

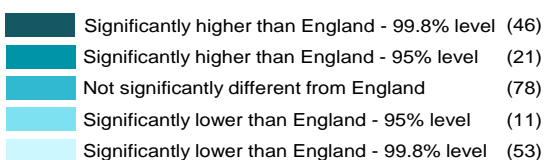
SCREENING SERVICES

MAP 30: Percentage coverage for initial screening tests for men aged 65 years in the NHS abdominal aortic aneurysm (AAA) screening programme by CCG

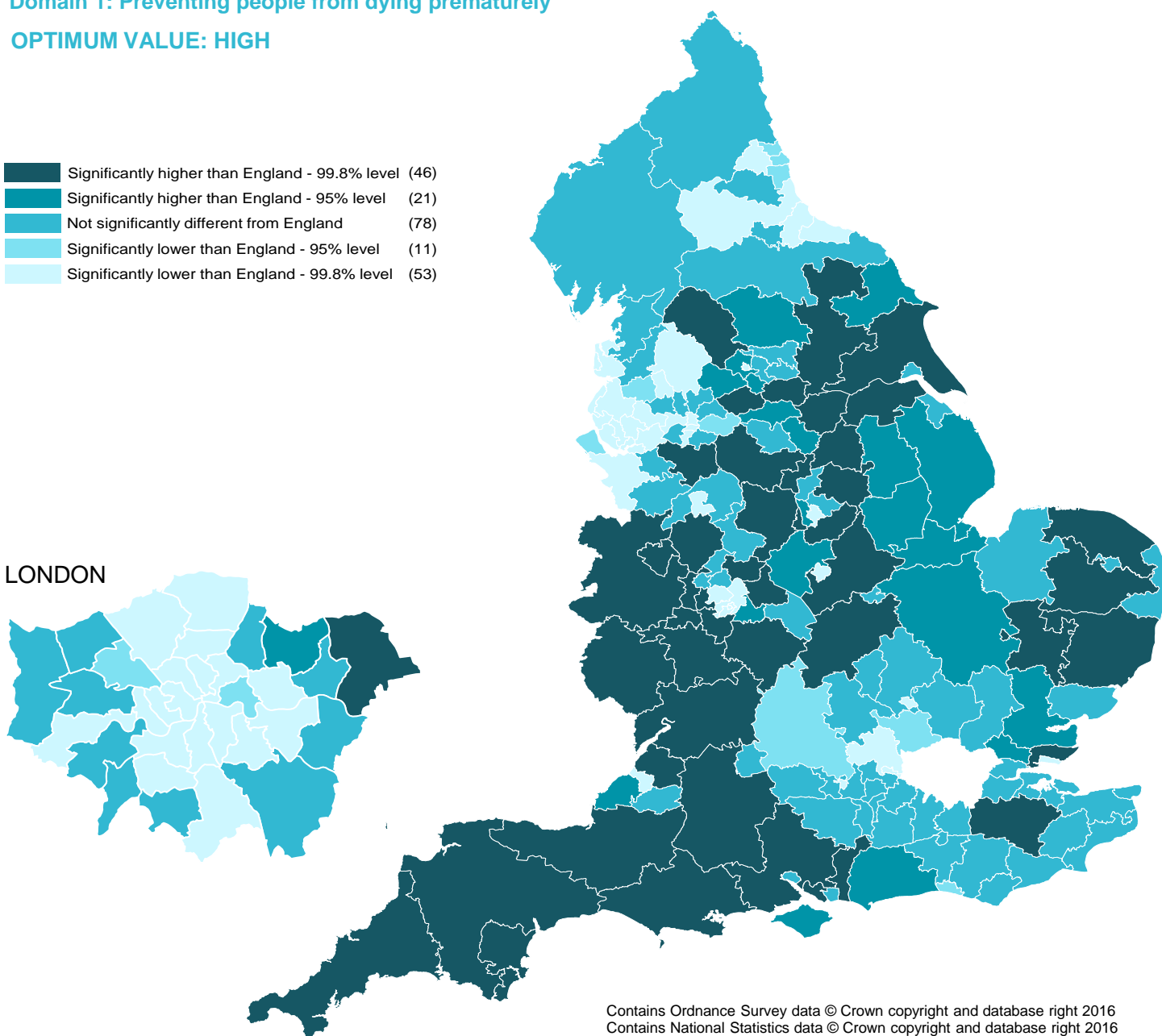
2014/15

Domain 1: Preventing people from dying prematurely

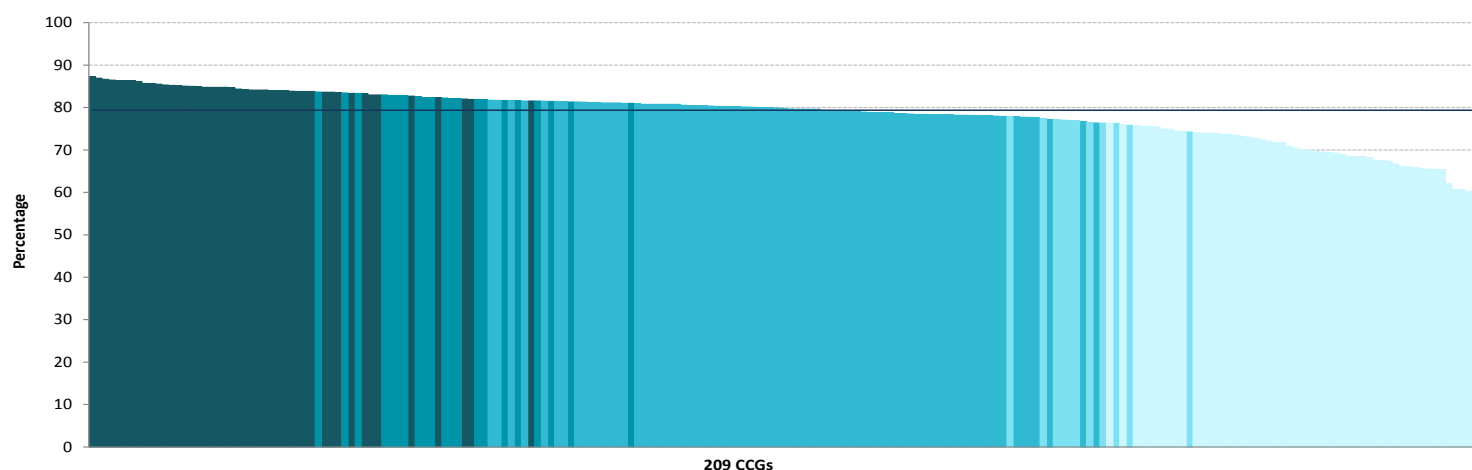
OPTIMUM VALUE: HIGH



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209 CCGs

Context

An aneurysm is the result of stretching caused by a weakness in the wall of an artery, usually as a result of degeneration due to ageing and external factors such as smoking, high levels of cholesterol and high levels of blood pressure. Although aneurysms can occur in any artery, one of the common places for aneurysm formation is the abdominal aorta.

Aneurysms can be asymptomatic, but with a larger aneurysm (>5.5cm) there is a risk of rupture, which can cause severe internal bleeding. Four out of five people with a ruptured aortic aneurysm will die.¹

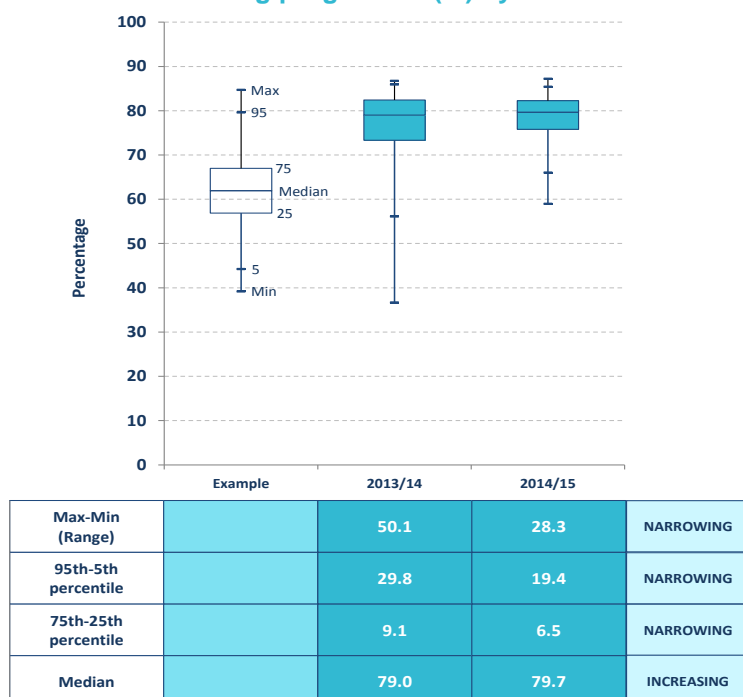
The aim of the NHS abdominal aortic aneurysm (AAA) screening programme is to reduce AAA-related mortality in men aged 65-74 years. The screening programme is open to all men over the age of 65 years, in which a non-invasive ultrasound test is performed to detect AAA. Participants are given the results immediately, and a letter containing the results is also sent to each participant's GP.

Magnitude of variation

The map and column chart display the latest period (2014/15), during which CCG values ranged from 59.0% to 87.2%, which is a 1.5-fold difference between CCGs. The England value for 2014/15 was 79.3%.

The boxplot shows the distribution of CCG values for the period 2013/14 to 2014/15. The statistical significance of changes in the three variation measures or the median was not tested for those indicators with fewer than three data periods.

Map 30: Boxplot of coverage of initial tests for men in NHS AAA screening programme (%) by CCG



One reason for warranted variation in the coverage of initial screening test for AAA is the choice about whether to participate by men eligible and invited for screening.

The socioeconomic profile of local populations, however, is known to affect rates of screening acceptance.

Reasons for unwarranted variation could include differences in:

- the way local providers of AAA screening services manage the possibility of non-attendance – in some local AAA screening programmes pre-notification lists are sent to GPs with a request to be informed about any men who are unfit for screening, such as people with learning disabilities
- strategies used to reach underserved groups in the local population
- the handling and recording of call and recall information for men eligible for screening
- accessibility of screening venues

Differences in the prevalence of obesity in local populations can affect the number of conclusive scans obtained by ultrasound. Fatty tissue can obscure the image of the aorta resulting in a non-visualised scan. To obtain a clear image men with an initial non-visualised scan need to be scanned at the medical imaging unit of the local vascular service.

Options for action

Commissioners need to specify that local providers of AAA screening services adhere to:

- the service specification and the care pathway for the NHS AAA screening programme (see 'Resources')
- the standards set for the AAA screening programme by the NHS national screening programme (see 'Resources')
- the failsafe processes that support the implementation of the care pathway for AAA screening (see 'Resources')

Commissioners also need to specify that local screening services refer participants to treatment centres that adhere to the framework for improving the results of elective AAA repair developed by The Vascular Society of Great Britain & Ireland (see 'Resources').

¹ Reimerink JJ, van den Laan MJ, Koelemay MJ, Balm R, Legemate DA. Systematic review and meta-analysis of population-based mortality from ruptured abdominal aortic aneurysm. *British Journal of Surgery* 2013; 100; 1405-1413. doi: 10.1002/bjs.9235

Commissioners need to ensure that all local providers of AAA screening services:

- implement appropriate and effective interventions to reduce the likelihood of non-attendance and to address non-attendance following the initial invitation to participate; for instance, providers could check with relevant GPs whether there are any reasons or barriers that may hinder an individual's participation – an invitation can then be sent that is more appropriate to an individual's circumstances, such as information about the screening programme that is easy to read, in large print or in a different language
- establish robust communication processes with any prison service in the local area to ensure that men who have been detained and are eligible for screening are invited and have the opportunity to participate – this is important because GPs will not necessarily be aware of any change in residence as it is not mandatory to inform them

To ensure systematic screening for AAA – the handling and recording of call and recall information and the recording and managing of ultrasound images – commissioners need to specify that providers of local AAA screening services use the national Screening Management and Referrals Tracking (SMaRT) IT system to record the national minimum data set (NMDS)

Providers of local AAA screening services need to ensure that all healthcare professionals involved in the programme update their knowledge regularly (see 'Resources').

