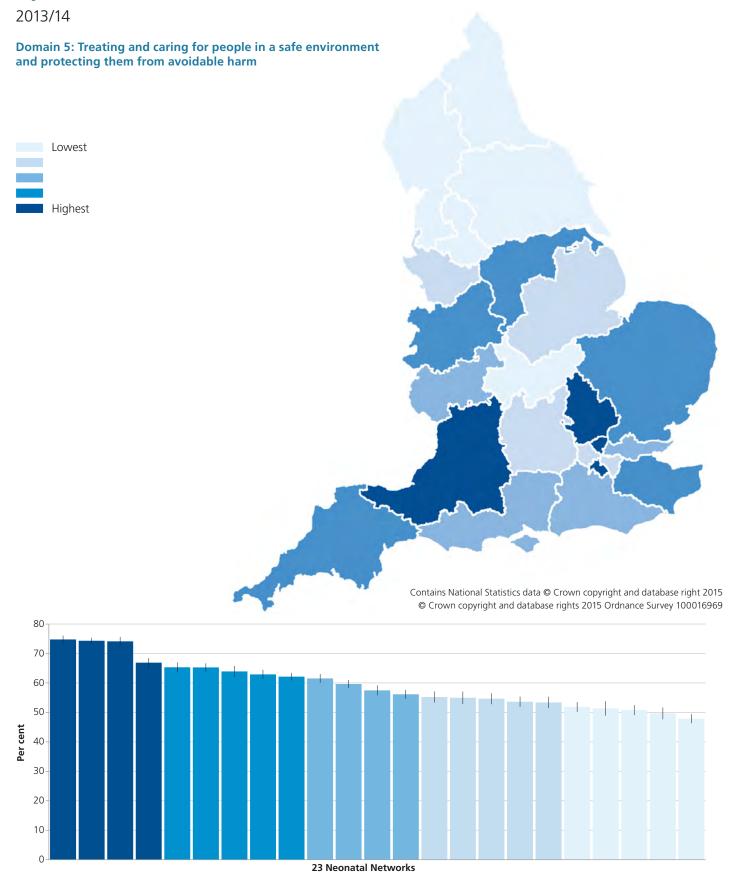
Map 68: Percentage of full-term babies (≥37 weeks' gestational age at birth) admitted to specialist neonatal care by neonatal network



Most neonatal care in hospital involves the management of premature babies. The number of premature babies is determined by local demography and socio-economic deprivation, and is less amenable to change through commissioning; however, sick babies of any gestation may be admitted to a neonatal unit for several reasons amenable to intervention.

The number of term admissions to neonatal units is increasing year on year, and in many cases these admissions could be

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

- > smoking habit and alcohol consumption;
- > conditions such as diabetes.

The nature of intrapartum and postnatal care can affect the need for specialist neonatal care – for instance, newborn babies can have respiratory distress syndrome as a complication of birth by Caesarean section, which may result in admission to a neonatal unit for treatment.

Reducing the admissions of full-term babies to specialist neonatal care:

- **>** is beneficial for the families involved;
- could save substantial costs and thereby facilitate resource reallocation.

"Admission of full term babies to neonatal care" is a national quality indicator in the NHS Outcomes Framework 2015/16.

Magnitude of variation

For neonatal networks in England, the percentage of full-term babies (≥37 weeks' gestational age at birth) admitted to specialist neonatal care ranged from 47.9% to 74.8% (1.6-fold variation).1

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

Possible reasons for the degree of variation observed are differences in:

- > codina:
- > maternal health status;
- access to antenatal care;
- > clinical practice in perinatal care or neonatal team clinical decision-making;
- **>** the number of skilled midwives on postnatal wards;
- **>** admission criteria to neonatal units, special care baby units and transitional care within individual hospitals.

There are parallels with the results of 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 of the variation observed may result from different levels of provision, thereby exemplifying a supply-side cause of unwarranted variation (see Glossary, page 273).

Options for action

To reduce or avoid the number of admissions, neonatal units need to undertake local clinical reviews of reasons for admission and identify appropriate areas for action and necessary service improvements. It is advisable that these reviews are undertaken jointly by maternity and neonatal services.

Each neonatal network needs to develop standardised guidelines for clinical admission criteria, and implement available best-practice resources for reducing term admissions.

Commissioners need to specify that service providers and clinicians implement NHS England's care bundle for reducing stillbirths (see "Resources"), the recommendations in which will reduce the risk of perinatal morbidity that would otherwise result in admission to neonatal care.

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

- interventions to reduce alcohol and smoking during pregnancy;
- > access to antenatal care and screening;
- the impact of Caesarean section undertaken prior to 39 completed weeks in conjunction with admissions of fullterm babies to specialist neonatal care for management of respiratory symptoms;
- > the adequacy of numbers of skilled staff, including 24-hour Consultant presence on delivery suite, and appropriateness of midwifery staffing;
- > implementation and adherence to national guidance on antenatal, intrapartum and postnatal care and management.

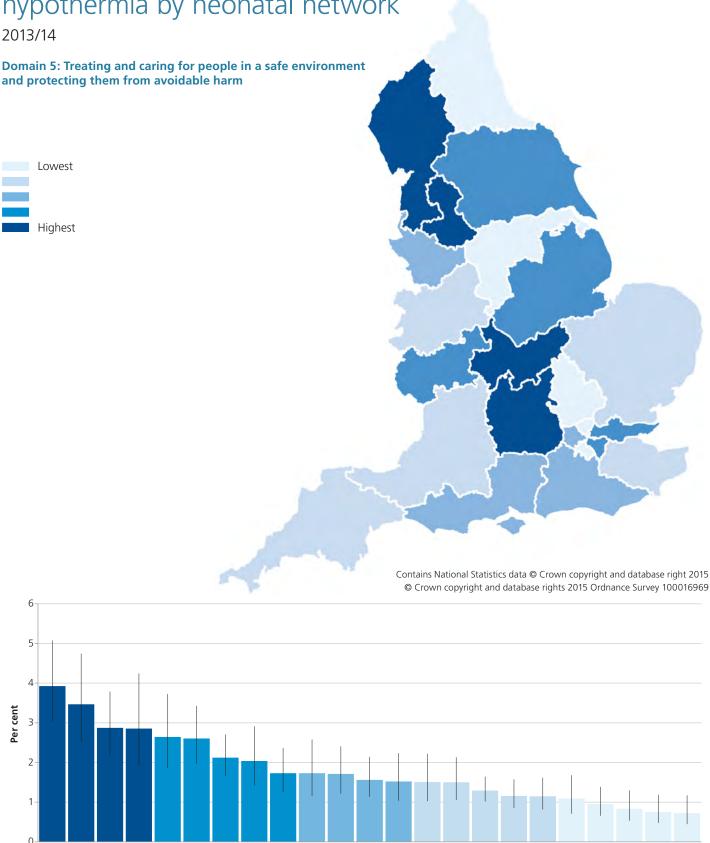
Performance data could be analysed and benchmarked to enable comparisons:

- **>** among units in each neonatal network;
- > among neonatal networks in England;
- **>** with other countries that have developed economies.

- > NICE. Postnatal care. NICE guidelines [CG37]. December 2014. http://www.nice.org.uk/CG037
- > NICE. Specialist neonatal care quality standard. NICE quality standard [QS4]. October 2010. http://www.nice.org.uk/guidance/qs4
- > NHS England. Saving Babies Lives: Reducing Stillbirth a neonatal death: A care bundle (sic). http://www.6cs.england.nhs.uk/ pg/cv_content/content/view/148581/95584

¹ Data for the numerator have been provided by the Neonatal Data Analysis Unit, Imperial College London, from the National Neonatal Research Database.

Map 69: Percentage of normally formed full-term babies (≥37 weeks' gestational age at birth) admitted to neonatal intensive care who received therapeutic hypothermia by neonatal network



23 Neonatal Networks

Neonatal encephalopathy is a common reason for babies born at full term (≥37 completed weeks' gestation) to be admitted to neonatal intensive care. The commonest cause for neonatal encephalopathy is hypoxic-ischaemic encephalopathy (HIE) secondary to perinatal asphyxia. For babies with HIE, early initiation of therapeutic hypothermia ("cooling") is now standard in specialist neonatal care in England.

The risk of death or severe handicap in survivors of moderate or severe HIE is approximately 25% and 75%, respectively.¹ Even those children without motor impairments:

- **>** have lower cognitive scores on long-term follow-up;
- have poorer scholastic attainment in independent National Attainment Tests;
- > often need educational support.²

This represents a considerable burden not only to the individual, the family and the NHS, but also to society as a whole.

Risk factors for HIE before delivery include maternal health, severe pre-eclampsia or placental insufficiency; during delivery, they include perinatal infection, placental abruption, misinterpretation of fetal well-being or reduced oxygen delivery to the fetus from, for example, cord prolapse or shoulder dystocia. Early recognition and management of these risk factors would help to minimise the incidence of HIE.

Early recognition and treatment of neonatal encephalopathy has an impact on mortality and long-term morbidity outcomes. Once recognised, early initiation of therapeutic hypothermia ("cooling") has been shown to reduce mortality and morbidity associated with HIE.

Magnitude of variation

For neonatal networks in England, the percentage of normally formed full-term babies admitted to neonatal intensive care who received therapeutic hypothermia ranged from 0.7% to 3.9% (5.4-fold variation).³

Possible reasons for the degree of variation observed include differences in:

- > incidence;
- > timing of diagnosis;
- ➤ thresholds for the initiation of therapeutic hypothermia ("cooling").

Variation in incidence may be due to differences in:

- > maternal health status;
- **>** access to specialist antenatal care;
- **>** the number and skill-mix of midwifery teams;
- **>** the clinical practice of obstetric teams.

Variation in diagnosis/treatment may be due to differences in:

- > diagnosis of neonatal encephalopathy by neonatal teams;
- **>** the interpretation of the threshold to initiate treatment;
- access to equipment and/or skill-mix to initiate and maintain therapeutic hypothermia.

Options for action

Commissioners need to specify that service providers:

- meet the standards for maternity and neonatal care outlined by NICE and the Royal Colleges (see "Resources");
- > deliver high-quality antenatal care to all pregnant women, particularly women from different ethnic groups and in lower socio-economic groups.

Equitable service provision includes:

- antenatal education and information on antenatal health and nutrition;
- access to antenatal screening for infections and congenital malformations.

For these babies to receive the care they need in the right clinical setting as quickly as possible, it depends upon:

- **>** appropriate assessment of high-risk pregnancies;
- → allocation to the appropriate level of maternity care (and anticipating the level of neonatal care commensurate with the risk).

Maternity networks are responsible for ensuring that individual units within their network have the capacity and workforce to offer safe, appropriate and evidence-based practice, in order to reduce the numbers of babies born and admitted with neonatal encephalopathy.

Neonatal networks must monitor risk-adjusted outcomes for neonatal encephalopathy, and ensure the network, and each unit within the network, have the workforce skilled in assessing and treating HIE appropriately, and the equipment and staffing to initiate and maintain therapeutic hypothermia, in order to minimise mortality and long-term morbidity.

Commissioners and service providers are both responsible for investigating the causes of within- and between-network variation, ranging from public health measures to maternity care and neonatal care.

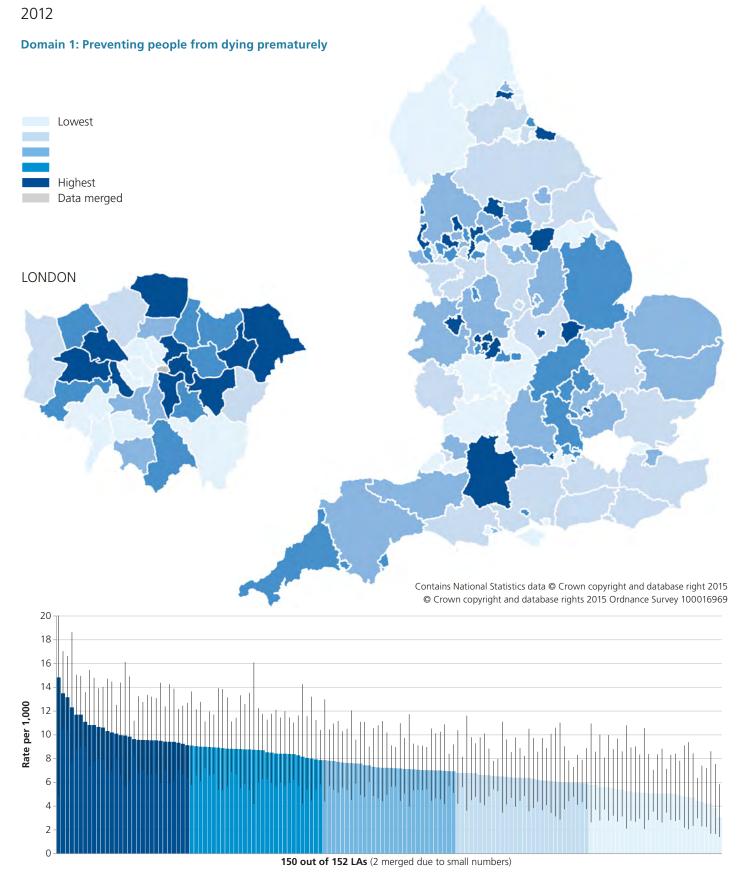
- Royal College of Obstetricians and Gynaecologists (RCOG). Standards for Maternity Care. Published 1/06/2008. http://www.rcog.org.uk/womens-health/clinical-guidance/standards-maternity-care
- NICE Specialist neonatal care quality standard. NICE quality standard [QS4]. October 2010. https://www.nice.org.uk/guidance/qs4
- NICE. Therapeutic hypothermia with intracorporeal temperature monitoring for hypoxic perinatal brain injury. NICE interventional procedure guidance [IPG347]. May 2010. http://www.nice.org.uk/guidance/ipg347

¹ Evans K, Rigby AS, Hamilton P, Titchiner N, Hall DM. The relationships between neonatal encephalopathy and cerebral palsy: a cohort study. J Obstet Gynaecol 2001;21(2):114-120. http://www.ncbi.nlm.nih.gov/pubmed/12521875

² Marlow N, Rose AS, Rands CE, Draper ES. Neuropsychological and educational problems at school age associated with neonatal encephalopathy. Arch Dis Child Fetal Neonatal Ed 2005;90(5):F380-F387. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1721935/

³ Data for the numerator have been provided by the Neonatal Data Analysis Unit, Imperial College London, from the National Neonatal Research Database.

Map 70: Rate of stillbirths and neonatal deaths (under 28 days) per all live-births and stillbirths by upper-tier local authority



Stillbirths and neonatal deaths affect around 1 in 150 pregnancies in the UK, and are among the most feared outcomes for any new parent. These deaths cause distress and anguish for a wide circle of family members, and have a profound effect on the healthcare professionals involved.

Stillbirths account for around 65% of perinatal deaths. In the UK, stillbirth is delivery of a baby showing no signs of life at birth at or after 24 weeks' gestation; other countries use different gestational age thresholds. More than 90% of stillbirths happen before the onset of labour. At least 50% of stillbirths are unexplained, however:

- > 10% are due to lethal anomalies;
- **>** 5% are related to maternal disease (mostly diabetes);
- **>** 5−10% are intrapartum (many of these preterm);
- ➤ 10-15% are associated with abruption or other causes of bleeding;
- 10% are due to other specific causes, such as infection or pre-eclampsia.

Magnitude of variation

For upper-tier local authorities (UTLAs), the rate of stillbirths and neonatal deaths (under 28 days) ranged from 3.1 to 14.8 per all 1000 live-births and stillbirths (4.8-fold). When the five UTLAs with the highest rates and the five UTLAs with the lowest rates are excluded, the range is 4.4–11.7 per all 1000 live-births and stillbirths, and the variation is 2.6-fold.

One reason for the degree of variation observed is differences in the demography of local populations. Socio-economic factors are an important predictor of stillbirth, as reflected in the spread of stillbirth across England. The correlation between social inequality and perinatal mortality is high, together with associated modifiable factors such as maternal smoking. Unexplained antepartum stillbirths account for 50% of the deprivation gap, and a greater understanding of these stillbirths is necessary to reduce socio-economic inequalities.²

Other factors that could contribute to the degree of variation observed are differences in:

- the penetration of novel techniques to treat lifethreatening neonatal conditions, such as therapeutic hypothermia, which were being adopted during the timeperiod for this indicator and could explain some of the variation in neonatal survival;
- > the reporting of early neonatal deaths for deliveries before the threshold of viability (commonly referred to as 23 weeks' gestation), some practitioners may, despite the fact that a baby shows signs of life before death is confirmed, make a pragmatic decision not to record this as an early neonatal death but as a late fetal loss, which does not require issuing a birth and death certificate.

Options for action

The evidence base for interventions to reduce stillbirths is contentious, largely because it remains a relatively uncommon event, making it a challenge to design a study with an adequate level of power.

There are currently several national initiatives with the aim of reducing stillbirth. The first MBRRACE-UK report on perinatal deaths published in June 2015 (see "Resources") provides recommendations about action that can be taken by both commissioners and service providers. NHS England is leading the development of a care bundle for reducing stillbirth, "Saving Babies' Lives" (at the time of writing, soon to be published), which will be rolled out nationally.

Despite the lack of a robust evidence base, widespread commitment to national surveillance and audit of cases of stillbirth and neonatal deaths is needed through:

- ➤ the MBRRACE-UK programme (see "Resources");
- other initiatives that focus on specific sub-groups, such as the RCOG's "Each Baby Counts" programme, which focuses on intrapartum-related perinatal deaths (see "Resources").

There is a need to standardise local reviews of perinatal deaths in a structured tool. At the time of writing, the Department of Health and NHS England are in the process of considering how to develop such a tool.

It is possible to undertake targeted public health initiatives, such as interventions to reduce maternal smoking.

- MBRRACE-UK: Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK. https://www.npeu.ox.ac.uk/mbrrace-uk
- Manktelow BN, Smith LK, Evans TA et al on behalf of the MBRRACE-UK collaboration. Perinatal Mortality Surveillance Report. UK Perinatal Deaths for births from January to December 2013. June 2015. Department of Health Sciences, University of Leicester. https://www.npeu.ox.ac.uk/mbrrace-uk/reports
- Royal College of Obstetricians and Gynaecologists. Each Baby Counts. https://www.rcog.org.uk/eachbabycounts
- Royal College of Obstetricians and Gynaecologists. Late Intrauterine Fetal Death and Stillbirth. Green-top Guideline No. 55. October 2010. https://www.rcog.org.uk/globalassets/documents/guidelines/gtg-55-31072013.pdf
- Centre for Maternal and Child Enquiries (CEMACE) Perinatal Mortality 2009: United Kingdom. CEMACE: 2011. http://www.hqip.org.uk/assets/NCAPOP-Library/CMACE-Reports/35.-March-2011-Perinatal-Mortality-2009.pdf
- Smith GCS. Prevention of stillbirth. The Obstetrician and Gynaecologist 2015; doi: 10.1111/tog.12197 http://onlinelibrary. wiley.com/doi/10.1111/tog.12197/abstract

¹ Owing to small numbers, Isles of Scilly local authority has been merged with Cornwall, and City of London local authority has been merged with Hackney.

