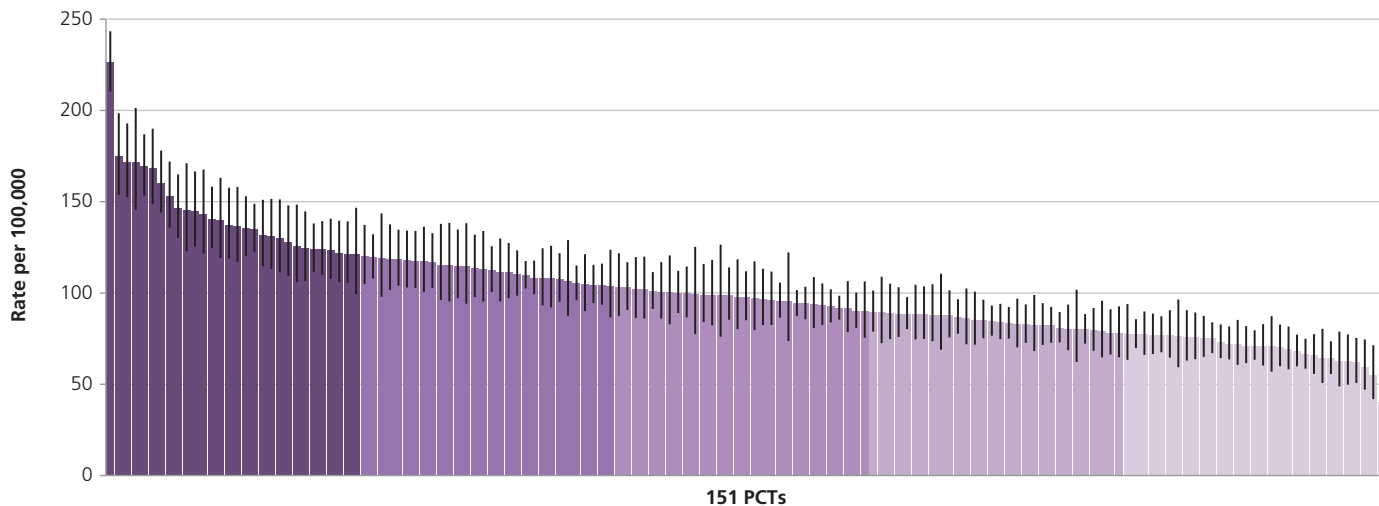
Domain 2: Enhancing quality of life for people with long-term conditions



LONDON



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## Context

Diagnostic gastro-intestinal (GI) endoscopy enables the GI tract to be visualised directly, and for biopsies to be carried out to aid diagnosis. Endoscopy is undertaken in children to diagnose or exclude serious GI disease, such as inflammatory bowel disease, coeliac disease, enteropathy and reflux oesophagitis.

The symptoms that most commonly result in referral for diagnostic GI endoscopy are abdominal pain, failure to thrive, recurrent vomiting and diarrhoea and/or blood per rectum. Where medical investigations (including GI endoscopy) fail to find an organic cause for these symptoms, a diagnosis of functional GI disorder (GI symptoms without structural or physical abnormalities) is considered.

Most research suggests that functional GI disorders are still the commonest outcome following a diagnostic GI endoscopy, i.e. no physical abnormality is found, which suggests that the existing selection criteria for GI endoscopy are not appropriate. The large number of children who undergo the procedure without receiving a diagnosis may affect the well-being of children and their families. It also has resource implications.

However, the value of diagnostic GI endoscopy to exclude serious underlying illness is vital. Unwarranted delay or poor availability of paediatric endoscopy may compromise the diagnostic work-up and care of children with chronic GI symptoms.

## Magnitude of variation

For PCTs in England, the admission rate for children for upper and/or lower GI endoscopy per 100,000 population aged 0–17 years ranged from 39.9 to 226.3 (6-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 62.5–168.4 per 100,000 population aged 0–17 years, and the variation is 2.7-fold.

It is unlikely that this degree of variation can be explained by differences in the number of children with symptoms or the incidence of serious organic GI disease. The most likely reasons for this variation are:

- differences in selection criteria and threshold for diagnostic GI endoscopy;
- poor access to endoscopy in some areas of the country.

Unexpectedly low rates of GI endoscopy may reflect inadequate provision or poor access, leading to delayed or missed diagnosis in the local population of children.

Over the past decade, the rates of diagnostic GI endoscopy have greatly increased in the UK, as in most developed countries, resulting in earlier and more accurate diagnosis of severe GI disease. However, to maximise yield and reduce unnecessary risks to patients, evidence-based guidance is needed on the selection of children who are most likely to benefit from undergoing diagnostic GI endoscopy.

## Options for action

At present, there is no national guidance.

Commissioners and clinicians could collaborate to agree local criteria for diagnostic GI endoscopies in children based on best available evidence. Criteria need to be outcome- as well as process-based, and should be benchmarked against the agreements made in other local areas to ensure equity of access and high-quality outcomes.

A networked system of delivering paediatric endoscopy will have considerable impact on rationalising the criteria for endoscopy:

- ensuring that levels of activity relate to local population needs;
- enabling the comparison of outcomes;
- providing support for quality assurance.

## RESOURCES

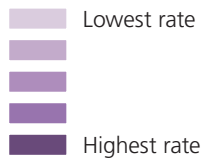
- British Society for Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN). Report of the BSPGHAN Working Group to Develop Criteria for DGH Gastroenterology, Hepatology and Nutrition Services. [http://www.bspghan.org.uk/document/DGH\\_SERVICES\\_BSPGHAN.DOC](http://www.bspghan.org.uk/document/DGH_SERVICES_BSPGHAN.DOC)
- British Society for Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN). Guide for Purchasers of PGHN Services. <http://www.bspghan.org.uk/information/guides.shtml>
- Royal College of Paediatrics and Child Health (2004) Commissioning Tertiary and Specialised Services for Children and Young People. [http://www.rcpch.ac.uk/sites/default/files/asset\\_library/Publications/C/Tert.pdf](http://www.rcpch.ac.uk/sites/default/files/asset_library/Publications/C/Tert.pdf)

**PROBLEMS OF THE GASTRO-INTESTINAL SYSTEM**

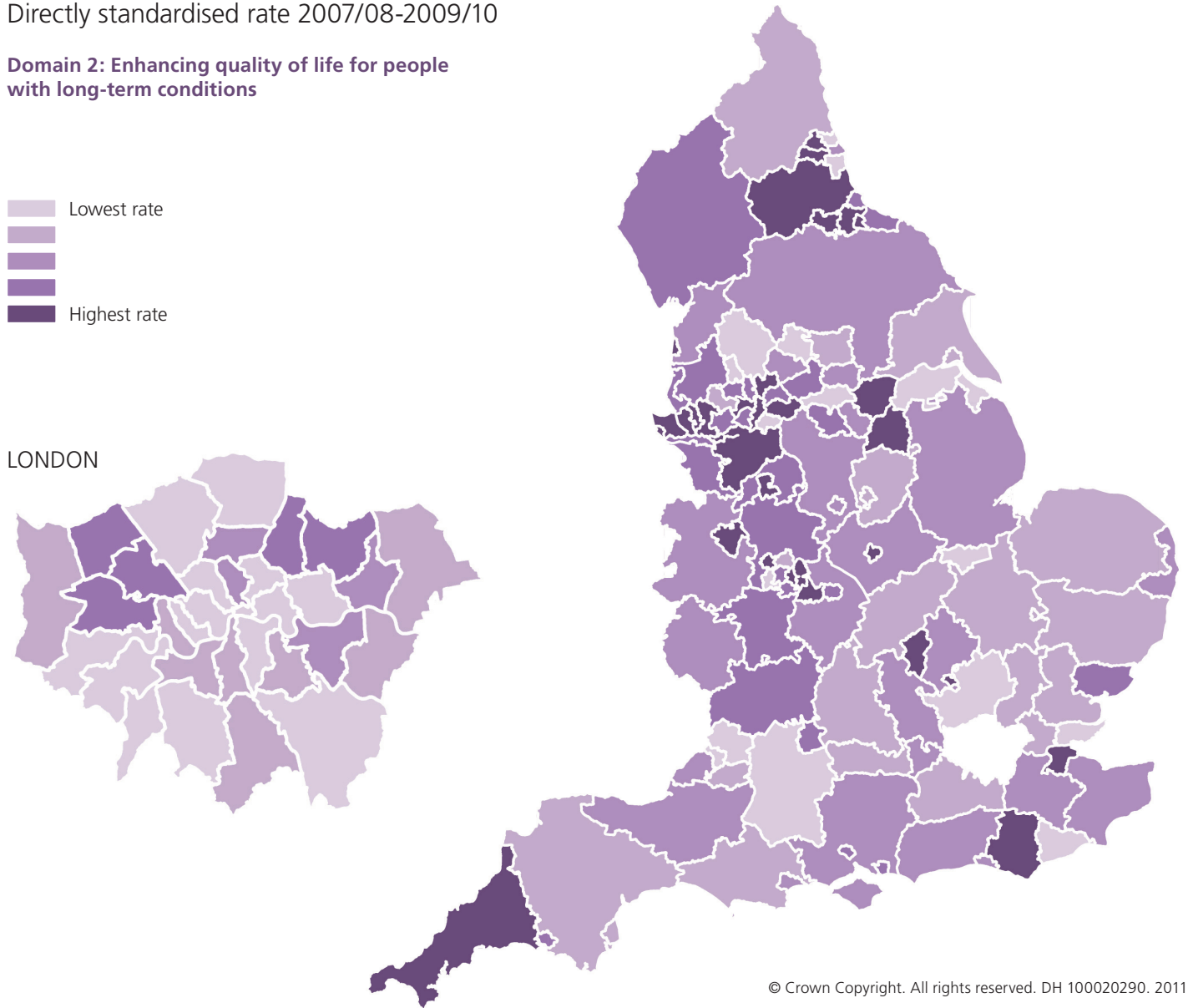
# Map 24: Emergency admission rate for inflammatory bowel disease (IBD) in children per population aged 0–17 years by PCT