RESOURCES

- Public Health England. Pathway Standards for NHS Abdominal Aortic Aneurysm Screening Programme. Version 1.2/April 2016.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/512707/AAA_pathway_standards.pdf
- NHS England (prepared by Public Health England). NHS public health functions agreement 2016-17. Service specification no.23. NHS Abdominal Aortic Aneurysm Screening Programme. February 2016.
<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/04/serv-spec-23-abdominal-aortic-aneurysm.pdf>
- NHS Screening Programmes. Abdominal aortic aneurysm screening: care pathway. Version 1.0/08-2015.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/493976/AAAS_-_revision_1.pdf
- NHS Screening Programmes. Abdominal aortic

aneurysm screening failsafe processes. Version 2.1/September 2015.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/463734/AAA_screening_2015-09-23_Failsafe_v2.1.pdf

- The Vascular Society of Great Britain & Ireland. Framework for improving the results of elective AAA repair 2011. <http://www.vascularsociety.org.uk/wp-content/uploads/2012/11/VSGBI-AAA-QIF-2011-v4.pdf>
- NHS Screening Programmes. Continuing Professional Development for Screening. Abdominal aortic aneurysm. <http://cpd.screening.nhs.uk/aaa>

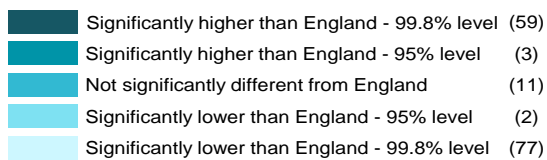
SCREENING SERVICES

MAP 31: Percentage of eligible people aged 60-74 years with a screening test result recorded in the previous 2.5 years from the NHS bowel cancer screening programme (NHS BCSP) by upper-tier local authority

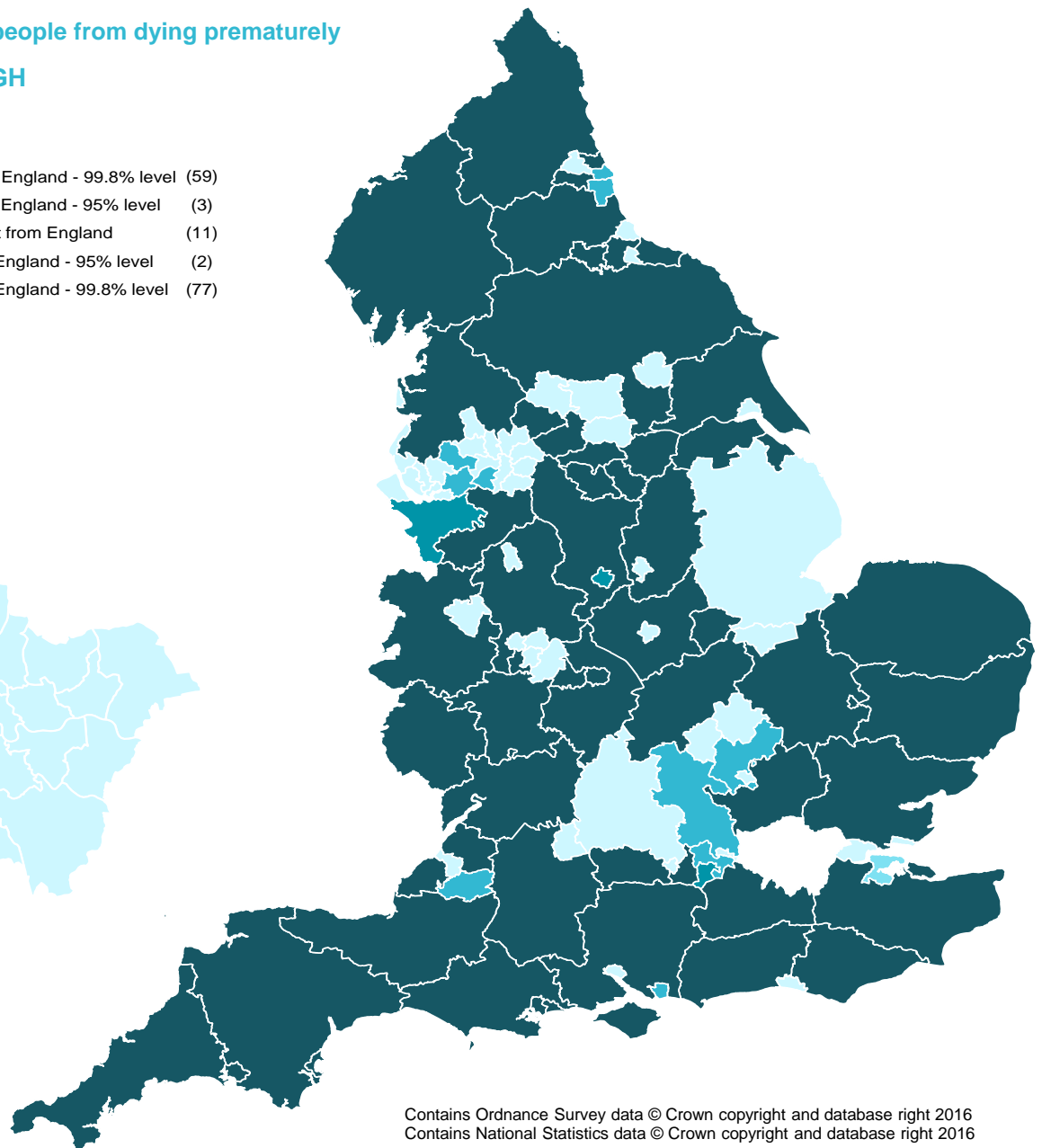
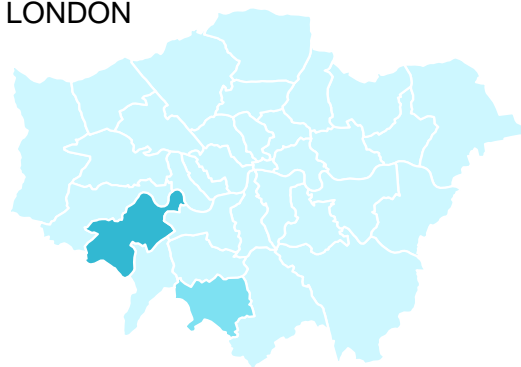
At 31 March 2015

Domain 1: Preventing people from dying prematurely

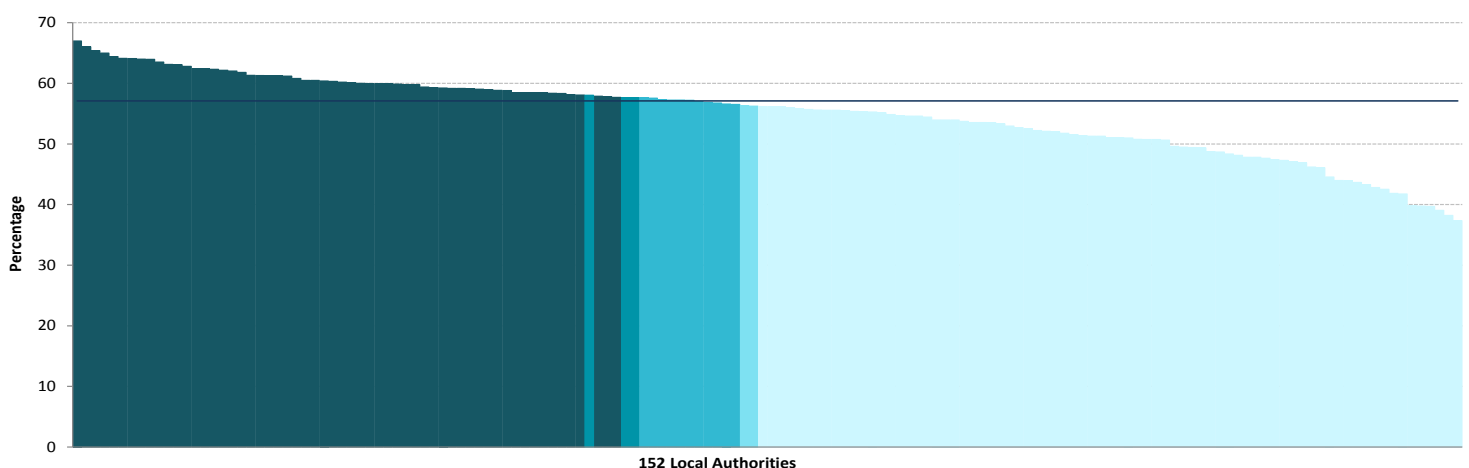
OPTIMUM VALUE: HIGH



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Context

Bowel cancer is the fourth most common cancer in the UK: there were 41,112 new cases in 2013.¹ In the last ten years the UK incidence rate has increased by 5%.¹ The UK incidence rate for men is the twentieth highest in Europe, and for women it is the seventeenth highest.¹

In 2012 in the UK there were 16,187 deaths from bowel cancer; it is thought that 54% of cases are preventable.¹ In 2010/11 in England and Wales 57% of people survived for ten years or more.¹

In England bowel cancer is more common in men living in the most-deprived areas.

The NHS Bowel Cancer Screening Programme (NHS BCSP) offers screening every two years to all men and women aged 60-74 years, using the faecal occult blood test (FOBT), with the aim of reducing deaths from bowel cancer.

When compared with patients diagnosed following an emergency presentation or GP referral, people identified through the NHS BCSP are more likely to have an early cancer which can often be treated without major surgery and has a better survival rate.

Magnitude of variation

The map and column chart display the latest time-point (31 March 2015), during which local authority values ranged from 37.3% to 67%, which is a 1.8-fold difference between local authorities. The England value at 31 March 2015 was 57.1%.

The boxplot shows the distribution of local authority values at 31 March 2015.

One in five (32 out of 152) local authorities have less than half their eligible population with a screening test result recorded in the last 2.5 years.

The main reason for warranted variation in the percentage of eligible people with a screening test result recorded is the proportion of people in the local population who choose to undertake the FOBT once received through the post. Factors that might influence whether people undertake the test are the practicalities and acceptability of using the FOBT kit.

The socioeconomic profile of the local population can also affect uptake of the screening test for bowel cancer.

One possible reason for unwarranted variation is differences in local systems for the follow-up of

people who do not use the FOBT kit once received.

Options for action

To reduce variation in the percentage of eligible people with a screening test result recorded, commissioners need to follow the service specification for the NHS BCSP (see 'Resources').

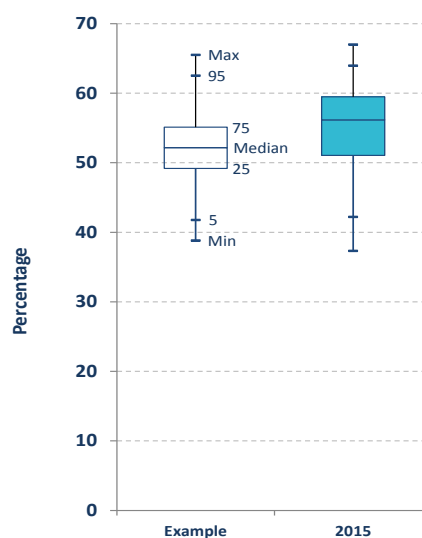
In recent years there have been several trials and initiatives designed with the aim of identifying ways to increase uptake in the NHS BCSP, and the following interventions have been found to be successful:

- a letter of endorsement from the person's GP
- an enhanced patient leaflet
- health promotion in a face-to-face consultation

Commissioners need to specify that screening service providers use these methods to increase uptake, especially when contacting groups in the population who are less likely to respond.

In addition the recent recommendation of the UK National Screening Committee (published in January 2016) to replace the FOBT with the faecal immunochemical test (FIT) could help to reduce the degree of variation observed because the FIT is much simpler and easier to perform, and produces a greater yield overall, when compared with the FOBT.

Map 31: Boxplot of people with test result in the previous 2.5 years in NHS BCSP (%) by local authority



	Example	2015
Max-Min (Range)		29.7
95th-5th percentile		21.8
75th-25th percentile		8.4
Median		56.2

¹ Cancer Research UK. Bowel cancer statistics. <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bowel-cancer>

RESOURCES

- Healthcare Quality Improvement Partnership. National Bowel Cancer Audit Report 2015.
<http://www.hscic.gov.uk/catalogue/PUB19500/nati-clin-audi-supp-prog-bowe-canc-2015.pdf>
- NHS public health functions agreement 2015-16. Service specification no.26 Bowel Cancer Screening Programme.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/383200/1516_No26_NHS_Bowel_Cancer_Screening_Programme_Final.pdf
- Public Health England. Quality assurance guidelines for colonoscopy. NHS BCSP Publication No 6 February 2011.
<https://www.gov.uk/government/publications/bowel-cancer-screening-colonoscopy-quality-assurance>
- NICE. Clinical Knowledge Summaries. Bowel Screening. Last revised October 2014.
<http://cks.nice.org.uk/bowel-screening>
- Cairns SR, Scholefield JH, Steele RJ et al developed on behalf of The British Society of Gastroenterology, and the Association of Coloproctology for Great Britain and Northern Ireland. Guidelines for colorectal cancer screening and surveillance in moderate and high risk groups (update from 2002). Gut 2010; 59: 666-690. doi: 10.1136/gut2009.179804
http://www.bsg.org.uk/images/stories/docs/clinical/guidelines/endoscopy/ccs_10.pdf

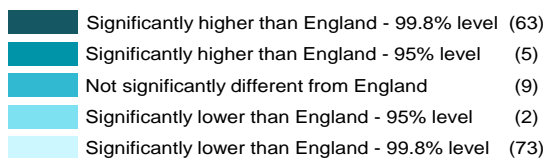
SCREENING SERVICES

MAP 32: Percentage of eligible women aged 53-70 years screened adequately within the previous three years in the NHS breast screening programme (NHS BSP) by upper-tier local authority