² Seaton SE et al. Socioeconomic inequalities in the rate of stillbirths by cause: a population-based study. BMJ Open 2012 Jun 25;2(3). pii: e001100. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3383980/

Map 71: Percentage of preterm babies (<33 weeks' gestational age at birth) who received any maternal breast milk at discharge to home from neonatal care by neonatal network 2013 **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 Lowest Highest Contains National Statistics data © Crown copyright and database right 2015 © Crown copyright and database rights 2015 Ordnance Survey 100016969 100 90 80 70 60 50 40 30 20 10

23 Neonatal Networks

Exclusive breastfeeding of infants up to 6 months is recommended by the World Health Organization and the Department of Health. This is not always possible in the first few weeks following delivery in infants born <33 weeks' gestation due to the lack of nutritive sucking reflex and the clinical condition of infants born at early gestations. The benefits of breast milk, however, in these babies include:

- > reductions in serious gastro-intestinal (necrotising enterocolitis) and systemic infections;
- > improved neurodevelopmental outcomes;
- **>** improvements in maternal bonding and psychology.

In babies born <33 weeks' gestation, breast milk in the short and long term is associated with reduced mortality and morbidity when compared with breast milk substitutes.¹

As medical care advances, more babies born at earlier gestations are surviving for longer into childhood and beyond, resulting in a growing population of children with complex medical needs. The role of breastfeeding in this group has considerable potential for improving population health and increasing value to the NHS by:

- reducing neonatal complications resulting in lifelong morbidity;
- **>** improving neurodevelopmental outcomes.

Many factors influence whether babies receive maternal breast milk during their stay on a neonatal unit and at discharge:

- > maternal health at the time of birth;
- > early lactation support;
- infants' nutritional needs during stay and at time of discharge;
- > neonatal morbidity;
- > production of maternal breast milk.

Preterm infants often have higher nutritional demands than those born at term. To address this, preterm infants may receive supplemented preterm formula, or breast milk that is fortified. Unless mothers are supported and encouraged to fortify breast milk in neonatal units, the need for nutritional supplementation may lead to use of supplemented preterm formula at the expense of breastfeeding.

Mothers of infants admitted to the neonatal unit are more likely to have undergone a traumatic delivery with obstetric complications. Maternal/infant separation and maternal anxiety associated with preterm delivery increase the challenges of initiating and sustaining breast-milk production. These mothers need much more support to initiate the expressing of breast milk, and to establish and maintain breastfeeding.

Magnitude of variation

For neonatal networks in England, the percentage of preterm babies who received any maternal breast milk at discharge to home from neonatal care ranged from 36.2% to 84.1% (2.3–fold variation).²

The reasons for variation in breastfeeding rates among preterm infants are similar to those that influence breastfeeding rates overall: socio-economic status, and ethnicity.

The degree of impact of these social factors in babies born <33 weeks' gestation, however, is substantially less than that in babies born at full term due to the greater emphasis by neonatal units on the immediate short-term benefits of breast milk among preterm neonates.

Options for action

Each neonatal network needs:

- > to identify the proportion of babies born at <33 weeks in the individual units;
- > to establish the proportion of babies who received (i) exclusive breast milk at discharge, and (ii) some breast milk at discharge.

In addition, neonatal networks need to share and implement examples of good practice that have led to an increase in breastfeeding rates at discharge.

Commissioners need to specify that service providers:

- provide adequate support for mothers on neonatal units and on postnatal wards to initiate early expressing of breast milk within 6 hours following delivery;
- > provide support in optimising maternal nutrition to enhance nutritional intake from maternal breast milk and thereby reduce the need for formula supplementation;
- **>** make available appropriate equipment to allow early expression of milk;
- ➤ make available equipment for expressing breast milk following discharge or provide information on pump hire schemes in the community setting;
- allocate appropriate resource to facilitate the role of neonatal outreach staff in supporting ongoing breastfeeding in preterm infants;
- encourage mother-and-baby contact in the neonatal unit through "kangaroo" care to promote breast milk production;
- > identify groups in whom breastfeeding rates are low and target interventions at these groups.

Health professionals need to be aware of the psychological effect of having a preterm infant, and to support mothers in understanding the importance of breast milk/breastfeeding in the care of their babies in a highly medicalised environment.

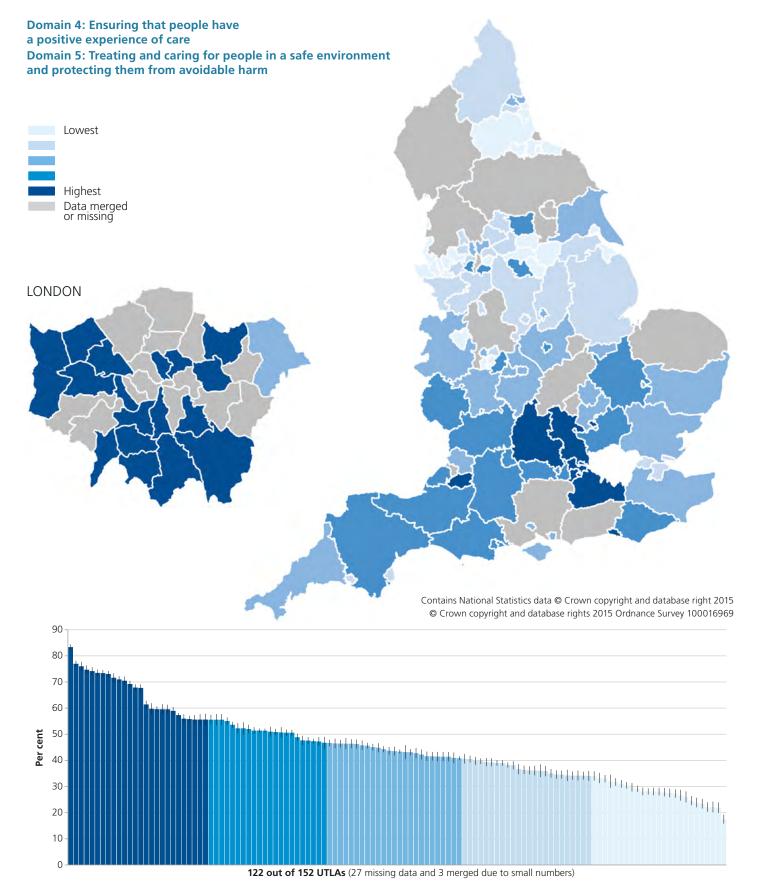
- > Best Beginnings. Resources to support breastfeeding, particularly for babies who require specialist neonatal unit care. http://www.bestbeginnings.org.uk/fbtb-sick-or-pre-term
- ➤ Battersby C, Santhakumaran S, Upton M et al on behalf of the East of England Perinatal Networks, the UK Neonatal Collaborative and the Neonatal Data Analysis Unit. Impact of a regional care bundle on maternal breast milk use in preterm infants: outcomes of the East of England Quality Improvement Programme. Arch Dis Child Fetal Neonatal Ed 2014; 99(5):F395-401.

¹ Renfrew MJ, Craig D, Dyson L, McCormick F, Rice S, King SE et al. Breastfeeding promotion for infants in neonatal units: a systematic review and economic analysis. Health Technol Assess 2009;13(40). http://www.journalslibrary.nihr.ac.uk/__data/assets/pdf_file/0008/64718/FullReport-hta13400.pdf

² Data for the numerator have been provided by the Neonatal Data Analysis Unit, Imperial College London, from the National Neonatal Research Database.

Map 72: Percentage of infants who were totally or partially breastfeeding at 6–8 weeks by upper-tier local authority

2012/13



The World Health Organization (WHO) and the Department of Health recommend exclusive breastfeeding of infants up to the age of six months. Although a minority of babies cannot be breastfeed by reason of maternal health or other problems, 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; and reduced lifetime risk of obesity and diabetes. Women who breastfeed have a reduced risk of ovarian cancer and of breast cancer. Increasing rates of breastfeeding in infants have an overall cost-benefit for families, the NHS and wider society.^{1,2}

This indicator is in the Public Health Outcomes Framework 2013–16, and was recommended as a national outcome measure in the Children & Young People's Outcomes Forum report.

Magnitude of variation

For upper-tier local authorities (UTLAs) in England, the percentage of infants who were totally or partially breastfeeding at 6–8 weeks ranged from 17.5% to 83.3% (4.8-fold variation).³ When the four UTLAs with the highest percentages and the four UTLAs with the lowest percentages are excluded, the range is 23.4–74.2%, and the variation is 3.2-fold (see Table 72.1 for data from 2011/12⁴).

Although the exclusions are not directly comparable, the variation in breastfeeding appears to have persisted at just over threefold in recent years, possibly due to the negative correlation of breastfeeding with some socio-cultural factors.

Breastfeeding is a complex issue. Reasons for the degree of variation observed include differences in the level of deprivation in different localities⁵, the ethnic profile in local populations, and maternal age.

These data suggest that considerable unwarranted variation exists. As many new mothers require support to initiate and sustain breastfeeding, reasons for unwarranted variation may include differences in the provision of, and access to local community midwifery support, health visitor support, and perinatal care.

Options for action

Any commissioning decisions and service changes need to be evidence-based, and take into account the needs of the local population. Commissioners need to specify that service providers review the proportion of infants being breastfed in the local population at 6–8 weeks following delivery:

- > to assess whether performance locally compares favourably with that in other localities with similar populations;
- > to understand the reasons for low rates of breastfeeding;
- to identify any unwarranted variations among social, ethnic or other groups in order to target relevant interventions and resources.

Commissioners need to ensure that local breastfeeding services and interventions are integrated with wider public

health strategies, and with primary and community services.6

Commissioners also need to specify that service providers seek out and share good practice particularly among localities with a similar socio-economic and ethnic profile, ensuring adequate assistance for all mothers and families to establish breastfeeding, and to prolong its duration, including:

- **>** education, both antenatal and postnatal;
- > support through community midwives, health visitor services, GP surgeries, pharmacies and the third sector;
- **>** public health messages about the benefits of breastfeeding.

Service providers need to identify local population groups with low breastfeeding rates in order to implement targeted interventions, not only to change cultural perceptions of breastfeeding but also to provide education and support that addresses socio-cultural factors. See "Resources" for projects in Scotland that used social marketing principles:

- 1. to raise breastfeeding rates among young women in lower socio-economic groups (NHS Ayrshire and Arran);
- to make structural and procedural changes to enable the Breast Feeding Support Team to work better with community midwives and health visitors (NHS Fife).

- NICE. Postnatal care. NICE guidelines [CG37]. December 2014. http://www.nice.org.uk/CG037
- > NICE. Maternal and child nutrition. NICE guidelines [PH11]. March 2008. http://guidance.nice.org.uk/PH11
- National Social Marketing Centre and NHS Health Scotland. North West Kilmarnock Breastfeeding Project. http://www.healthscotland.com/uploads/documents/16561-NorthWestKilmarnockBreastfeedingProject.pdf
- National Social Marketing Centre and NHS Health Scotland. Fife Breastfeeding Support Project. http://www.healthscotland. com/uploads/documents/15848-FifeBreastfeedingSupportProject2011.pdf
- 1 Chief Medical Officer's annual report 2012: Our Children Deserve Better: Prevention Pays. Annex 9: Atlas of Variation in Healthcare for Children and Young People. https://www.gov. uk/government/uploads/system/uploads/attachment_data/ file/252672/33571_2901304_CMO_Chapter_Anx_9.pdf
- 2 Pokhrel S, Quigley MA, Fox-Rushby J et al. Potential economic impacts from improving breastfeeding rates in the UK. Arch Dis Child doi:10.1136/archdischild-2014-306701. http://adc.bmj. com/content/early/2014/11/12/archdischild-2014-306701.full. pdf+html
- 3 Data are missing for 27 UTLAs; for three UTLAs, data have been merged due to small numbers. Isles of Scilly local authority has been merged with Cornwall, City of London local authority has been merged with Hackney, and Rutland local authority has been merged with Leicestershire.
- 4 For data prior to 2011/12, see ChiMat website http://atlas.chimat. org.uk/IAS/dataviews/view?viewId=22 (these data are available by UTLA for 2010/11-2013/14)
- 5 Oakley L et al. Factors associated with breastfeeding in England: an analysis by primary care trust. *BMJ* Open 2013; 3:e002765. http:// bmjopen.bmj.com/content/3/6/e002765.full.pdf+html
- 6 Caroline Wright on behalf of Public Health England. Progress in Breastfeeding in London. 2013 report. http://www.lho.org.uk/ Download/Public/18210/1/Progress%20in%20breastfeeding%20 in%20London%20final%20report%2012%20Aug.pdf

Table 72.1: Percentage of infants who were totally or partially breastfeeding at 6–8 weeks for two consecutive financial years

Financial year	Geography	Range	Fold difference		Fold difference after exclusion	Publication
2012/13	UTLA	17.5-83.3%	4.8	23.4-74.2%	3.2	
2011/12	UTLA	19.7-82.8%	4.2	22.7–75.7%	3.3	CMO's Annual Report 2012 ¹

Map 73: Score rating women's experience of labour and birth by NHS Trust

Directly standardised for age and parity, February 2013 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 Lowest score Highest score LONDON Contains National Statistics data © Crown copyright and database right 2015 © Crown copyright and database rights 2015 Ordnance Survey 100016969 10 8 Score out of 10 4 3 137 NHS Trusts

Women's experiences of birth remain with them for decades and can influence the manner in which they relate to and bond with their baby. The experience of labour and birth, whether "good" or "bad", has considerable implications for a woman's psychological well-being and her relationships with her family.¹⁻⁴ For many women, even those who have given birth before, anticipation of labour and birth can give rise to anxiety, uncertainty and, on occasion, outright fear.

Women can be aided through good antenatal preparation, and especially through continuity of carer. Indeed, women place great value on dedicated one-to-one care from a midwife during labour and birth.⁵

This indicator is based on responses to the Care Quality Commission Maternity Services Survey 2013 from 23,000 women aged 16 years and over who had a live-birth during February 2013.⁶ At the time of survey completion, England was experiencing its highest birth rate for 40 years.

Magnitude of variation

For NHS Trusts in England, the score rating women's experience of labour and birth ranged from 8.0 to 9.4 (1.2–fold variation). When the five NHS Trusts with the highest scores and the five NHS Trusts with the lowest scores are excluded, the range is 8.2–9.2, and the variation is 1.1-fold.

Reasons for the degree of variation observed include differences in:

- access to good-quality antenatal preparation classes this is patchy, and often available only to women who are able to pay for private provision;
- > women's expectations of, and level of preparation for, labour and birth, which will be influenced by their previous experiences, and cultural factors;
- > the extent to which the experience is woman-centred and personalised, including a supportive environment, but in particular the availability of midwives to provide one-to-one care during the active phase of labour and the birth.

Options for action

Commissioners need to specify that service providers:

comply with NICE guidance and quality standard (CG62, QS22 & NG4; see "Resources");

- > include preparation for labour as part of antenatal care;
- > support "continuity of carer" models for the whole package of care – antenatal, labour and birth – because they maximise the potential for positive experiences while minimising interventions";
- > offer choice of midwifery-led birth options for women at low risk of complications, which will reduce intervention rates among this low-risk group and release the obstetricled delivery units for those women who require this type of care (NICE CG190; see "Resources")8;
- > ensure midwifery staffing levels are sufficient to provide one-to-one care from a dedicated midwife for all women in labour irrespective of the prevailing workload.

Clinicians need to bear in mind that, in addition to the health of mother and baby at the end of labour and birth, women and their partners want the overall process to be positive. The way in which care is provided must be respectful, maintain the woman's dignity, and involve her as a central and active participant during the active phase of labour and birth. If interventions or changes to what had originally been planned need to be considered, it is important to involve the woman fully by taking time to provide the relevant information and explore all the options.

- NICE. Intrapartum care: care of healthy women and their babies during childbirth. NICE guidelines [CG190]. December 2014. https://www.nice.org.uk/guidance/cg190
- NICE. Antenatal care. NICE guidelines [CG62]. March 2008. http://www.nice.org.uk/guidance/cg62
- NICE. Antenatal care. NICE quality standard [QS22]. September 2012. https://www.nice.org.uk/guidance/gs22
- NICE pathways. Antenatal care overview. http://pathways.nice.org.uk/pathways/antenatal-care
- NICE. Safe midwifery staffing for maternity settings. NICE guidelines [NG4]. February 2015. http://www.nice.org.uk/guidance/ng4
- NICE pathways. Safe midwifery staffing for maternity settings overview. http://pathways.nice.org.uk/pathways/safemidwifery-staffing-for-maternity-settings
- National Childbirth Trust, Royal College of Midwives and Royal College of Obstetricians and Gynaecologists. Making sense of commissioning Maternity Services in England – some issues for Clinical Commissioning Groups to consider. https://www.rcog. org.uk/globalassets/documents/guidelines/guidelinessupporting-commissioners/advice-to-ccgs.pdf

¹ Grekin R, O'Hara M (2014) Prevalence and risk factors of postpartum posttraumatic stress disorder: A meta-analysis. *Clin Psychol Rev* 34(5): 389-401. http://www.ncbi.nlm.nih.gov/pubmed/24952134

² Wiklund I, Edman G, Ryding D et al (2008) Expectation and experiences of childbirth in primiparae with caesarean section. *British Journal of Obstetrics and Gynaecology* 115(3): 324-31. http://www.ncbi.nlm.nih.gov/pubmed/18190368

³ Lemola S, Stadlmayr W, Grob A (2007) Maternal adjustment five months after birth: the impact of the subjective experience of childbirth and emotional support from the partner. *Journal of Reproductive and Infant Psychology* 25(3): 190-202. http://www.tandfonline.com/doi/abs/10.1080/02646830701467231

⁴ Simkin P. Just another day in a woman's life? Part 1 Women's long tern perceptions of their first birth experience. Birth 1991; 18: 203-210.

