Public Health England

NHS

NHS Sickle Cell and Thalassaemia Screening Programme

Data Report 2014/15: Trends and performance analysis

Public Health England leads the NHS Screening Programmes

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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About PHE screening

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better informed decisions. National population screening programmes are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the four UK countries. The Screening Quality Assurance Service ensures programmes are safe and effective by checking that national standards are met. PHE leads the NHS Screening Programmes and hosts the UK NSC secretariat.

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Executive summary

In 2014/15 approximately 710,000 women received antenatal screening for sickle cell disease and thalassaemia conditions, of which 14,000 (approximately 2%) were identified as screen positive. There were 408 prenatal diagnostic (PND) tests performed, which represents approximately 50% of the number of 'high-risk' couples identified in antenatal screening.

Approximately 661,000 samples were screened as part of newborn screening for sickle cell disease, of which 278 (one in 2,379) were identified with significant conditions and approximately 9,000 (one in 74) were identified as carriers. While beta thalassaemia is not currently screened for in newborn screening, F-only cases are picked up as a by-product of screening for sickle cell disease. These are likely to be beta thalassaemia major cases and require follow-up. In 2014/15 there were 22 F-only cases reported by the newborn screening laboratories in England.

Completion of the family origin questionnaire (FOQ) has continued to improve in high prevalence areas and is now at 92%, while rates have been more consistent in low prevalence areas ranging from 96-98% since 2010/11. Variation of performance by trust has decreased each year and the majority of trusts nationally are above the achievable level for programme standard AOaiii.

The proportion of samples received where the woman has declined antenatal screening has continued to decrease each year and is now at 0.26% in England. This could suggest better acceptance of the antenatal screening programme, and could also reflect the work of the voluntary sector in engaging with the community.

Reported uptake of testing of the baby's father has declined by 3% compared to last year, falling from 63.0% to 60.4%. However, the rate has remained at approximately 60% nationally, 80% in low prevalence areas, and 58% in high prevalence areas for the fourth consecutive year.

Early testing is important in antenatal screening as a series of tests may be required to make informed choices. The target is for pregnant women to receive screening by 10 weeks gestation and for all testing to be completed by 12 weeks and 6 days gestation. Approximately 49% of antenatal screening is being performed by 10 weeks gestation nationally, which is a similar level compared to last year. The data shows small increases each year in the median proportion of women screened by 10 weeks gestation, but there is still a lot of variation in performance between trusts. The proportion of tests performed by 10 weeks appears lower in high prevalence areas than in low prevalence areas, which could mean that those at high risk of being a carrier are less likely to be tested early in the pregnancy. Prenatal diagnostic (PND) data shows a

decline of approximately 10% in the proportion of PND tests performed by 12 weeks and 6 days, and an increase by the same proportion in those tested in the 13th or 14th week of pregnancy. The proportion being tested in the 15th week or later remains at approximately 30%. Unless the parents' results are already known, early PND testing is dependent on early antenatal screening which means that it is important to improve the proportion of antenatal screening tests performed by 10 weeks gestation in order to offer informed choice.

Newborn screening rates for both affected babies and carriers continue to decline in London, where the rates are the highest in the country, but it is difficult to identify the cause for this based on the data. The number of samples screened in London has remained at approximately 130,000 for the past 3 years, but this decline may reflect a change in demographics in the region. Rates in the rest of England have remained steady at approximately 0.23 per 1,000 babies screened identified with a significant condition and 8.6 per 1,000 babies screened identified as a carrier.

There has been an increase in the rate of declined newborn screening, and the rate is now at 1.5 per 1,000 babies screened. The biggest increases appear to be in the 'other' grouping which comprises 'Chinese', 'any other ethnic category' and 'not stated' ONS ethnic categories, followed by the 'black Caribbean' ethnic category.

This year we requested some new fields which look at the processes in newborn screening. This data indicates that approximately 99% of screen positive babies have their initial clinical referral by 8 weeks of age (median 16 days), which suggests that programme standard NP4 (effective follow-up of infants with positive screening results) to be both realistic and achievable. Approximately 86% of screen positive babies are reported to have had their first visit to a paediatrician at a specialist health team or local health team by 90 days (median 58 days).

Abbreviations

AN	Antenatal
CCG	Clinical commissioning group
CHRD	Child health record department
FOQ	Family Origin Questionnaire
Hb	Haemoglobin – see glossary for haemoglobin variants
HP	High prevalence
HPFH	Hereditary persistence of fetal haemoglobin
KPI	Key performance indicator
LP	Low prevalence
MCH	Mean cell haemoglobin
NAD	No abnormality detected
NB	Newborn
NBS	Newborn blood spot
NICE	National Institute for Health and Clinical Excellence
NIGB	National Information Governance Board
ONS	Office for National Statistics
PCT	Primary care trust
PHE	Public Health England
PND	Prenatal diagnosis
SCD	Sickle cell disease
SCT	Sickle cell and thalassaemia
SHA	Strategic health authority
UK NSC	United Kingdom National Screening Committee

Glossary

Alpha plus thalassaemia (-α/αα or -α/-α):
This is found in all ethnic groups, with a high carrier frequency in populations in some parts of Africa, in the Caribbean and in South and Southeast Asia. Even if both partners are carriers, there is no risk to the fetus. Homozygous alpha plus thalassaemia is not a clinically significant disorder with respect to genetic or obstetric complications, but can cause diagnostic confusion with carriers of alpha zero thalassaemia or iron deficiency.

Alpha thalassaemia major, or Hb Barts hydrops fetalis (--/--):
A severe anaemia that affects the fetus. No normal fetal haemoglobin is produced and this leads to stillbirth or neonatal death.

Alpha zero thalassaemia (--/αα):
This carries the potential for a clinically significant disorder if both parents are carriers. If both parents are carriers of alpha zero thalassaemia, there is a risk of having a fetus with alpha thalassaemia major and the mother runs the risk of obstetric complications, particularly in the third trimester of pregnancy. The mutations are almost always due to a gene deletion. If one partner carries alpha zero thalassaemia and the other alpha plus thalassaemia, then there is a risk of having a child with Hb H disease. Prenatal diagnosis is not usually indicated for Hb H disease.

'At-risk' couples:
Pregnancies identified with a potential risk of an affected baby, based on antenatal screening results for both parents. Cases where the father is not available for testing or where father results cannot be linked to mother results are also considered to be 'at risk' for an affected pregnancy. The number of 'at-risk' couples includes 'high-risk' couples (see below).

Beta thalassaemia major:
A severe anaemia caused by inheritance of 2 beta thalassaemia genes, resulting in a lack of normal haemoglobin production. Treatment by regular blood transfusions and drugs to remove excess iron leads to long-term survival. Some affected children can be 'cured' by bone marrow transplantation.

Carrier (also referred to as trait):
An individual who carries a single altered gene where 2 altered genes are required for an individual to be affected with a condition that may require treatment. The carrier can pass on the gene to their offspring. The most common haemoglobin carrier states in the UK are Hb S, C, D, E and beta thalassaemia.

Family origins:
A term used to describe a person's ancestry.

Haemoglobin:
The substance in our blood that carries oxygen around the body. Hb A is normal adult haemoglobin, and Hb F is fetal haemoglobin.