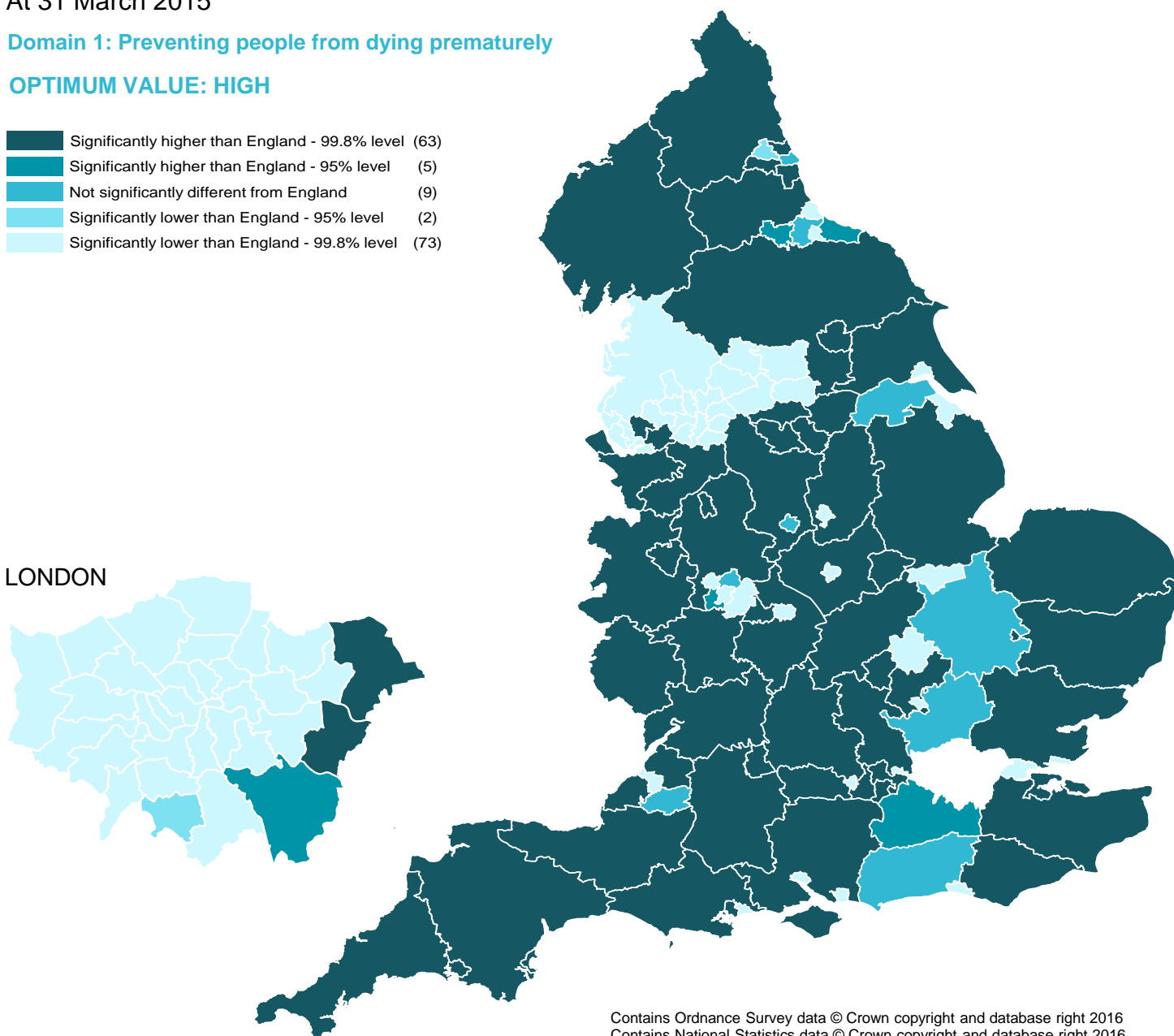
At 31 March 2015

Domain 1: Preventing people from dying prematurely

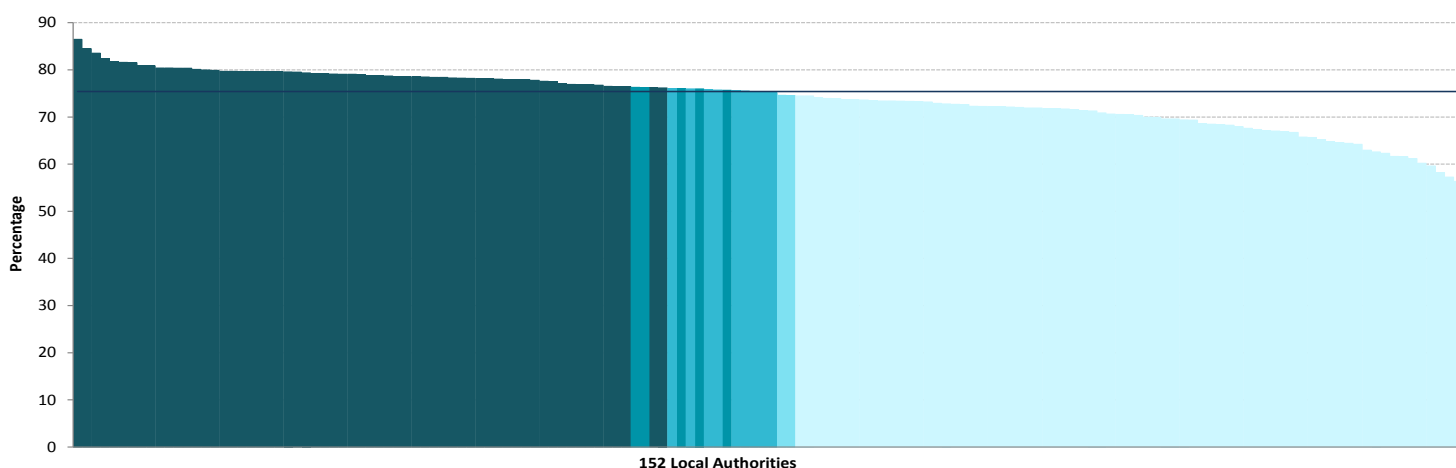
OPTIMUM VALUE: HIGH



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152 Local Authorities

Context

Breast cancer is the most common cancer in the UK. There were 53,696 new cases in 2013.¹ The UK incidence rate is the sixth highest in Europe, and in the last ten years the rate has increased by 4%.¹

In 2012 in the UK there were 11,716 deaths from breast cancer; 27% of cases are considered to be preventable.¹ In 2010/11 in England and Wales 78% of women survived for ten years or more.¹

In England breast cancer is less common in women living in the most-deprived areas, although these women once diagnosed have a similar survival outcome when compared with less-deprived women detected at screening. This is not the case where there are different routes of presentation (other than through screening). The outcome for women diagnosed in the most-deprived areas is poorer when compared with women diagnosed in the least-deprived areas: overall, one-year survival is 94% and 97%, respectively.²

The NHS breast screening programme (NHS BSP) invites all women aged 50-70 years for breast screening every three years. The aim of breast screening is to reduce mortality from breast cancer by detecting the condition at an early stage when there is the possibility of effective treatment.

In addition the national Age Extension Trial randomises half the population aged 47-49 years and 71-73 years to receive a screening invitation. This randomised control trial is the largest in the world that has been designed to investigate the efficacy of screening women outside the target age of 50-70 years, for which there is currently no evidence of efficacy.

In total, 2.11 million women aged 45 years and over were screened in the programme in 2014/15, an increase of 1.3% when compared with 2013/14.

Coverage for women aged 53-70 years was 75.4% at 31 March 2015, a decrease of 0.5% when compared with the same point in 2014 (the national minimum standard is 70% or above).

Magnitude of variation

The map and column chart display the latest time-point (31 March 2015), during which local authority values ranged from 56.3% to 86.4%, which is a 1.5-fold difference between local authorities. The England value at 31 March 2015 was 75.4%.

The boxplot shows the distribution of local authority values for the period 31 March 2010 to 31 March 2015. There was no significant change in any of the three variation measures between 31 March 2010 to 31 March 2015.

Map 32: Boxplot of women screened within previous three years in NHS BSP (%) by local authority



¹ Cancer Research UK. Breast cancer statistics. <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer>

² NCIN Short Report. Breast Cancer (female) routes to diagnosis short report. http://www.ncin.org.uk/publications/routes_to_diagnosis

There was a small but statistically significant decrease in the median of local authority values from 76.3% at 31 March 2010 to 75.2% at 31 March 2015.

Almost one-quarter of local authorities (n=35) failed to meet the national minimum standard of 70% of women to be adequately screened.

The main reason for warranted variation in the percentage of eligible women screened adequately is the proportion of women in the local population who choose to accept the invitation to screening.

Possible reasons for unwarranted variation are differences in:

- strategies used to reach underserved groups in the local population
- local capacity and resources to screen the eligible population within the required 36-month schedule
- changes in the eligible screening population, which may mean that some women are called for screening beyond the required 36-month target
- the socioeconomic profile of local populations, which affects rates of screening acceptance

In addition, the literature accompanying the screening invitation, entitled “NHS Screening: helping you decide”, is designed to allow women to attend screening on the basis of fully informed consent. The influence of this leaflet on acceptance rates may differ according to the profile of the local population served.

Options for action

To reduce variation in the percentage of eligible women screened adequately in the NHS BSP, commissioners need to follow the service specification for the breast cancer screening programme (see ‘Resources’). In addition commissioners need to specify that service providers adhere to all the NHS BSP guidance documents referenced in the national service specification.

It is recommended that NHS England public health commissioners and PHE Area Teams identify strategies and mechanisms that have helped to increase coverage at a local level to ensure that methods are shared in a national forum facilitating the dissemination of good practice.

All screening services need to seek advice and support from the screening quality assurance service where there are issues with adherence to national targets for screening round length.

RESOURCES

- Health & Social Care Information Centre (HSCIC). Breast Screening Programme, England – 2014-15 [NS]. February 24, 2016. <http://www.hscic.gov.uk/catalogue/PUB20018>
- Public Health England. Clinical Guidelines for Breast Cancer Screening Assessment. Third edition. NHSBSP Publication No 49 June 2010. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/465528/nhsbsp49_June2010.pdf
- NHS England. NHS public health functions agreement 2016-17. Service specification no.24 Breast Screening Programme. <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/02/serv-spec-24.pdf>
- Public Health England. Breast screening: professional guidance. <https://www.gov.uk/government/collections/breast-screening-professional-guidance>
- NICE. Clinical Knowledge Summaries. Breast Screening. Last revised November 2011. <http://cks.nice.org.uk/breast-screening#!scenario>

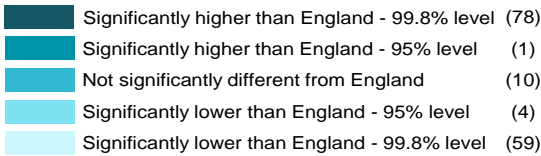
SCREENING SERVICES

MAP 33: Percentage of eligible women aged 25-64 years screened adequately in the NHS cervical screening programme (NHS CSP) by upper-tier local authority

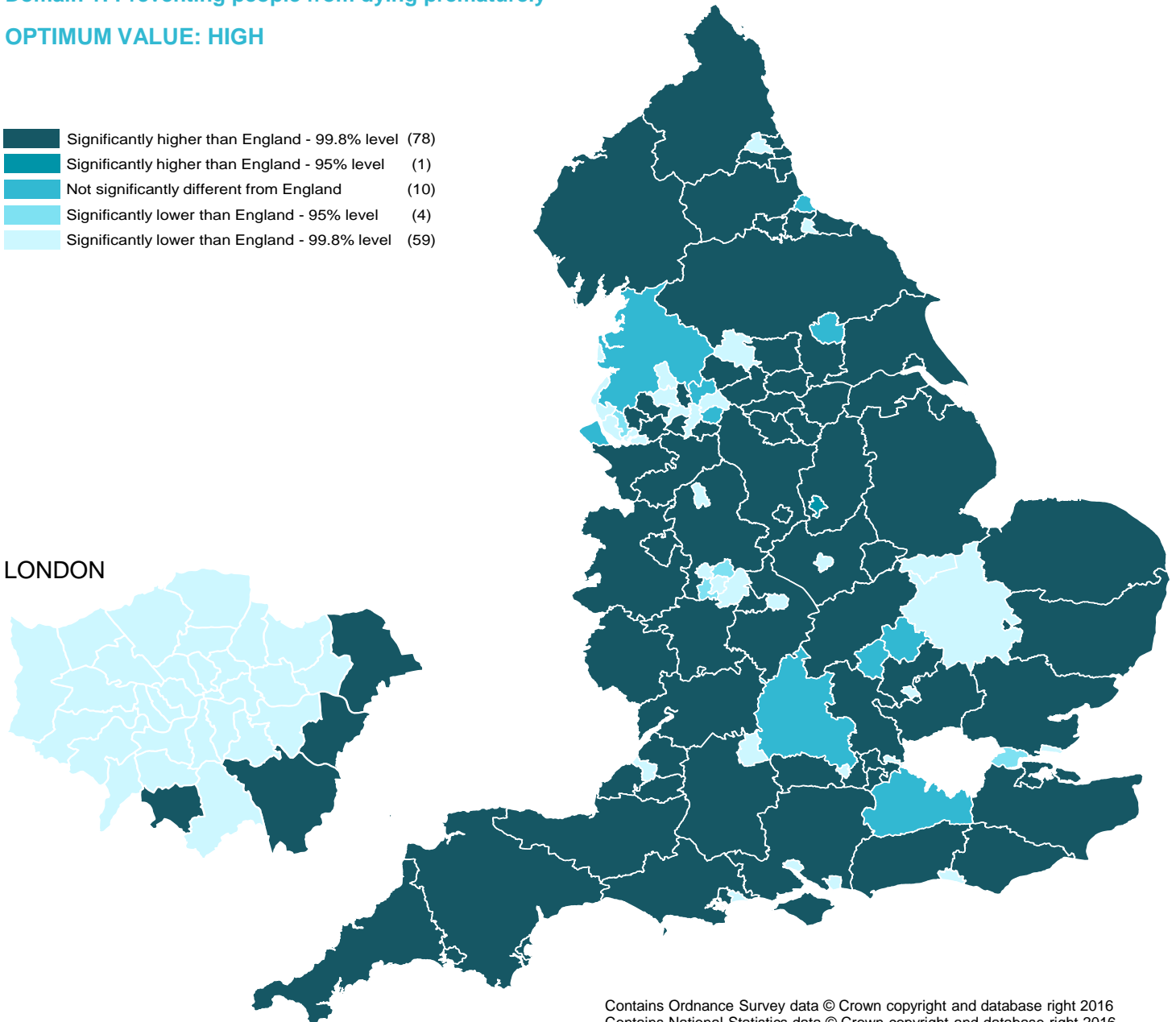
At 31 March 2015

Domain 1: Preventing people from dying prematurely

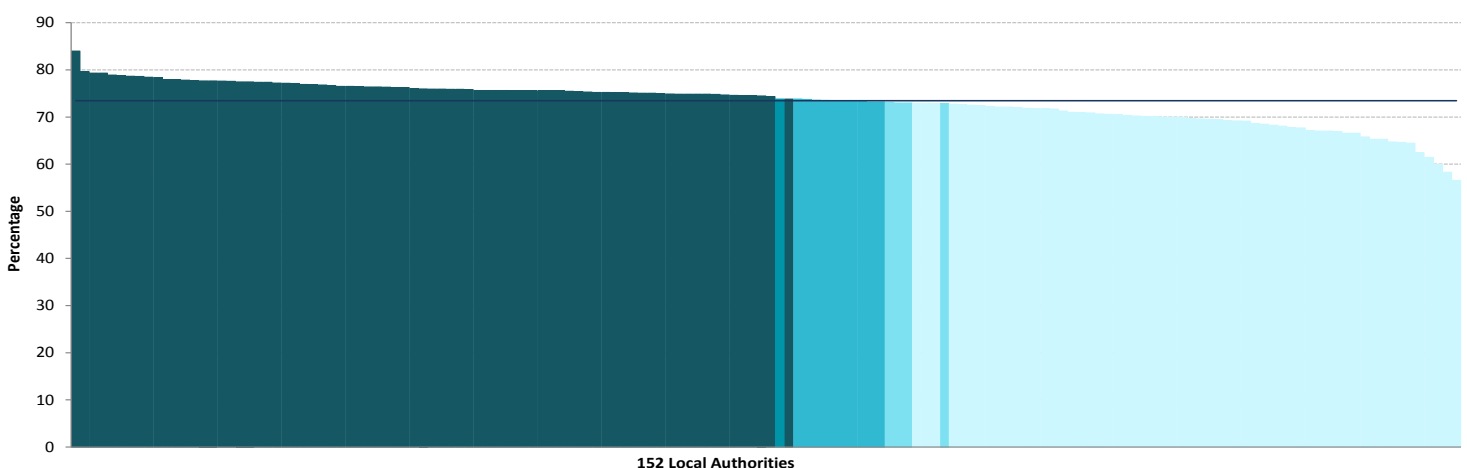
OPTIMUM VALUE: HIGH



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152 Local Authorities

Context

Cervical cancer is the 20th most common cancer in the UK. There were 3,207 new cases in 2013.¹ The UK incidence rate is the 12th lowest in Europe, and in the last ten years the rate has remained stable.²