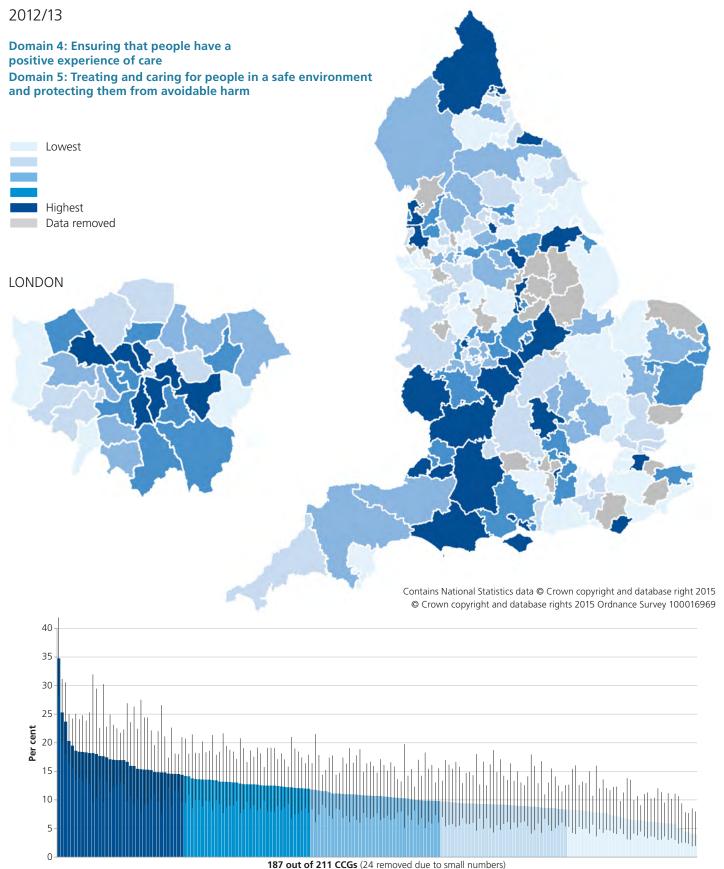
⁵ National Childbirth Trust (2013) Support overdue: women's experiences of maternity services. May 2013. http://www.thewi.org.uk/campaigns/current-campaigns-and-initiatives/more-midwives/?a=49857

⁶ Care Quality Commission Maternity Services Survey 2013. http://www.cqc.org.uk/content/maternity-services-survey-2013

⁷ Sandall J, Soltani H, Gates S et al. 2013. Midwife-led continuity models versus other models of care for childbearing women. *Cochrane Database of Systematic Reviews*, 8, DOI: 10.1002/14651858.CD004667.pub3. http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD004667.pub3/abstract

⁸ Brocklehurst P et al (2011) Perinatal and maternal outcomes by planned place of birth for healthy women with low risk pregnancies: the Birthplace in England national prospective cohort study. *BMJ* 343:7840. http://www.bmj.com/content/343/bmj.d7400

Map 74: Percentage of re-admissions to hospital following an elective Caesarean section that occurred within 28 days of discharge by CCG



Elective (or planned) Caesarean sections are those scheduled before the onset of labour¹, and are usually planned at least 48 hours in advance. In England, around 10% of all deliveries are carried out by elective Caesarean section.²

Elective Caesareans are performed for many reasons, including breech presentation, a small-for-gestational-age fetus, placental insufficiency or abnormality, elective repeat Caesarean section, and maternal request. When compared with emergency Caesarean section, elective Caesarean section offers an opportunity to anticipate and prevent complications as much as possible.

Re-admission to hospital following an elective Caesarean section can be for a variety of maternal reasons: surgical site infection, chest or womb infection, urinary tract infection, uncontrolled postoperative pain, anaemia requiring a blood transfusion, venous thrombo-embolism, mental health conditions or, very rarely, visceral damage from the surgery. It can also occur for lactation problems or complications arising in the baby, where the mother is well but needs to be close and for this reason is accommodated on the postnatal ward. The emotional and social consequences of any re-admission arise from the length of time for which a new family is apart from one another.

Magnitude of variation

For CCGs in England, the percentage of re-admissions to hospital following an elective Caesarean section that occurred within 28 days of discharge ranged from 4.0% to 34.8% (8.7-fold variation).³ When the six CCGs with the highest percentages and the six CCGs with the lowest percentages are excluded, the range is 5.8–18.4%, and the variation is 3.2-fold.

One reason for the degree of variation observed is differences in the demography of local populations. Levels of obesity, smoking rates, co-morbidities (such as gestational or Type 1 or Type 2 diabetes) and socio-economic deprivation will have a direct impact on surgical complications. Higher rates of smoking and obesity will contribute to wound infection, endometritis and venous thrombo-embolism.

The degree of variation may also reflect different models of postnatal care, with some CCGs managing minor complications in the community, whereas others will rely to a greater extent on hospital services.

High re-admission rates may reflect a higher incidence of localised infections or difficulties in the education of breastfeeding, which may be the result of either discharge too soon from hospital or inadequate community support. Low re-admission rates could reveal reduced capacity in hospital; higher thresholds for re-admission may exist where there are bed shortages, particularly for borderline cases. These conflicting interpretations raise the issue of whether re-admission rates are valid measures of quality of care.

Options for action

To reduce re-admission rates, commissioners need to:

place managed networks of community care into quality frameworks – a managed network of care that integrates

- community midwifery, health visitors, physiotherapists and general practitioners may be effective in reducing hospital re-admissions by tackling minor problems in the community, or offering near-patient testing to reduce the need for hospital-based tests;
- > consider appropriate commissioning of enhanced community services to deal with specific problems related to re-admission.

Commissioners also need to specify that service providers:

- > introduce a surgical checklist, including antibiotic administration;
- conduct clinical audit to determine local reasons for re-admission:
- > consider local integration of re-admission data into maternity dashboard;
- > review clinical pathways for re-admission and consider a joint hospital-community protocol for management of specific conditions;
- **>** consider the cost-effectiveness of offering alternative accommodation to mothers who are attending hospital only to look after a baby who has been re-admitted.

Clinicians need to ensure that:

- **>** women have appropriate advice relevant to their specific medical condition, and are prescribed appropriate prophylaxis (for venous thrombo-embolism or wound infection) following a risk assessment;
- **>** handover documentation is complete to avoid data loss during the transition to a community healthcare provider.

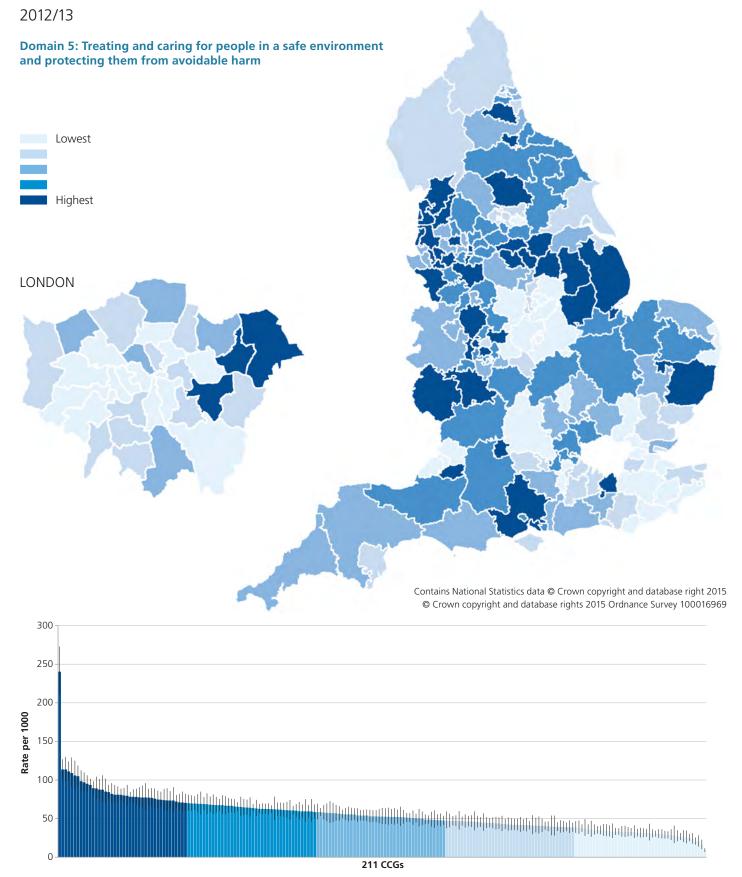
- NICE. Postnatal care. NICE guidelines [CG37]. December 2014. https://www.nice.org.uk/guidance/cg37
- NICE. Caesarean section. NICE guidelines [CG132]. November 2011. https://www.nice.org.uk/guidance/cg132
- NICE. Maternal and child nutrition NICE guidelines [PH11]. March 2008. https://www.nice.org.uk/guidance/ph11
- Royal College of Obstetricians and Gynaecologists. Reducing the Risk of Venous Thromboembolism during Pregnancy and the Puerperium. Green-top Guideline No. 37a. April 2015. https://www.rcog.org.uk/globalassets/documents/ guidelines/gtg-37a.pdf
- Royal College of Obstetricians and Gynaecologists. Maternity Dashboard: Clinical Performance and Governance Score Card. Good Practice No. 7. January 2008. https://www.rcog.org.uk/globalassets/documents/ guidelines/goodpractice7maternitydashboard2008.pdf
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¹ NICE. Postnatal care. NICE guidelines [CG37]. December 2014. https://www.nice.org.uk/guidance/cg37

² Health and Social Care Information Centre. NHS Maternity Statistics – England, 2012-13. http://www.hscic.gov.uk/catalogue/PUB12744

³ Data from 24 CCGs have been removed due to small numbers.

Map 75: Rate of emergency admissions to hospital of babies within 14 days of being born per number of deliveries by CCG



In a review of maternity services in England, the Healthcare Commission 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."1

Postnatal care provision crosses acute and primary healthcare sectors, with the majority of care taking place in the mother'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.

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

Magnitude of variation

For CCGs in England, the rate of emergency admissions to hospital of babies within 14 days of being born ranged from 9.0 to 240.3 per 1000 deliveries (26.7-fold variation). When the seven CCGs with the highest rates and the seven CCGs with the lowest rates are excluded, the range is 26.4–98.4 per 1000 deliveries, and the variation is 3.7-fold.

The data for 2011/12 by upper-tier local authority were relatively similar: after exclusions, the range was 24.3 to 107.1 per 1000 deliveries, and the variation was 4.5-fold.²

The degree of variation observed may be related to differences in:

- **>** access to routine clinical examination, and appropriate duration of postnatal observation of the woman and her baby;
- **>** access to routine infant screening to detect potential disorders:
- **>** access to support for infant feeding in the immediate postnatal period;
- ongoing provision of information and support in the community;
- > thresholds for referral and admission to hospital in emergency departments.

Options for action

Commissioners need to specify that service providers deliver antenatal education and information to parents.

Commissioners also need to specify that service providers implement 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;
- early postnatal discharge should occur only for low-risk deliveries and babies, and only where early postnatal community midwifery support is available.

Individualised assessments of mother and infant should be undertaken as soon as possible after delivery. 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;
- > to understand who to contact for further information and advice.

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 (see "Resources"), including:

- > prompt evaluation and treatment for babies who develop jaundice, especially within the first 24 hours;
- **>** for babies aged ≥24 hours, monitoring and systematically recording the intensity of the jaundice together with the baby's overall well-being with particular regard to hydration and alertness.

Healthcare professionals need to encourage the mother of a breastfed baby who has signs of jaundice to breastfeed frequently; if the baby is significantly jaundiced or appears unwell, evaluation of the serum bilirubin level should be carried out.

- > NICE. Postnatal care. NICE guidelines [CG37]. December 2014. http://www.nice.org.uk/CG037
- > NICE. Neonatal jaundice. NICE guidelines [CG98]. May 2010. https://www.nice.org.uk/guidance/cg98
- > Baby Friendly Initiative. http://www.babyfriendly.org.uk
- Royal College of Obstetricians and Gynaecologists. Standards for Maternity Care. Published 1/06/2008. http://www.rcog.org.uk/ womens-health/clinical-guidance/standards-maternity-care

¹ Healthcare Commission (2008) Towards better births: A review of maternity services in England.

Chief Medical Officer's annual report 2012: Our Children Deserve Better: Prevention Pays. Annex 9: Atlas of Variation in Healthcare for Children and Young People. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/252672/33571_2901304_CMO_Chapter_ Anx_9.pdf

Map 76: Percentage of immunisation completion for routine vaccinations against diphtheria, tetanus, pertussis, polio and Haemophilus influenzae type b (DTaP/IPV/Hib) at 2 years by upper-tier local authority 2012/13 **Domain 1: Preventing people from dying prematurely** Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm Lowest Highest Data merged LONDON Contains National Statistics data © Crown copyright and database right 2015 © Crown copyright and database rights 2015 Ordnance Survey 100016969 100 90 80 70 60 50 40 30 20 10

149 out of 152 UTLAs (3 merged due to small numbers)

"Vaccination has greatly reduced the burden of infectious diseases. Only clean water, also considered to be a basic human right, performs better."1

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 levels of population immunity to some infectious diseases may protect those who are not immunised, an effect known as "herd immunity".

Vaccines are cost-effective, and the economic benefits of the vaccines currently included in the routine childhood immunisation schedule for England have been demonstrated.2

Despite concerted efforts to promote uptake, opportunities for immunisation are missed.3,4 Increased investment, such as in Surestart programmes, does not guarantee:

- > improvement in overall rates⁵;
- > reduction of socio-economic inequalities in uptake⁶.

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, rotavirus, pneumococcus, measles, mumps and rubella (German measles).

Three vaccinations have been selected for visualisation, showing rate of:

- > completion at 2 years for combined 5-in-1 vaccine for diphtheria, tetanus, pertussis, polio and Haemophilus influenzae type b (DTaP/IPV/Hib);
- > completion at 2 years for pneumococcal conjugate vaccine (PCV)
- > coverage at 2 years for measles, mumps and rubella (MMR) vaccine.

"Population vaccination coverage" is included in the Public Health Outcomes Framework 2013-16.

Magnitude of variation

Map 76: DTaP/IPV/Hib vaccine (page 204)

For upper-tier local authorities (UTLAs) in England, the percentage of immunisation completion for routine vaccinations against DTaP/IPV/Hib at 2 years ranged from 81.9% to 99.4% (1.2-fold variation).7 When the five UTLAs with the highest percentages and the five UTLAs with the lowest percentages are excluded the range is 89.9% to 98.8%, and the variation is 1.1-fold (see Table 76.1 for data from 2011/128).

This means that the percentage of children who did **not** receive the full course of DTaP/IPV/Hib vaccination ranged from 0.6% to 18.1% (30-fold variation); when the five UTLAs with the highest percentages and the five UTLAs with the lowest percentages are excluded, the range is 1.2% to 10.1% and the variation is 8-fold (see Table 76.2 for data from 2011/128).

Map 77: PCV vaccine (page 207)

For UTLAs in England, the percentage of immunisation completion for routine vaccinations against PCV at 2 years ranged from 75.1% to 97.5% (1.3-fold variation).7 When the five UTLAs with the highest percentages and the five UTLAs with the lowest percentages are excluded the range is 82.0-96.9%, and

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://ia201119.eu.archive.org/ tna/20061004085342/hpa.org.uk/hpa/publications/HPA_protect_health_children/protect_health_children.htm

³ Conway SP (1999) Opportunistic immunisation in hospital. Archives of Diseases in Childhood 81:422 doi:10.1136/adc.81.5.422. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1718117/pdf/v081p00422.pdf

⁴ Walton S, Elliman D, Bedford H (2007) Missed opportunities to vaccinate children admitted to a paediatric tertiary hospital. Archives of Diseases in Childhood 92:620 doi:10.1136/adc.2006.104778. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2083800/pdf/620.pdf

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. http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(08)61687-

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 Owing to small numbers, Isles of Scilly local authority has been merged with Cornwall, City of London local authority has been merged with Hackney, and Rutland local authority has been merged with Leicestershire.

⁸ For data from 2009/10 by PCT, see Child Health Atlas, Maps 2-4, pages 24-27.

the variation is 1.2-fold (see Table 77.1 for data from 2011/128).

This means that the percentage of children who did **not** receive the full course of PCV vaccination ranged from 2.5% to 24.9% (10-fold variation); when the five UTLAs with the highest percentages and the five UTLAs with the lowest percentages are excluded, the range is 3.1% to 18.0%, and the variation is 6-fold (see Table 77.2 for data from 2011/12⁸).

Map 78: MMR vaccine (page 208)

For UTLAs in England, the percentage of immunisation coverage for routine vaccinations against MMR at 2 years ranged from 77.4% to 98.4% (1.3-fold variation).⁷ When the five UTLAs with the highest percentages and the five UTLAs with the lowest percentages are excluded, the range is 82.8–96.9%, and the variation is 1.2-fold.⁸

This means that the percentage of children who did **not** receive the full course of MMR vaccination ranged from 1.6% to 22.6% (14-fold variation); when the five UTLAs with the highest percentages and the five UTLAs with the lowest percentages are excluded, the range is 3.1–17.2%, and the variation is 5.5-fold.

In comparison with 2011/12 data available for two of the indicators (combined DTaP/IPV/Hib vaccine and PCV vaccine), it would appear that the degree of variation observed has not diminished.

These data mask an overall improvement in vaccination coverage, in terms of median performance as well as in the range shifting (after exclusions) towards higher proportions of vaccinations. Although encouraging, the data highlight there is further scope for ensuring equitable uptake of vaccinations across England.