Haemoglobin disease:
Mild or serious diseases that can occur in people who have inherited 2 haemoglobin gene variants. The most common haemoglobin diseases are sickle cell diseases and thalassaemia disorders, also called haemoglobinopathies. Haemoglobin variants include:

Hb S – sickle haemoglobin
Hb C – haemoglobin C
Hb D – haemoglobin D
Hb E – haemoglobin E

Examples of newborn screening results include FS (baby with fetal and sickle haemoglobins – probable sickle cell disease) and FAS (baby with fetal, adult, and sickle haemoglobins – probable sickle cell carrier).

'High-risk' couples:
Pregnancies that are identified as having a high risk of an affected baby. These are identified based on the combinations of mother and father antenatal test results which are considered to indicate a high risk of an affected baby (represented by the dark orange boxes on the antenatal data return, see Appendix Two).

Prevalence:
The proportion of people in a population who have an attribute or a given disease.

Sickle cell disease:
A group of inherited diseases that are characterised by sickling of red blood cells when there is a shortage of oxygen. The most common sickle cell diseases are sickle cell anaemia (Hb SS), haemoglobin SC disease, and haemoglobin S/beta thalassaemia. Sickle cell diseases can cause episodes of acute pain (crisis), anaemia, increased risk of infections, and chest problems. They can be life threatening, particularly for young children.

Thalassaemia major:
A group of inherited conditions caused by a reduction in the amount of haemoglobin produced. People with a thalassaemia condition have various degrees of severe anaemia.

Variant:
A change from the usual, for example, in a gene or protein. A variant haemoglobin gene may result in sickle or another type of haemoglobin in the body.

List of charts and tables

Antenatal screening

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Key performance indicators

1. Introduction

1.1. About the NHS Sickle Cell and Thalassaemia Screening Programme

The NHS Sickle Cell and Thalassaemia Screening Programme was set up in England in 2001 following a government commitment in the NHS Plan in 2000 and is the world's first linked antenatal and newborn screening programme. Our mission statement is to develop a linked programme of high quality screening and care in order to:

- ensure a high quality, accessible screening programme throughout England
- support people to make informed choices during pregnancy and ensure timely transition into appropriate follow up and treatment
- improve infant health through prompt identification of affected babies and timely transition into clinical care
- promote greater understanding and awareness of the conditions and the value of screening

1.2. Methodology

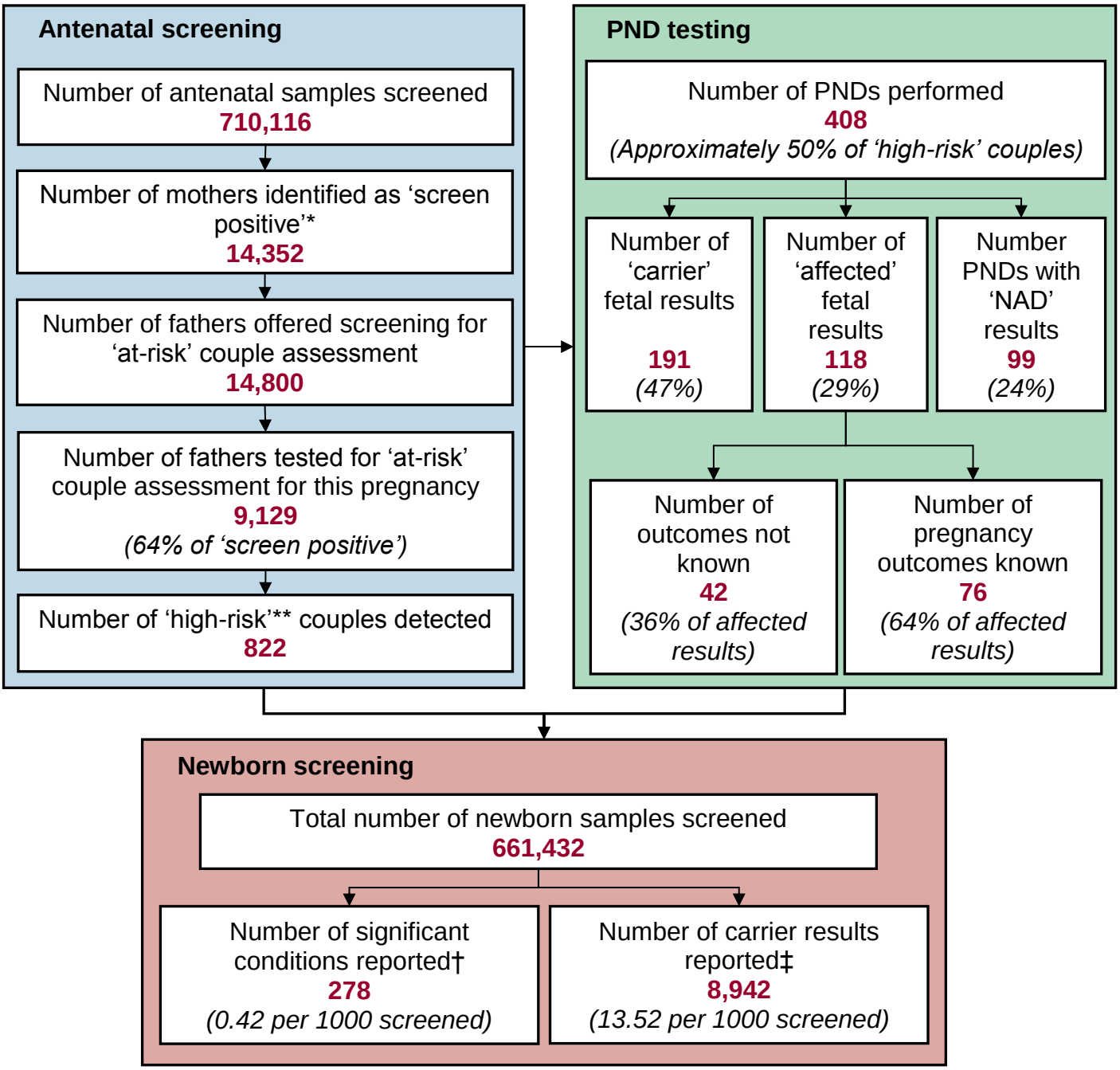
Timely annual data returns are required from all screening laboratories in accordance with laboratory guidance[1] and *Service Specification no. 18: NHS Sickle Cell and Thalassaemia Screening Programme*[2]. Data is collated by the laboratories and submitted to the NHS Sickle Cell and Thalassaemia Screening Programme via spreadsheet-based data return templates. On receipt, the data is checked for any discrepancies or aspects that would benefit from clarification and if needed is followed up with the relevant laboratory.

For the antenatal laboratories in particular, we recognise the difficulty of data collection in the absence of standardised data collection tools and IT systems. We try to ask for limited data and work hard to justify all data requests, ensuring there are no gaps and no duplication across the screening pathway and between screening programmes. PND data is requested several months after the requests for data is sent to the antenatal and newborn laboratories. This is to allow time for complete gestation in all pregnancies in order to give a more complete set of data on pregnancy outcomes following PND testing.

The newborn data received by the programme sometimes includes data for areas outside of England. These are excluded in our analysis. Prevalence data by region and by ethnicity is compared and laboratories contacted for clarification if inconsistencies are found. While the NHS Sickle Cell and Thalassaemia Screening Programme only has a remit for England, we are hoping to include data from the newborn laboratories in Scotland, Wales, and Northern Ireland in future years.