In 2012 in the UK there were 919 deaths from cervical cancer; 100% of cases are considered to be preventable.² In 2010/11 in England and Wales 63% of women survived for ten years or more.²

In England cervical cancer is more common in women living in the most-deprived areas.

Women aged 25-64 years are invited for cervical screening: those aged 25-49 years are invited every three years, and those aged 50-64 years are invited every five years. The aim of the NHS cervical screening programme ([NHS CSP](#)) is to reduce the incidence of and mortality from cervical cancer.

Since its introduction the NHS CSP has helped to halve the number of cervical cancer cases, and it has been estimated that the NHS CSP saves approximately 4,500 lives per year in England.³

In total, 4.31 million women aged 25-64 years and over were invited for cervical screening in 2014/15, and 3.12 million women were tested in the programme, a decrease of 3.3% when compared with 2013/14.

Age-appropriate coverage is defined as the percentage of women in a population eligible for screening at a given point in time who were screened adequately within a specified period (within 3.5 years for women aged 25-49 years, and within 5.5 years for women aged 50-64 years). The minimum threshold is set at 80%. Age-appropriate coverage for women aged 25-64 years was 73.5% at 31 March 2015, a decrease of 0.7% when compared with the same point in 2014. Coverage among women aged 25-49 years was 71.2% at 31 March 2015, a decrease of 0.6% when compared with the same point in 2014, and for women aged 50-64 years it was 78.4%, a decrease of 1.0% when compared with the same point in 2014.

Magnitude of variation

The map and column chart display the latest period (31 March 2015), during which local authority values ranged from 56.5% to 84%, which is a 1.5-fold difference between local authorities. The England value at 31 March 2015 was 73.5%.

The boxplot shows the distribution of local authority values for the period 31 March 2010 to 31 March 2015. There was no significant change in any of the three variation measures between 31 March 2010 to 31 March 2015.

Only one local authority district achieved the minimum threshold rate of 80% at 31 March 2015.

Map 33: Boxplot of women screened adequately in NHS CSP (%) by local authority



¹ Cancer Research UK. Cervical cancer statistics. <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer>

² 'Adequately' defined as: 3.5 years since last test in women aged 25-49 years; 5.5 years since last test in women aged 50-64 years

³ Peto J, Gilham C, Fletcher O et al. The cervical cancer epidemic that screening has prevented in the UK. *Lancet* 2004; 364: 249-256.

There was a small but statistically significant decrease in the median of local authority values from 75.9% at 31 March 2010 to 74.4% at 31 March 2015.

The main reason for warranted variation in the percentage of eligible women screened adequately is the proportion of women in the eligible population who choose to accept the invitation to screening.

Possible reasons for unwarranted variation include differences in:

- strategies used to reach underserved groups in the local population
- access to screening
- inappropriate cessation of invitation to the screening programme

Options for action

Commissioners and providers of cervical screening services have a duty to recognise the diversity of their population. Both commissioners and primary care providers need to understand the barriers to women attending for cervical screening, and to initiate strategies to address any barriers identified.

Interventions found to improve most consistently participation in cancer screening in underserved populations are:

- pre-screening reminders
- personalised reminders for non-participants
- GP endorsement of cervical screening

To reduce variation in the percentage of eligible women screened adequately, commissioners need:

- to engage with service providers to ensure there is adequate accessibility to and provision of cervical screening
- to ensure that service providers follow the service specification for the cervical cancer screening programme (see 'Resources')
- to specify that service providers adhere to the colposcopy and management guidance for cervical screening (see 'Resources')
- to engage with service providers to ensure there is adequate training of health professionals responsible for taking the samples

RESOURCES

- Health & Social Care Information Centre (HSCIC). Cervical Screening Programme, England – 2014-15 [NS]. November 10, 2015.
<http://www.hscic.gov.uk/catalogue/PUB18932/nhs-cervical-stat-eng-2014-15-rep.pdf>

- NHS England. NHS public health functions agreement 2016-17. Service specification no.25 Cervical Screening.
<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/02/serv-spec-25.pdf>
- Public Health England. NHS Cervical Screening Programme. Colposcopy and Programme Management. NHS CSP Publication number 20. Third Edition March 2016.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/515817/NHSCSP_colposcopy_management.pdf
- Public Health England. Cervical screening: professional guidance.
<https://www.gov.uk/government/collections/cervical-screening-professional-guidance>
- NICE. Clinical Knowledge Summaries. Cervical Screening. Last revised February 2015.
<http://cks.nice.org.uk/cervical-screening#!scenario>

SCREENING SERVICES

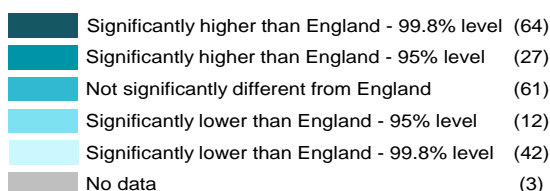
MAP 34: Percentage of babies eligible for testing in the NHS newborn blood spot (NBS) screening programme who had a conclusive result recorded on the Child Health Information System (CHIS) within an effective timeframe¹ by CCG²

July–September 2015

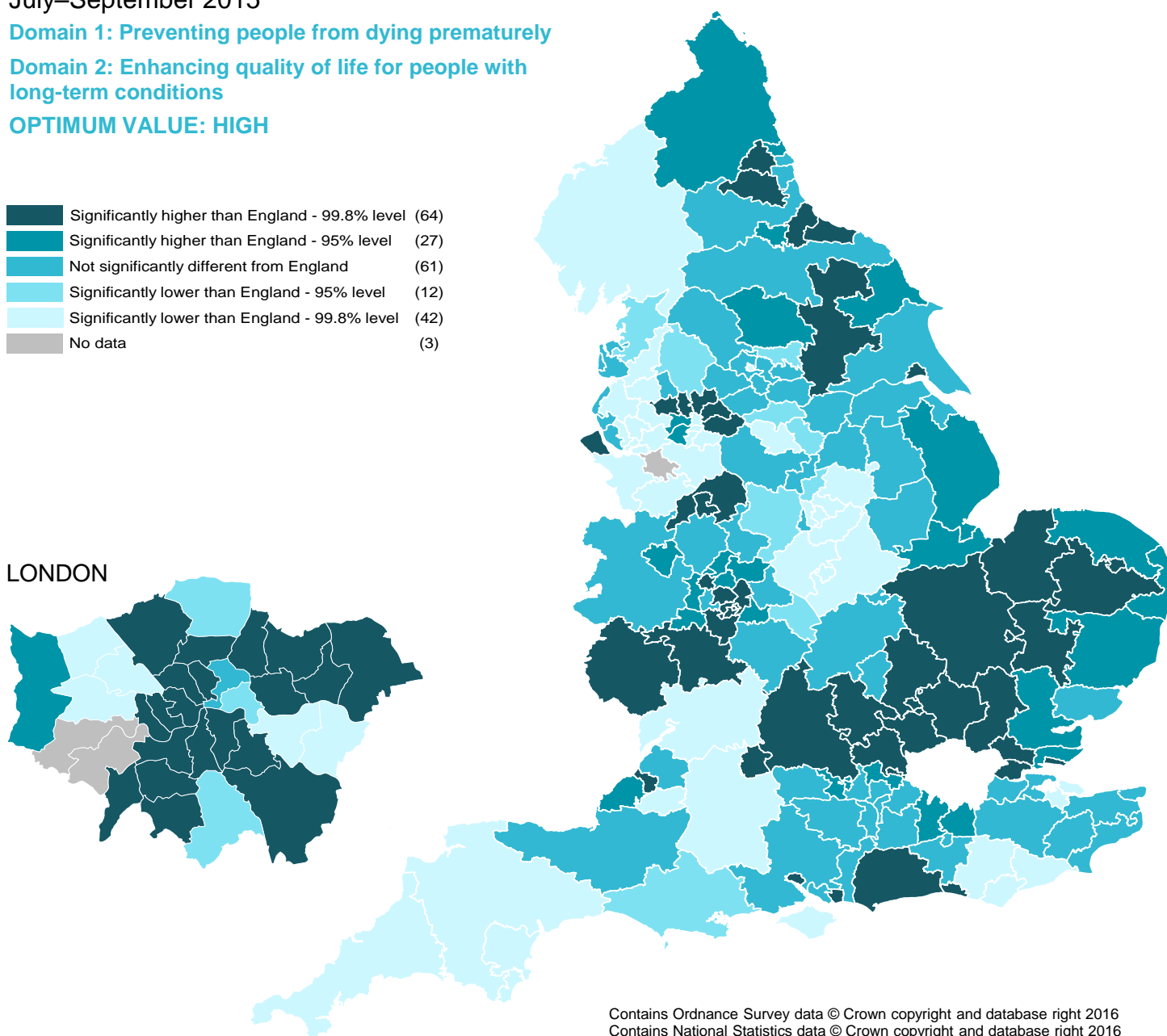
Domain 1: Preventing people from dying prematurely

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

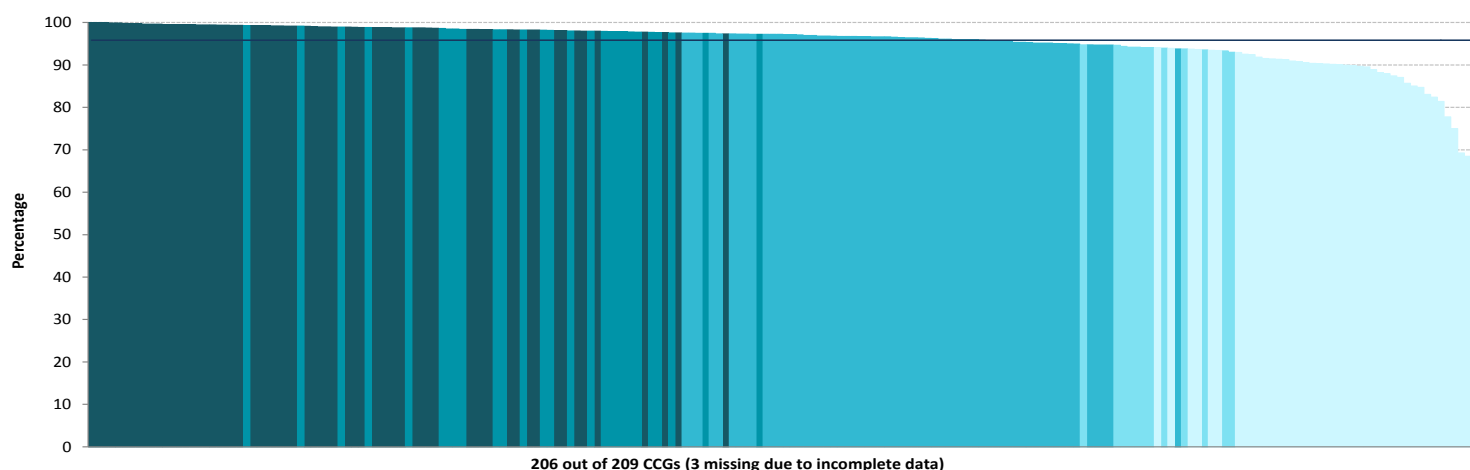
OPTIMUM VALUE: HIGH



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SCREENING SERVICES

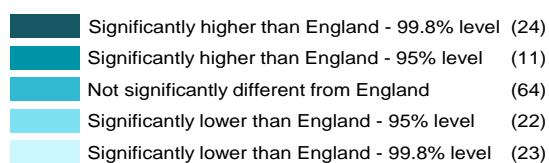
MAP 35: Percentage of babies who required a repeat test due to an avoidable failure in the sampling process during the NHS newborn blood spot (NBS) screening programme by maternity service