Table 76.1: Percentage of immunisation completion for routine vaccinations against DTaP/IPV/Hib at 2 years for two financial years

Financial year	Geography	Range	Fold difference		Fold difference after exclusion	Publication
2012/13	UTLA	81.9-99.4%	1.2	89.9-98.8%	1.1	
2011/12	UTLA	85.7-98.8%	1.2	90.0-98.6%	1.1	CMO's Annual Report 2012 ⁹

Table 76.2: Percentage of children at 2 years who did not receive the full course of DTaP/IPV/Hib vaccination for two financial years

Financial year	Geography	Range	Fold difference		Fold difference after exclusion	Publication
2012/13	UTLA	0.6-18.1%	30	1.2-10.1%	9	
2011/12	UTLA	1.2-14.3%	12	1.4-10.0%	7	CMO's Annual Report 20129

Table 77.1: Percentage of immunisation completion for routine vaccinations against PCV at 2 years for two financial years

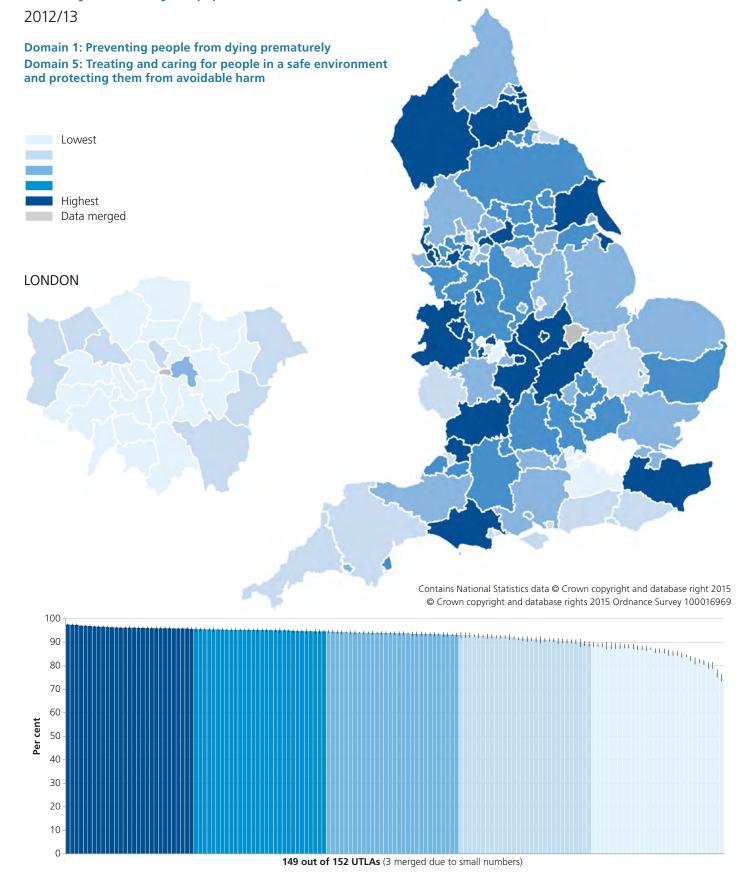
Financial year	Geography	Range	Fold difference		Fold difference after exclusion	Publication
2012/13	UTLA	75.1–97.5%	1.3	82.0-96.9%	1.2	
2011/12	UTLA	74.7-97.0%	1.3	81.1-96.3%	1.2	CMO's Annual Report 20129

Table 77.2: Percentage of children at 2 years who did not receive the full course of PCV vaccination for two financial years

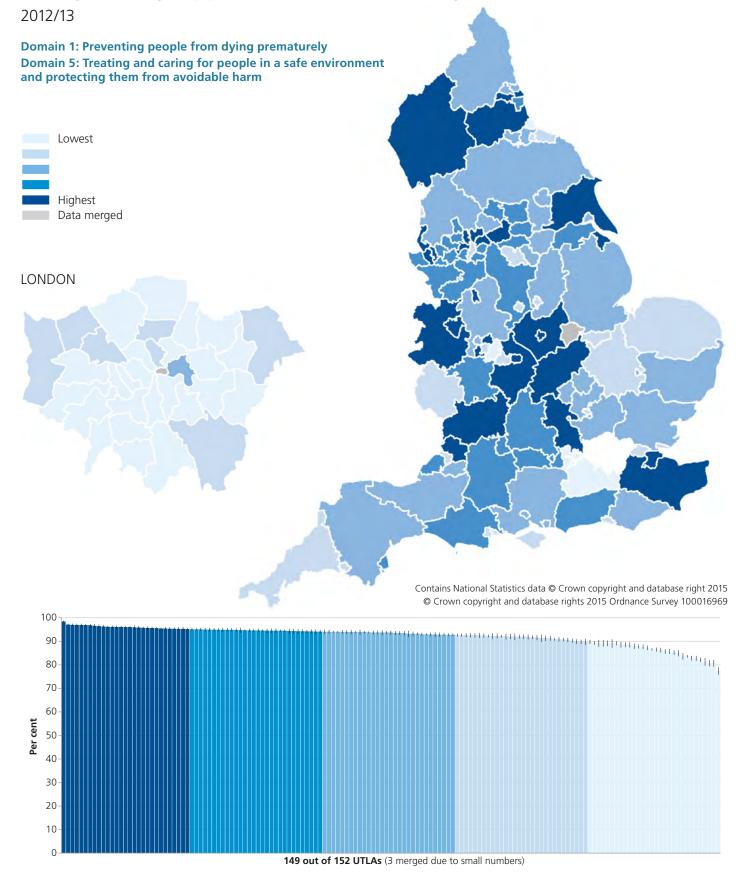
Financial year	Geography	Range	Fold difference		Fold difference after exclusion	Publication
2012/13	UTLA	2.5-24.9%	10	3.1-18.0%	6	
2011/12	UTLA	3.0-25.3%	8	3.7-18.9%	5	CMO's Annual Report 2012 ⁹

⁹ Chief Medical Officer's annual report 2012: Our Children deserve Better: Prevention Pays. Annex 9: Atlas of Variation in Healthcare for Children and Young People. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/252672/33571_2901304_CMO_Chapter_Anx_9.pdf

Map 77: Percentage of immunisation completion for routine vaccinations against pneumococcal disease (PCV) at 2 years by upper-tier local authority



Map 78: Percentage of immunisation coverage for routine vaccinations against measles, mumps and rubella (MMR) at 2 years by upper-tier local authority



Possible reasons for the degree of variation observed in the uptake of immunisation include differences in:

- **>** access to immunisation services;
- > families' cultural and/or religious beliefs;
- **>** families' perceptions of the risks associated with vaccination.

Options for action

NICE recommends that commissioners ensure local systems for information and data collection can identify children who have missed immunisations, and offer parents or carers the opportunity for their child to receive them in a timely manner (see "Resources").

Although the improvements shown in the population coverage for certain vaccines is welcome, they may not reflect a uniform improvement across all population subgroups. Commissioners need to specify that service providers target at-risk groups for improvement in immunisation rates, particularly among children who:

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

To increase immunisation uptake in groups in whom it is low, NICE (see "Resources") recommends:

- **>** improving access to immunisation services, such as by extending clinic times, and ensuring that clinics are "child friendly";
- **>** providing parents or carers with tailored information and support, and the opportunity to discuss any concerns they might have;
- > checking a child's immunisation status during health appointments and when they join nurseries, playgroups or schools, and offering them vaccination(s).

When working to increase uptake rates, it is important to bear in mind that the reasons why some children undergo partial immunisation may be different from those given by people who refuse to have their children immunised with one or more vaccines.¹⁰

To improve and maximise immunisation rates at a population level, especially in light of recent changes in the structure and organisation of commissioning and public health in England, there is a need for:

- > clinical leadership among public health, primary care and secondary care health professionals;
- > effective joint working among organisations and professionals.

The role of child public health, currently the least wellrepresented specialist function of community paediatric teams¹¹, is vital to the promotion of child health in general, and of immunisation as a key aspect of child health promotion.

CASE-STUDIES

- > NHS Manchester Immunisation Promotion Project (IPP): Adopting 'active patient management principles' (see Casestudy 3, page 264)
- **>** For a report on increasing the uptake of MMR vaccinations in London using social marketing principles, see "Resources"

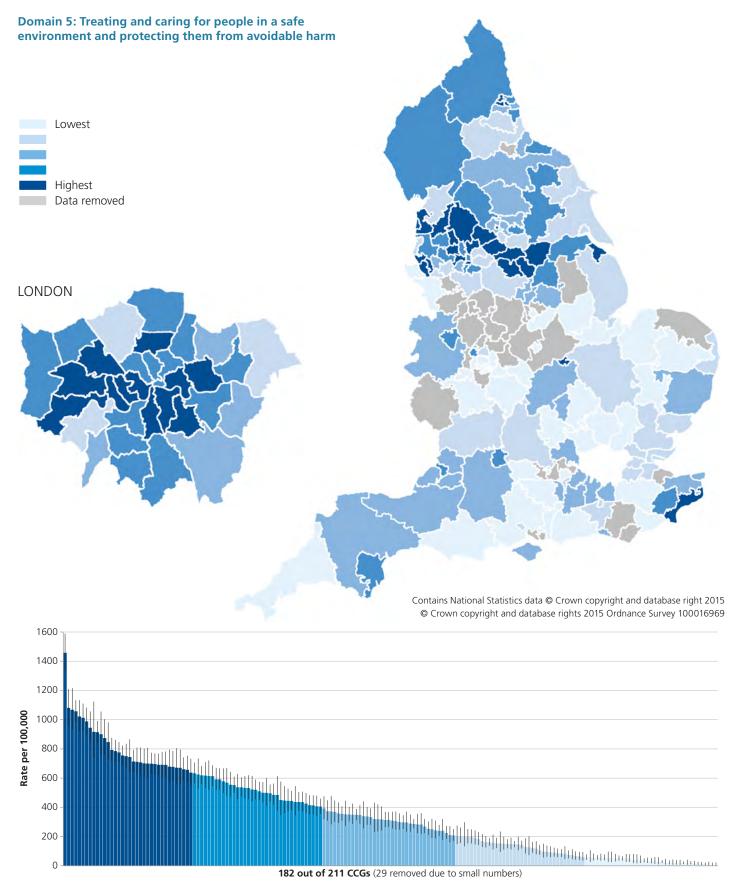
- **>** NICE. Reducing differences in the uptake of immunisations. NICE guidelines [PH21]. September 2009. http://www.nice.org.uk/PH21
- **>** Commissioning Support for London. Increasing the uptake of MMR in London. Report of social marketing project. November 2009. http://www.londonhp.nhs.uk/wpcontent/uploads/2011/03/MMR-Social-Marketing-Project-Report-Nov09.pdf
- > Chisnell J on behalf of Devon County Council. Factors influencing vaccination uptake. Literature Review. June 2014. http://www.england.nhs.uk/south/wp-content/ uploads/sites/6/2014/08/influe-vacc-lit-rev.pdf

¹⁰ 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. prospective cohort study. British Medical Journal 332:1312. http://www.ncbi.nlm.nih.gov/pmc/articles/ PMC1473111/pdf/bmj33201312.pdf

¹¹ Royal College of Paediatrics and Child Health. Medical Workforce Census 2011. June 2013, RCPCH, London. http://www.rcpch.ac.uk/system/files/ protected/page/RCPCH%20census%20FINAL_0.pdf

Map 79: Rate of admission to hospital for dental caries in children aged 1–4 years per population by CCG

Age-specific rate, 1–4 years, 2010/11–2012/13



Tooth decay in childhood is common, but preventable. Early childhood caries can have considerable impact on the health and well-being of pre-school children, and represents a sizeable burden on healthcare services in the form of emergency hospital and dental attendances, hospitalisation and operative intervention.

The occurrence of early childhood caries is a public health problem that is multifactorial in origin. It is associated with socioeconomic deprivation, but has specific risk factors that include a diet rich in fermentable carbohydrates, poor oral hygiene practices, and the acquisition of specific cariogenic bacteria.¹

Dental health in England has improved over the past 50 years, as a result of public health interventions such as oral health education, dietary changes and improved access to dental services. Despite these improvements, dental health remains a problem particularly among the most-deprived population groups.

Dental extraction in children under 5 years old cannot usually be done safely outside the hospital setting; for most cases, it requires in-hospital support for anaesthesia. This indicator includes, therefore, the majority of elective dental extractions in this age-group, as well as emergency admissions for caries.

"Tooth decay in children aged 5" is included in the Public Health Outcomes Framework 2013-16.

Magnitude of variation

For CCGs in England, the rate of admission to hospital for dental caries in children aged 1-4 years ranged from 0 to 1458 per 100,000 population.² When the six CCGs with the highest rates and the six CCGs with the lowest rates are excluded, the range is 15–988 per 100,000 population, and the variation is 66.0-fold (see Table 79.1 for data from 2011/12 by local authority).

There are marked socio-economic inequalities associated with oral health, related to:

- **>** an increased risk of developing caries;
- **>** poor access to dental care.

Although the rate of admission for dental caries is correlated with deprivation, the degree of variation observed is very high, and cannot be explained by population factors alone.

Reasons for unwarranted variation include differences in:

> preventive and public health interventions in the population;

- **>** early recognition of children at risk of developing dental caries:
- **>** access to dental care:
- assessment of dental emergencies and criteria for admission for operative intervention.

Options for action

The hospital admission rate is only one indicator of the state of dental health among children and young people, and it is highly likely to under-estimate the population prevalence of disease.

Commissioners and local authorities need:

- > to monitor closely the dental health of their local population of young children, including prevalence and incidence data;
- > to promote public education on dental health, including dietary choices, oral hygiene and regular dental review;
- > to maximise access to dental services and early interventions, in particular among at-risk groups such as deprived populations;
- > to prioritise evidence-based preventive interventions, such as water fluoridation.

Commissioners need to specify that service providers follow NICE guidance (see "Resources"), including:

- > undertaking oral health needs assessments;
- > developing a local strategy on oral health;
- **>** delivering community-based interventions and activities.

- > NICE (2002). Oral health promotion: A guide to effective working in pre-school settings. http://www.nice.org.uk/proxy/?source Url=http%3a%2f%2fwww.nice.org.uk%2fnicemedia%2fd ocuments%2fohp_preschool.pdf
- NICE. Oral health: approaches for local authorities and their partners to improve the oral health of their communities. Guidelines [PH55] October 2014. http://www.nice.org.uk/guidance/PH55
- **>** European Academy of Paediatric Dentistry (2008). Guidelines on prevention of early dental caries: An EAPD Policy Document. http://www.eapd.eu/dat/1722F50D/file.pdf
- SIGN. Dental interventions to prevent caries in children. Guideline No 138, March 2014. http://www.sign.ac.uk/guidelines/ fulltext/138/index.html

Table 79.1: Rate of admission to hospital for dental caries in children aged 1-4 years per 100,000 population for two time-periods

Time-period	Geography	Range	Fold difference		Fold difference after exclusion	Publication
2010/11–2012/13	CCG	0-1458	-	15–988	66	
2009/10–2011/12	Upper-tier local authority	7–1550	221	26–1041	40	CMO's Annual Report 2012 ³

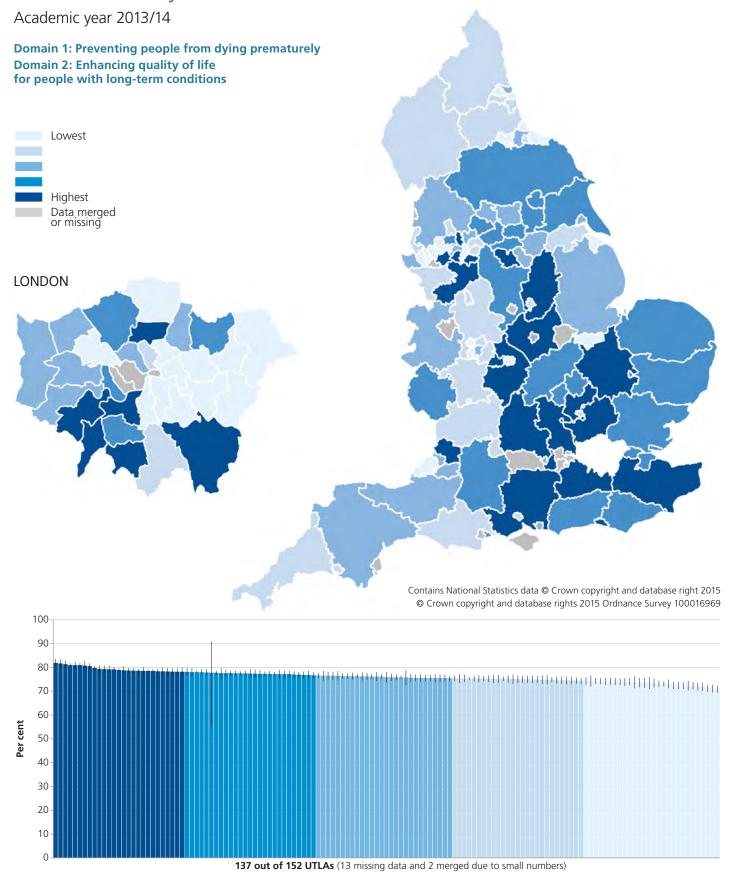
¹ Harris R, Nicoll AD, Adair PM, Pine CM. Risk factors for dental caries in young children: a systematic review of the literature. Community Dental Health 2004; 21:71-85. http://www.who.int/oral_health/media/en/orh_cdh_0304_05_risk_factors.pdf

Data for 29 CCGs have been removed due to small numbers.

Chief Medical Officer's annual report 2012: Our Children Deserve Better: Prevention Pays. Annex 9: Atlas of Variation in Healthcare for Children and

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/252672/33571_2901304_CMO_Chapter_Anx_9.pdf

Map 80: Percentage of pupils in school Reception Year (aged 4–5 years) with healthy weight by upper-tier local authority



Obesity is a considerable public health problem, both in England and globally, and there is strong evidence of a positive association between obesity and an increased risk of mortality.¹

Childhood obesity presents a particular challenge for two main reasons:

- ➤ childhood obesity rates have been steadily increasing for the past decade; data for pupils in school Year 6 show annual increases in obesity prevalence by 0.32% per year², although there is some evidence to suggest that rates may now be reaching a plateau;
- it is associated with an increased risk of obesity/overweight in adulthood.

Obesity is strongly associated with poor physical and emotional health, including:

- > Type 2 diabetes mellitus;
- > non-alcoholic liver disease, the most common chronic disease of the liver in children and young people in countries with developed economies;
- **>** lower self-reported physical and psychosocial well-being;
- an increased lifetime risk of cardiovascular disease, and of certain cancers.

The causes of obesity are complex and multifactorial. Rates of obesity vary among age-groups, between genders, and by geographical distribution and socio-economic status. Over the past few years, social inequalities in obesity appear to have been increasing.²

An overview of the social and biological aspects of obesity is provided in the Foresight report (see "Resources").

The National Child Measurement Programme (NCMP) measures the height and weight of over one million children aged 4–5 and 10–11 years each year in primary schools in England. These surveillance data can help to increase understanding of the patterns and trends in underweight, healthy weight, overweight, and obesity among children.

Excess weight in 4–5 and 10–11 year-olds is included in the Public Health Outcomes Framework 2013–16.

For this indicator, healthy weight is defined as a body mass index (BMI) greater than the 2nd centile but less than the 85th centile of the UK90 growth reference.

Magnitude of variation

Map 80: Healthy weight in pupils in school Reception Year

For upper-tier local authorities (UTLAs) in England, the percentage of pupils in school Reception Year (aged 4–5 years) with healthy weight ranged from 70.9% to 81.9% (1.2-fold variation).³ When the five UTLAs with the highest percentages and the five UTLAs with the lowest percentages are excluded, the range is 72.3–80.9%, and the variation is 1.1-fold.