Directly standardised rate 2007/08-2009/10

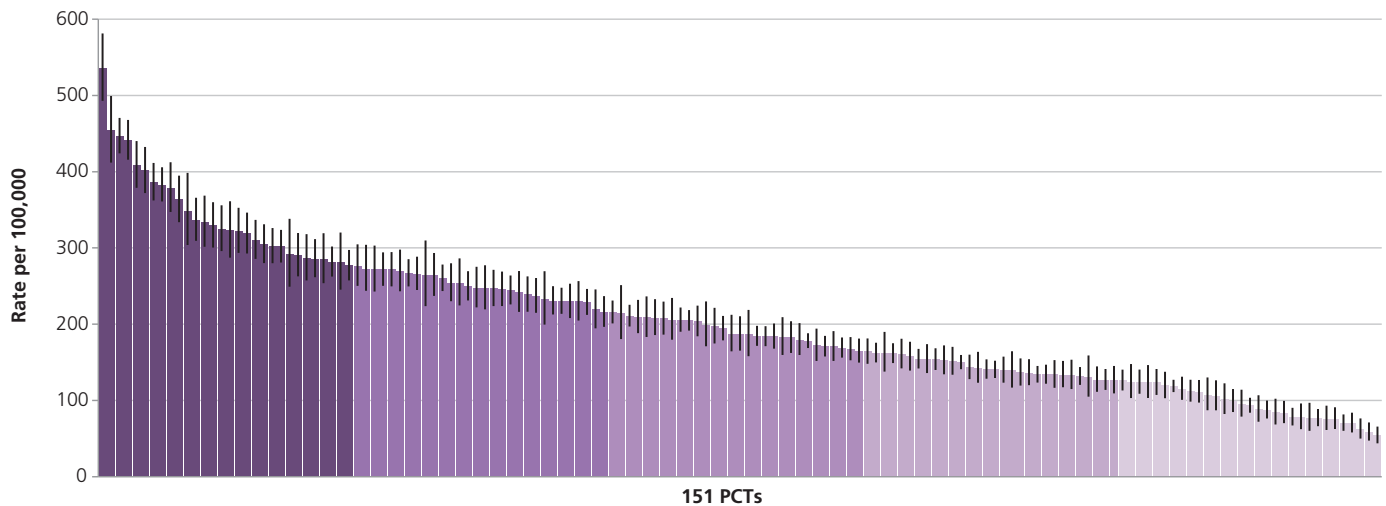
Domain 2: Enhancing quality of life for people with long-term conditions



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## Context

Inflammatory bowel disease (IBD) is a collective term that encompasses Crohn's disease and ulcerative colitis, two major chronic disorders in which there is inflammation of parts of the gastro-intestinal tract. There are about 250,000 people with IBD in the UK. IBD predominantly affects young people, with peak incidence between 10 and 40 years of age. One-quarter of all people with IBD present to health services for the first time below the age of 18 years.

Apart from gastro-intestinal symptoms, such as abdominal pain and diarrhoea, IBD is associated with other symptoms such as weight loss, lethargy, growth and pubertal failure, failure to thrive and joint problems. After treating the active inflammation in the initial phase, the goal of ongoing IBD care is to maintain remission and minimise exacerbations. This is important not only to prevent the physical effects the exacerbations cause, but also to minimise the impact on the child's growth, puberty and development.

Approximately half of all NHS expenditure on patients with IBD is for inpatient management.

Frequency of exacerbations, particularly when they lead to episodes of unplanned admission to hospital, is one indicator of the quality of the ongoing management of children with IBD. Reducing unplanned admissions for IBD can reduce expenditure and improve outcomes for patients.

## Magnitude of variation

For PCTs in England, the emergency admission rate for IBD in children per 100,000 population aged 0–17 years ranged from 53.9 to 535.7 (10-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 75.8–401.3 per 100,000 population aged 0–17 years, and the variation is fivefold.

One reason for warranted variation is the incidence of disease. Although children of Asian descent are at slightly higher risk of developing ulcerative colitis, this cannot account for the degree of variation observed.

Reasons for unwarranted variation could be factors in:

- › the chronic management of children with IBD;
- › the recognition and early treatment of exacerbations.

## Options for action

Network-based systems of care will enable improved:

- › benchmarking of services;
- › data collection and comparison;
- › education for local providers and primary care.

Community-based IBD services can be cost-effective if they facilitate early recognition and treatment of exacerbations that would otherwise result in admission to hospital.

Commissioners need to work with providers to ensure that:

- › a personal treatment plan is in place for all children and young people with IBD;
- › there is adequate support for children and their families in self-management and early recognition of exacerbations.

Commissioners can use the Service Standards developed by the IBD Standards Group (see "Resources") as guidance when assuring the quality of the service they are commissioning.

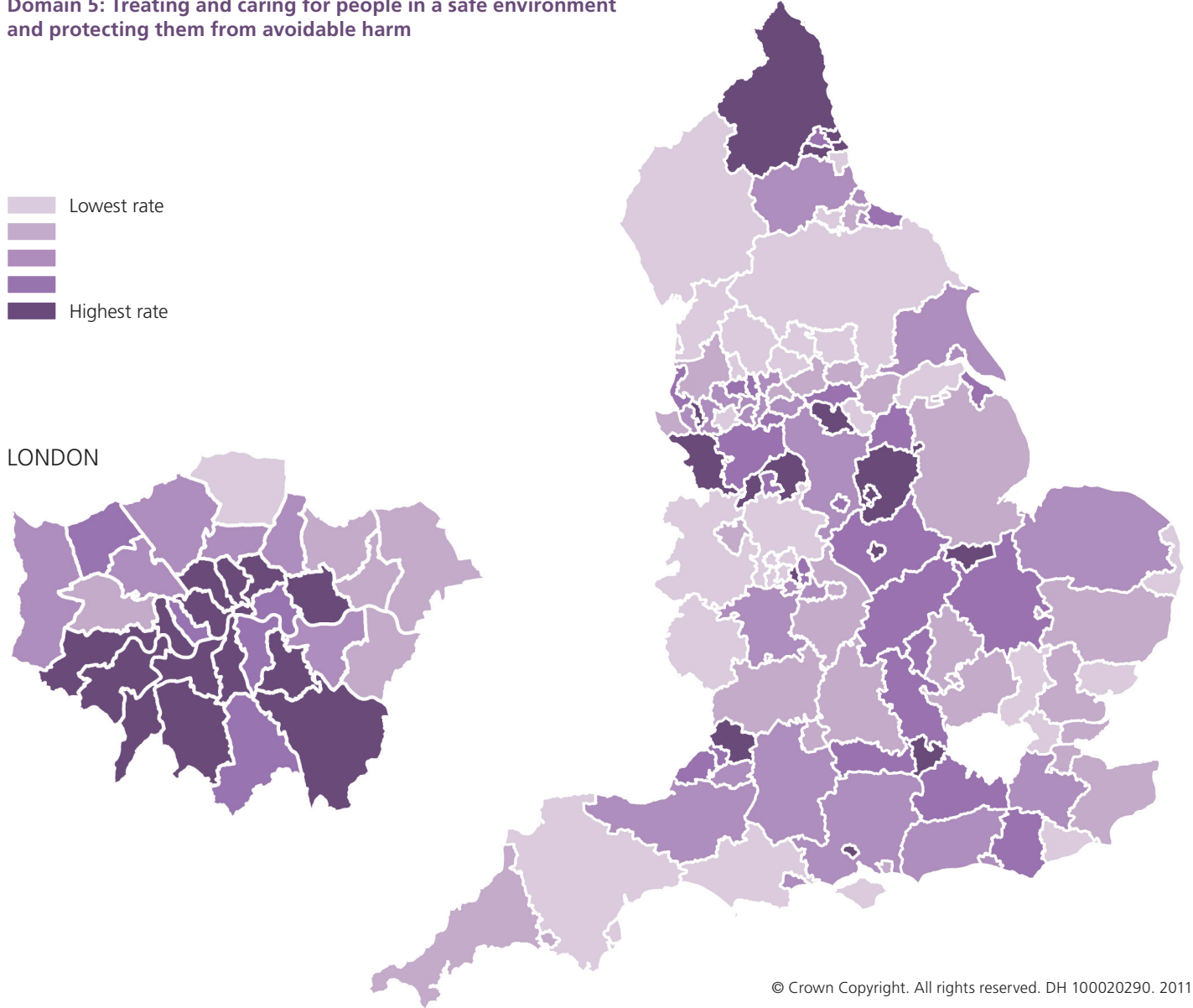
## RESOURCES

- › UK IBD Working Group on behalf of the British Society for Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN) (2008) Guidelines for the Management of Inflammatory Bowel Disease (IBD) in Children in the United Kingdom. [http://bspghan.org.uk/working\\_groups/documents/IBDGuidelines\\_000.pdf](http://bspghan.org.uk/working_groups/documents/IBDGuidelines_000.pdf)
- › The IBD Standards Group (2009) Quality Care: Service Standards for the healthcare of people who have Inflammatory Bowel Disease (IBD). [http://www.ibdstandards.org.uk/uploaded\\_files/IBDstandards.pdf](http://www.ibdstandards.org.uk/uploaded_files/IBDstandards.pdf)
- › Inflammatory Bowel Disease Quality Improvement Programme (IBDQIP): a pilot programme run by the Royal College of Physicians, and funded by the Health Foundation, which allows local IBD services to benchmark their performance and share best practice. The pilot is currently being evaluated. <http://www.ibdqip.co.uk/>