July–September 2015

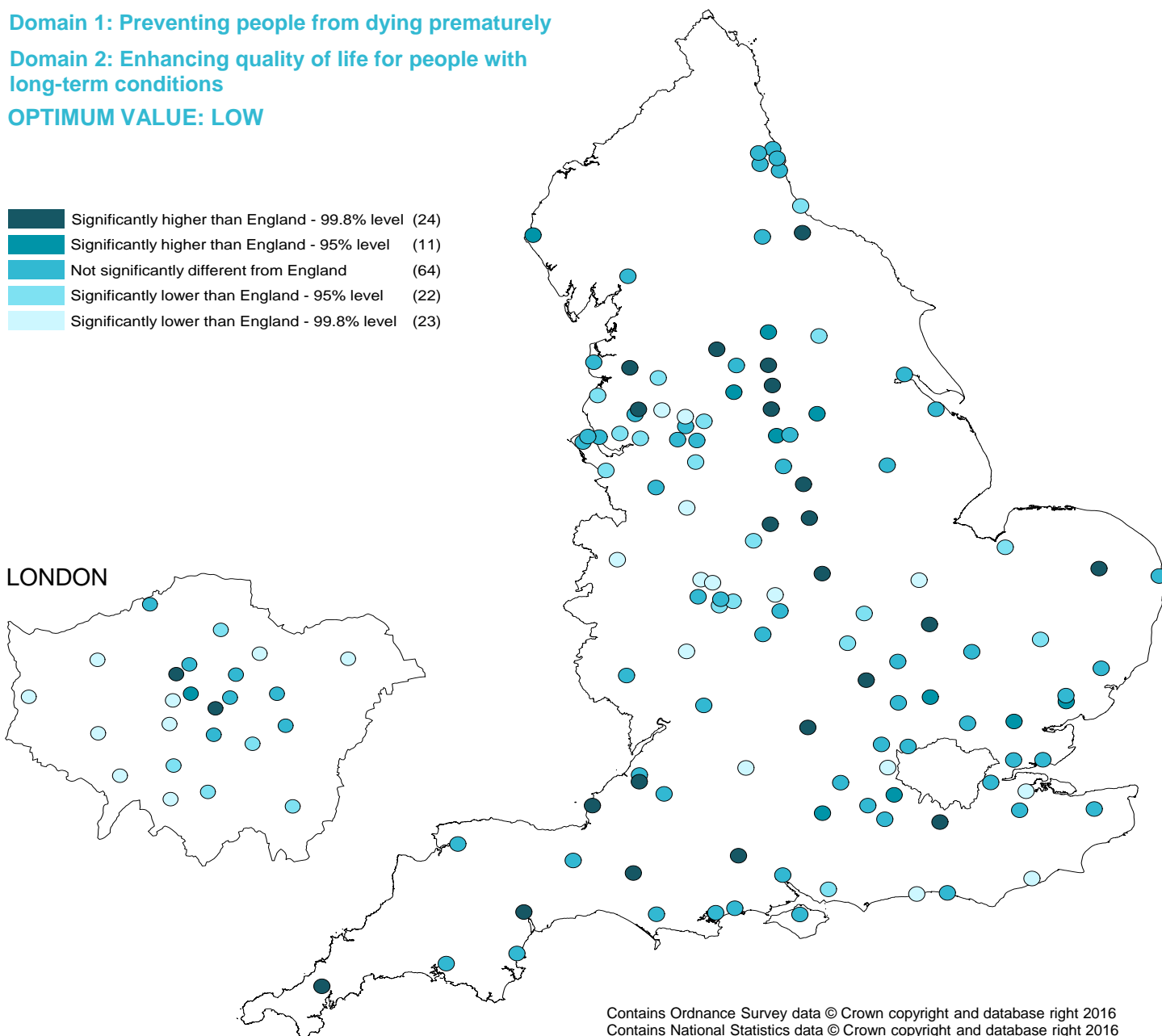
Domain 1: Preventing people from dying prematurely

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

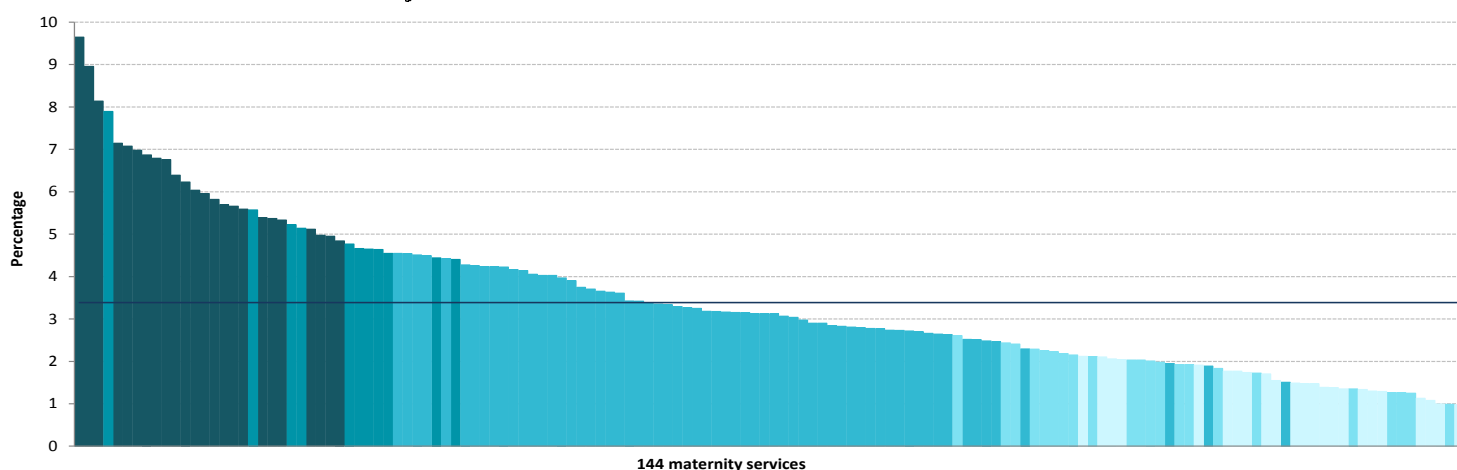
OPTIMUM VALUE: LOW



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Context

The aim of the NHS newborn blood spot (NBS) screening programme is to identify rare conditions that can lead to serious illness, development problems and death. The NHS NBS screening programme screens for nine conditions:

- sickle cell disease (SCD)
- cystic fibrosis (CF)
- congenital hypothyroidism (CHT)
- inherited metabolic diseases (IMDs), which are genetic diseases that affect the metabolism:
 - phenylketonuria (PKU)
 - medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
 - maple syrup urine disease (MSUD)
 - isovaleric acidemia (IVA)
 - glutaric aciduria type 1 (GA1)
 - homocystinuria (HCU)

Blood is taken from a child's heel at the age of five days (the first day of life is day 0). Parents verbally agree to the test, and assent is recorded in the baby's child health record. Parents can choose not to have their child screened for the conditions: parents can decline screening for SCD, CF and CHT as individual conditions, but for the six IMDs screening can be declined only for the group of diseases rather than individual conditions.

Magnitude of variation

Map 34: Percentage of babies with a conclusive result by CCG

The map and column chart display the latest period (July-September 2015), during which CCG values ranged from 62.4% to 100.0%, which is a 1.6-fold difference between CCGs. The England value for this quarter was 95.8%.

The boxplot shows the distribution of CCG values for the period April-June 2014 to July-September 2015.

The range between the maximum and minimum values widened significantly which is entirely due to a downward trend in the minimum CCG value. A closer examination of individual CCG values reveals that an increasing number of CCG have rates below 80%.

There was no significant change in the 95th to 5th percentile gap, in the 75th to 25th percentile gap, nor in the median between April-June 2014 to July-September 2015.

One reason for warranted variation in the uptake of NBS screening is parental choice about having their baby screened for rare conditions.

Possible reasons for unwarranted variation in the proportion of babies with a conclusive result are differences in the number of avoidable incidents such as:

- babies who miss screening
- samples failing to arrive at screening laboratories
- samples delayed in transit to screening laboratories
- failure of the equipment, assay or process in the laboratory, but this is very rare
- errors in the notification of birth in the Patient Demographic Service
- failure of the maternity IT system
- failure of the child health information system (CHIS)
- errors in data entry errors for CHIS
- errors in the submission or quality control of data, or missing data, for the key performance indicators

Map 35: Percentage of babies requiring a repeat test by maternity service

The map and column chart display the latest period (July-September 2015), during which the values ranged from 1.0% to 9.6%, which is a 9.9-fold difference between maternity services. The England value for this quarter was 3.4%. Almost 40% (n=57) of maternity services had a higher proportion of babies that needed retesting compared to the England rate.

The boxplot shows the distribution of maternity service values for the period April-June 2014 to July-September 2015. There was no significant change in any of the three variation measures or the median between April-June 2014 to July-September 2015.

Possible reasons for unwarranted variation in the percentage of babies from whom a repeat blood sample is taken are differences in:

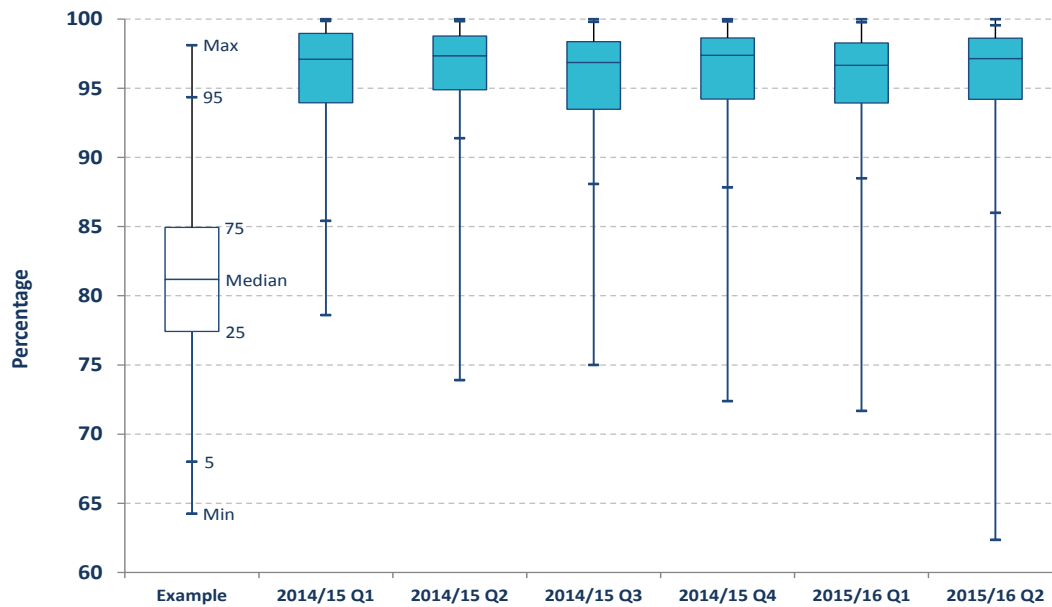
- training and education of health professionals involved in local NHS NBS screening services
- the skill and experience of health professionals involved in local NHS NBS screening services
- the device used to take the samples

Since April 2015, screening laboratories have been following a national consensus on blood spot sample quality criteria for requesting a repeat sample; however, compliance with these criteria is not currently being audited.

¹ For this indicator phenylketonuria (PKU) is used as a proxy for all tests and the test must be completed by 17 days of age.

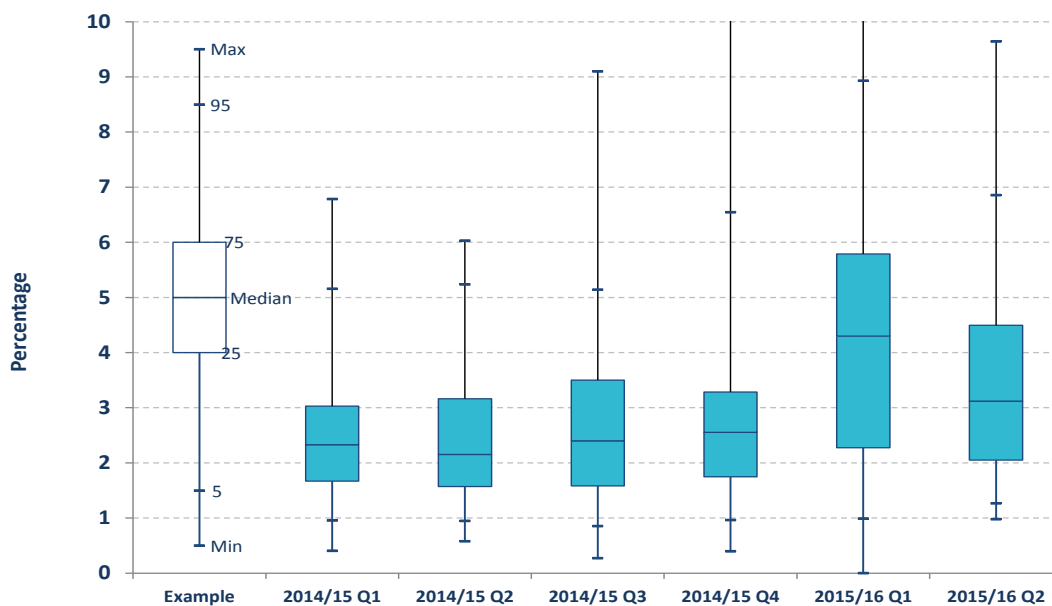
² Babies need to be registered within the CCG both at birth and on the last day of the reporting period.