Current versions of the antenatal and newborn data returns can be found at https://www.gov.uk/government/collections/sickle-cell-and-thalassaemia-screening-data-collection.

2. Overview of national screening figures



Note: These figures represent total numbers reported and numbers may differ from those elsewhere where exclusions have been made based on missing or unavailable data.
**'Screen positive' in antenatal screening includes both sickle cell haemoglobin variants and thalassaemia results.*
†'Significant conditions' in newborn screening comprises FS, FSC, FS Other and FE.
‡'Carrier results' in newborn screening comprises FAS, FAC, FAD, FAE and other carriers.
*** 'High risk' comprises cases where both parents are carriers or affected and there is a high risk that the baby will be affected by a significant condition. This number excludes low-risk cases and cases where the father was not available for testing.*

3. Antenatal screening and prenatal diagnostic testing data

3.1. Response rates and data quality

Response rate:

The SCT Screening Programme received 140 out of the 143 antenatal screening data returns requested across England. Data was also received from all 3 prenatal diagnostic (PND) laboratories, including pregnancy outcome data. We would like to thank all of the laboratories for their efforts in submitting this data.

Data quality:

Antenatal screening data
Not all antenatal laboratories were able to provide complete data for all of the requested fields. Exclusions have been made where there is missing data to reduce bias when reporting rates which means that figures may differ between charts and tables. Where exclusions have been made, these are specified in the relevant footnotes.

Figures on booking bloods tested by 10 weeks are often dependent on completion of the FOQ to obtain gestational information. This means that the figures presented on timeliness of testing offer a base rate, but actual proportions achieving this standard may be higher.

The number of father specimens received may not include cases where the father's results were previously known, and so the rates for father uptake may in fact be higher than those shown. Some laboratories are unable to match mother results to father results and so cannot provide the number of high-risk couples. As a result, the actual number of high-risk couples is likely to be higher than reported.

Some laboratories use figures that are provided by maternity units to determine the number of booking bloods received as they are unable to distinguish between antenatal and non-antenatal specimens. This may distort the figures slightly as maternity units may refer samples to more than one laboratory and so the number of booking bloods received may appear higher than it actually is. Some laboratories cover more than one hospital and we ask for separate data returns for each hospital covered. As a result, the number of laboratories represented where data is broken down to this level may be higher than the actual number of laboratories that provide screening for sickle cell and thalassaemia.

The data presented in this report represents the data provided by the antenatal laboratories. We are aware that figures may differ from those from other data sources.

We are aware that the number of screen positive and screen negative women, plus pending results does not add up to the number of booking bloods received. This is due to the way that

data is provided by some laboratories. The difference may be accounted for, to a degree, by the inclusion of other haemoglobinopathy variants which are outside the scope of the SCT screening programme and would not be considered to be 'screen positive'.

It should be noted that some high prevalence laboratories provide screening services for low prevalence maternity services. While we request that data from laboratories is provided separately by site, some laboratories cannot differentiate between samples received, which could affect the figures.

Prenatal diagnostic (PND) testing data
Non-identifiable data is provided by the PND laboratories at patient level, but there are some gaps in the data. Approximately 1.5% of PND tests performed did not have gestational information and approximately 36% of affected results did not have information on pregnancy outcomes (whether the couple continued the pregnancy, miscarried, or opted for termination).

3.2. Numbers screened and detected in antenatal screening

National:

Table AN-1 shows overall screening figures for 2014/15 with no exclusions made for missing data. In 2014/15 laboratories reported a total of 710,166 booking bloods received, of which 14,354 were reported as screen positive for clinically significant haemoglobin variants (approximately 1 in 50 women screened). This figure includes women who were not tested due to a previous screen positive result, where an egg donor was used, where they have had a bone marrow transplant, and women who have other haemoglobin variants requiring father testing.

'High-risk' couples comprise pregnancies where both parents are identified as either carriers or as affected and there is a high risk that the baby will be affected by a significant condition. In 2014/15 there were 822 high risk couples (approximately one in 18 screen positive women) reported by the laboratories. This figure excludes cases where the father was not available for testing, or where the father's result cannot be matched with the mother's result to determine risk, and so the actual number of high-risk couples is expected to be higher.

We would expect the number of high-risk couples in antenatal screening to be approximately 4 times the number of newborn screen positive cases identified with significant conditions (FS, FSC, FS-Other and FE results) plus 4 times the number of babies with an F-only newborn result (which are potential beta thalassaemia affected results), plus terminations of affected pregnancies following PND testing, giving an estimate of approximately 1,250 high-risk pregnancies.

Table AN-1. Antenatal screening results by region, 2014/15: England

Region	No. of Labs	Booking bloods received (BBs)	Booking bloods tested by 10 wks		FOQ Attached		Screen 'positive' women		Screen 'negative' women		Result pending		High risk couples identified	
	Submitted/ Total Labs	n	n	% of BBs	n	% of BBs	n	% of BBs	n	% of BBs	n	% of BBs	n	% of screen 'positive women
East of England	12 / 12	55,656	29,283	52.61	54,101	97.21	576	1.03	43,165	77.56	19	0.03	43	7.47
East Midlands	11 / 12	65,738	43,503	66.18	64,136	97.56	1,032	1.57	63,862	97.15	*	*	85	8.24
London	23 / 24	145,682	41,217	28.29	125,268	85.99	7,129	4.89	138,165	94.84	16	0.01	380	5.33
North East	10 / 10	31,907	15,649	49.05	31,694	99.33	242	0.76	27,675	86.74	8	0.03	19	7.85
North West	19 / 19	87,236	34,358	39.39	84,361	96.70	1,082	1.24	77,240	88.54	9	0.01	55	5.08
South Central	10 / 10	53,801	28,220	52.45	51,363	95.47	835	1.55	51,203	95.17	34	0.06	55	6.59
South East Coast	12 / 12	59,039	10,911	18.48	57,860	98.00	644	1.09	58,301	98.75	9	0.02	28	4.35
South West	17 / 17	64,270	25,347	39.44	58,559	91.11	451	0.70	59,668	92.84	5	0.01	12	2.66
West Midlands	14 / 15	75,217	27,003	35.90	71,916	95.61	1,543	2.05	72,660	96.60	7	0.01	85	5.51
Yorkshire and The Humber	12 / 12	71,620	39,663	55.38	70,436	98.35	820	1.14	49,955	69.75	*	*	60	7.32
Total England	140 / 143	710,166	295,154	41.56	669,694	94.30	14,354	2.02	641,894	90.39	111	0.02	822	5.73

**Numbers less than five have been suppressed*

High prevalence areas:

Table AN-2 shows the antenatal screening figures for high prevalence areas only for 2014/15, as reported by the high prevalence antenatal screening laboratories. A total of 389,689 samples were reported by high prevalence laboratories, of which 12,112 were reported as screen positive (approximately one in 32 women screened). Of these screen positive women, 710 couples (1 in 17 screen positive women) were identified as being at high risk of having an affected pregnancy.