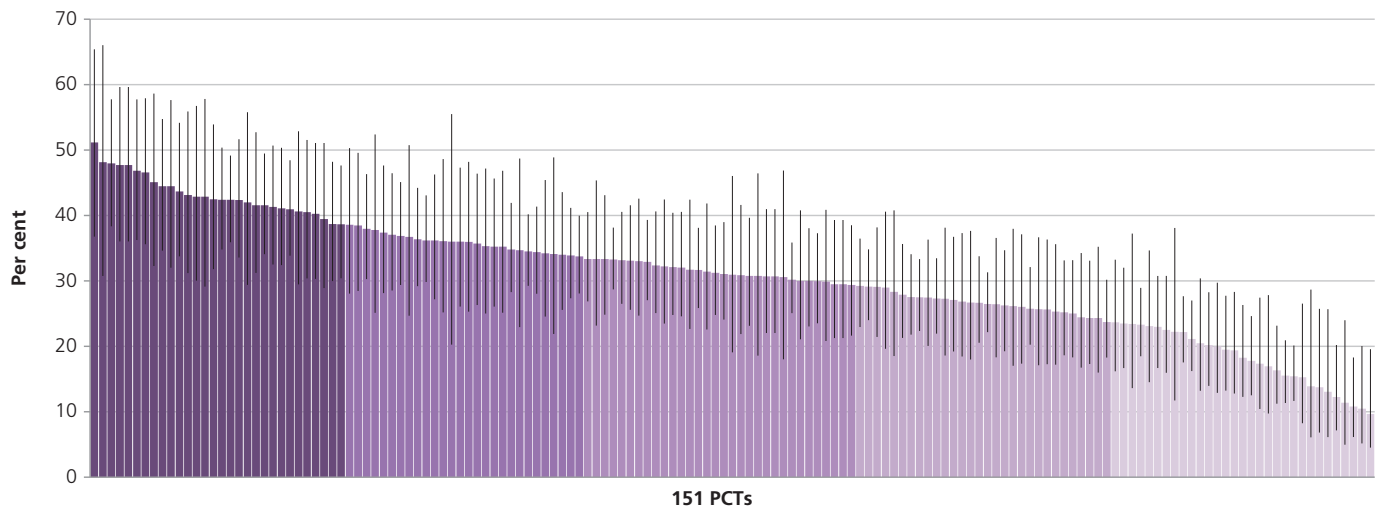
**PROBLEMS OF THE GENITO-URINARY SYSTEM**

**Map 25:** Proportion (%) of all elective orchidopexy procedures performed before the age of 2 years by PCT  
2007/08–2009/10

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



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## Context

Undescended testis is one of four major conditions screened for during the NHS Newborn and Infant Physical Examination (NIPE) Programme (see “Resources”). Boys with undescended testes are at:

- risk of undiagnosed testicular torsion, which may result in the loss of the testis;
- increased risk of testicular cancer;
- possible risk of loss of fertility.

More than 3% of boys have an undescended testis at birth, which resolves during the first year of life in about three-quarters of those affected.<sup>1</sup> If the condition persists beyond 12 months of age, children should be referred for orchidopexy.

During orchidopexy, an undescended testis, and associated structures, is freed and brought down to the correct position in the scrotum. The commonest reason for elective orchidopexy is an undescended testis.

To reduce the risk of torsion and lifelong risk of malignancy, evidence-based guidelines recommend that treatment for undescended testes be completed before 18 months of age.<sup>2</sup> In a retrospective study of all children undergoing orchidopexy in the UK from 1997 to 2005, only 1 in 5 children underwent operation by the recommended age limit of 18 months.<sup>3</sup>

Although intervention is recommended by 18 months, the nature of the data means that an integer value of under 2 years of age has been used for this indicator.

## Magnitude of variation

For PCTs in England, the proportion of all elective orchidopexy procedures performed before the age of 2 years ranged from 9.7% to 51.2% (5-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 13.0–46.8%, and the variation is 3.6-fold.

Poor compliance with evidence-based guidance may be due to several factors, including:

- Delayed recognition and diagnosis of undescended testes;
- Delayed referral for surgical intervention;
- Insufficient capacity in surgical services to meet demand, leading to delays between referral and surgery;
- Failure to coordinate the screening pathway through to successful treatment.

1 Berkowitz GS, Lapinski RH, Dolgin SE, et al. (1993) Prevalence and natural history of cryptorchidism. *Pediatrics* 92: 44-9

2 Tekgül S, Riedmiller H, Gerharz E, Hoebcke P, Kocvara R, Nijman R, Radmayr Chr, Stein R (2011) *Guidelines on Paediatric Urology*. European Association of Urology, and European Society for Paediatric Urology. [http://www.uroweb.org/gls/pdf/19\\_Paediatric\\_Urology.pdf](http://www.uroweb.org/gls/pdf/19_Paediatric_Urology.pdf)

3 McCabe JE, Kenny SE (2008) Orchidopexy for undescended testis in England: is it evidence based? *Journal of Pediatric Surgery* 43: 353-357.

4 Children's Surgical Forum (2010) *Ensuring the Provision of General Paediatric Surgery in the District General Hospital: Guidance to commissioners and service planners*. Royal College of Surgeons of England <http://www.rcseng.ac.uk/publications/docs/general-paediatric-surgery-guidance/?searchterm=Ensuring%20the%20provision%20of%20general%20paediatric%20surgery>

5 Brown JJ, Wacogne I, Fleckney S et al. (2004) Achieving early surgery for undescended testes: quality improvement through a multi-faceted approach to guideline implementation. *Child: care, health and development* 30: 97-102.

6 Royal College of Paediatrics and Child Health (2011) RCPCH Medical Workforce Census 2009. <http://www.rcpch.ac.uk/sites/default/files/RCPCH%20Workforce%20Census%202009.pdf>

## Options for action

Managed clinical networks for general paediatric surgery can help to improve the quality and safety of surgical services for children by facilitating:

- integrated care pathways;
- better staff training and education;
- benchmarking and meaningful audit to drive service improvements.<sup>4</sup>

The pathway from screening for undescended testis to orchidopexy is complex, involving repeated episodes of care with many different practitioners over many months at a time when parents are often still adapting to life with a young child. It requires a coordinated approach, and excellent communication between health professionals. Improved communication and referral processes, involving GPs, families and hospital teams, can facilitate and enhance the patient pathway.<sup>5</sup>

Commissioners need to take a systems approach to tackling unwarranted variation in elective orchidopexy as part of the Healthy Child Programme (HCP). In the most recent RCPCH Census in 2009, only 38 of 180 (21%) community child health service providers had an HCP Coordinator in post, as recommended.<sup>6</sup> Routine reporting of age at orchidopexy (obtainable from HES data) would be a useful quality measure for the screening programme. Commissioners need to identify variation in local practice using this indicator, and target interventions to optimise the patient pathway and improve education and training for staff and families.