Map 34: Boxplot of babies eligible for NHS NBS screening programme with a conclusive result on CHIS within an effective timeframe (%) by CCG



Max-Min (Range)		21.4	26.1	25.0	27.6	28.3	37.6	WIDENING Significant
95th-5th percentile		14.5	8.5	11.7	12.0	11.3	13.6	No significant change
75th-25th percentile		5.0	3.9	4.9	4.4	4.4	4.4	No significant change
Median		97.1	97.4	96.9	97.4	96.7	97.2	No significant change

Map 35: Boxplot of babies requiring a repeat test in the NHS NBS screening programme (%) by maternity service



Max-Min (Range)		6.4	5.5	8.8	32.9	13.9	8.7	No significant change
95th-5th percentile		4.2	4.3	4.3	5.6	7.9	5.6	No significant change
75th-25th percentile		1.4	1.6	1.9	1.5	3.5	2.4	No significant change
Median		2.3	2.2	2.4	2.6	4.3	3.1	No significant change

Options for action

Commissioners need to specify that providers of local NHS NBS screening services:

- adhere to the service specification and care pathway (see 'Resources') for the NHS NBS screening programme
- implement the NHS newborn blood spot failsafe solution (NBSFS; see 'Resources') to ensure that babies affected by any of the conditions do not suffer serious harm from avoidable incidents – if harm does occur it has serious consequences for the baby and the parents, and incurs additional costs for the care and treatment of the affected baby

To reduce the need to take repeat blood samples and avoid any harm to the baby as a result of delays in diagnosis and treatment, providers of local NHS NBS screening services need to ensure that all health professionals involved in the screening programme:

- adhere to the revised guidelines for NBS sampling (see 'Resources')
- undertake continuing professional development for screening (see 'Resources')

Commissioners and providers of local NHS NBS screening services need to ensure that all screening laboratories and CHISs are using the v4.2 status codes and subcodes for reporting screening results (see 'Resources').

RESOURCES

- NHS England (prepared by Public Health England). NHS public health functions agreement 2016-17. Service specification no.19. NHS Newborn Blood Spot Screening Programme. February 2016. <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/04/serv-spec-19-chld-blood-spot-screening.pdf>
- NHS Screening Programmes. Newborn blood spot screening: care pathway. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/494003/Diagram_NBS_final_V3.pdf
- NHS Screening Programmes. NHS Newborn Blood Spot Screening Programme. Failsafe processes. Version 1.1, August 2011. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/456192/NBS_Failsafe_processes_v1.1.pdf
- NHS Screening Programmes. Continuing Professional Development for Screening. Education and Training for the Newborn Blood Spot Programme. <http://cpd.screening.nhs.uk/newbornbloodspot>

- NHS Screening Programmes. Status codes for newborn blood spot screening v4.2. December 2014. <https://www.gov.uk/government/publications/status-codes-for-the-newborn-blood-spot-nbs-screening-programme>
- NHS Screening Programmes. Guidelines for Newborn Blood Spot Sampling. March 2016. <https://www.gov.uk/government/publications/newborn-blood-spot-screening-sampling-guidelines>
- Public Health England. Output and information requirements specification: for the Child Health Information service and systems. 24 March 2015. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/417076/Child_Health_Information_240315.pdf
- NHS England. Child Health Information Services (CHIS) Provider Services Specification. 10 August 2015. <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2013/05/chis-provider-service-spec.pdf>

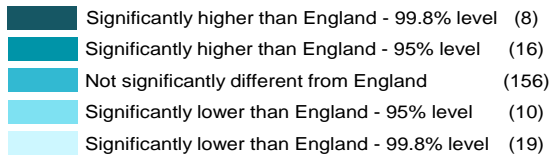
SCREENING SERVICES

MAP 36: Percentage of referred babies who had an audiological assessment within four weeks of the decision to refer or by 44 weeks' gestational age by CCG

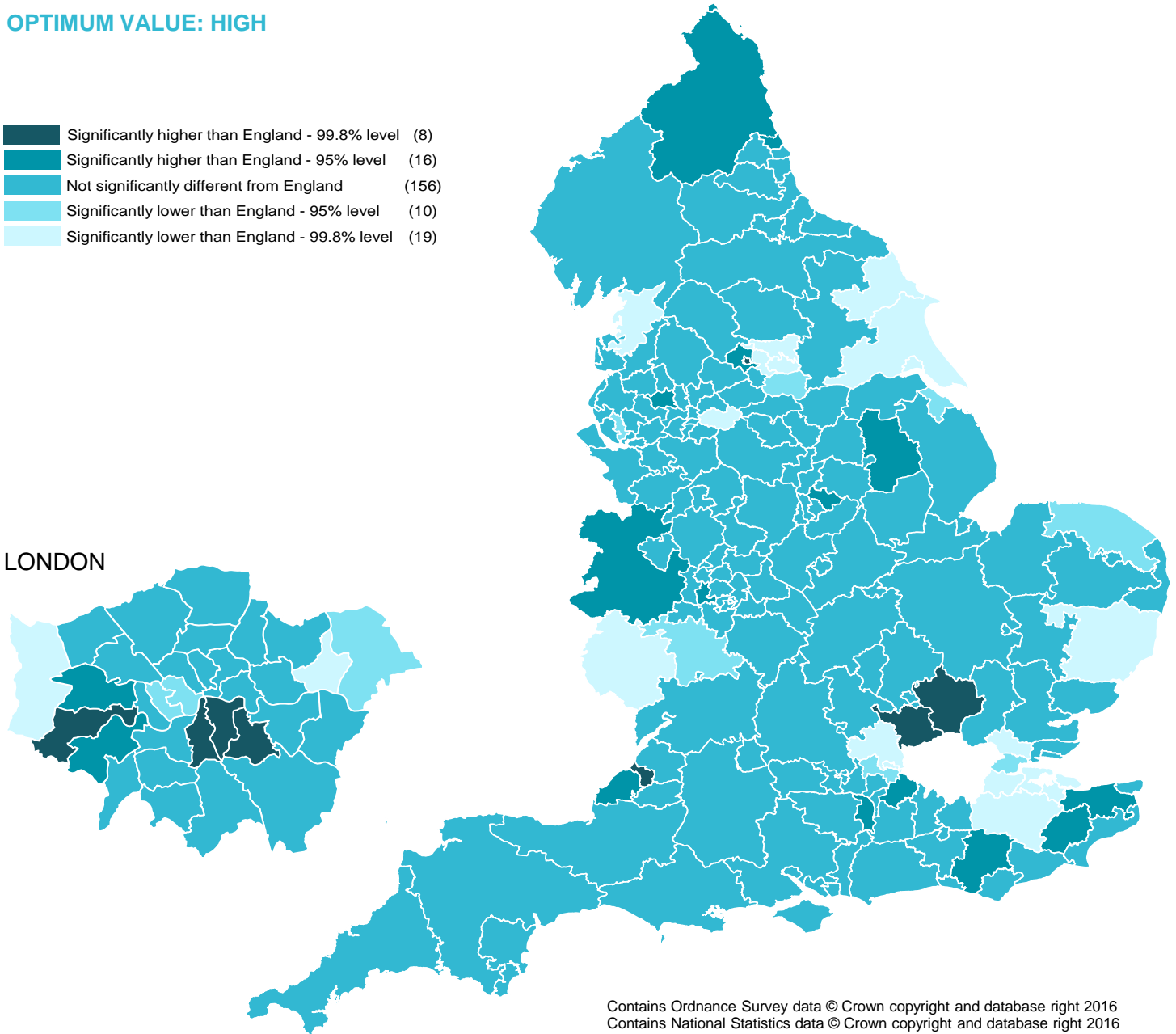
2014/15

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

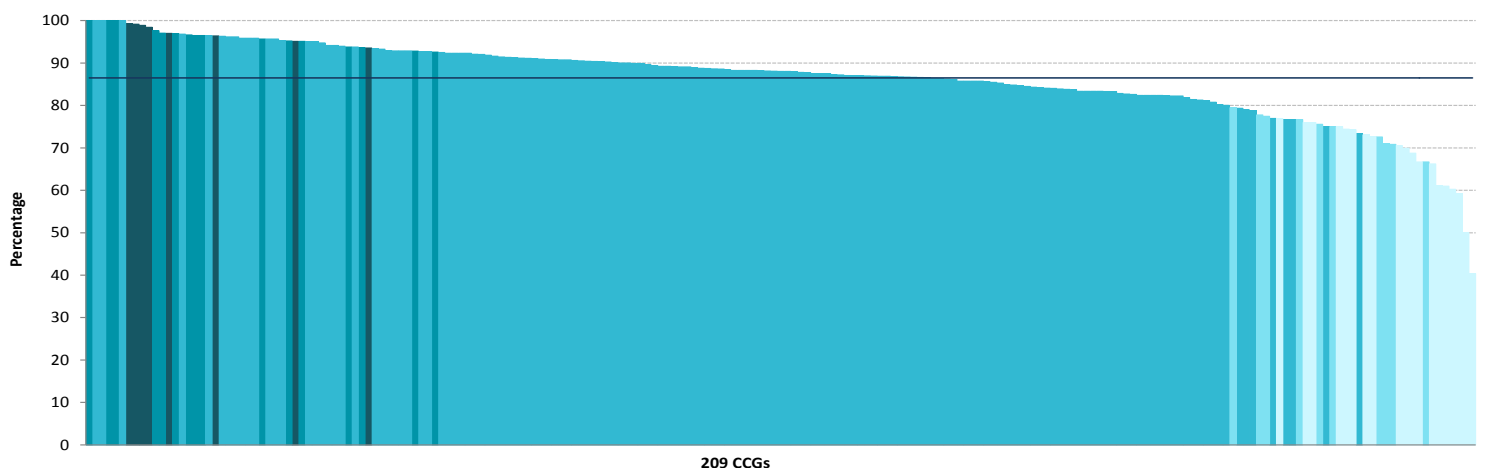
OPTIMUM VALUE: HIGH



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Context

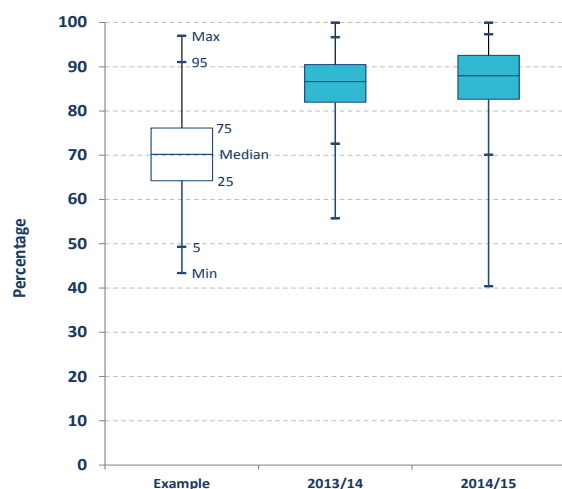
Each year around 1,300 babies are born with permanent childhood hearing impairment. In England 35,000 children are affected by hearing loss, and receive treatment, care and support services from the NHS, social care and education services. About £250 million per year is spent on paediatric audiology and education services for children, and on related family support services.

Early identification by the NHS newborn hearing screening programme (NHS NHSP) has dramatically improved early diagnosis and promoted early intervention to reduce the impact of hearing loss, giving children a better chance of developing speech and language skills, and of making the most of social and emotional interaction from an early age. There are also better outcomes for the family.

The parents of all babies born or resident in England should be offered hearing screening for their baby within four to five weeks of birth. The test can take place in hospital, in an outpatient clinic or at home by a health visitor. Babies that miss screening should receive it as soon as possible, but not after three months of age.

Through the NHS NHSP children are referred to paediatric diagnostic audiology services if they have a poor response in either one ear or both ears at screening. The average referral rate to paediatric diagnostic audiology services is 2.6%: for about 0.7% of referrals, babies do not have a clear response in both ears at screening; for 1.9%, babies do not have a clear response in one ear at screening.

Map 36: Boxplot of referred babies with audiological assessment (%) by CCG



Max-Min (Range)		44.3	59.6	WIDENING
95th-5th percentile		24.0	27.2	WIDENING
75th-25th percentile		8.5	9.9	WIDENING
Median		86.7	88.0	INCREASING

Each year in England around 18,000 children are referred from the NHS NHSP for electrophysiological audiological assessment. Following assessment children are diagnosed as:

- permanently deaf
- in need of further diagnostic testing
- hearing within normal limits

Of the 1,300 children identified as deaf by the NHS NHSP in a year, 770 will have bilateral deafness; of those 770 children, 135 will be profoundly deaf.

The NHS NHSP has programme standards and service specifications (see 'Resources'). The key performance indicator relating to referral for audiological assessment is:

"The proportion of babies with a no clear response result in one or both ears or other result that require an immediate onward referral for audiological assessment who receive audiological assessment within the required timescale."

Reducing the degree of variation in the percentage of babies receiving audiological assessment within four weeks of referral will reduce the level of inequity for newborn babies and their parents who are offered hearing screening, and thereby enable better outcomes to be achieved.

Magnitude of variation

The map and column chart display the latest period (2014/15), during which CCG values ranged from 40.4% to 100%, which is a 2.5-fold difference between CCGs. The England value for 2014/15 was 86.5%.

The boxplot shows the distribution of CCG values for the period 2013/14 to 2014/15.

The statistical significance of changes in the three variation measures or the median was not tested for those indicators with fewer than three data periods.

Reasons for warranted variation include differences in the levels of risk, multi-morbidity and genetic aetiologies in different geographical areas.

Attendance at an assessment can be determined by factors affecting a baby's parents, including constraints on their ability to travel and/or financial constraints.

Possible reasons for unwarranted variation relating to service provision include differences in:

- capacity
- quality of management of audiology assessment services
- prioritisation of services
- peer-to-peer network support
- arrangements for cover
- accessibility of venues for audiological assessment

Options for action

To reduce unwarranted variation in the percentage of babies receiving audiological assessment within four weeks of referral, commissioners need to specify that all hearing screening service providers:

- adhere to the NHS England service specification (see 'Resources'), and supporting documents to ensure that a hearing screening programme is set up correctly and meets the standards set by the national screening team
- follow the care pathways for the NHS NHSP screening and referral process (see 'Resources')
- report on key performance indicators, as set and reviewed by the national screening team (see 'Resources'), explore arrangements for peer-review within service networks of performance and participate in and maintain accreditation to defined quality standards operating under the umbrella of the United Kingdom Accreditation Schemes (UKAS) and Improving Quality in Physiological Services (IQIPS; see 'Resources')

To ensure that hearing screeners are competent and able independently to screen babies, commissioners and providers of local hearing screening services need to make certain that all hearing screeners have completed:

- training in line with programme requirements and standards (see 'Resources')
- an objective structured clinical examination (OSCE; see 'Resources')

It is also important to widen the focus for action and consider the degree of variation from screening to intervention via diagnosis to ensure that the whole pathway to intervention is not subject to unwarranted

variation. Therefore, commissioners and service providers need to work together to investigate the interface between local screening services, paediatric audiology services and education services.