This means that across England, after exclusions, 19.1–27.7% of 4–5 year-old children are an unhealthy weight (overweight, obese or underweight; 1.6-fold variation), which equates to 2–3 children in every ten 4–5 year-olds. The UTLA data for 2011/12 were similar: after exclusions, the range was 17.8–26.8% (1.5-fold variation).⁴

Map 81: Healthy weight in pupils in school Year 6

For UTLAs in England, the percentage of pupils in school Year 6 (aged 10–11 years) with healthy weight ranged from 52.4% to 75.3% (1.4-fold variation).⁵ When the five UTLAs with the highest percentages and the five UTLAs with the lowest percentages are excluded, the range is 57.0–71.3%, and the variation is 1.2-fold.

This means that across England, after exclusions, 28.7–43.0% of 10–11 year-old children are an unhealthy weight (overweight, obese or underweight; 1.5-fold variation), which equates to 3–4 children in every ten 10–11 year-olds. The UTLA data for 2011/12 were similar: after exclusions, the range was 28.1–40.6% (1.4-fold variation).⁴

The degree of variation observed in healthy weight is related to differences in the level of deprivation, which in turn is associated with children's diet and level of physical activity.

For both age-groups, there is a clear association between obesity and living in an area of deprivation, with obesity prevalence among the most deprived 10% of areas nearly twice that among the least deprived 10% of areas. Moreover, the inequalities gap appears to be increasing:

- among children in school Year 6, the prevalence of obesity has been stable for the least deprived, but has been steadily increasing from 2006/07 to 2012/13 among the most deprived (see Figure 81.1, page 214);
- > a similar disparity is seen for children in school Reception Year, with obesity prevalence remaining unchanged during that period for the most deprived, but a steady reduction among the least deprived.

For children classed as overweight, there is no such relationship with deprivation, either in school Reception Year or in school Year 6. This would suggest that progression from overweight to obesity is more common in children from more-deprived areas.

¹ Berrington de Gonzalez A, Hartge P, Cerhan JR et al. Body-mass index and mortality among 1.46 million white adults. N Engl J Med. 2010; 363: 2211–9. [PMID: 21121834]. http://www.nejm.org/doi/pdf/10.1056/NEJMoa1000367

² Public Health England (PHE) Obesity. http://www.noo.org.uk. [Accessed 11th Feb 2015].

³ Data from 13 UTLAs are missing; for 2 UTLAs, owing to small numbers, Isles of Scilly local authority has been merged with Cornwall, and City of London local authority has been merged with Hackney.

⁴ Chief Medical Officer's annual report 2012: Our Children deserve Better: Prevention Pays. Annex 9: Atlas of Variation in Healthcare for Children and Young People. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/252672/33571_2901304_CMO_Chapter_ Anx_9.pdf

⁵ Data from seven UTLAs are missing; for two UTLAs, owing to small numbers, Isles of Scilly local authority has been merged with Cornwall, and City of London local authority has been merged with Hackney.

There is also variation in healthy weight by ethnic group, which is independent of the level of deprivation.

Other potential reasons for the degree of variation observed include differences in:

- local food environments (see "Resources" for a link to a map of density of fast food outlets in relation to deprivation);
- access to green space and other environments for physical activity;
- **>** parental knowledge and education.

Options for action

To increase the proportion of children with healthy weight, commissioners, service providers and local Health and Wellbeing Boards in partnership need:

- > to review the proportions of overweight and obese children and young people in local populations, and compare them with those in demographically similar localities;
- > to ascertain whether local variations are warranted or unwarranted;
- > to develop or refine a local strategy for reducing obesity including promoting targeted interventions for the most deprived populations such interventions are likely to yield greatest reward, particularly those interventions addressing the progression from overweight to obesity.

The NCMP has an online tool (see "Resources") that can be used to investigate prevalence of underweight, healthy weight, overweight, and obesity for children in school Reception Year (age 4–5 years) and school Year 6 (age 10–11 years) at local authority level; data from 2006/07 to 2013/14 are now available. Data quality indicators are also available.

Treatment of obesity in children and young people is complicated by the fact that reducing caloric intake alone may interfere with growth and development. There is evidence that a coordinated and multi-component approach involving both healthy eating and physical activity can be effective, particularly if implemented as part of a school- or family-

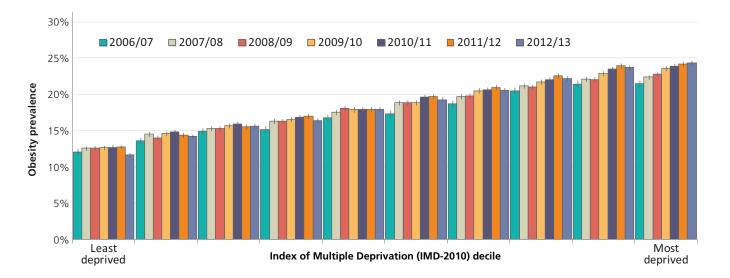
based initiative, and delivered by adequately resourced and trained community- and school-based professionals.

NICE have produced evidence-based guidance on a life-course, pathway approach to prevention and interventions for obesity (see "Resources"). A life-course approach is also promoted in the national strategy for action on obesity in England "Healthy Lives, Healthy People" (see "Resources").

Evidence on interventions and policy is available in the Foresight report (see "Resources").

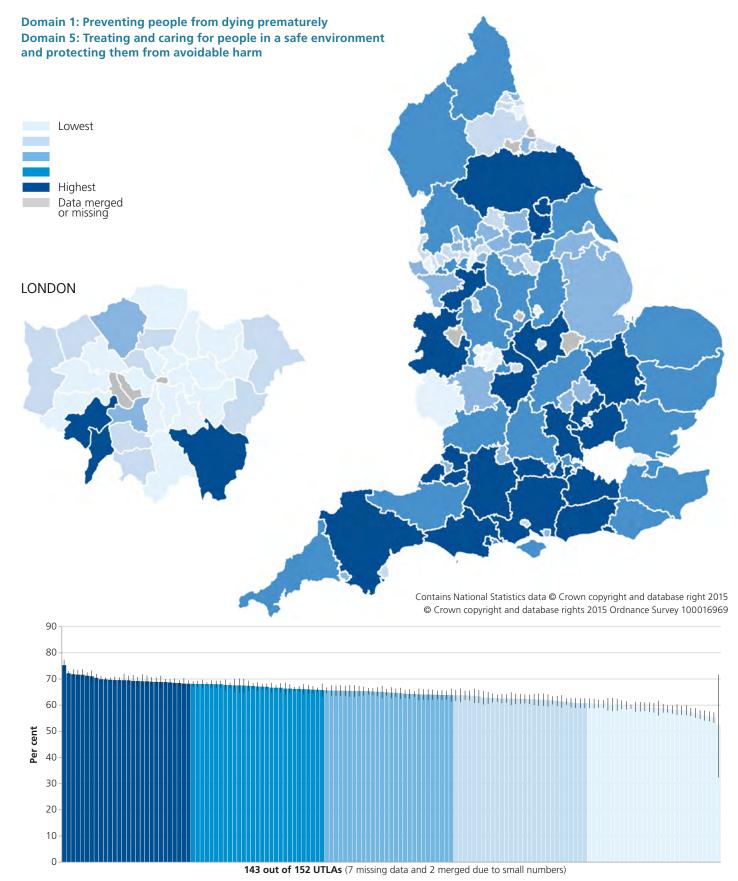
- Public Health England National Child Measurement Programme (NCMP). NCMP Local Authority Profile. http://fingertips.phe. org.uk/profile/national-child-measurement-programme
- Government Office for Science. Foresight Report: Tackling Obesities – Future Choices. 2007. http://www.bis.gov.uk/ assets/foresight/docs/obesity/17.pdf
- Public Health England (PHE) Obesity data and tools. http://www.noo.org.uk/visualisation
- Ridler C, Dinsdale H, Rutter H. National Child Measurement Programme: Changes in children's body mass index between 2006/7 and 2011/12. 2013. Oxford: National Obesity Observatory. http://www.noo.org.uk/uploads/doc/vid_17929_NCMP_ Changes_children.pdf
- Department of Health. Healthy Lives, Healthy People: A call to action on obesity in England. London. 2011 https://www.gov. uk/government/uploads/system/uploads/attachment_data/ file/134840/dh_130487.pdf.pdf
- NICE. Obesity: Guidance on the prevention of overweight and obesity in adults and children. NICE guidelines [CG43]. December 2006. http://www.nice.org.uk/cg043
- NICE. Obesity: identification, assessment and management of overweight and obesity in children, young people and adults. NICE guidelines [CG189]. November 2014. This guidance updates and replaces section 1.2 of NICE CG43 (see above). http://www.nice.org.uk/guidance/cg189
- Public Health England (PHE) Guide to online tools for valuing physical activity, sport and obesity programmes. October 2014. http://www.noo.org.uk/securefiles/150211_1446//online_ tools_briefing_13011_%20FINAL.PDF
- Public Health England (PHE). Obesity and the environment. Fast food outlets. Relationship between density of fast food outlet and deprivation by local authority. http://www.noo.org.uk/ uploads/doc/vid_15683_FastFoodOutletMap2.pdf

Figure 81.1: Obesity prevalence by deprivation decile and year of measurement: children in school Year 6 (aged 10–11 years) 2006/07–2012/13 (Public Health England. Patterns and trends in child obesity. A presentation of the latest data on child obesity. 2014. http://www.noo.org.uk/gsf.php5?f=14604&fv=19565)



Map 81: Percentage of pupils in school Year 6 (aged 10–11 years) with healthy weight by upper-tier local authority

Academic year 2013/14



Map 82: Percentage of children and young people aged 0–24 years with diabetes in the National Paediatric Diabetes Audit (NPDA) whose median HbA1c measurement was less than 58 mmol/mol (7.5%) by paediatric diabetes unit 2012/13 Domain 2: Enhancing quality of life for people with long-term conditions Lowest Highest No data LONDON Contains National Statistics data © Crown copyright and database right 2015 © Crown copyright and database rights 2015 Ordnance Survey 100016969 100 90 80 70 60 Per cent 50 40 30 20

162 out of 163 Paediatric Diabetes Units (1 removed due to incomplete data)

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. Until August 2015, national and international guidance recommended an HbA1c of lower than 58 mmol/mol for children with diabetes. Recent NICE guidance has reduced this threshold further to 48 mmol/mol. The data presented here will therefore underestimate the proportion of children with suboptimal glycaemic control and who are at risk of complications. 1,2

The National Paediatric Diabetes Audit (NPDA) publish outcomes for children and young people with diabetes in England annually. These data here come from the 2012/13 audit. As accurate 2013/14 data become available, this indicator will be updated in the online InstantAtlas.

Data from the NPDA show that only 15.9% of children and young people with diabetes in England in 2012/13 had an HbA1c value within the recommended target level of <58 mmol/mol³, a decrease from 17.4% in 2011/12, but higher than the two years prior to that. The large majority of children who fall outside this range are at increased risk of developing complications.

By comparison, in Germany and Austria in 2011, 50–55% of children and young people aged under 21 years achieved an HbA1c of <58 mmol/mol.4

The magnitude of variation in glycaemic control of children and young people with diabetes is high both nationally and internationally.5,6

Paediatric diabetes care has been subject to a national Best Practice Tariff since 2012.

Magnitude of variation

For paediatric diabetes units in England, the percentage of children and young people aged 0-24 years with diabetes in the NPDA whose median HbA1c measurement was <58 mmol/mol ranged from 1.2% to 72.7% (60.6-fold variation).⁷ When the five paediatric diabetes units with the highest percentages and the five paediatric diabetes units with the lowest percentages are excluded, the range is 5.6-29.3%, and the variation is 5.2-fold.

Reasons for warranted variation include differences in:

- > the ethnic profile of the local population of children and young people with diabetes;
- **>** the level of deprivation in different localities³.

Despite this, warranted variation and individual patient behaviour cannot explain the relatively large degree of variation observed. Possible reasons for unwarranted variation include differences in:

- **>** the nature of care provided at individual paediatric diabetes units;
- the way in which units provide education about the condition to children and young people and their families.

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 need to specify that service providers and clinicians target resource and efforts at at-risk groups to ensure equity of health outcomes for children and young people with diabetes.

Commissioners also need to review minimum service specifications to ensure they are in line with current NICE guidance (see "Resources") and Department of Health policy on service configuration (see "Resources"). Local, regional and national peer-review of services can promote best practice, and help to assess performance and improve outcomes.

In accordance with NICE technology appraisal guidance (see "Resources"), where clinically indicated, service providers should give patients access to appropriate technologies, such as insulin pumps and continuous glucose monitoring.

To improve outcomes for children and young people with diabetes, education is pivotal. Commissioners need to specify that service providers deliver standardised self-management education programmes individually tailored for each child, their family and school.

Service providers also need to ensure that standardised specialist training is provided for all healthcare professionals involved in the care of children and young people with diabetes.

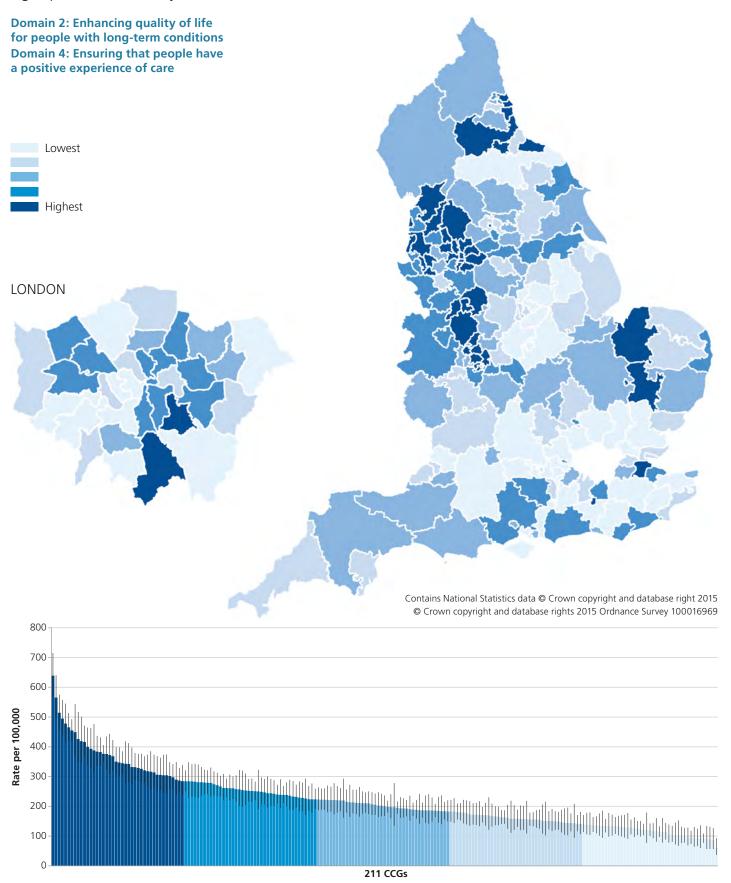
CASE-STUDIES

- Oxfordshire Childrens Diabetes Service The Primary Schools Intervention Programme (see Case-study 4, page 265)
- See also Child Health Atlas, Case-study 1: Yorkshire and Humber Paediatric Diabetes Network. http://www.rightcare.nhs.uk/ index.php/nhs-atlas/case-study-1-yorkshire-and-humberpaediatric-diabetes-network/

- > NICE. Diabetes (type 1 and type 2) in children and young people: diagnosis and management. NICE guidelines [NG18]. August 2015. http://www.nice.org.uk/guidance/ng18
- > NICE. Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus. NICE technology appraisal guidance [TA151]. July 2008. http://guidance.nice.org.uk/TA151
- > NICE. Commissioning an insulin pump therapy service. http://www.nice.nhs.uk/usingguidance/ commissioningguides/insulinpumps/commissioning.jsp
- > Department of Health (2007) Making every young person with diabetes matter. http://www.diabetes.org.uk/Documents/ Reports/MakingEveryYoungPersonMatter.pdf
- > 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.
- 1 NICE. Diabetes (type 1 and type 2) in children and young people: diagnosis and management. NICE guidelines [NG18]. August 2015. http://www.nice.org.uk/guidance/ng18
- 2 ISPAD Clinical Practice Consensus Guidelines. https://www.ispad. org/content/ispad-clinical-practice-consensus-guidelines-2014
- 3 National Paediatric Diabetes Audit Report 2012/13. http://www.rcpch.ac.uk/system/files/protected/page/ NPDA%202012-13%20Core%20Report%202nd%20FINAL%20 v%203.3.pdf
- 4 DPV-Wiss database German & Austrian National database for children and young people with diabetes. http://buster.zibmt.uni-ulm.de/dpv/index.php/en/
- 5 http://www.hvidoeregroup.org/
- 6 http://www.sweet-project.eu
- 7 Data from one paediatric diabetes unit are missing.

Map 83: Emergency asthma admission rate for children aged 0–18 years per population by CCG

Age-specific rate, 0-18 years, 2012/13



Asthma is an inflammatory disorder affecting the airways, characterised by breathlessness, wheezing and coughing particularly at night. The most common type of asthma is allergic asthma triggered by immunoglobulin E (IgE) antibodies generated in response to environmental allergens such as dust mites, pollen and moulds.

Asthma is the commonest long-term medical condition in childhood. Of the 5.4 million people in the UK currently being treated for asthma, 1.1 million are children (~20%).

Emergency admissions should be avoided whenever possible.

Interventions that improve health outcomes for people with asthma include:

- > self-management education that incorporates written personalised asthma actions plans (PAAPs);
- > regular pro-active structured clinical reviews in primary care, including discussion and use of a written PAAP:
- > education for clinicians.

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 2015/16.

Magnitude of variation

Map 83: Emergency admissions

For CCGs in England, the emergency asthma admission rate for children aged 0–18 years ranged from 60 to 639 per 100,000 population (10.6-fold variation). When the seven CCGs with the highest emergency admission

rates and the seven CCGs with the lowest emergency admission rates are excluded, the range is 93-449 per 100,000 population, and the variation is 4.8-fold (see Table 83.1 for data from 2011/12 by upper-tier local authority¹).

The degree of variation observed in the rate of emergency admission may be due to:

- > 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 units.

Bed capacity could also be a factor in determining admission criteria.

When compared with previous financial years, it would appear that the variation observed for emergency admission rates for children with asthma is relatively high and of a similar degree although as can be seen from Table 83.1, the geographical and population units of analysis are different. Nonetheless, it would appear there is scope for greater equity in the provision of asthma services across England.

Map 84: Mean length of stay

For CCGs in England, the mean length of stay for asthma in children aged 0-18 years ranged from 0.6 days to 2.4 days (4.4-fold variation). When the seven CCGs with the longest mean lengths of stay and the seven CCGs with the shortest mean lengths of stay are excluded, the range is 0.8-2.0 days, and the variation is 2.4-fold.