## RESOURCES

- NHS Newborn and Infant Physical Examination (NIPE) Programme: guidance on the clinical aspects of the physical screening programme, and resources on standards and local quality assurance processes. <http://newbornphysical.screening.nhs.uk/>
- Children's Surgical Forum (2010) *Ensuring the Provision of General Paediatric Surgery in the District General Hospital: Guidance to commissioners and service planners*. Royal College of Surgeons of England. <http://www.rcseng.ac.uk/publications/docs/general-paediatric-surgery-guidance/?searchterm=Ensuring%20the%20provision%20of%20general%20paediatric%20surgery>

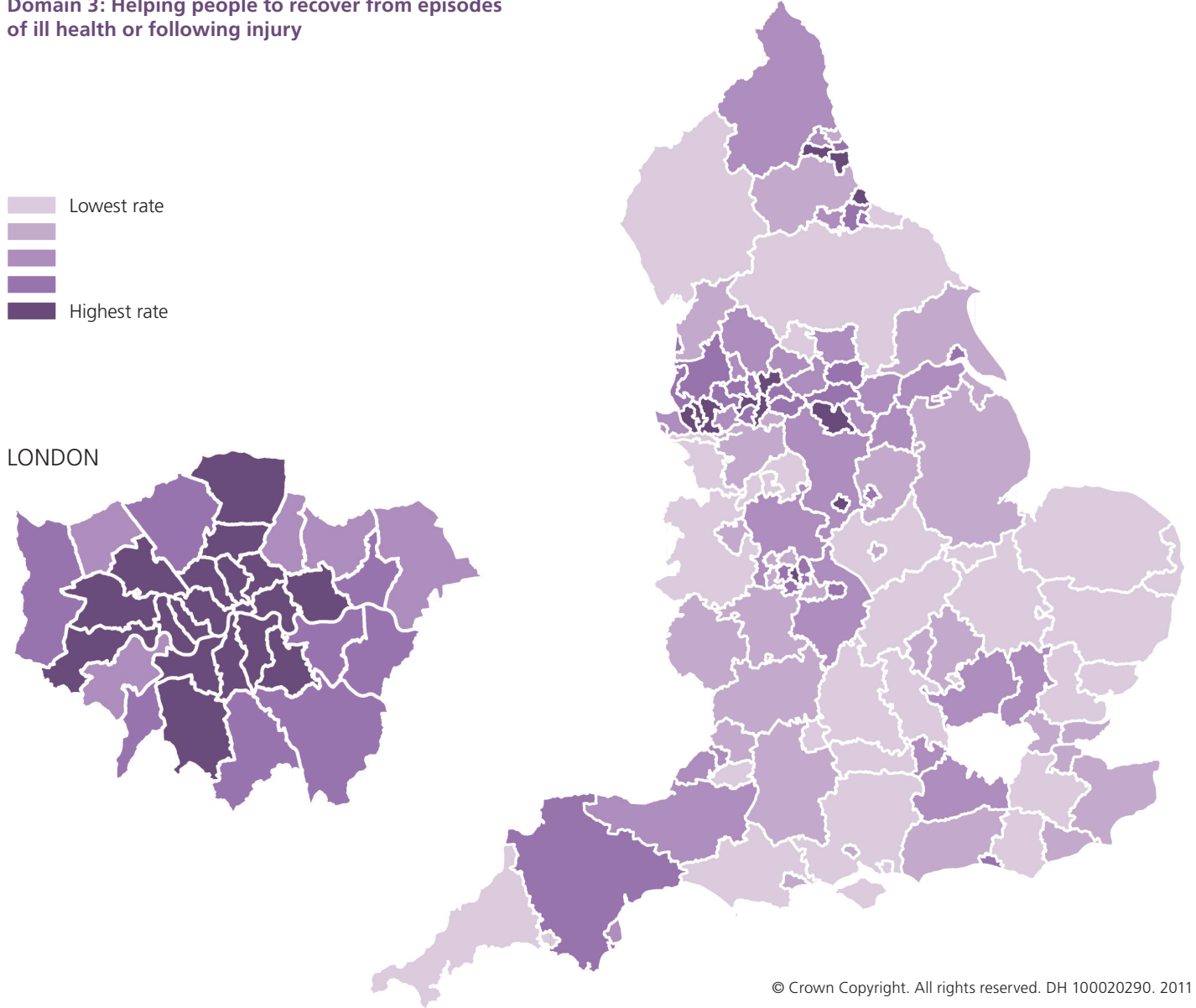


### EMERGENCY CARE

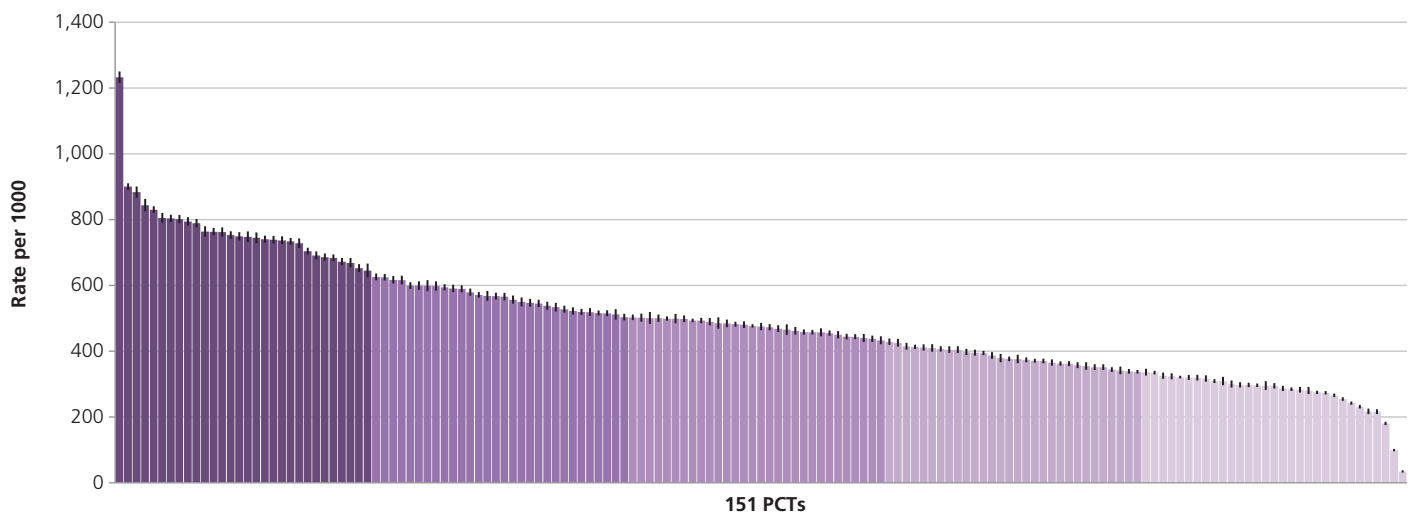
## Map 26: Rate of accident and emergency (A&E) attendances per population aged under 5 years by PCT

Directly standardised rate 2009/10

Domain 3: Helping people to recover from episodes of ill health or following injury



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## Context

In 2010, there were 20.6 million attendances to accident and emergency (A&E) departments in England.<sup>1</sup> In 2009/10, more than one-quarter (27.6%) of attendances were made by children and young people (0–19 years).<sup>2</sup>

Emergency department attendance for accidental injury occurs most commonly in the 0–4-year age-group. According to a recent large study, the same age-group accounts for nearly 70% of self-referrals to A&E for medical problems, such as respiratory problems or feverish illnesses.<sup>3</sup> Reducing the variation in A&E attendance for the 0–4-year age-group is likely to realise considerable financial savings, and relieve pressure on over-stretched A&E services.

## Magnitude of variation

For PCTs in England, the rate of A&E attendances per 1000 population aged under 5 years ranged from 34.3 to 1232.6 (36-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 231.1–805.4 per 1000 population aged under 5 years, and the variation is 3.5-fold.

There is a correlation between deprivation and higher A&E attendance rates.<sup>4,5</sup> However, deprivation cannot be the sole reason for the degree of variation observed: among the 10 most-deprived PCTs, there is about 1.8-fold variation in A&E attendance rates, and among the 10 least-deprived PCTs, the variation is sixfold (see Figure 26.1, page 74).

Although public health measures such as accident prevention and family education on the appropriate use of health services are important, differences in the provision of local primary and community care, and in particular out-of-hours urgent care, are likely to account for much of the variation in the demand for emergency care in young children.

## Options for action

Commissioners need to study local demand for emergency services in order to commission services that reflect local needs. Studying local variation in presentation to emergency departments can help to identify the causes of unwarranted variation, and ensure that the appropriate balance of community- and hospital-based services is provided.

Although injury and accident prevention is a public

health issue, local health services are responsible for supporting education on injury prevention.

Commissioners need to assure the quality of local primary and community-based care to ensure children have the appropriate level of access in relation to their healthcare needs.

Primary care professionals and hospital paediatricians need to agree on standards and guidelines for the recognition and management of common conditions, for instance, ensuring that NICE guidance on the recognition and management of a young feverish child (see “Resources”) is widely disseminated and followed.