Table AN-2. Antenatal screening results by region, 2014/15: high prevalence areas

Region	No. of Labs	Booking bloods received (BBs)	Booking bloods tested by 10 wks		FOQ Attached		Screen 'positive' women		Screen 'negative' women		Result pending		High-risk couples identified	
	Submitted/ Total Labs	n	n	% of BBs	n	% of BBs	n	% of BBs	n	% of BBs	n	% of BBs	n	% of screen 'positive women
East of England	2 / 2	10,111	4,036	39.92	9,935	98.26	211	2.09	9,909	98.00	*	*	26	12.32
East Midlands	7 / 7	44,393	28,421	64.02	42,916	96.67	908	2.05	42,883	96.60	*	*	75	8.26
London	23 / 24	145,682	41,217	28.29	125,268	85.99	7,129	4.89	138,165	94.84	16	0.01	380	5.33
North East	1 / 1	6,486	3,790	58.43	6,473	99.80	90	1.39	6,396	98.61	*	*	12	13.33
North West	7 / 7	49,376	17,629	35.70	47,244	95.68	915	1.85	46,562	94.30	5	0.01	48	5.25
South Central	6 / 6	33,146	18,105	54.62	30,957	93.40	609	1.84	32,054	96.71	26	0.08	40	6.57
South East Coast	2 / 2	10,968	2,921	26.63	10,593	96.58	260	2.37	10,569	96.36	*	*	13	5.00
South West	2 / 2	11,728	3,990	34.02	11,480	97.89	154	1.31	11,427	97.43	*	*	2	1.30
West Midlands	7 / 7	48,877	14,543	29.75	46,083	94.28	1,351	2.76	46,556	95.25	6	0.01	78	5.77
Yorkshire and The Humber	3 / 3	28,922	14,596	50.47	27,884	96.41	485	1.68	18,046	62.40	*	*	36	7.42
Total England	60 / 61	389,689	149,248	38.30	358,833	92.08	12,112	3.11	362,567	93.04	55	0.01	710	5.86

**Numbers less than five have been suppressed*

Low prevalence areas:

Table AN-3 shows the antenatal screening figures for low prevalence areas only for 2014/15, as reported by the low prevalence antenatal screening laboratories. A total of 320,477 samples were reported by low prevalence laboratories, of which 2,242 were reported as screen positive (approximately 1 in 143 women screened). Of these screen positive women, 112 couples (one in 20 screen positive women) were identified as being at high risk of having an affected pregnancy.

Table AN-3. Antenatal screening results by region, 2014/15: low prevalence areas

Region	No. of Labs	Booking bloods received (BBs)	Booking bloods tested by 10 wks		FOQ Attached		Screen 'positive' women		Screen 'negative' women		Result pending		High-risk couples identified	
	Submitted/ Total Labs	n	n	% of BBs	n	% of BBs	n	% of BBs	n	% of BBs	n	% of BBs	n	% of screen 'positive women
East of England	10 / 10	45,545	25,247	55.43	44,166	96.97	365	0.80	33,256	73.02	19	0.04	17	4.66
East Midlands	4 / 5	21,345	15,082	70.66	21,220	99.41	124	0.58	20,979	98.29	*	*	10	8.06
London	0 / 0	-	-	-	-	-	-	-	-	-	-	-	-	-
North East	9 / 9	25,421	11,859	46.65	25,221	99.21	152	0.60	21,279	83.71	8	0.03	7	4.61
North West	12 / 12	37,860	16,729	44.19	37,117	98.04	167	0.44	30,678	81.03	4	0.01	7	4.19
South Central	4 / 4	20,655	10,115	48.97	20,406	98.79	226	1.09	19,149	92.71	8	0.04	15	6.64
South East Coast	10 / 10	48,071	7,990	16.62	47,267	98.33	384	0.80	47,732	99.29	9	0.02	15	3.91
South West	15 / 15	52,542	21,357	40.65	47,079	89.60	297	0.57	48,241	91.81	5	0.01	10	3.37
West Midlands	7 / 8	26,340	12,460	47.30	25,833	98.08	192	0.73	26,104	99.10	*	*	7	3.65
Yorkshire and The Humber	9 / 9	42,698	25,067	58.71	42,552	99.66	335	0.78	31,909	74.73	*	*	24	7.16
Total England	80 / 82	320,477	145,906	45.53	310,861	97.00	2,242	0.70	279,327	87.16	56	0.02	112	5.00

**Numbers less than five have been suppressed*

3.3. The Family Origin Questionnaire

Samples with a family origin questionnaire attached

The family origin questionnaire (FOQ) is used as a screening tool in both high and low prevalence areas, and it is important that a FOQ form is completed for each sample. The proportion of booking bloods received with a FOQ attached links to programme standard AO1aiii and KPI ST3 (completion of FOQ). Table AN-4 shows the numbers and proportion of booking bloods received by the laboratories with a completed FOQ by region in the past 3 years. Nationally 94% of samples have a completed FOQ, with rates highest in the North East and lowest in London.

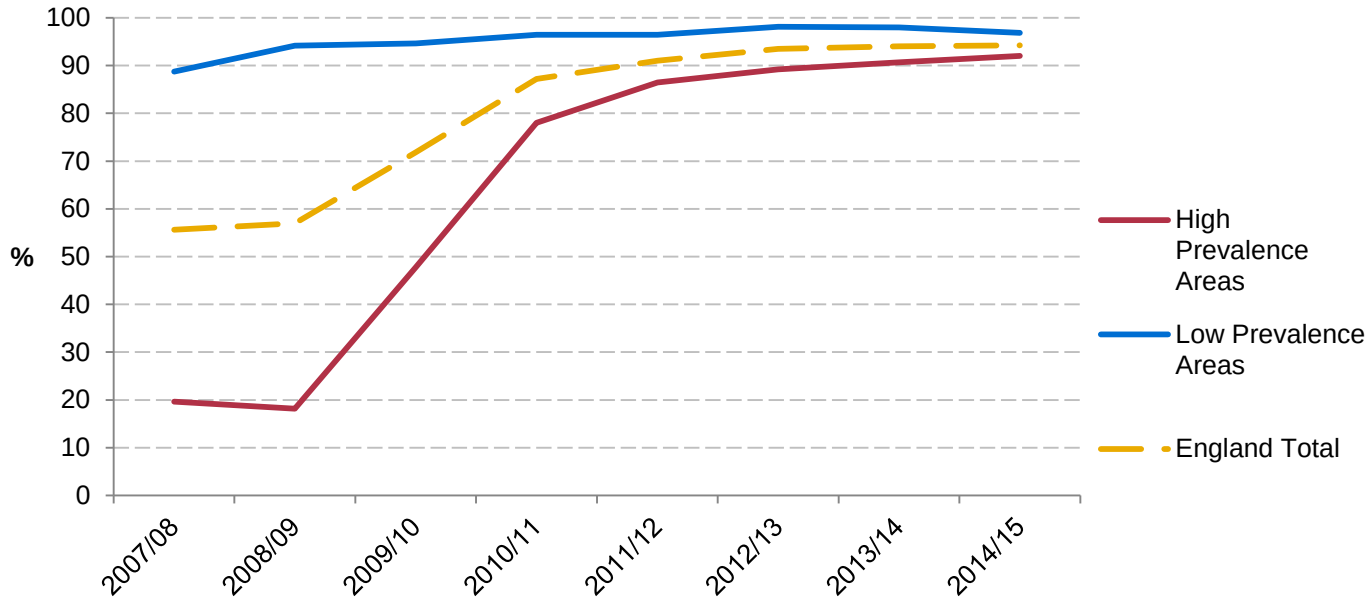
Figure AN-1 shows the trends in proportion of booking bloods received with a FOQ attached since 2007/08, comparing high and low prevalence areas. The proportion of booking bloods in high prevalence areas with a FOQ attached continues to increase and is now at 92%, but in low prevalence areas the figure appears to have levelled-off and decreased by 1% to 97%. Programme standard AO1aiii[3] sets an acceptable level of 90% and achievable level of 95% of samples submitted to the laboratory with a completed FOQ. Both high and low prevalence areas are currently meeting the acceptable level for this standard when grouped together, but the achievable level is not yet being met in high prevalence areas.