RESOURCES

- NHS England (prepared by Public Health England). Public health functions to be exercised by NHS England. Service specification No.20. NHS Newborn Hearing Screening Programme. 2016/17 <https://www.england.nhs.uk/commissioning/pub-hlth-res/>
- Public Health England. Newborn Hearing Screening: care pathways. Last updated 20 November 2015. <https://www.gov.uk/government/publications/newborn-hearing-screening-care-pathways>
- National Screening Team. Key performance indicators. [The full eSP reference guide is available to NHSP professionals on the extranet.](#) Login page: <http://legacy.screening.nhs.uk/nhsp-extranet>
- NHS Screening Programmes. Continuing Professional Development for Screening: Newborn Hearing Screening e-learning. Updated January 2016. <http://cpd.screening.nhs.uk/nhsp-elearning>
- NHS Screening Programmes. Continuing Professional Development for Screening: Screener training. <http://cpd.screening.nhs.uk/cms.php?folder=5183>
- Health Knowledge. Screening – Angela Raffle. <http://www.healthknowledge.org.uk/interactive-learning/screening>
- Improving Quality in Physiological Services (IQIPS). <https://www.iqips.org.uk/>

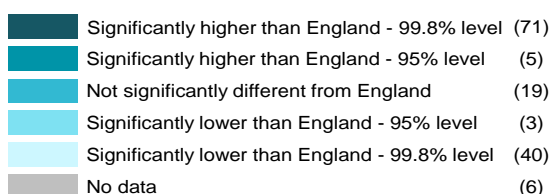
SCREENING SERVICES

MAP 37: Percentage of women tested in the NHS antenatal sickle cell and thalassaemia screening programme with a conclusive result by 10 weeks' gestation by maternity service

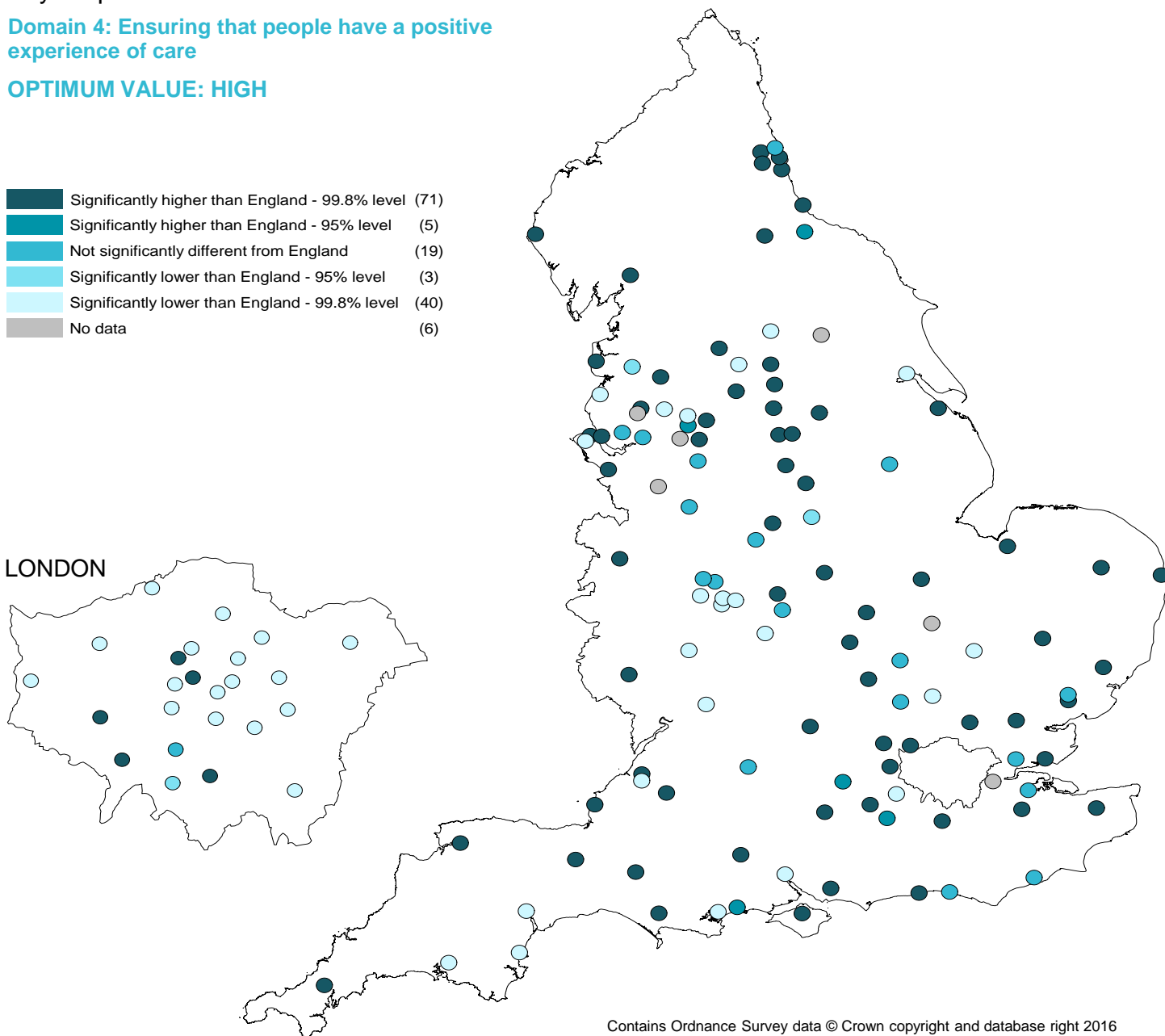
July–September 2015

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

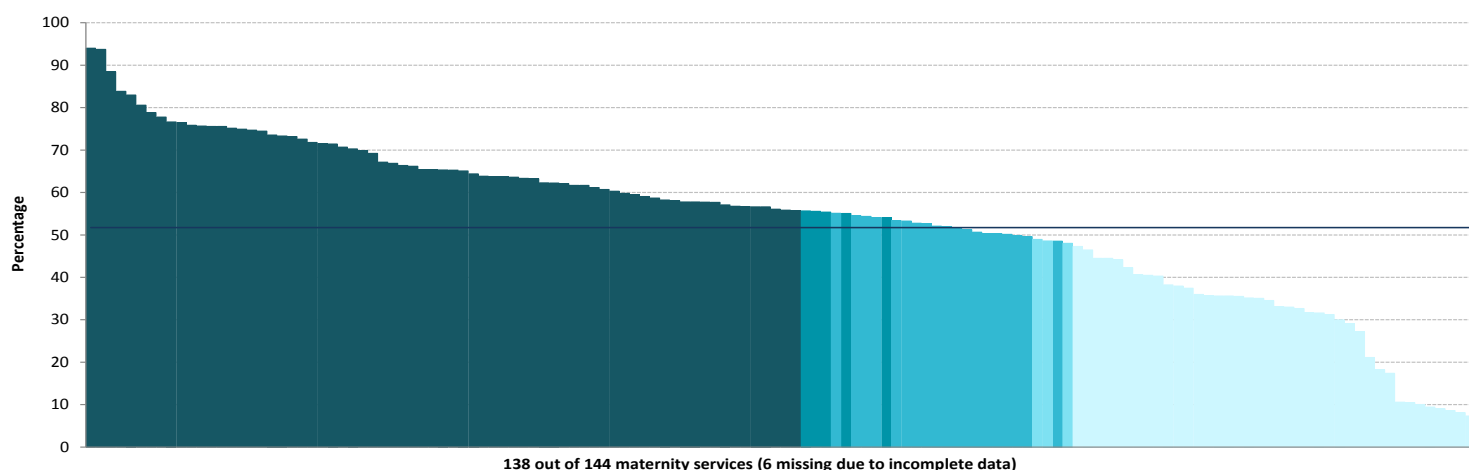
OPTIMUM VALUE: HIGH



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138 out of 144 maternity services (6 missing due to incomplete data)

Context

Sickle cell disease is a group of inherited conditions that affect the quality of haemoglobin, and its capacity to carry oxygen around the body. Sickle cell anaemia is the most severe form of the disease. Other sickle cell conditions that require treatment include haemoglobin SC disease and S beta thalassaemia. In sickle cell disease red blood cells deform and break down intermittently leading to blocked blood vessels. Complications include episodes of severe pain, stroke and respiratory collapse, as well as anaemia and susceptibility to infections. People with sickle cell disease have a reduced life expectancy.

In England sickle cell disease occurs in 1 in 2,000 live births, being most common in people of Black African or Caribbean origin.

Thalassaemia is a group of inherited conditions that affect the amount of haemoglobin produced and its capacity to carry oxygen around the body. Beta thalassaemia major is the most severe type; other thalassaemias include alpha thalassaemia major, beta thalassaemia intermedia and haemoglobin H disorder. In addition to anaemia, symptoms include fatigue, palpitations and shortness of breath. Some people also experience delayed growth, osteoporosis and reduced fertility. Thalassaemia mainly affects people of Mediterranean, Middle Eastern, South Asian and South East Asian origin.

People with a haemoglobin disorder will have inherited two genes for unusual red blood cells, one from the mother and one from the father, who are referred to as genetic carriers of the disease, that is, they have the sickle cell or thalassaemia gene. If both parents are carriers, however, there is a 25% chance (one in four) that the baby will inherit a haemoglobin disorder requiring treatment. The severity of the condition that the baby inherits depends on the combination of genes received from each parent.

People who are genetic carriers usually do not experience health problems, but carriers of the sickle cell gene can do so in situations where there is a lack of oxygen, such as having an anaesthetic or participating in extreme sports.

The NHS Sickle Cell and Thalassaemia screening programme is one of the antenatal and newborn NHS population screening programmes, screening for:

- genetic carriers for sickle cell, thalassaemia and other haemoglobin disorders
- sickle cell disease

- thalassaemia
- haemoglobin disorders

These two indicators¹ focus on antenatal screening for sickle cell and thalassaemia. The aim of antenatal screening is to identify expectant parents who are genetic carriers of an unusual form of haemoglobin in order to offer them reproductive choice. In the first instance screening is offered to all pregnant women, and then to fathers-to-be where antenatal screening shows the mother is a genetic carrier. As part of antenatal screening health professionals ask about family origins and the responses are recorded on a family origin questionnaire (FOQ), which is sent to the laboratory together with the blood samples.

Where both patients are identified as carriers counselling is offered together with prenatal diagnosis for the fetus. If prenatal diagnosis is accepted and the baby is found to have an inherited blood disorder further counselling is offered to the parents, and the option to terminate the pregnancy if required.

The aim is to perform prenatal diagnosis by 12+6 weeks' gestation. To achieve this aim the target is to offer the initial screening test by 10 weeks' gestation, which allows couples to complete all the tests and consider the option of an early termination if they wish.

All newborn babies are screened for sickle cell disorders as part of the NHS newborn blood spot (NBS) screening programme (maps 34 and 35); the test can also identify babies who are carriers for sickle cell. Newborn screening for thalassaemia is not recommended by the UK National Screening Committee but it formally supports the current practice of the reporting clinically significant thalassaemias (including beta thalassaemia major) found as a by product of newborn screening for sickle cell disease.

There is clinical and service guidance for the management of sickle cell disease in childhood (see 'Resources').

Magnitude of variation

Map 37: Timeliness of test

The map and column chart display the latest period (July-September 2015), during which the values ranged from 7.3% to 94.0%, which is a 12.9-fold difference between maternity services. The England value for this period was 51.7%.

¹ In the NHS national screening programmes these are key performance indicators ST2 and ST3.