## RESOURCES

- NICE Guidance (2007) Feverish illness in children – Assessment and initial management in children younger than 5 years. Clinical guidelines, CG47. <http://www.nice.org.uk/CG047>
- Child Accident Prevention Trust (CAPT): resources for professionals and guidance for NHS and other organisations. <http://www.capt.org.uk/resources>
- CAPT “Making the Link”: website designed for senior practitioners and policy-makers with case-studies of local injury prevention strategies and tools for child accident prevention. <http://www.makingthelink.net>
- Latest policy updates and publications relating to paediatric urgent and emergency care. <http://www.rcpch.ac.uk/child-health/standards-care/service-configuration/emergency-and-urgent-care/emergency-and-urgent-car>
- *Right Care, Right Place, Right Time?* Intercollegiate document setting clear standards and guidance for service planning and commissioning of urgent and emergency care services for children 0-16 years, in a local pathway model. <http://www.rcpch.ac.uk/sites/default/files/20111130%20intercollegiate%20UEC%20document%20final.pdf>
- Fernandes A (2011) *Guidance for commissioning integrated urgent and emergency care. A ‘whole system’ approach.* Royal College of General Practitioners Centre for Commissioning. <http://commissioning.rcgp.org.uk/wp-content/uploads/2011/09/RCGP-Urgent-Emergency-Commissioning-Guide-v2.pdf>
- NHS Institute for Innovation and Improvement. Children and Young People Emergency and Urgent Care website. [http://www.institute.nhs.uk/quality\\_and\\_value/high\\_volume\\_care/focus\\_on%3a\\_emergency\\_and\\_urgent\\_care\\_pathway.html](http://www.institute.nhs.uk/quality_and_value/high_volume_care/focus_on%3a_emergency_and_urgent_care_pathway.html)
- “Spotting the Sick Child” is a new interactive tool commissioned by the Department of Health to support health professionals in the assessment of the acutely sick child. <https://www.spottingthesickchild.com/?>

1 Department of Health. Accident and Emergency.

<http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/Perfomedataandstatistics/AccidentandEmergency/index.htm>

2 NHS Information Centre. [http://www.ic.nhs.uk/webfiles/publications/004\\_Hospital\\_Care/HES/aandeattendance0910/AE\\_Attendances\\_in\\_England\\_Experimental\\_statistics\\_2009-10\\_v2.pdf](http://www.ic.nhs.uk/webfiles/publications/004_Hospital_Care/HES/aandeattendance0910/AE_Attendances_in_England_Experimental_statistics_2009-10_v2.pdf)

3 Sands R, Shanmugavadivel D, Stephenson T, Wood D (2011) Medical problems presenting to paediatric emergency departments: 10 years on. *Emerg Med J* doi: 10.1136/emj.2010.106229

4 Hull S, Rees Jones I, Moser K (1998) Relation of rates of self referral to A&E departments to deprivation. *British Medical Journal* 317: 538.

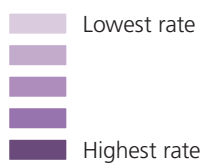
5 Lambe S, Washington D, Fink A et al. (2003) Waiting times in California’s emergency departments. *Annals of Emergency Medicine* 41: 34-44.

**END-OF-LIFE CARE**

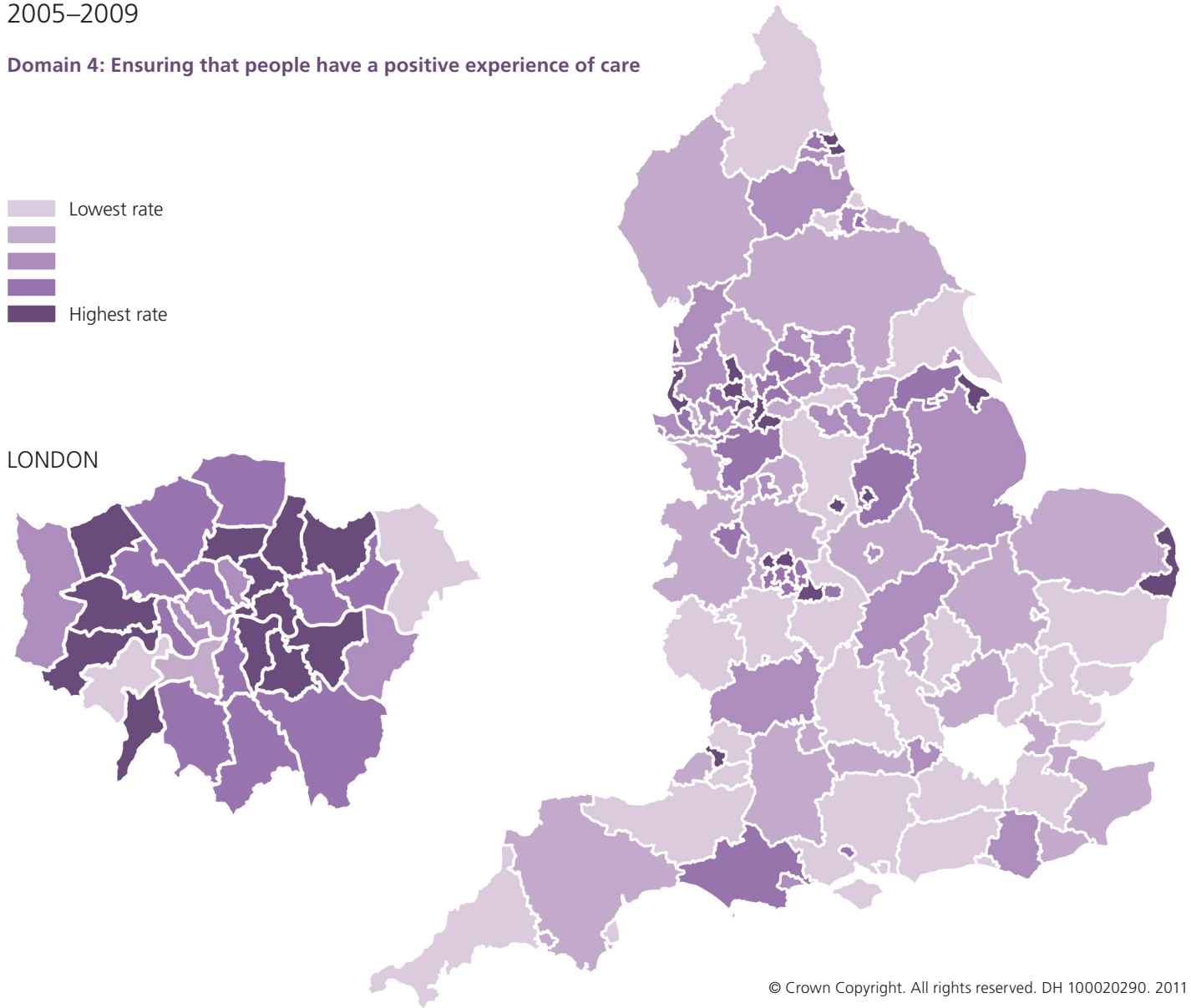
**Map 27:** Percentage of all deaths in children aged 0–17 years with life-limiting conditions that occur in hospital by PCT

2005–2009

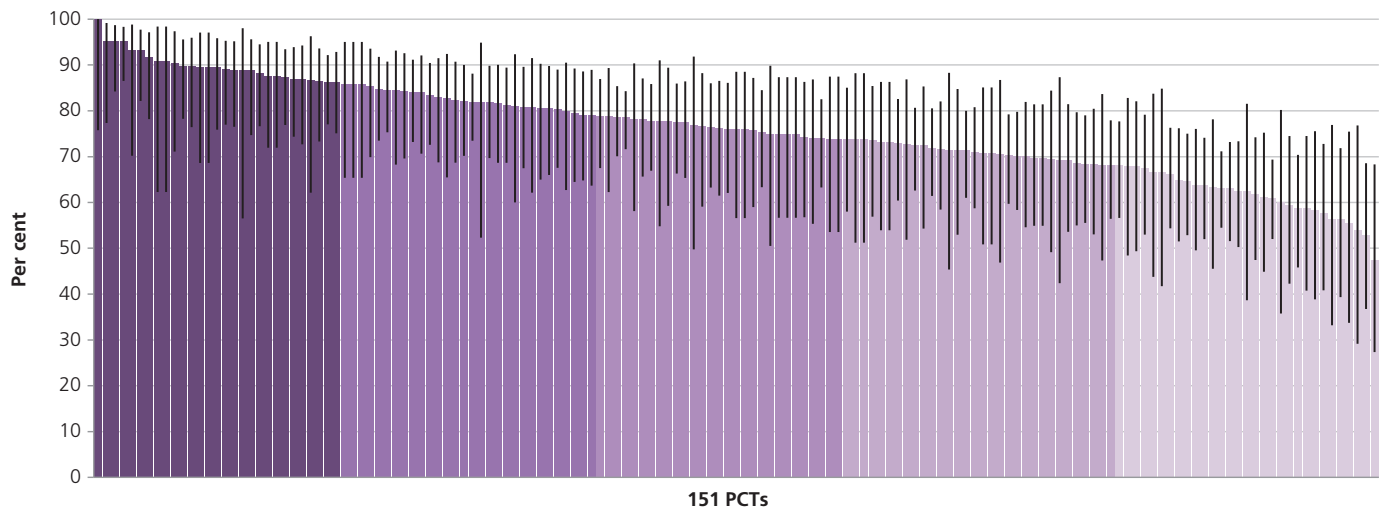
Domain 4: Ensuring that people have a positive experience of care



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## Context

Life-limiting conditions are those in which no reasonable hope of cure exists and from which children or young people will die prematurely. Most children with life-limiting conditions and their families express a preference for death to take place at home. However, even when that is medically possible, lack of community support can prevent this preference being realised.

This indicator is one of many showing the quality of palliative care services. Palliative care is not simply about “end of life” care. It is an active process that encompasses physical, emotional and social support to maximise quality of life for children throughout their life-course, from the moment of diagnosis to providing support for families during the bereavement process.

## Magnitude of variation

For PCTs in England, the percentage of all deaths in children aged 0–17 years with life-limiting conditions that occur in hospital ranged from 47.4% to 100% (2.1-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 56.3–93.3%, and the variation is 1.7-fold.