The degree of variation observed in length of stay in hospital may be related to disease severity. For geographical regions, however, these data show no

Table 83.1: Emergency asthma admission rate for children aged 0-18 years per 100,000 population for two financial years

Finan	ncial year	Geography		Fold difference	Range after exclusion	Fold difference after exclusion	Publication
20	012/13	CCG	60.1-639.1	10.6	93.0-449.2	4.8	
20	011/12	UTLA	73.4-484.4	6.6	102.2-384.1	3.8	CMO's Annual Report 2012 ²

¹ For similar data from 2009/10 by PCT, see Child Health Atlas, Map 19, pages 56-57; for similar data from 2010/11 by PCT, see Respiratory Disease Atlas, Map 14, pages 46-47;

Chief Medical Officer's annual report 2012: Our Children Deserve Better: Prevention Pays. Annex 9: Atlas of Variation in Healthcare for Children and Young People. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/252672/33571_2901304_CMO_Chapter_ Anx 9.pdf

correlation between emergency admission rate and mean length of stay, which would suggest there are other factors involved, such as differences in:

- > inpatient management of asthma;
- **>** discharge criteria for paediatric units.

Bed capacity could also be a factor in determining discharge criteria.

Options for action

To identify unwarranted variation in the local management of long-term conditions such as asthma, commissioners can use the Disease Management Information Toolkit (DMIT; see "Resources").

As the causes of asthma are multifactorial, action to reduce emergency admission requires a whole pathway approach, including public health, and primary and secondary care. Commissioners need to specify that all service providers:

- > use the British Thoracic Society/Scottish Intercollegiate Guidelines Network (BTS/SIGN) guidelines (see "Resources") as the basis of the clinical asthma pathways for which they are responsible locally;
- > implement the NICE quality standards for asthma (see "Resources") that are relevant to children.

Hospital-based admission is an opportunity to review self-management skills. Service providers need to ensure that:

- > every child with asthma has a written PAAP according to the BTS/SIGN guideline on management of asthma, and the NICE quality standards for asthma; symptom-based plans are generally preferable for children:
- > every child admitted to hospital with an acute exacerbation of asthma has a structured review by a member of a specialist respiratory team before discharge, in accordance with the NICE quality standards for asthma.

Primary care service providers could audit the number and percentage of children with asthma receiving an annual review, and in particular those children who:

- > over-use bronchodilators;
- **>** are on higher treatment steps;
- > have asthma attacks;
- **>** have complex needs;
- > belong to an at-risk ethnic minority group and who have attended emergency care.

Commissioners need to ensure that service providers support clinicians:

- > in implementing up-to-date evidence on best practice, such as omalizumab for severe persistent allergic asthma;3
- **>** by providing training interventions especially for clinicians in primary care that include educational outreach visits.

Any school-based asthma education programmes need to be targeted at the children's health professionals as well as the children themselves.

School nursing, primary care and paediatric asthma networks need to work together to optimise other vital aspects of the overall care of the child with asthma such as:

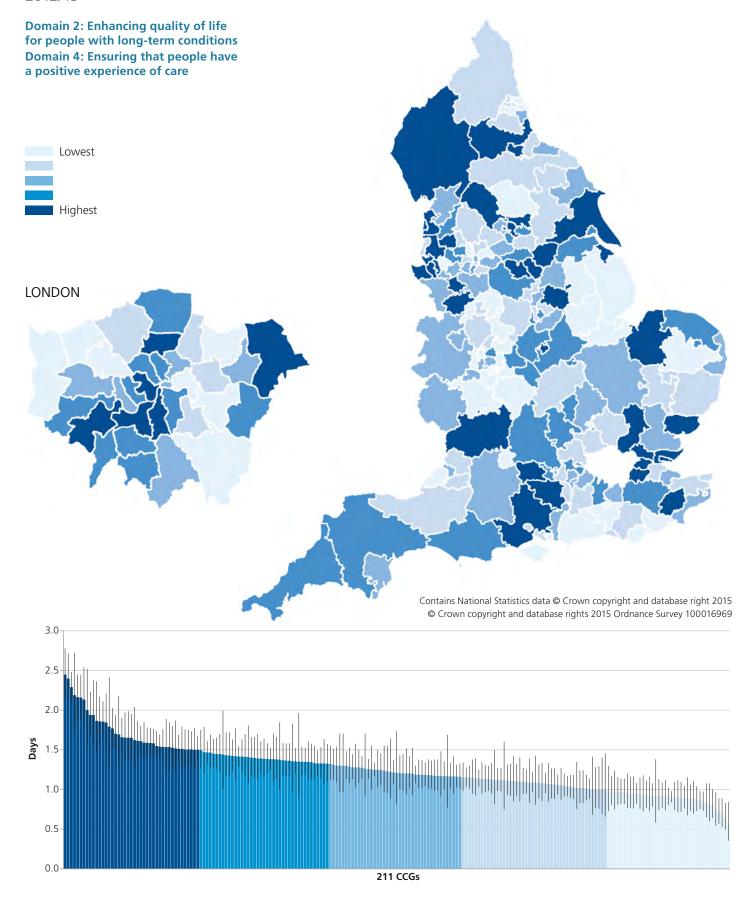
- **>** parental education;
- > school medication management.

- **>** Disease Management Information Toolkit (DMIT). http://atlas.chimat.org.uk/IAS/dmit
- > NICE. Quality standards for asthma. NICE quality standard [QS25]. February 2013. http://www.nice.org.uk/guidance/gs25
- **>** BTS/SIGN. SIGN 141. British guideline on the management of asthma. A national clinical guideline. October 2014. https://www.brit-thoracic.org.uk/document-library/ clinical-information/asthma/btssign-asthmaguideline-2014/
- **>** BTS/SIGN. QRG 141. British guideline on the management of asthma. Quick reference guide. October 2014. https://www.brit-thoracic.org.uk/document-library/ clinical-information/asthma/btssign-asthmaguideline-quick-reference-guide-2014/

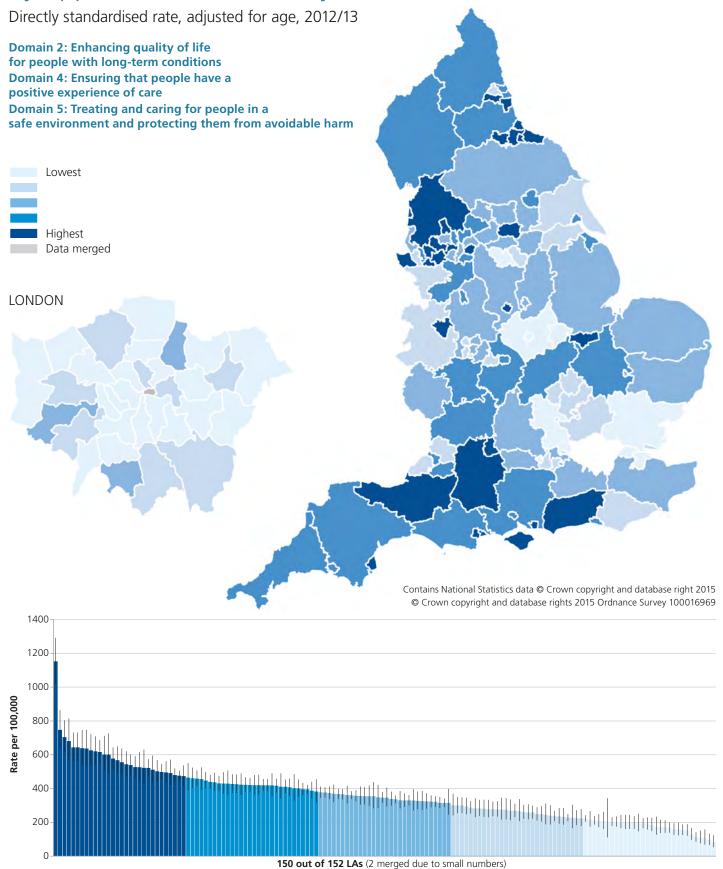
³ NICE. Omalizumab for treating severe persistent allergic asthma (review of technology appraisal guidance 133 and 201). NICE technology appraisal guidance [TA278]. April 2013. http://publications.nice.org.uk/omalizumab-for-treating-severe-persistent-allergic-asthma-review-oftechnology-appraisal-guidance-ta278

Map 84: Mean length of stay (days) for asthma in children aged 0-18 years by CCG

2012/13



Map 85: Rate of admission to hospital for self-harm in children and young people aged 10-24 years per population by upper-tier local authority



Self-harm refers to a variety of deliberate actions through which young people physically hurt themselves. Most commonly, this involves self-injury (such as cutting or burning), or self-poisoning with medications. This indicator does not include other activities sometimes referred to as "self-harm", such as over- or under-eating, body tattooing or piercing, and excessive consumption of recreational drugs and alcohol.

In most young people, self-harm is a maladaptive response to underlying emotional distress. Self-harm is more prevalent among young people with underlying mental health problems. Although self-harm is associated with a slightly higher risk of suicide, the vast majority of young people who self-harm do not have suicidal intentions.¹

Young people who present to emergency departments with self-harm undergo a specialist assessment by Child and Adolescent Mental Health Services (CAMHS) professionals prior to discharge, which, in practice, may lead to an emergency hospital admission.

Negative attitudes and lack of expertise among professionals in emergency departments and acute hospitals can be detrimental to the care experience of young people who self-harm.

"Hospital admissions as a result of self-harm" is a national quality Indicator in the Public Health Outcomes Framework 2013-16.

Magnitude of variation

For upper-tier local authorities (UTLAs) in England, the rate of admission to hospital for self-harm in children and young people aged 10–24 years ranged from 82 to 1152 per 100,000 population (14.0-fold variation).² When the five UTLAs with the highest rates and the five UTLAs with the lowest rates are excluded, the range is 128–644 per 100,000 population, and the variation is 5.0-fold.

Reasons for the degree of variation observed include differences in:

- **>** the prevalence of mental health problems in local populations, which is correlated with risk factors such as socio-economic deprivation, learning disability, and childhood adversity (e.g. adverse family circumstances, and childhood trauma);
- > the provision of primary prevention, including support for young people at school and in the community;
- early recognition of the problem by parents, carers, and health and education professionals;
- **>** access to early interventions;
- access to effective secondary prevention interventions for children and young people who present as an emergency;
- clinical thresholds for admission to hospital following an episode of self-harm;
- access to timely specialist CAMHS assessment in the emergency department to avoid the need for hospital admission unless there are medical or psychiatric indications.

Options for action

Commissioners need to undertake local surveillance to ascertain trends in and the prevalence of self-harm in children and young people to underpin the allocation of resources for mental health promotion, prevention, and early intervention in the local population of children and young people.

To improve the quality of care and support for children and young people who self-harm:

- > commissioners need to specify to service providers and clinicians that the relevant care pathways, from community care to hospital care through to specialist mental health services, comply with the NICE quality standard and associated commissioning support tools (see "Resources");
- professionals in emergency departments and acute hospitals need to use resources, such as those provided on MindEd, the children and young people's mental health e-portal (see "Resources"), to increase specific learning and engage in professional development.

Children and young people presenting to emergency departments with self-harm represent the tip of the iceberg, however; the majority of incidents of self-harm among young people never present to any health services. Therefore, although hospital admissions for self-harm are opportunities for secondary prevention, it is likely that the following interventions will have a greater impact on outcomes:

- > mental health promotion;
- early identification, including public education and training for health and education professionals on risk factors and signs of self-harming behaviour in children and young people;
- **>** early intervention, including support from community mental health and youth work professionals;
- primary prevention, including population approaches to increase resilience, such as commissioning for improved mental health in schools.

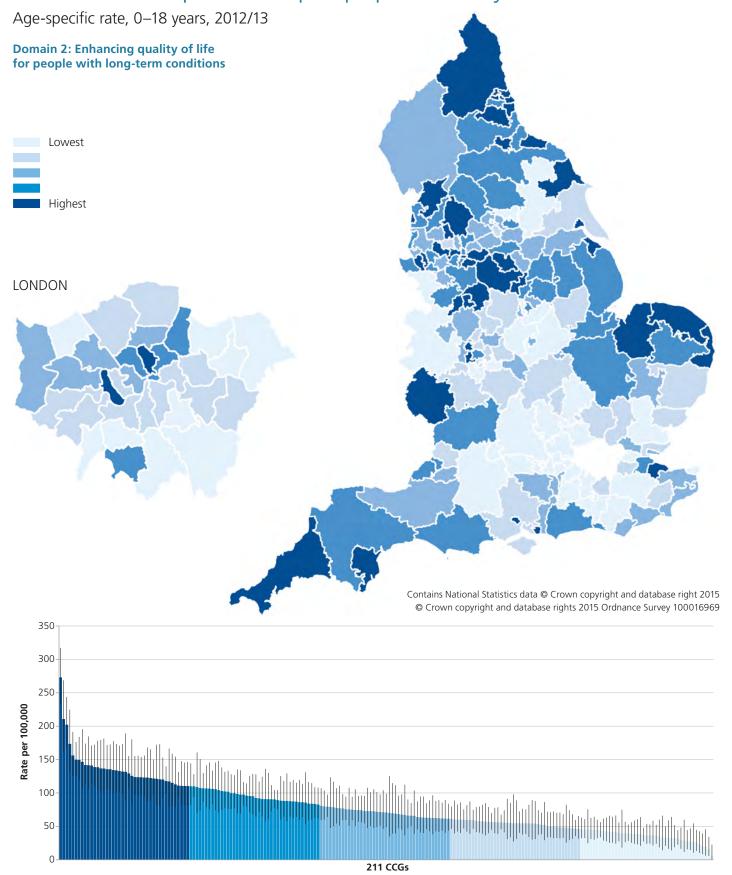
Research is needed to determine whether there is variation in the prevalence of self-harm, access to timely CAMHS assessment in the emergency department, or the decision to admit young people to hospital for inpatient care.

- NICE. Quality standard for self-harm. NICE quality standard [QS34]. June 2013. http://www.nice.org.uk/guidance/qs34/
- > CMG50: NICE support for commissioning for self-harm. http://www.nice.org.uk/guidance/qs34/resources/cmg50nice-support-for-commissioning-for-selfharm
- > Children & Young People's Mental Health Coalition. Guidance for schools on how to support children and young people's mental health: "Resilience and Results". http://www.cypmhc.org.uk/ resources/resilience_results/
- > MindEd. http://www.minded.org.uk
- No health without mental health. A cross-government mental health outcomes strategy for people of all ages. 2011. https://www.gov.uk/government/uploads/system/uploads/ attachment_data/file/213761/dh_124058.pdf
- > HMG/DH. The Children and Young Persons Improving Access to Psychological Therapies (CYP IAPT) programme, aimed at improving the care and outcomes of patients in CYP IAPT services in England. http://www.cypiapt.org

¹ Hawton K, James A. Suicide and deliberate self-harm in young people. BMJ 2005; 330; 891-894. http://www.ncbi.nlm.nih.gov/ pmc/articles/PMC556165/pdf/bmj33000891.pdf

² Owing to small numbers, Isles of Scilly local authority has been merged with Cornwall, and City of London local authority has been merged with Hackney.

Map 86: Rate of children and young people aged 0–18 years with three or more admissions to hospital per year for mental health problems per population by CCG



Approximately one in ten (10%) of 5- to 16-year-olds have a mental health disorder diagnosed at some point during childhood.1 This proportion rises steeply in adulthood, to one in four adults experiencing a mental disorder in any one year.² Half of the adults who will be diagnosed with mental illness will have shown symptoms by 14 years of age, and threequarters of adults diagnosed will have shown symptoms by 20 years of age.3

The societal cost of mental ill health has been estimated at £105 billion, and is predicted to increase.4 Much of this cost is the consequence of early onset disorders, which are recurrent or persistent. There are clinical and financial reasons to provide children and young people with mental health disorders with the most effective intervention in as timely a way as possible.

For this indicator, the focus is those children and young people with recurrent emergency admissions to hospital for mental health disorders. Recurrent emergency admissions could indicate:

- **>** severity of the mental health problems;
- children and young people for whom community-based mental healthcare is inadequate;
- **>** a combination of the two reasons listed above.

Children and young people experiencing recurrent emergency admissions to hospital for mental health problems might benefit from therapy in specialist child and adolescent mental health inpatient facilities, for which capacity is limited. In selected patients, such inpatient psychiatric admissions can be crucial, conferring benefit on those children most in need. Evidence-based management of this limited resource is critical.

Magnitude of variation

For CCGs in England, the rate of children and young people aged 0–18 years with three or more admissions to hospital per year for mental health problems ranged from 6.3 to 273 per 100,000 population (43.5-fold variation). When the seven CCGs with the highest rates and the seven CCGs with the lowest rates are excluded, the range is 27–147 per 100,000 population, and the variation is 5.3-fold.

Possible reasons for the degree of variation observed include differences in:

- **>** the organisation, level of provision and extent of local specialist ambulatory care services and facilities;
- > the application of diagnostic criteria for mental health problems in children and young people.

Options for action

Specialist ambulatory care services perform a gate-keeping role for inpatient care. Commissioners need to specify that service providers consider the provision of intensive ambulatory or outreach services for vulnerable groups, which may be clinically, and cost-, effective, together with admission to hospital when appropriate.

Commissioners also need to specify that service providers including clinicians review local data for case-mix, duration of treatment, and outcomes, and plan inpatient and ambulatory services accordingly. National data will be available through the child and adolescent mental health services (CAMHS) national dataset (see "Resources"), which will enable commissioners to investigate a range of indicators measuring the performance of local services.

It is important for CAMHS, local authorities and the voluntary sector to work in partnership to improve the quality and effectiveness of community-based mental health services for children and young people, which in turn will influence admission rates and lengths of stay. This could be achieved through partnership working on the Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) programme (see "Resources").