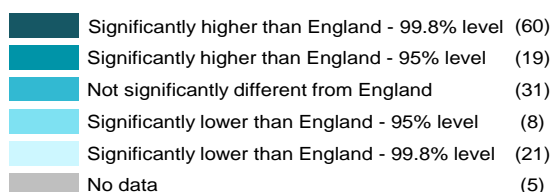
SCREENING SERVICES

MAP 38: Percentage of samples in the NHS antenatal sickle cell and thalassaemia screening programme submitted to the laboratory with a completed family origin questionnaire (FOQ) by maternity service

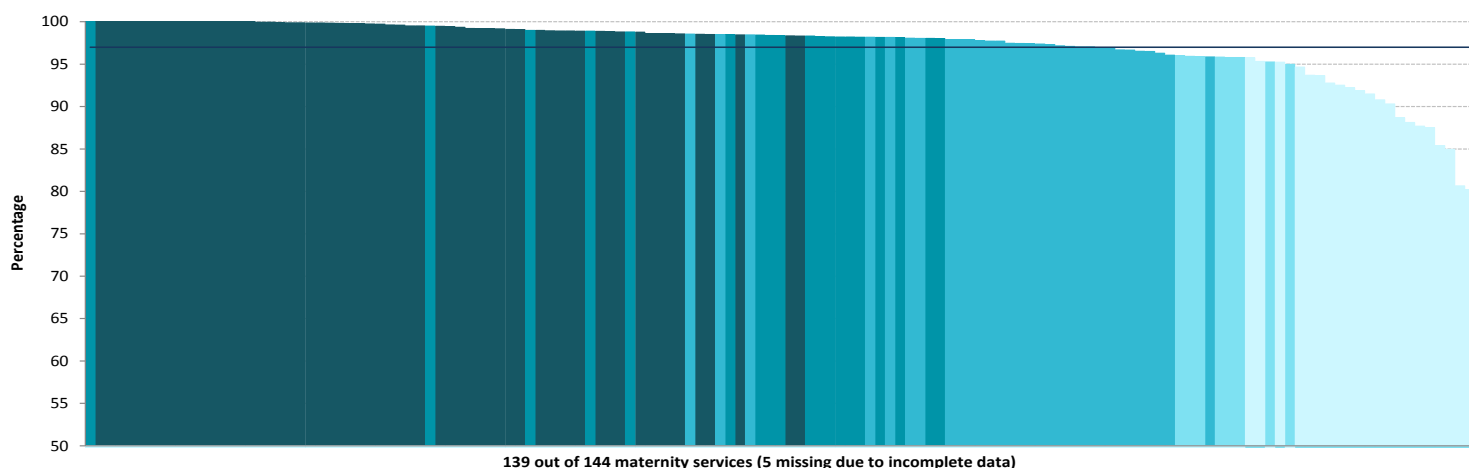
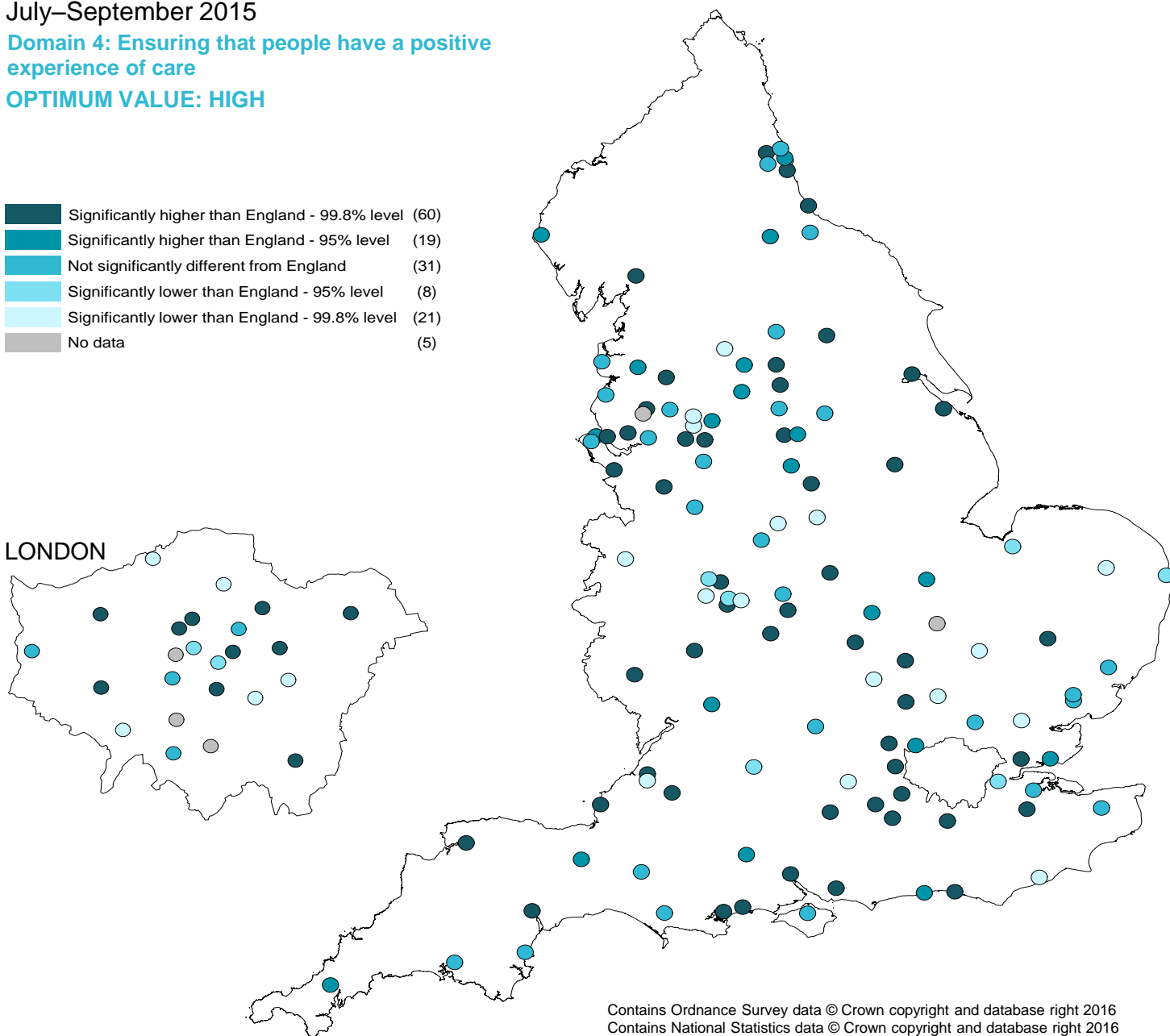
July–September 2015

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

OPTIMUM VALUE: HIGH



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One-third of the reported screening sites (n=46) had less than 50% of women receiving a conclusive test result in the specified time period.

The boxplot shows the distribution of maternity service values for the period April-June 2013 to July-September 2015.

The 75th to 25th percentile gap narrowed significantly indicating a contraction of the middle ranked 50% of maternity services values, closer to the median value.

There was no significant change in either the maximum to minimum range or in the 95th to 5th percentile gap.

There was no significant change in the median maternity service value.

Variation in the timeliness of test has been associated with problems in service delivery, such as:

- lack of direct access to maternity services
- long intervals between a woman presenting at her GP and being booked by maternity services
- lack of understanding by healthcare professionals of the importance of testing early
- differing standards for the timing of antenatal booking

There is also an association between a woman's

gestation at the point in time when screening is offered and the uptake of prenatal diagnosis (PND): an early offer of screening is associated with greater uptake of PND.

Map 38: Completion of FOQs

The map and column chart display the latest period (July-September 2015), during which Maternity Service values ranged from 80.2% to 100.0%, which is a 1.2-fold difference between maternity services. The England value for this period was 97.0%.

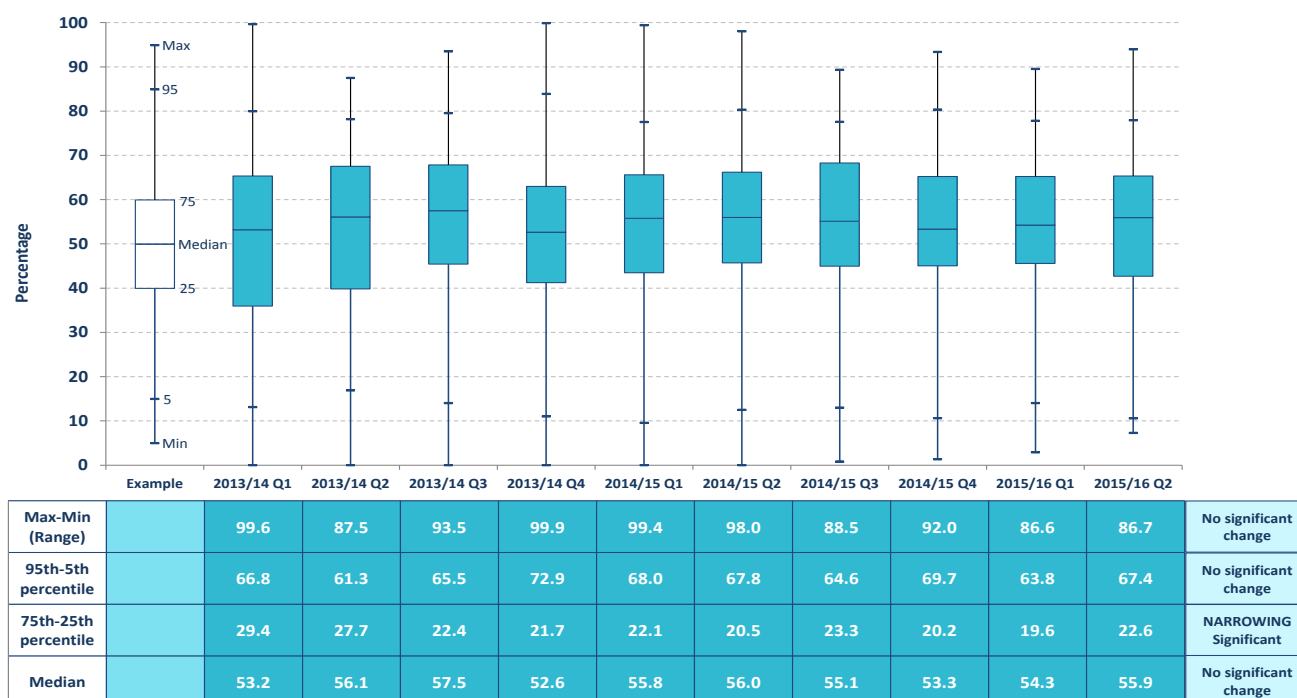
The boxplot shows the distribution of maternity service values for the period April-June 2013 to July-September 2015.

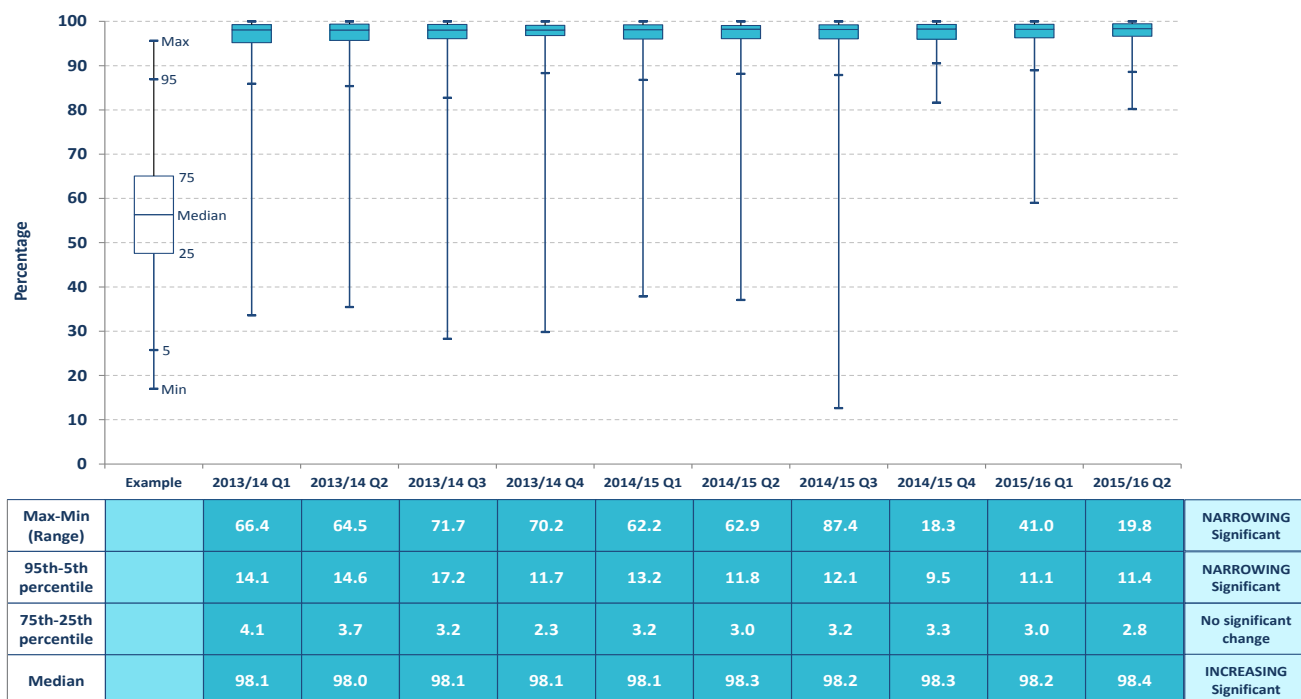
The maximum to minimum range narrowed significantly, which was entirely due to an increase in the minimum maternity service value in the three most recent quarters. The 95th to 5th percentile gap narrowed significantly which was mainly due to a steady increase in the 5th percentile.

There was a very slight increase in the median maternity service value which was statistically significant.

One reason for unwarranted variation in the submission of completed FOQs to the laboratory is failure of health professionals to fill out and send the questionnaire with the blood sample, although education about the importance of FOQs and the development and implementation of an electronic version has increased the number completed and submitted to the laboratory.

Map 37: Boxplot of women in NHS antenatal sickle cell and thalassaemia screening programme with conclusive result by 10 weeks (%) by maternity service



Map 38: Boxplot of samples with completed FOQ in NHS antenatal sickle cell and thalassaemia screening programme (%) by maternity service

Options for action

Commissioners need to specify that service providers adhere to:

- the standards for the linked NHS Antenatal and Newborn Screening Programme (see 'Resources')
- the service specification and the care pathway for the sickle cell and thalassaemia screening programme (see 'Resources')

Commissioners also need to specify that laboratories responsible for testing blood samples and reporting the results of screening follow the recommendations in the "Sickle Cell and Thalassaemia: Handbook for Laboratories" (see 'Resources').

Providers of local sickle cell and thalassaemia screening services need to ensure that all health professionals involved undertake continuing professional development (see 'Resources').

RESOURCES

- NHS Screening Programmes Sickle Cell & Thalassaemia. NHS Sickle Cell and Thalassaemia Screening Programme. Standards for the linked Antenatal and Newborn Screening Programme. Second Edition. October 2011. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/402208/Standards2ndEdition_1.pdf
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- East Midlands Specialised Commissioning Group. The National Haemoglobinopathies Project: a guide to effectively commissioning high-quality sickle cell and thalassaemia services. July 2011. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/409928/NationalHaemoglobinopathiesProjectFinalV2.pdf
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