Table AN-4. Booking bloods received with a FOQ attached, 2012-15: England by region

Region	2012/13			2013/14			2014/15		
	Booking Bloods (BBs)	FOQ attached	% of BBs	Booking Bloods (BBs)	FOQ attached	% of BBs	Booking Bloods (BBs)	FOQ attached	% of BBs
East Midlands	74,847	72,865	97.4	74,380	72,732	97.8	65,738	64,136	97.6
East of England	56,292	54,806	97.4	53,987	52,512	97.3	50,165	48,573	96.8
London	116,374	96,177	82.6	141,535	116,404	82.2	134,524	115,341	85.7
North East	33,288	32,799	98.5	33,171	31,672	95.5	31,907	31,694	99.3
North West	91,004	86,892	95.5	90,926	87,955	96.7	87,236	84,361	96.7
South Central	49,049	45,261	92.3	52,918	49,199	93.0	53,801	51,363	95.5
South East Coast	57,885	56,366	97.4	58,525	57,291	97.9	53,473	52,293	97.8
South West	62,659	61,541	98.2	61,972	61,172	98.7	60,579	54,790	90.4
West Midlands	77,760	70,691	90.9	71,733	69,088	96.3	75,217	71,916	95.6
Yorkshire and The Humber	71,773	68,751	95.8	71,894	70,489	98.0	71,620	70,436	98.3
England Total	690,931	646,149	93.5	711,041	668,514	94.0	684,260	644,903	94.2

Exclusions based on missing or unavailable data for the data fields shown, or where the number of FOQs was higher than the number of booking bloods received: 2012/13: 6; 2013/14: 5; 2014/15: 6.

Figure AN-1. Booking bloods received with a FOQ attached, 2007-15: England by prevalence



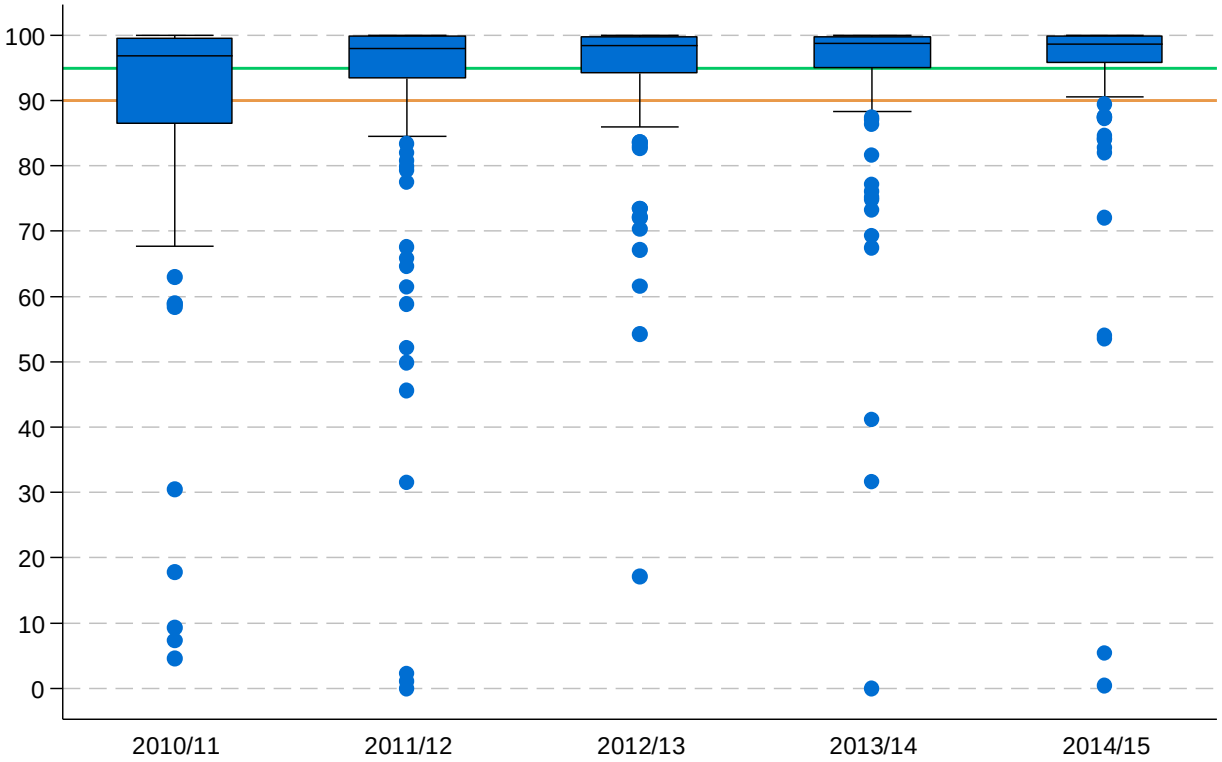
Exclusions based on missing or unavailable data for the data fields shown, or where the number of FOQs was higher than the number of booking bloods received: 2007/08: 38; 2008/09: 24; 2009/10: 21; 2010/11: 9; 2011/12: 3; 2012/13: 6; 2013/14: 5; 2014/15: 6

	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15
High prevalence areas	19.6	18.2	47.8	78.0	86.4	89.2	90.7	92.1
Low prevalence areas	88.7	94.2	94.6	96.5	96.5	98.1	98.0	96.9
England total	55.6	56.9	71.8	87.2	91.0	93.5	94.0	94.2

Figure AN-2 shows the variation in performance by laboratory each year since 2010/11. The boxes represent the interquartile ranges (IQR) for each year, which contain half of the values reported for that year. The boxes are separated by a line representing the median performance for that year. From this data we can see that in addition to there having been high performers at or close to 100% each year, the variation between the highest and lowest performers has decreased each year and the median value has increased. There are also fewer outliers (represented by the dots beneath the whiskers), which also indicates an improvement in performance over time.