- > Department of Health Children and Young People's Mental Health and Well-being Taskforce. Report on improving outcomes for children and young people's mental health is anticipated in Spring 2015. https://www.gov.uk/government/groups/ children-and-young-peoples-mental-health-and-wellbeing-taskforce
- > Department of Health (2011) No health without mental health. A cross-government mental health outcomes strategy for people of all ages. https://www.gov.uk/government/uploads/system/ uploads/attachment_data/file/213761/dh_124058.pdf
- Children & Young People's Mental Health Coalition. Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) programme. http://www.cypiapt.org/
- Child and Adolescent Mental Health Services National dataset. http://data.gov.uk/dataset/effectiveness_of_child_and_ adolescent_mental_health_camhs_services
- > Royal College of Psychiatrists. Quality Network for Inpatient CAMHS (QNIC) standards. http://www.rcpsych.ac.uk/quality/ quality, accreditation audit/qnic1.aspx

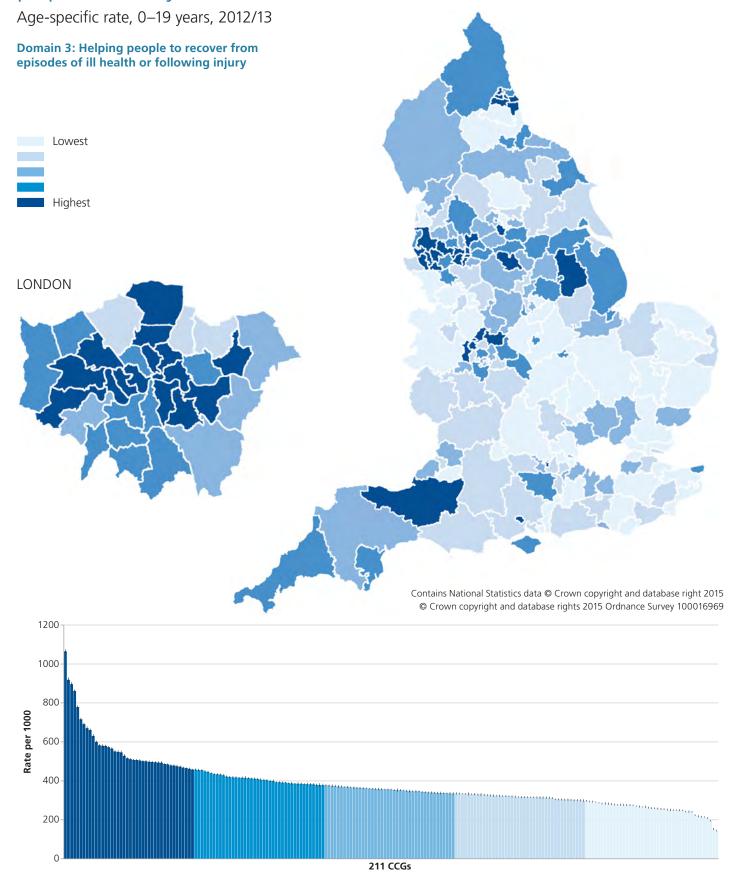
¹ Office for National Statistics (2005) Mental health of children and young people in Great Britain, 2004. Summary report. http://www.hscic.gov.uk/catalogue/PUB06116/ment-heal-chil-youn-peop-gb-2004-rep2.pdf

Mental Health Foundation (2007) The Fundamental Facts. The latest facts and figures on mental health http://www.mentalhealth.org.uk/content/assets/PDF/publications/fundamental_facts_2007.pdf?view=Standard

Department of Health (2011) No health without mental health. A cross-government mental health outcomes strategy for people of all ages. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf

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

Map 87: Rate of accident and emergency (A&E) attendance in children and young people aged 0–19 years per population by CCG



In 2012/13, there were 18.3 million accident and emergency (A&E) attendances recorded at major A&E departments, single specialty A&E departments, walk-in centres and minor injuries units in England, representing an increase of 4% from 2011/12.¹ More than one-quarter (26.5%) of these attendances were made by children and young people aged 0–19 years.¹

Attendance to A&E by children and young people is related to several factors, including:

- patient and carer knowledge and expectations of illness in childhood;
- > the degree of public understanding about which urgent care services to access when;
- > timely access to primary care.

In the recent NHS England Urgent and Emergency Care Review (see "Resources"), it was found that the capacity of primary care to manage the healthcare needs of children and young people is more stretched than it has ever been, and out-of-hours access is a particular issue.²

Emergency department attendance for accidental injury occurs most commonly in children aged under five years. The same age-group accounts for nearly 70% of self-referrals to A&E for medical problems, such as respiratory problems or feverish illnesses.³ Targeting a reduction in the variation in A&E attendance for the under-5-year age-group is likely to realise considerable financial savings, and reduce pressure on overstretched A&E services.

Magnitude of variation

For CCGs in England, the rate of A&E attendance in children and young people aged 0–19 years ranged from 144 to 1065 per 100,000 population (7.4-fold variation). When the seven CCGs with the highest rates and the seven CCGs with the lowest rates are excluded, the range is 224–671 per 100,000 population, and the variation is 3.0-fold.

The degree of variation observed after exclusions was similar when the rate of A&E attendances was assessed in children under 5 years of age (3-fold in 2009/10 by PCT⁴; 3.1-fold in 2011/12 by local authority⁵).

Reasons for the degree of variation include differences in:

- the provision of local primary and community care, particularly out-of-hours urgent care;
- **>** public health measures such as accident prevention or family education on appropriate use of health services.

The provision of local primary and community care is likely to account for much of the ongoing variation in the demand for emergency care for young children.

Options for action

Commissioners need:

- > to investigate variation in presentation to emergency departments to identify causes of unwarranted variation in their local area;
- > to study the specific pattern of demand for emergency services in order to commission services that reflect local needs, and to ensure that the right balance of community-and hospital-based services is provided using a whole-system approach (see "Resources");
- > to specify and assure the quality of local primary and community-based care to ensure children have the appropriate level of access to services other than those in A&E in relation to their healthcare needs.

Commissioners also need to specify to service providers that care delivered in emergency care settings meets the standards defined by the Intercollegiate Committee (see "Resources").

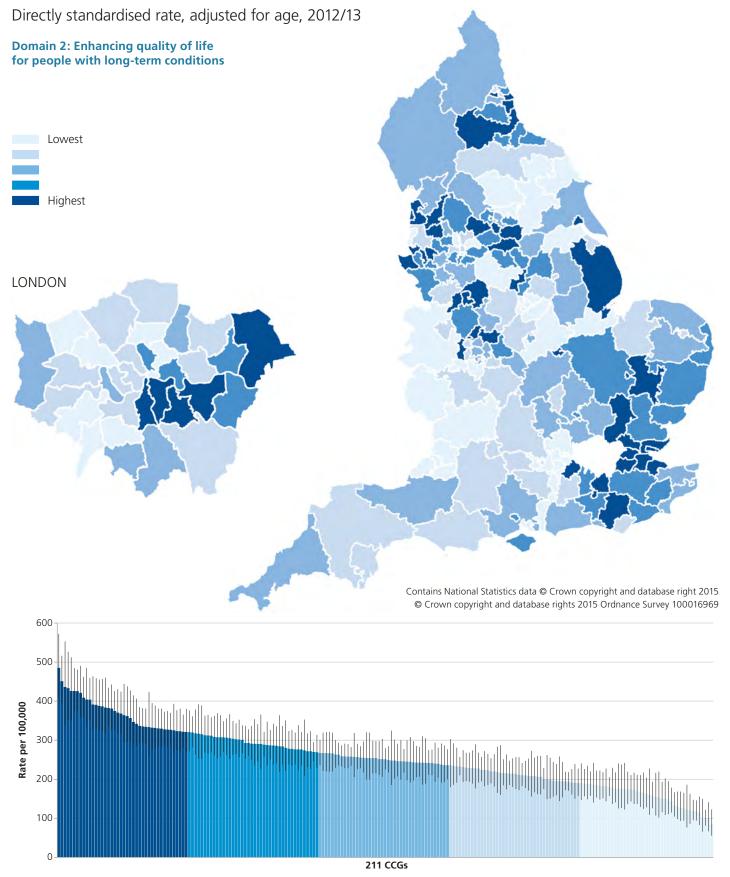
Primary care professionals and local hospital paediatricians need to agree on standards and guidelines for the management of common conditions. For instance, ensuring that NICE guidance on the recognition and management of a young (under 5 years of age) feverish child (see "Resources") is widely disseminated and followed.

Although injury and accident prevention is a public health issue, it is also the responsibility of local health services to support education on the prevention of injury.

- > NHS England (2013) Transforming urgent and emergency care services in England. Urgent and Emergency Care Review. End of Phase 1 Report. High quality care for all, now and for future generations. November 2013. http://www.nhs.uk/NHSEngland/keogh-review/Documents/UECR.Ph1Report.FV.pdf
- NHS England (2014) Transforming urgent and emergency care services in England - Update on the Urgent and Emergency Care Review. http://www.nhs.uk/NHSEngland/keogh-review/ Documents/uecreviewupdate.FV.pdf
- NICE. Feverish illness in children: Assessment and initial management in children younger than 5 years. NICE guidelines [CG160] May 2013. http://www.nice.org.uk/guidance/cg160
- Intercollegiate Committee for Standards for Children and Young People in Emergency Care Settings (2012) Standards for Children and Young People in Emergency Care Settings. http://www. rcpch.ac.uk/sites/default/files/page/Intercollegiate%20 Emegency%20Standards%202012%20FINAL%20WEB.pdf
- > Royal College of General Practice/Practitioners. Guidance for commissioning Integrated Urgent and Emergency Care (2011) A 'whole system' approach. August 2011. http://www.rcgp.org.uk/policy/~/media/Files/CIRC/Audit/Urgent_emergency_care_whole_system_approach.ashx
- 1 Health & Social Care Information Centre. Hospital Episode Statistics: Accident and Emergency Attendances in England 2012–13. http://www.hscic.gov.uk/catalogue/PUB13464/acci-emer-atte-eng-2012-2013-rep.pdf
- 2 NHS England (2013) High quality care for all, now and for future generations: Transforming urgent and emergency care services in England. The Evidence Base from the Urgent and Emergency Care Review. http://www.england.nhs.uk/wp-content/uploads/2013/06/urg-emerg-care-ev-bse.pdf
- 3 Sands R et al (2012) Medical problems presenting to paediatric emergency departments: 10 years on. Emergency Medicine Journal 29: 379-382.
- 4 NHS Right Care (2012) NHS Atlas of Variation in Healthcare for Children and Young People. March 2012. http://www.rightcare.nhs.uk/index.php/atlas/children-and-young-adults/
- 5 Chief Medical Officer's annual report 2012: Our Children Deserve Better: Prevention Pays. Annex 9: Atlas of Variation in Healthcare for Children and Young People.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/252672/33571_2901304_CMO_Chapter_Anx_9.pdf

Map 88: Rate of elective admission to hospital for tonsillectomy in children aged 0–17 years per population by CCG



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

In England, treatment for SRBD accounts for about 25% of tonsillectomies (combined with adenoidectomy) in children. Sleep-related breathing disorders and OSA comprise a spectrum of conditions where upper airway obstruction during sleep produces poor sleep quality, daytime fatigue, poor school performance and, in severe cases, serious disorders of cardiopulmonary function. There is currently a lack of robust evidence to inform the appropriate threshold for surgical intervention.

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. Failure to intervene for children who fulfill the treatment criteria may be just as harmful, however, 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 loss of parental income.

Magnitude of variation

For CCGs in England, the rate of elective admission to hospital for tonsillectomy in children aged 0-17 years ranged from 84 to 485 per 100,000 population (5.7-fold variation). When the seven CCGs with the highest rates and the seven CCGs with the lowest rates are excluded, the range is 120-421 per 100,000 population, and the variation is 3.5-fold (see Table 88.1 for 2011/12 data by upper-tier local authority¹).

The reason for the degree of variation observed in tonsillectomy rates is often ascribed to differences in professional culture, referred to as a "surgical signature" by Wennberg (see Glossary, page 00).

The data for 2012/13 appear to show a further reduction in rates of tonsillectomy particularly for localities at the lower end of the range; however, there seems to have been little change in the degree of variation observed even though data from previous time-periods are presented at different geographies.

It is not possible to state with certainty what the "optimal rate" for tonsillectomy in children might be. The historical over-use of tonsillectomy in children has received much attention and been the subject of research and investigation, but there is a danger that this trend of over-use has been reversed in some localities to the extent that children who may benefit from the procedure are now unable to obtain access to it.

Options for action

Commissioners need to specify that service providers ask clinicians to investigate this further reduction in tonsillectomy rates at the lower end of the range to ascertain whether it reflects a clinically appropriate reduction in over-use locally, and not an indiscriminate reduction in activity, which could result in unmet need, poorer outcomes, and represent lower value in the long term.

Commissioners need to follow national guidelines (see "Resources") when commissioning services to ensure equity of access for clinically justified interventions, while reducing unnecessary interventions that divert resource from children who fulfil clinical criteria. The Scottish Intercollegiate Guidelines Network (SIGN) evidence-based indications for tonsillectomy for the treatment of recurrent tonsillitis (see "Resources") state that 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.

In the absence of national evidence-based clinical guidance for thresholds for tonsillectomy for SRBD, commissioners and clinicians need to reach agreement on local criteria, which need to be:

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

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

- SIGN (2010) 117 Management of sore throat and indications for tonsillectomy. A national clinical guideline. April 2010. http://www.sign.ac.uk/guidelines/fulltext/117/index.html
- > NICE. Surgical management of otitis media with effusion in children. NICE guidelines [CG60]. February 2008. http://guidance.nice.org.uk/CG60
- > NHS Right Care, Royal College of Surgeons and ENT-UK (2013) Commissioning guide: Tonsillectomy. https://www.rcseng.ac.uk/healthcare-bodies/docs/ published-guides/tonsillectomy
- NHS Right Care, Royal College of Surgeons and ENT-UK. Procedures Explorer Tool, to support commissioning for CCGs, which highlights local and regional variation for each surgical procedure. http://rcs.methods.co.uk/pet.html

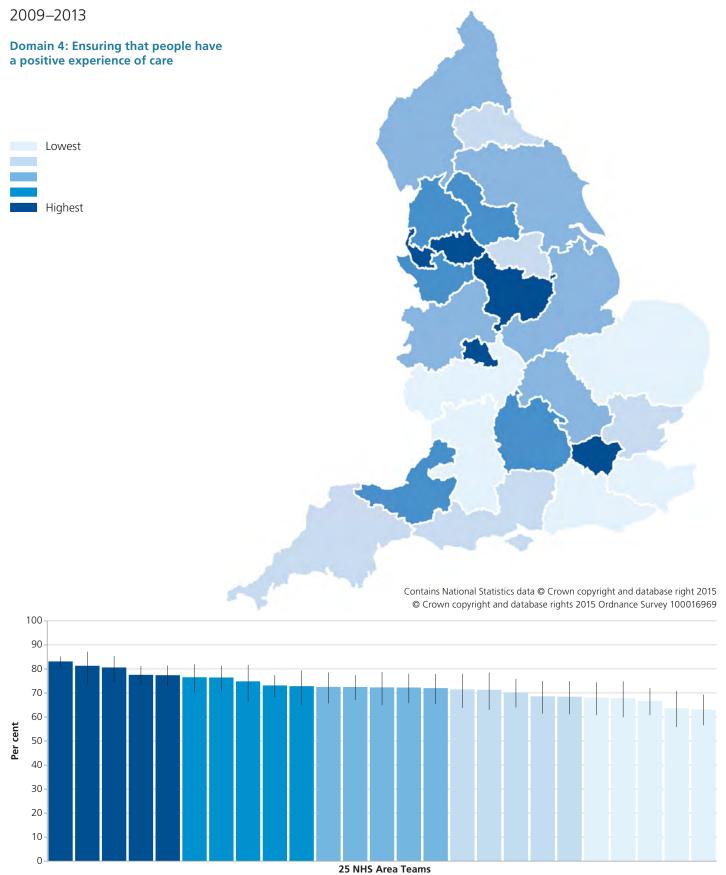
Table 88.1: Rate of elective admission to hospital for tonsillectomy in children aged 0-17 years per 100,000 population for two financial years

Financial year	Geography	Range	Fold difference		Fold difference after exclusion	Publication
2012/13	CCG	84-485	5.7	120-421	3.5	
2011/12	Upper-tier local authority	99–512	5.2	130–376	2.9	CMO's Annual Report 2012 ²

¹ For data from 2007/08-2009/10 by PCT, refer to Child Health Atlas, Map 22, pages 62-63.

Chief Medical Officer's annual report 2012: Our Children deserve Better: Prevention Pays. Annex 9: Atlas of Variation in Healthcare for Children and Young People. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/252672/33571_2901304_CMO_Chapter_ Anx_9.pdf

Map 89: Percentage of all deaths in children aged 0–17 years with life-limiting conditions that occurred in hospital by NHS area team



Life-limiting conditions are those for which no reasonable hope of cure exists, and from which children or young people will die prematurely. There are an estimated 49,000 children and young people with a life-limiting condition in the UK.¹

Most children with life-limiting conditions and their families express a preference for death to take place at home. Lack of community support can prevent this preference being realised, even when it is medically possible to support death at home.

The focus of this indicator is the quality of palliative care services for children. Palliative care is an active process encompassing physical, emotional and social support for the child extending from the moment of diagnosis to maximising their quality of life, and providing support for the child's family during bereavement. It is not simply about "end of life" care.

Magnitude of variation

For NHS area teams in England, the percentage of all deaths in children aged 0–17 years with life-limiting conditions that occurred in hospital ranged from 63.1% to 83.1% (1.3-fold variation; see Table 89.1 for 2008–2012 data²).

Table 89.1: Percentage of all deaths in children aged 0–17 years with life-limiting conditions that occurred in hospital for two time-periods

Time period	Geography	Range	Fold difference
2009–2013	NHS area team	63.1-83.1%	1.3
2008-2012	NHS area team	73.3-92.2%	1.3

This means that the percentage of children dying out of hospital ranged from 16.9% to 36.9%, a variation of 2.2-fold. At NHS area team level, only 1–3 children out of ten with life-limiting conditions died at home or other preferred place of death, such as a specialist hospice.

Although the degree of variation has remained constant over the two time-periods, the percentage of children with life-limiting conditions dying in hospital has declined, as has the degree of variation in the percentage of children dying out of hospital (from 3.4-fold to 2.2-fold).

Despite this shift, 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 need to specify that service providers and clinicians review the proportion of children dying in local hospitals, and investigate whether this reflects family choice.

Commissioners also need to specify that the review includes other indicators relating to the quality of palliative care for children with life-limiting conditions and their families, 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, together with their families, at the end of a child's life.

It is important that care teams work with a child's family:

- > to clarify the family's wishes for end-of-life care in terms of not only the place of care but also the type of care;
- > to identify the support and resources a family needs to enable their child to die in the place of their choice.

To ensure that efficient and effective 24-hour end-of-life care is available, commissioners and service providers need to consider modelling local services as a network with strong clinical leadership.