The corollary is that after exclusions the percentage of children dying out of hospital (at home or in a hospice) ranged from 6.7% to 43.7%, a variation of 6.5-fold.

The relatively high percentage of children dying in hospital may reflect the nature of service provision and level of support available to families outside hospital.

## Options for action

Commissioners and clinicians need to review the proportion of children dying in local hospitals and investigate whether this reflects family choice. The care team should work with the family to clarify the family’s wishes for end-of-life care, in terms of the type of care and place of care. Families should be provided with the

support and resources they need to enable their child to die in the place of their choice.

Commissioners also need to review other indicators relating to the quality of palliative care provided for families and children with life-limiting conditions, such as:

- › the number of children who have an end-of-life care plan;
- › whether choice in place of death is offered to the child’s family;
- › whether there are adequate resources to provide care and support 24 hours a day 7 days a week within the child’s home or other preferred place of death, such as a children’s hospice.

Commissioners need to ascertain whether the workforce has the skills, knowledge and expertise to support children at end of life together with their families (see “Resources”).

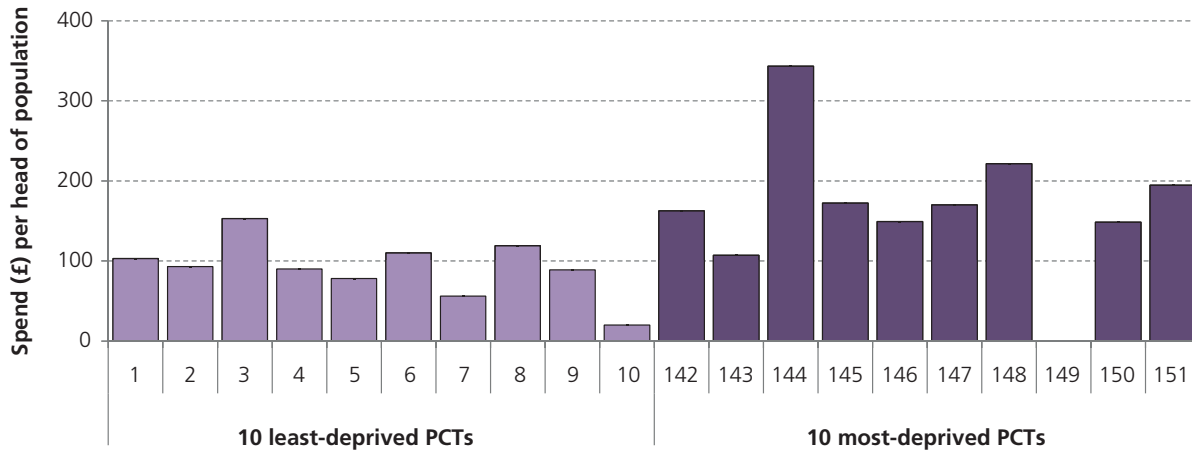
The availability of efficient and effective end-of-life care for children and young people depends on strong clinical leadership, with local networks of service providers working together to make 24-hour palliative care a reality.

## RESOURCES

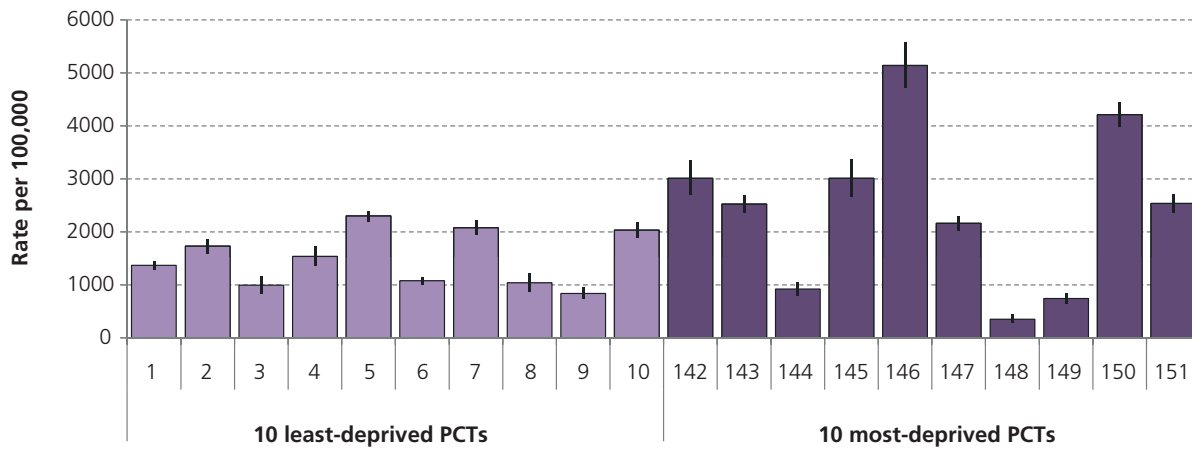
- › Department of Health (2008) *Better Care: Better Lives – Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions*. Provides a framework for the level of service that commissioners and clinicians need to be delivering for children’s palliative care. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_083106](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083106).
- › “Together for Short Lives” website: information and resources for professionals, and children and their families. <http://www.togetherforshortlives.org.uk>
- › “Skills for Health” has identified the workforce functions mapped to the specific National Occupational Standards required to care for children with life-limiting and life-threatening conditions. <http://www.skillsforhealth.org.uk/about-us/news/caring-for-children-with-life%11limiting-and-life%11threatening-conditions/>

# Additional visualisations for Maps 1, 20 and 26

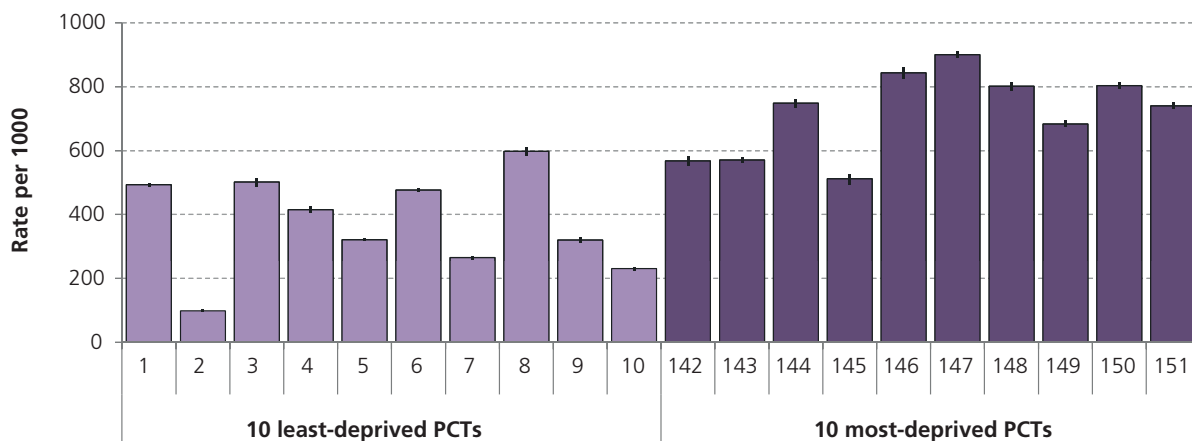
**Figure 1.2:** Rate of expenditure on community child health services per head of population aged 0–17 years 2008/09 among the 10 least-deprived and 10 most-deprived PCTs (IMD 2010)



**Figure 20.2:** Rate of admissions for bronchiolitis in children per 100,000 population aged under 2 years 2007/08–2009/10 among the 10 least-deprived and the 10 most-deprived PCTs (IMD 2010)



**Figure 26.1:** Rate of A&E attendances per 1000 population aged under 5 years 2009/10 among the 10 least-deprived and 10 most-deprived PCTs (IMD 2010)



# Case-study 1: Yorkshire and Humber Paediatric Diabetes Network

## The setting

Yorkshire and Humber Strategic Health Authority (SHA) served a population of over 900,000 children aged 0–14 years.<sup>1</sup> Within the area, 21 secondary care units provide care for children and young people with diabetes, including Bassetlaw Hospital, which is affiliated with Doncaster Hospital as part of the Doncaster and Bassetlaw Hospitals NHS Foundation Trust. The geographical coverage encompasses 14 PCTs.

In 2009/10, the population of children and young people, aged 0–24 years, with diabetes who received care within the region was 2400; for those aged 0–15 years, the number was 1635.

## The problem

Demographic and clinical data on children and young people with diabetes have been collected for the Yorkshire Register of Diabetes in Children and Young People (YRDCYP) since 1978, and the register contains records of over 7000 children, stretching back 33 years for some units.

Through analysis of this dataset, clinicians and public health specialists made four observations:

- Yorkshire and Humber has a higher incidence of diabetes in children and young people than the national average;
- Incidence of diabetes in children and young people in the region has been rising steadily since 1978;
- There was wide variation in the rates of children and young people with diabetes being admitted to hospitals;
- There was wide variation in the proportion children with diabetes with very good and very poor control

of their diabetes in the region (as measured by HbA1c values of <7.5% and >9.5%)

## What action was taken?

The 21 services in Yorkshire and Humber SHA agreed to collaborate on reducing variation and improving outcomes for children and young people with diabetes in the region.