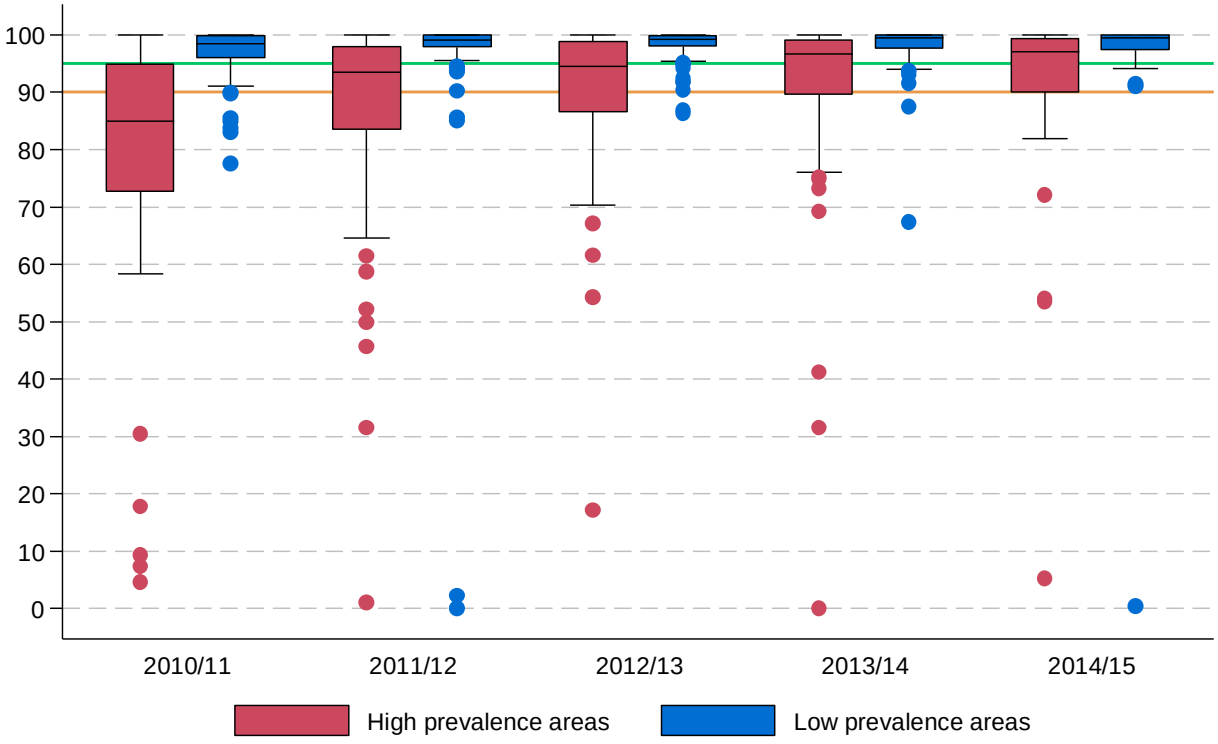
Figure AN-3 shows this information broken down into high and low prevalence areas. Low prevalence areas have seen some improvement over time and there are fewer outliers each year, but the biggest improvements have been in the high prevalence areas which have seen the median value increase and the amount of variation between the highest and lowest performers decrease. In 2014/15 the whole of the IQR is above the 90% acceptable level for the first time.

Figure AN-2. Variation between laboratories for completion of the FOQ, 2010-15: England



Exclusions based on missing or unavailable data, or the proportion was greater than 100%: 2010/11:9; 2011/12: 3; 2012/13: 6; 2013/14: 5; 2014/15: 6.

Figure AN-3. Variation between laboratories for completion of the FOQ, 2010-15: England by prevalence



Exclusions based on missing or unavailable data, or the proportion was greater than 100%: 2010/11:9; 2011/12: 3; 2012/13: 6; 2013/14: 5; 2014/15: 6.

Using the FOQ to identify risk of alpha thalassaemia

Women who have a mean cell haemoglobin (MCH) of less than 25pg are potentially carriers of alpha zero thalassaemia. If both parents are carriers then there is a 1 in 4 chance of their baby inheriting alpha thalassaemia major. Alpha thalassaemia is common in certain parts of the world, and the FOQ can be used to ascertain the family origin of women who are most at risk of being carriers. If the FOQ shows that the woman has family origins from a high-risk area, she will be considered to be at high risk of being a carrier for alpha zero thalassaemia and father testing should be offered. If no FOQ information is provided, laboratories are unable to exclude this risk which may lead to unnecessary testing.

Table AN-5 shows the number and proportion of booking bloods received with a FOQ attached, the number of women with a MCH less than 25pg, and the number of high-risk alpha zero women identified. These figures are broken down by high and low prevalence areas in Table AN-6 and Table AN-7. In low prevalence areas where FOQ completion has been high for a number of years, the proportion of booking bloods received which are identified as high risk for alpha zero thalassaemia appear consistent year-to-year. In high prevalence areas where there has been an improvement in FOQ completion each year, however, a decrease can be seen in the proportion of booking bloods identified as high risk of alpha zero thalassaemia. This indicates the benefit of using the FOQ to reduce unnecessary testing for alpha zero thalassaemia.

Table AN-5. Use of the FOQ in determining women at high risk of carrying alpha zero thalassaemia, 2008-15: England

Year	Booking bloods received (BBs)	FOQ attached		MCH < 25pg	High risk alpha0	
	n	n	% of BBs	n	n	% of BBs
2008/09	550,430	313,181	56.90	17,776	4,812	0.87
2009/10	519,866	386,871	74.42	16,282	2,071	0.40
2010/11	655,152	570,687	87.11	20,509	3,530	0.54
2011/12	681,841	622,499	91.30	21,062	3,161	0.46
2012/13	676,884	632,299	93.41	23,368	2,519	0.37
2013/14	670,940	634,529	94.57	20,561	2,598	0.39
2014/15	671,012	632,471	94.26	20,663	2,441	0.36
Total for four year period	4,426,125	3,792,537	85.69	140,221	21,132	0.48

Exclusions based on missing or unavailable data for the data fields shown, or where the number of FOQs was higher than the number of booking bloods received: 2008/09: 30; 2009/10: 30; 2010/11: 12; 2011/12: 11; 2012/13: 11; 2013/14: 11; 2014/15: 10.

Table AN-6. Use of the FOQ in determining women at high risk of carrying alpha zero thalassaemia, 2008-15: high prevalence areas

Year	Booking bloods received (BBs)	FOQ attached		MCH < 25pg	High risk alpha0	
	n	n	% of BBs	n	n	% of BBs
2008/09	271,815	51,375	18.90	12,937	4,031	1.48
2009/10	236,843	119,305	50.37	11,463	1,179	0.50
2010/11	328,967	255,854	77.77	14,861	2,185	0.66
2011/12	369,639	317,377	85.86	15,589	1,911	0.52
2012/13	353,141	314,694	89.11	17,041	1,775	0.50
2013/14	352,930	322,773	91.46	13,710	1,742	0.49
2014/15	364,704	335,713	92.05	15,265	1,564	0.43
Total for four year period	2,278,039	1,717,091	75.38	100,866	14,387	0.63

Exclusions based on missing or unavailable data for the data fields shown, or where the number of FOQs was higher than the number of booking bloods received: 2008/09: 21; 2009/10: 22; 2010/11: 7; 2011/12: 4; 2012/13: 6; 2013/14: 6; 2014/15: 6.

Table AN-7. Use of the FOQ in determining women at high risk of carrying alpha zero thalassaemia, 2008-15: low prevalence areas

Year	Booking bloods received (BBs)	FOQ attached		MCH < 25pg	High risk alpha0	
	n	n	% of BBs	n	n	% of BBs
2008/09	278,615	261,806	93.97	4,839	781	0.28
2009/10	283,023	267,566	94.54	4,819	892	0.32
2010/11	326,185	314,833	96.52	5,648	1,345	0.41
2011/12	312,202	305,122	97.73	5,473	1,250	0.40
2012/13	323,743	317,605	98.10	6,327	744	0.23
2013/14	318,010	311,756	98.03	6,851	856	0.27
2014/15	306,308	296,758	96.88	5,398	877	0.29
Total for four year period	2,148,086	2,075,446	96.62	39,355	6,745	0.31

Exclusions based on missing or unavailable data for the data fields shown, or where the number of FOQs was higher than the number of booking bloods received: 2008/09: 9; 2009/10: 8; 2010/11: 5; 2011/12: 7; 2012/13: 5; 2013/14: 5; 2014/15: 4.