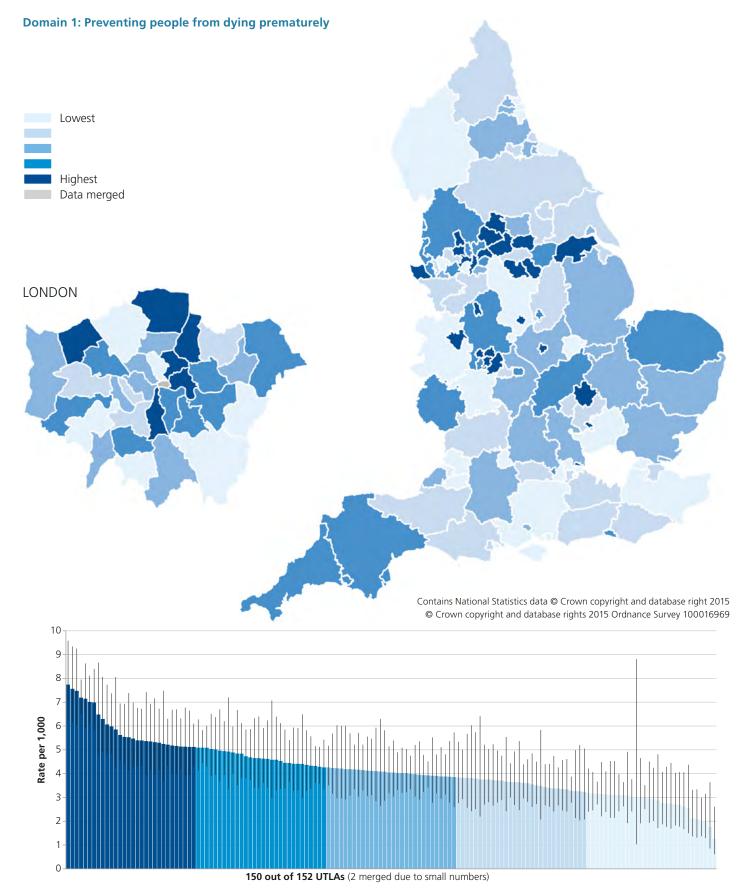
- > Department of Health (2008) Better Care: Better Lives Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions. A framework for the level of service that commissioners and clinicians need to deliver for children's palliative care.
 - http://eprints.uwe.ac.uk/5178/1/Download.pdf
- "Together for Short Lives": information and resources for professionals, and children and their families, including standards framework and core care pathways for children's palliative care services. http://www. togetherforshortlives.org.uk/assets/0000/4121/ TfSL_A_Core_Care_Pathway__ONLINE_.pdf
- ➤ NHS England. 2013/14 NHS Standard Contract for Paediatric Medicine: Palliative Care. Particulars, Schedule 2 The Services, A Service Specifications. http://www.england.nhs.uk/wp-content/uploads/2013/06/e03-paedi-med-pall.pdf

¹ Fraser LK, Parslow RC, McKinney PA et al (2012) Life-Limiting and Life-threatening Conditions in children and young people in the United Kingdom; Final Report for Together for Short Lives: Paediatric Epidemiology Unit, Leeds University. https://www.togetherforshortlives.org.uk/assets/0000/1100/Leeds_University___Children_s_Hospices_UK_-_Ethnicity_Report.pdf

² For 2005-2009 data by PCT, refer to the Child Health Atlas, Map 27, pages 72-73.

Map 90: Rate of mortality in infants aged under one year per all live-births by upper-tier local authority

2010-2012



Mortality is an important indicator of population health. For children in countries with developed economies, such as England, deaths are relatively rare. Despite this, the results of recent analyses have shown that child mortality in the UK, having been comparatively low a few decades ago, is now the worst among comparable countries in Western Europe.^{1,2,3} Following an analysis of WHO data, Wolfe et al concluded that if the UK's health system did as well as that of Sweden as many as 1500 children might not die every year.⁴

According to ONS statistics, rates tend to be higher in the Midlands and north of England, with the exception of the north-east which has a trend towards lower mortality for all age-groups (it is significant only for infant deaths), and lower in the south and east of England.⁵

The indicator for infant mortality measures all deaths in children who die before their first birthday, and is associated with:

- > maternal antenatal health and nutrition;
- **>** perinatal and neonatal healthcare.

Low birthweight and prematurity are risk factors for infant mortality, and both are strongly correlated with deprivation. In turn, infant mortality is strongly correlated with deprivation and, as an outcome measure, it is related as much to the wider socio-economic determinants of health as to the quality of healthcare and related services.

Although the majority of childhood deaths occur in infancy, this peak often eclipses a second peak in

adolescence. In the UK, 60–70% of children who die have a long-term condition.⁶

For adolescents, injury is the most common cause of death, although the rate of mortality from injury in the UK is relatively low when compared with that in other Western countries.² Much of the rest of adolescent mortality is related to non-communicable diseases. When compared with a group of European Union (EU) and other countries in the WHO Mortality Database (referred to as EU15+, comprising original members of the EU, and Australia, Canada, and Norway), the UK's performance is among the worst in every age-group.²

Infant mortality is included in the NHS Outcomes Framework 2015/16. Child mortality and infant mortality were recommended for inclusion as national outcome measures in the Children and Young People's Health Outcomes Forum report (2012)⁷.

Magnitude of variation

Map 90: Infant mortality

For upper-tier local authorities (UTLAs) in England, the rate of mortality in infants aged under one year ranged from 1.3 to 7.7 per all 1000 live-births (6.1-fold variation).⁸ When the five UTLAs with the highest rates and the five UTLAs with the lowest rates are excluded, the range is 2.1–7.0 per all 1000 live-births, and the variation is 3.3-fold (see Table 90.1 for data from 2009–11).

Map 91: Child mortality

For UTLAs in England, the rate of mortality in children

Table 90.1: Rate of mortality in infants aged under one year per all 1000 live-births for two time-periods

Time-period	Geography	Range	Fold difference		Fold difference after exclusion	
2010–2012	UTLA	1.3-7.7	6.1	2.1-7.0	3.3	
2009–2011	UTLA	2.2-8.0	3.6	2.6-7.5	2.9	CMO's Annual Report 2012 ⁹

¹ Wolfe I, Macfarlane A, Donkin A et al on behalf of Royal College of Paediatrics and Child Health, National Children's Bureau and British Association for Child and Adolescent Public Health. Why children die: death in infants, children and young people in the UK. Part A. May 2014. http://ncb.org.uk/media/1130496/rcpch_ncb_may_2014_-_why_children_die__part_a.pdf

² Viner RM, Hargreaves DS, Coffey C et al. Deaths in young people aged 0-24 years in the UK compared with the EU15+ countries, 1970-2008: analysis of the WHO Mortality Database. Lancet 2014; 384: 880-892. http://dx.doi.org/10.1016/S0140-6736(14)60485-2

³ Wang H, Liddell CA, Coates MM et al. Global, regional, and national levels of neonatal, infant, and under-5 mortality during 1990–2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet* 2014; 384: 957–79.

⁴ Wolfe I, Cass H, Thompson MJ et al. Improving child health services in the UK: insights from Europe and their implication for NHS reforms. *British Medical Journal* 2011; 342:d1277.

⁵ Sidebotham P, Fraser J, Fleming P et al. Patterns of child death in England and Wales. *Lancet* 2014; 384:904-914.

⁶ Hardelid P, Dattani N, Davey J et al. Overview of child deaths in the four UK countries. http://www.rcpch.ac.uk/system/files/protected/page/CHR-UK%20MODULE%20B%20REVISED%20v2%2015112013.pdf

⁷ Lewis I, Lenehan C (Co-chairs, Forum) (2012) Report of the Children and Young People's Health Outcomes Forum. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216852/CYP-report.pdf

⁸ Owing to small numbers, Isles of Scilly local authority has been merged with Cornwall, and City of London local authority has been merged with Hackney

⁹ Chief Medical Officer's annual report 2012: Our Children Deserve Better: Prevention Pays. Annex 9: Atlas of Variation in Healthcare for Children and Young People. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/252672/33571_2901304_CMO_Chapter_ Anx 9.pdf

aged 1–17 years ranged from 4.0 to 22 per 100,000 population (5.5-fold variation).8 When the five UTLAs with the highest rates and the five UTLAs with the lowest rates are excluded, the range is 6.0–20 per 100,000 population, and the variation is 3.3-fold (see Table 91.1 for data from 2009–2011). As the number of child deaths is relatively small, child mortality rates at UTLA level are subject to greater random variation. Consequently, the values for the range and fold difference are more likely to be exaggerated when compared with other indicators based on larger numbers of events.

The confidence intervals for this indicator are very wide: caution needs to be exercised when interpreting the data because the limits highlight that much of the variation within the indicator may not be statistically significant.

The main reason for the degree of variation observed in both infant and child mortality is differences in the level of socio-economic deprivation among localities.

Options for action

As the UK has not been able to match the gains in child, adolescent and young adult mortality made by other comparable countries since 1970, all commissioners and local authorities need to investigate and understand:

- patterns of infant and child mortality in their local population;
- the ways in which local patterns of infant and child mortality compare with those in populations that have similar demographic and socioeconomic characteristics (refer to NHS RightCare's Commissioning for Value programme, as part of which it is possible to identify any CCG's 10 closest peers, referred to as "Similar 10" CCGs; see "Resources").

Particular emphasis should be placed on mortality patterns among high-risk groups, such as vulnerable young people, or adolescents with long-term conditions.

To take action on infant mortality, commissioners need to specify that service providers follow NICE guidance and overviews (see "Resources"), in particular through:

ensuring the provision of high-quality antenatal, intrapartum and neonatal care, including the appropriateness of staffing capacity and the

- effectiveness of training of both community- and hospital-based health professionals
- providing preventative interventions, such as nutrition and maternal support;
- **>** assuring the quality of health services particularly primary and secondary paediatric care.

Commissioners also need to resource and target improvements in the care of children and young people with non-communicable diseases, in particular addressing:

- > the needs of children with long-term conditions;
- > the need for effective health promotion with respect to overweight and obesity, and smoking habit.

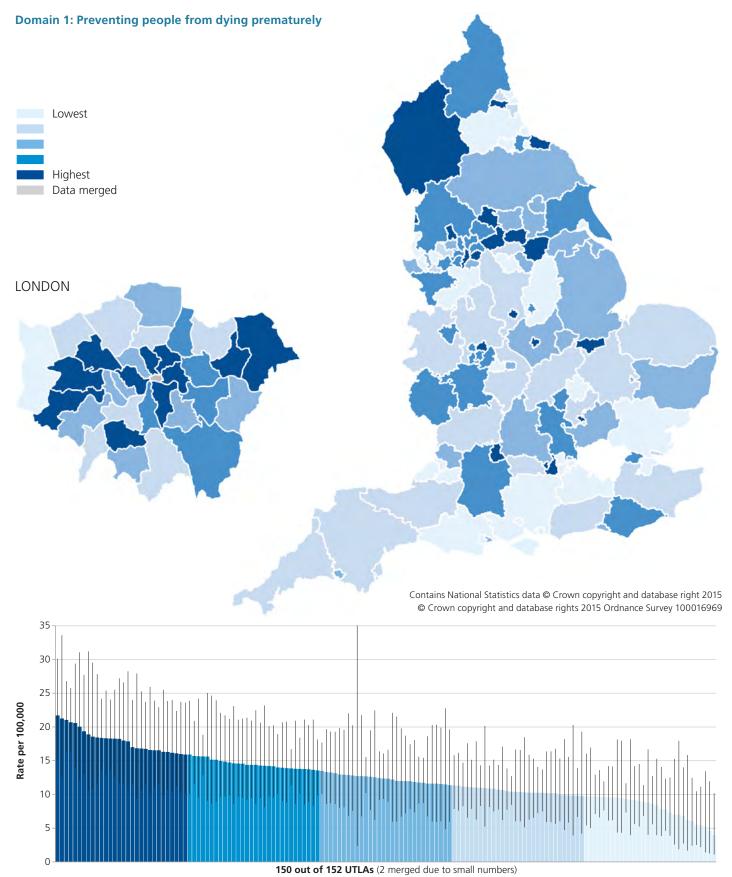
- ➤ NHS England (2014) Saving Babies Lives: Reducing Stillbirth a neonatal death: A care bundle (sic). http://www.6cs.england.nhs.uk/pg/cv_content/content/view/148581/95584
- Office for National Statistics (2013) Childhood, Infant and Perinatal Mortality in England and Wales, 2011. Released: 27 February 2013. http://www.ons.gov.uk/ons/ dcp171778_300596.pdf
- NICE. Antenatal care overview. http://pathways.nice.org.uk/pathways/antenatal-care
- NICE. Postnatal care. NICE Guidelines [CG37]. December 2014. http://www.nice.org.uk/CG037
- ➤ NICE. Specialist neonatal care quality standard. NICE quality standard [QS4]. October 2010. https://www.nice.org.uk/guidance/qs4
- ➤ NICE. Maternal and child nutrition. NICE Guidelines [PH11]. March 2008. http://guidance.nice.org.uk/PH11. This guidance has been partially updated by PH56 Vitamin D: increasing supplement use among at-risk groups. NICE Guidelines [PH56]. November 2014. http://www.nice.org.uk/guidance/ph56
- NHS England. Commissioning for Value. Scroll down towards the bottom of the page to find the file 'The data and methodology used to calculate the "Similar 10" CCGs'. It is located under the main heading "Commissioning for Value: Interactive Tools for CCGs 2013 versions" and from thence under the subheading "Download the data behind the packs and interactive tools 2013 versions". http://www.england.nhs.uk/resources/resources-forccgs/comm-for-value/
- ➤ Public Health England. Reducing infant mortality in London: An evidence-based resource. June 2015. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/431516/Reducing_infant_mortality_in_London_2015.pdf

Table 91.1: Rate of mortality in children aged 1–17 years per 100,000 population for two time-periods

Time-period	Geography	Range	Fold difference		Fold difference after exclusion	Publication
2010-2012	UTLA	4.0-21.7	5.5	6.0-20.1	3.3	
2009–2011	UTLA	6.9-23.7	3.4	7.9–21.1	2.7	CMO's Annual Report 2012 ⁹

Map 91: Rate of mortality in children aged 1–17 years per population by upper-tier local authority

Directly standardised rate, adjusted for age, 2010–2012



Case-study 4: Oxfordshire Childrens Diabetes Service – The Primary Schools Intervention Programme

Problem

Poorly controlled diabetes adversely affects a child's education. The child can experience concentration difficulties and alterations in mood and behaviour associated with high blood glucose levels, and acute cognitive effects associated with low blood glucose levels. If children develop Type 1 diabetes at an early age, they are dependent on an adult to check their blood glucose levels and administer insulin. It is important, therefore, that children with Type 1 diabetes receive support while at school.

Context

In the UK, 40% of children with Type 1 diabetes are of primary-school age. Historically, school teachers have regarded the care of children with diabetes as "medical" as opposed to "self-care". This view has prevented many children's diabetes services from using an intensive insulin regime for the treatment of primary-school children because it requires blood glucose testing in the middle of the day.

With the development of newer insulin analogues, better glycaemic control could be obtained with treatment regimens such as multiple-dose injections (MDI) and insulin pumps, for which insulin is required every time a child eats, together with a long-lasting insulin once a day. Such insulin regimens require:

- > monitoring of blood-glucose levels 2–7 times a day;
- > counting carbohydrate intake to adjust rapid-acting insulin dose or pump bolus at every meal;
- > using correction doses for high glucose levels;
- > treating hypoglycaemia appropriately.

Response

Parents of primary schoolchildren were asked about the problems they faced at school (see Box CS4.1) due to the anxieties about or ignorance of Type 1 diabetes by school staff.

Box CS4.1: Problems experienced at primary school identified by parents of children with Type 1 diabetes

- **>** Poor management of hypoglycaemia
- > Children prevented from going on school trips
- **>** Parents felt pressurised to give up work in order to attend school every day to administer insulin

In 2004. Oxfordshire Childrens Diabetes Service started all toddlers on MDI regimes, and from 2006 all children on MDI regimes. To ensure this programme of treatment was effective, it was necessary to negotiate with the Local Education Authority (LEA) and PCT to establish a diabetes management programme in primary schools (see Box CS4.2). This was a lengthy process (~2–3 years), which involved:

- > addressing various barriers from concerns about legal indemnity on behalf of the LEA to the nervousness of school staff in administering injections, especially if they were ignorant of the condition originally;
- > negotiating funding;
- > developing protocols;
- **>** defining the responsibilities of all parties very clearly.

A paediatric diabetes specialist nurse (PDSN) was employed to work directly with schools.

Box CS4.2: Oxfordshire Primary Schools Intervention Programme

- A primary-school aged child is diagnosed with Type 1 diabetes
- 2. Schools diabetes specialist nurse discusses with parents what support they feel they need from the child's school
- 3. A care plan is drawn up with the parents
- 4. The school Head Teacher is sent an introductory document, and a meeting with the school DSN is arranged
- 5. The introductory document describes the condition of diabetes, and explains the need for testing and the administration of insulin during the school day; it also defines the responsibilities the school, the parents and the diabetes team
- 6. Volunteers are trained by the DSN, and the parent agrees to go to the school to supervise until both the parent and volunteer are happy that the volunteer is competent (this process could take days or weeks)
- 7. The school DSN certifies volunteer competency
- 8. The hand-held Communication Record Book is used: parents provide carbohydrate content of meals, insulin doses for meals, correction doses for high blood sugar; volunteers follow advice, and sign for insulin doses given
- 9. All equipment is provided and updated by parents
- 10. There is annual evaluation of the Schools Intervention Programme including feedback, monitoring of risk events, and review of protocols through the Diabetes multidisciplinary clinical governance meetings

From 2010 to 2012, the PDSNs trained volunteers, identified by the schools, for three hours in:

- > the basic management of diabetes;
- ➤ the specifics of the care plan for an individual child, all of which were drawn up in partnership with each child's parents.

Volunteers were also taught how to use a hand-held Communication Record Book, designed by one of the PDSNs.

To allow for illness and annual leave, the aim was to train a minimum of three volunteers per child with Type 1 diabetes.

Outcomes

In total, 342 volunteers were trained to care for 132 children, a ratio of 2.6 volunteers to one child.

Over the period of the project, glycaemic control has improved in the 4–11 years age-group (ANOVA p<0.001; see Table CS4.1).

Table CS4.1: Improvement in glycaemic control during the Oxfordshire Primary Schools Intervention Project

Time-period	HbA1c level	
2001–2004	8.38 (1.09)%	
2005–2008	7.74 (0.81)%	
2009–2012	7.58 (0.69)%	

There has been increasing use of insulin pumps.

Informal feedback from parents is that the system is working well. There have been a small number of problems:

- ➤ there have been three needlestick injuries (school staff tried to re-sheath pen needles against instructions in training protocols);
- on a few occasions, the wrong dose of insulin has been administered.

Only one school refused to carry out the agreed care.

Key Message

Specialist diabetes services can take the initiative in changing the culture, skill sets and competencies in schools in order to support children with diabetes in achieving the goal of improved glycaemic control.

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