The Children and Young People Diabetes Programme Board (CYPDPB) was set up in 2008 to coordinate the efforts of the newly created paediatric diabetes regional network. The CYPDPB has a multidisciplinary membership, including management, researchers, public health professionals and patient/family representatives. Clinical leadership is embedded within the management structures, and there are strong, formal links to local commissioners of child health services.

The Board has coordinated a series of network-wide initiatives aimed at improving the care of children with diabetes in the region.

## Data collection and submission

The collection and submission of data was improved across the region by formalising links among the units, and the creation of a network facilitator post. Since 2008, the region has achieved a 100% data submission rate to the Paediatric National Diabetes Audit (NDA).

## Benchmarking and audit

The network produces reports of clinical practices and outcomes, highlighting variations in process, structure and outcomes for children with diabetes among providers. The first annual report was published in 2010<sup>2</sup> in conjunction with a detailed clinical audit of practice and outcomes.<sup>3</sup> Even within this relatively short timeframe, the open sharing of information has resulted

1 ONS, 2001.

2 Children and Young People with Diabetes Annual Report 2010-11. NHS Yorkshire and Humber. 2010.

3 Paediatric Epidemiology Group (2010) Clinical audit of children and young people with diabetes in the Yorkshire and Humber Strategic Health Authority, January 2007 to March 2010. University of Leeds.



in improved clinical outcomes, such as an increase in the proportion of children meeting the best practice standard for HbA1c measurement of <7.5%.<sup>2,3</sup>

### Shared learning and education

Regular meetings of the Board, with representation from all of the provider units, have facilitated the dissemination of local innovation and best practice. Pooling resources has meant that educational opportunities for staff in all units can be maximised. As of 2010, staff from units across the network have had the opportunity:

- To undertake accredited educational modules on diabetes care;
- To attend clinics on efficiency and technology use in diabetes care;
- To attend a network-wide study day centring on sharing good practice and learning from high-performing international units.

Economies of scale make these learning opportunities affordable and accessible to all within the network.

### Peer-review process

Based upon the approach of the National Cancer Peer Review, a peer-review process of diabetes services for children and young people has been piloted at three sites within the network. Eighteen multidisciplinary staff and parents from across the region were trained to review the care processes at individual units. Following the success of the pilot, the peer-review process is being rolled out to all 21 provider units in the network, all of which are expected to have completed this review by March 2012.

### Service specification for commissioning

To ensure minimum standards of care for children and young people with diabetes, the Board has developed a service specification to support the commissioning of a high-quality diabetes pathway at all units in the network.

### Learning points

The experience of the Yorkshire and Humber Paediatric Diabetes Network exemplifies the power of clinical and patient group leadership and collaborative

working. Creation of a network of providers across a large geographical area requires a shared vision and a considerable level of trust and engagement. This cannot be achieved without strong leadership from all of the clinicians involved.

The challenge of improving the processes and structures of diabetic care is the length of time it takes to translate action into improved outcomes for patients. Improvements in outcomes for diabetes care take time to achieve because of the complex nature of the disease, and the psychological, socio-economic and family factors which have such a strong influence on the level of diabetic control. Collaborative working across a network of providers enables processes and outcomes to be benchmarked and audited. As the Yorkshire and Humber network shows, reporting of variation in quality of care and outcomes has a powerful effect of driving improvements through local innovation and the sharing of best practice.

Outcomes across the network have improved, and the model has been replicated in most of the other SHAs in England, which is testament to the success of this network.

### Resources required

No structural investment was required to undertake this work.

With respect to resources, there were three main items:

- A network facilitator post (0.4 WTE);
- Strong clinical leadership, which required both enthusiasm and time;
- Patient group involvement.

With respect to data, although not all networks have the benefit of a regional dataset such as the YRDCYP, which is funded externally and hosted at a university academic centre, all units in England submit data to the Paediatric NDA and there is no reason why national audit data cannot be used for this purpose.

### Acknowledgements

This case-study is based on work led by Fiona Campbell, Consultant Paediatrician at The Leeds Teaching Hospitals NHS Trust.

## Case-study 2: Emergency admissions for epilepsy in children – work in Luton Primary Care Trust

### The setting

Luton Primary Care Trust (PCT) serves a local catchment population of just under 190,000 people. Approximately 30% of this population is from ethnic minority groups, predominantly South Asian, African-Caribbean, and Eastern European. The estimated number of children and young people (aged 0–19 years) it serves is 50,000.<sup>1</sup>

Almost all children with epilepsy residing in Luton PCT are managed by the epilepsy service at Luton and Dunstable NHS Foundation Trust. Approximately two-thirds of children under the care of the Luton and Dunstable Hospital NHS Foundation Trust epilepsy service reside in Luton PCT.

### The problem

In 2008, Luton PCT had the highest rate of emergency admissions for epilepsy per 100,000 children in England.<sup>2</sup> Using ChiMat's Disease Management Information Toolkit (DMIT), the Eastern Region Public Health Observatory compared Luton PCT's rate with those of other PCTs which had a similar demography and similar levels of deprivation, and found that Luton PCT's rate of emergency admission was double that of all but one other demographically similar PCT.

At the same time, analysis by Luton and Dunstable Hospital NHS Foundation Trust showed that the number of children presenting with epilepsy as an emergency attendance was almost twice the national average, and was one of the highest of any NHS Trust in the East of England region.

### The investigation

The community specialist epilepsy nurse with responsibility for Luton PCT undertook to investigate the causes of this unexplained variation, with support

from the Luton and Dunstable Hospital NHS Foundation Trust children's epilepsy service. Data on all emergency presentations for epilepsy were collected for one year including information on:

- › demographics of the attendances;
- › pre-hospital care;
- › emergency treatment and further therapy;
- › final outcomes of each episode of care.

### The results of investigation

Opportunities for intervention were identified at different points along the patient pathway.

**Demography:** Although children of South Asian origin comprise only 32% of children with epilepsy in Luton PCT, they accounted for 77% of presentations to the Emergency Department.

**Pre-hospital care:** "Rescue medication" is pre-prescribed emergency anticonvulsant medication that parents can be trained to give safely at home.<sup>3</sup>

Rescue medication had not been prescribed for 63% of the children who presented as emergencies; this may have been due to first attendance with prolonged seizure or not considered clinically appropriate previously.

Of those who had pre-prescribed rescue medication available, 25% did not use it, citing lack of confidence about usage – the ethnic background of all these respondents was South Asian.

**Treatment and outcomes:** Of all attendances, 48% did not require administration of anticonvulsant therapy

1 ONS, 2008.

2 For reference, see also Atlas 1.0, Map 10 Directly standardised rate of emergency admissions in persons with epilepsy per 100,000 population by PCT 2006/07–2008/09.

3 NICE (2012) The epilepsies. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. Clinical guidelines, CG137. <http://guidance.nice.org.uk/CG137>

in the Emergency Department. Despite this, 81% of attendances resulted in full admission to the children's ward. Further investigation through interviews with ambulance staff revealed a lack of both confidence and formal guidance on assessment of need to transport patients to the Emergency Department following seizure cessation at home.

## What action was taken?

Key themes that emerged from this in-depth analysis of local variation formed the basis for targeted intervention with respect to the care of individuals, the healthcare system, and population medicine.

**Education of families:** There are several possible reasons for the unwarranted variation in pre-hospital care and unplanned presentations in children from South Asian families:

- › Language barriers;
- › Inadequate health education;
- › Cultural perceptions of epilepsy.

As a result, the Specialist Epilepsy Nurse has undertaken a community-based project to improve the quality of healthcare information provision to South Asian families in partnership with Epilepsy Action and The Roald Dahl Marvellous Children's Charity. The aim of this project is to improve the targeting of information to families, particularly by overcoming linguistic and cultural barriers to improve people's understanding of epilepsy, in addition to providing detailed advice and support for managing acute episodes at home.

**Pre-hospital care:** A review was undertaken of all children in the epilepsy service to ensure rescue medication was prescribed where appropriate. Training needs for parents were also reviewed to facilitate administration of rescue medication confidently and safely.

**Education of ambulance service for pre-hospital management:** A formal education programme has been implemented for local ambulance staff to improve initial assessment of seizures in children.

In addition, local clinicians are working in partnership with ambulance staff to improve support for parental administration of rescue medication in the home.

Education and guidance have also been targeted at ambulance staff:

- › to improve out-of-hospital assessment and management of children immediately after a seizure;
- › to streamline the attendance of children who require hospital treatment;
- › to support the decision-making of families whose children are stable enough to remain at home.

**Network care pathways:** The Eastern Paediatric Epilepsy Network has developed care plans, clinical guidelines and specific patient information for the East of England region because epilepsy management has implications for the entire network. Uniformity and availability of clinical and parental advice is the first step to reducing unwarranted variations regionally.

A seizure urgent care pathway is being developed collaboratively by Luton and Dunstable Hospital NHS Foundation Trust, Cambridgeshire Community Services NHS Trust paediatric nursing teams and Bedfordshire & Hertfordshire Ambulance Service. This will follow similar pathways developed for other acute conditions, with the aim of informing and supporting healthcare professionals in seizure management across primary and secondary settings.