3.4. Tests not performed due to a known previous result

In 2014/15 programme guidance stated that women did not need to be tested again in the same or a subsequent pregnancy, provided that there were 2 or more previous results from an accredited laboratory, the red cell indices remained the same and could be used for a reliable interpretation, and the woman's identification had 3 or more matching data items[1].

This year the historical data on tests not performed due to a known previous result has been re-analysed to better account for laboratories which are re-testing all samples and to make fewer exclusions, and as a result, the figures differ from those published in previous years.

Table AN-8 shows the numbers and rates of pregnant women who were not tested due to a known previous result in England by region for the last 3 years. These figures combine previous screen positive and negative results and exclusions are only made where both of these fields were missing or unavailable. Laboratories that re-test all samples are included as zero. In 2014/15 approximately 2% of samples received were not re-tested due to a previous result, representing a small increase on the previous year, but this is still lower than in 2012/13.

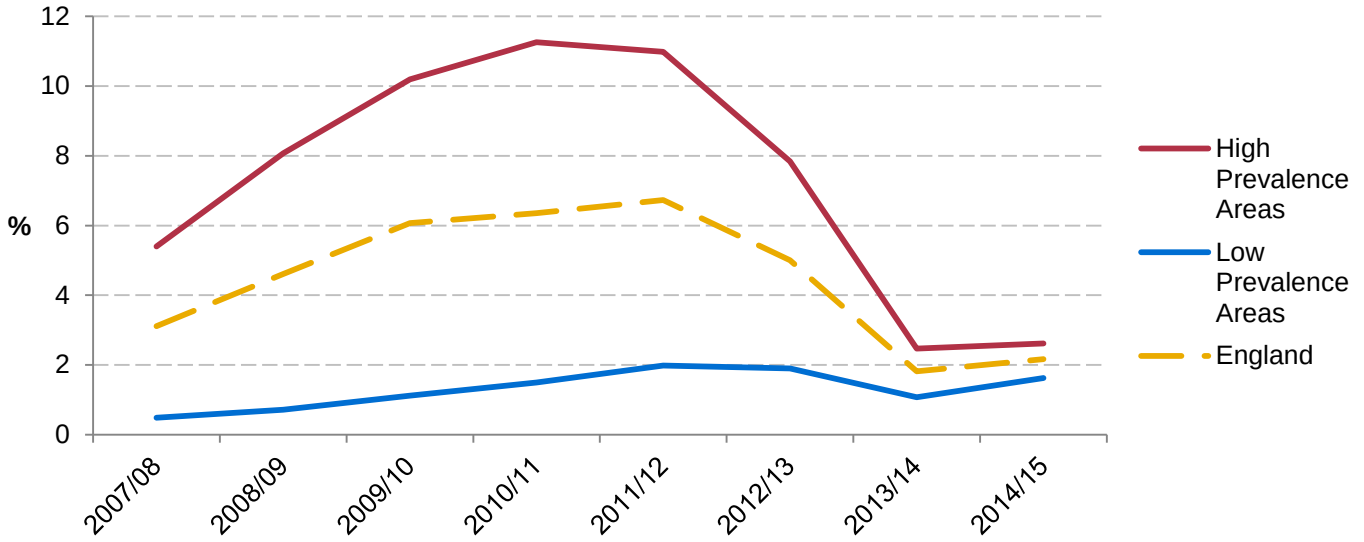
Figure AN-4 shows trends since 2007/08 in the proportion of pregnant women who were not tested due to a previous result. In high prevalence areas there appears to have been a decline in the proportion of samples that are not re-tested, but rates remain higher than in low prevalence areas. While rates in low prevalence areas appear to have increased compared to 2013/14, they appear consistent compared to previous years, ranging from 1.5 to 2% since 2010/11.

Table AN-8. Pregnant women for whom testing was not indicated due to a known previous results, 2012-15: England by region

Region	2012/13			2013/14			2014/15		
	Booking bloods received (BBs)	Known previous results	% of BBs	Booking bloods received (BBs)	Known previous results	% of BBs	Booking bloods received (BBs)	Known previous results	% of BBs
East Midlands	74,847	6,875	9.19	74,380	3,689	4.96	61,578	2,641	4.29
East of England	53,716	1,617	3.01	56,646	514	0.91	55,656	757	1.36
London	132,728	3,006	2.26	132,647	312	0.24	145,682	1,343	0.92
North East	33,288	2,882	8.66	33,171	432	1.30	31,907	368	1.15
North West	86,803	2,730	3.15	87,238	1,309	1.50	87,236	1,597	1.83
South Central	51,803	4,033	7.79	52,918	600	1.13	53,801	885	1.64
South East Coast	57,885	1,277	2.21	49,694	706	1.42	53,473	640	1.20
South West	65,570	791	1.21	62,985	687	1.09	60,105	1,797	2.99
West Midlands	74,943	8,298	11.07	71,094	2,434	3.42	73,315	2,894	3.95
Yorkshire and The Humber	54,261	2,832	5.22	42,276	1,387	3.28	47,807	1,580	3.30
England Total	685,844	34,341	5.01	663,049	12,070	1.82	670,560	14,502	2.16

Exclusions based on missing or unknown data on number of booking bloods received or where data on both previous screen positive and previous screen negative were missing or unavailable: 2012/13: 5; 2013/14: 14; 2014/15: 8.

Figure AN-4. Percentage of pregnant women for whom testing was not indicated due to a known previous test result, 2007-15: England by prevalence



Exclusions based on missing or unavailable data: 2007/08: 30; 2008/09: 20; 2009/10: 14; 2010/11: 11; 2011/12: 6; 2012/13: 5; 2013/14: 14; 2014/15: 8.

	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15
High prevalence areas	5.40	8.07	10.19	11.26	10.98	7.85	2.47	2.62
Low prevalence areas	0.48	0.72	1.12	1.50	1.98	1.91	1.07	1.63
England total	3.11	4.61	6.07	6.35	6.73	5.01	1.82	2.16

3.5. Declined screening tests

An important aspect of population screening is the element of choice, and as such, screening tests can be declined for a number of different reasons. Table AN-9 shows the numbers and rates of pregnant women who declined antenatal screening for sickle cell and thalassaemia, broken down by region for the past 3 years. In 2014/15 approximately 0.26% of booking bloods had screening for sickle cell and thalassaemia declined, down from 0.34% in the previous year.