A prospective survey is currently underway to evaluate the impact of these interventions on emergency admission rates.

## Learning points

Becoming aware that the Trust was a "performance outlier" was the trigger to seek to identify reasons for the variation. Socio-economic deprivation and ethnic demography are often the factors cited to explain the performance of outliers. However, as this case-study shows, in-depth investigation of local practices and populations can reveal areas for improvement in the care pathway irrespective of demography.

Furthermore, the investigation revealed unwarranted variations in care within the population itself. This is important for two reasons:

- › Identifying an at-risk population receiving substandard healthcare has implications for equity and quality of overall population health;

- › Identifying an “at risk” population in order to target interventions appropriately and cost-effectively.

The work outlined in this case-study was made possible by high-quality, pro-active clinical leadership from the multidisciplinary paediatric epilepsy team, particularly in the community setting. The strength of the network system of care was in providing a platform for collaboration to identify and tackle the causes of unwarranted variation. Local commissioners supported the implementation of local improvement strategies, and continue to support the work of the epilepsy specialist nurse and the community-based multidisciplinary specialist epilepsy team.

The scenario of a deprived local population and poor performance outcomes will be familiar to many local commissioners and clinicians, and addressing any variations in care can seem daunting in this context. Issues of public health and the socio-economic determinants of health may appear to be beyond the control of health services. However, pragmatic and meaningful solutions can be found to tackle seemingly intractable unwarranted variations in child healthcare. These require:

- › local clinical leadership;
- › collaborative multidisciplinary working;
- › the clinical expertise of a network system of care;
- › the support of commissioners.

## Resources required

Much of the resource required for this type of project is the time and expertise of a specialist epilepsy nurse, covering data collection as well as planning and implementation of interventions.

It is anticipated that much of the administrative work regarding data collection will be delegated to non-clinical staff for the second iteration of the survey, to allow the specialist epilepsy nurse to devote more time to the planning and implementation of interventions, although responsibility for oversight of data collection and interpretation will be retained.

Funding of approximately £6000 was obtained from

the two named charities to deliver the education programme.

## Further information and resources

- › Eastern Paediatric Epilepsy Network care plans and parental information. <http://www.networks.nhs.uk/nhs-networks/eastern-paediatric-epilepsy-network>
- › ChiMat Disease Management Information Toolkit (DMIT). <http://www.chimat.org.uk/default.aspx?QN=CHMTDMIT>

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- › Liz Stevens, Specialist Paediatric Nurse, Cambridgeshire Community Services NHS Trust;
- › Julia Yelloly, ChiMat Local Specialist, Eastern Region Public Health Observatory.



# Glossary of Essential Terms

## Introduction

Much of the disagreement that occurs during the commissioning or management of services arises because different people use the same term but have a different understanding of its meaning. This Glossary is provided to help develop a shared or common language. If there is a clear, short and memorable definition from the literature, this has been cited and presented in italics; where definitions in the literature are overly long, Right Care has composed and provided a short definition.

### Appropriate

*A procedure is termed appropriate if its benefits sufficiently outweigh its risks to make it worth performing ...*

Source: Kahan JP et al. (1994) Measuring the necessity of medical procedures. *Medical Care* 32: 352-365.

### Confidence intervals

*Confidence intervals give the range within which the true size of a treatment effect (which is never precisely known) lies, with a given degree of certainty (usually 95% or 99%).*

Source: Evans I, Thornton H, Chalmers I (2006) *Testing Treatments. Better Research for Better Healthcare*. The British Library.

### Costs

Cost are not only financial. Cost may be measured as the time used, the carbon produced, or the benefit that would be obtained if the resources were used for another group of patients (i.e. the opportunity cost).

### Effective care

*The extent to which an intervention, procedure regimen, or service produces a beneficial outcome under ideal circumstances (e.g., in a randomized controlled trial).*

Source: Canadian Agency for Drugs and Technologies in Health (2009) *Optimal Therapy Report: Cost effectiveness of blood glucose test strips in the management of adult patients with diabetes mellitus*. Volume 3, Issue 3.

### Efficiency

See also **Productivity**

*... efficiency can be defined as maximising well-being at the least cost to society.*

Source: Mitton C, Donaldson C (2004) *Priority setting toolkit. A guide to the use of economics in healthcare decision making*. BMJ Publishing Group.

### Equity

Equity is a subjective judgment of fairness.

### Health

*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*

Source: Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19 June-22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. The definition has not been amended since 1948. <http://www.who.int/suggestions/faq/en/index.html>

### Inequality

Inequality is objectively measured differences in health status, and healthcare access and outcome.



## Input, Output and Outcome

Input is a term used by economists to define the resources used, such as the number of hospital beds, to produce the output, such as the number of patients admitted per bed per year.

The economists' terminology is different from the language utilised in quality assurance, in which the terms structure, process and outcome are used. Input equates to structure and process, i.e. the number of beds and the number of admissions per bed, respectively. However, the outcome is distinct from the output. Outcome includes some measure of the effect the process has had on the patients, for example, the number of patients who were discharged to their own home.

## Integrated care

*Clinical integration, where care by professionals and providers to patients is integrated into a single or coherent process within and/or across professions such as through use of shared guidelines and protocols.*

Source: Kodner DL, Spreeuwenberg C (2002) Integrated care: meaning, logic, applications and implications – a discussion paper. *International Journal of Integrated Care* 2: 1-6.

## Mean (average)

The mean is the sum of values, e.g. size of populations, divided by the number of values, e.g. number of populations in the sample.

## Network

See also **System**

If a system is a set of activities with a common set of objectives, the network is the set of organisations and individuals that coordinate and deliver the activities within the system.

**Outcome**, see **Input**

**Output**, see **Input**

## Population medicine

Population medicine is a style of clinical practice in which the clinician is focused not only on the individual patients referred but also on the whole population in need.

## Preference-sensitive care

*... elective, or "preference-sensitive" care, interventions for which there is more than one option and where the outcomes will differ according to the option used. ... because patients delegate decision making to doctors, physician opinion rather than patient preference often determines which treatment patients receive. I argue that this can result in a serious but commonly overlooked medical error: operating on the wrong patients – on those who, were they fully informed, would not have wanted the operation they received.*

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

## Preference-sensitive treatment decisions

*Preference sensitive treatment decisions involve making value trade-offs between benefits and harms that should depend on informed patient choice.*

Source: O'Connor AM et al (2007) Toward the 'Tipping Point': Decision aids and informed patient choice. *Health Affairs* 26: 716-725.

## Productivity

See also **Efficiency**

Productivity is the relationship between inputs and outputs, such as the number of operations per theatre per year; efficiency is the relationship between outcomes and inputs, such as the number of successful operations per theatre per year.

## Quality

*The degree to which a service meets pre-set standards of goodness.*

Source: Donabedian A, personal communication.

## Range

The range is the difference between the highest and lowest value in the sample. The range provides a crude measure of the spread of the data.

## Safety

*Patient safety can, at its simplest, be defined as: The avoidance, prevention and amelioration of adverse outcomes or injuries stemming from the process of healthcare. ... the reduction of harm should be the primary aim of patient safety, not the elimination of error.*

Source: Vincent C (2006) *Patient Safety*. Churchill Livingstone.

### Shared decision-making

*In a shared decision, a health care provider communicates to the patient personalized information about the options, outcomes, probabilities, and scientific uncertainties of available treatment options, and the patient communicates his or her values and the relative importance he or she places on benefits and harms.*

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

### Standard deviation

See also **Variance**

The standard deviation is a measure of spread, and is the square root of the variance.

### Supply-sensitive care

*It differs in fundamental ways from both effective care and preference-sensitive care. Supply-sensitive care is not about a specific treatment per se; rather, it is about the frequency with which everyday medical care is used in treating patients with acute and chronic illnesses. Remedying variation in supply-sensitive care requires coming to terms with the "more care is better" assumption. Are physician services and hospitals in high-cost, high-use regions overused?*

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

### System

A set of activities with a common set of objectives with an annual report.

### Unwarranted variation

*Variation in the utilization of health care services that cannot be explained by variation in patient illness or patient preferences.*

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

### Value

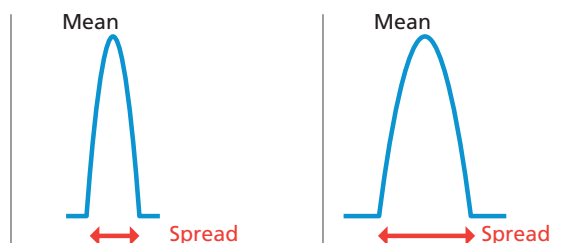
*... value is expressed as what we gain relative to what we give up – the benefit relative to the cost.*

Source: Institute of Medicine of the National Academies (2008) *Learning Healthcare System Concepts v. 2008*. The Roundtable on Evidence-Based Medicine, Institute of Medicine. Annual Report.

### Variance

See also **Range**

The variance is another measure of spread, which describes how far the values in the sample lie away from the mean value. It is the average of the squared differences from the mean and is a better measure of spread than the range.



*This figure illustrates how two populations may have the same mean value, but different degrees of variation or spread: the second population shows greater variation than the first.*

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