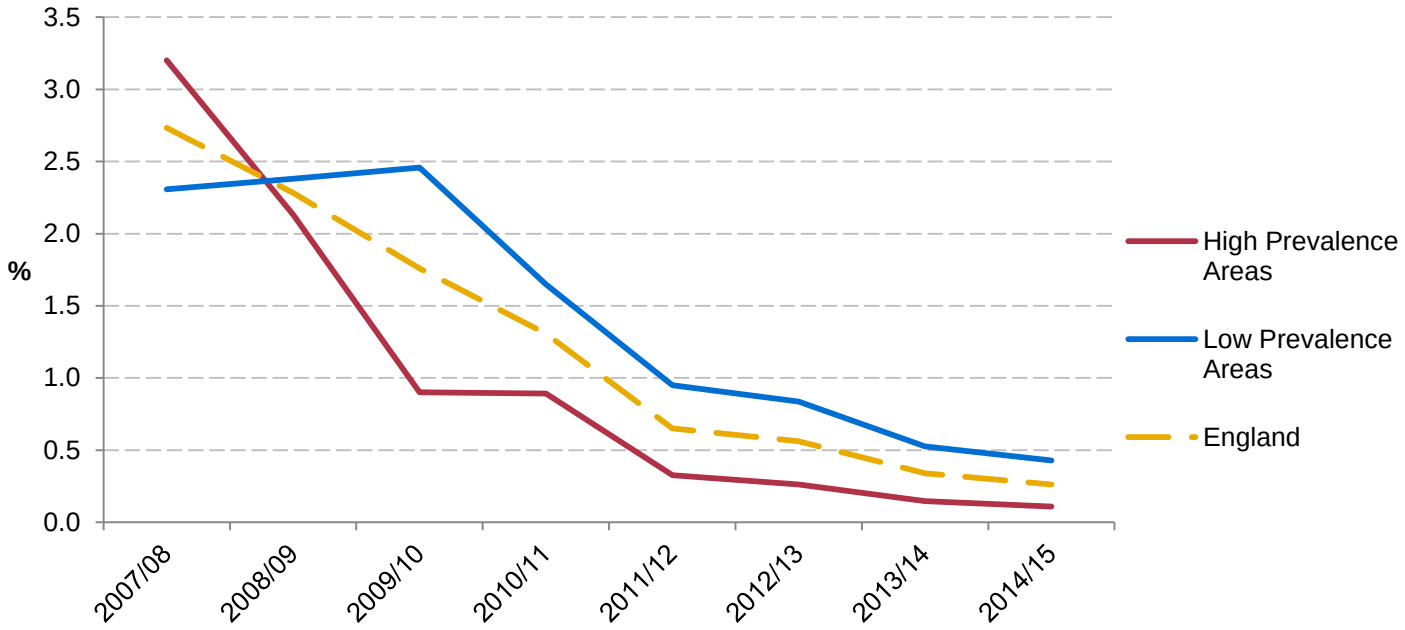
Figure AN-5 shows trends in the proportion of declines since 2007/08 by prevalence. Rates continue to fall in both high and low prevalence areas, but declines remain higher in low prevalence areas than in high prevalence areas.

Table AN-9. Declined tests by region, 2012-15: England

Region	2012/13			2013/14			2014/15		
	Booking bloods received (BBS)	Declined testing	% of BBs	Booking bloods received (BBS)	Declined testing	% of BBs	Booking bloods received (BBS)	Declined testing	% of BBs
East Midlands	74,847	222	0.30	74,380	93	0.13	65,738	121	0.18
East of England	56,292	568	1.01	59,290	426	0.72	55,656	355	0.64
London	103,108	76	0.07	105,994	49	0.05	126,075	60	0.05
North East	33,288	317	0.95	33,171	166	0.50	31,907	140	0.44
North West	75,294	555	0.74	73,911	121	0.16	72,244	57	0.08
South Central	47,740	80	0.17	48,783	79	0.16	53,801	71	0.13
South East Coast	52,783	258	0.49	50,834	67	0.13	51,249	97	0.19
South West	61,527	810	1.32	61,516	715	1.16	62,128	558	0.90
West Midlands	73,336	191	0.26	73,353	50	0.07	70,229	35	0.05
Yorkshire and The Humber	71,773	571	0.80	71,894	448	0.62	71,620	240	0.34
England Total	649,988	3,648	0.56	653,126	2,214	0.34	660,647	1,734	0.26

Exclusions based on missing or unavailable data: 2012/13: 14; 2013/14: 15; 2014/15: 12.

Figure AN-5. Declined tests as a percentage of booking bloods received, 2007-15: England by prevalence



Exclusions based on missing or unavailable data: 2007/08: 40; 2008/09: 46; 2009/10: 32; 2010/11: 17; 2011/12: 14; 2012/13: 14; 2013/14: 15; 2014/15: 12.

	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15
High prevalence areas	3.20	2.13	0.90	0.89	0.33	0.26	0.15	0.11
Low prevalence areas	2.31	2.38	2.46	1.65	0.95	0.84	0.53	0.43
England total	2.73	2.28	1.76	1.31	0.65	0.56	0.34	0.26

3.6. Testing of the baby's father

Programme standard AP2ii requires that all fathers of carrier women's babies are to be offered testing and counselled. Table AN-10 shows the uptake of father testing in England in 2014/15. The number of father specimens requested for each region was reported as higher than the number of screen positive women. This could be a result of local variation in policy for father tested, for example, if midwives collect specimens from both parents at the same time if they are both available at the initial booking. Another possible explanation may be that in cases where the mother's results are inconclusive, a sample may be requested from the baby's father but the mother is subsequently found to be screen negative.

It is not possible to assess the risk status of the pregnancy in cases where the baby's father was not available for testing. These cases are considered to be 'at risk', but are not included here in the number of 'high-risk' couples. These are estimated to account for approximately 38% of screen positive women (calculated from the number of screen positive women minus the number of father specimens received). As a result, the actual number of 'high-risk' pregnancies is likely to be higher than the figures shown in this data.

Table AN-10. Uptake of father testing, 2014/15: England by region

Region	Booking bloods received (BBs)	Screen positive women		Father specimens requested		Father specimens received		High risk' couples	
	n	n	% of BBs	n	% of screen positive women	n	% of fathers requested	n	% of fathers received
East Midlands	55,110	944	1.71	970	102.75	741	76.39	77	10.39
East of England	55,656	576	1.03	611	106.08	436	71.36	43	9.86
London	145,682	7,054	4.84	7,132	101.11	3,576	50.14	377	10.54
North East	31,907	242	0.76	242	100.00	194	80.17	19	9.79
North West	83,518	1,030	1.23	1,082	105.05	719	66.45	55	7.65
South Central	53,801	835	1.55	899	107.66	625	69.52	55	8.80
South East Coast	44,642	578	1.29	610	105.54	393	64.43	25	6.36
South West	57,813	384	0.66	413	107.55	332	80.39	12	3.61
West Midlands	72,370	1,542	2.13	1,591	103.18	1,004	63.10	85	8.47
Yorkshire and The Humber	63,390	785	1.24	829	105.61	665	80.22	54	8.12
England total	663,889	13,970	2.10	14,379	102.93	8,685	60.40	802	9.23

Excludes 11 laboratories where data on the number of booking bloods received, number of screen positive women, data on father specimens requested or received, or the number of 'high risk' couples was missing or unavailable.

Father uptake can be calculated from the number of father specimens requested and the number of father specimens received. Table AN-11 shows father uptake for antenatal testing for the last 3 years. Nationally, father uptake is at approximately 60%, representing a small drop compared to the previous years. Father uptake varied between regions, from approximately 50% in London to approximately 80% in the North East, and Yorkshire and the Humber. Figure AN-6 shows trends in father uptake since 2007/08 and shows father uptake rates to have been approximately 60% since 2011/12.

Figure AN-7 shows the variation in uptake of father testing broken down by high and low prevalence areas in the past 3 years. As also seen in Figure AN-6, rates appear to have been steady in this period in both high and low prevalence areas. In high prevalence areas there appears to have been an increase in the median value, but there remains variation between the highest and lowest values. In low prevalence areas the rates are higher and the median value appears to have been more consistent, although a drop can been seen in 2014/15. However, as with high prevalence areas, there remains variation between regions in the uptake of father testing.

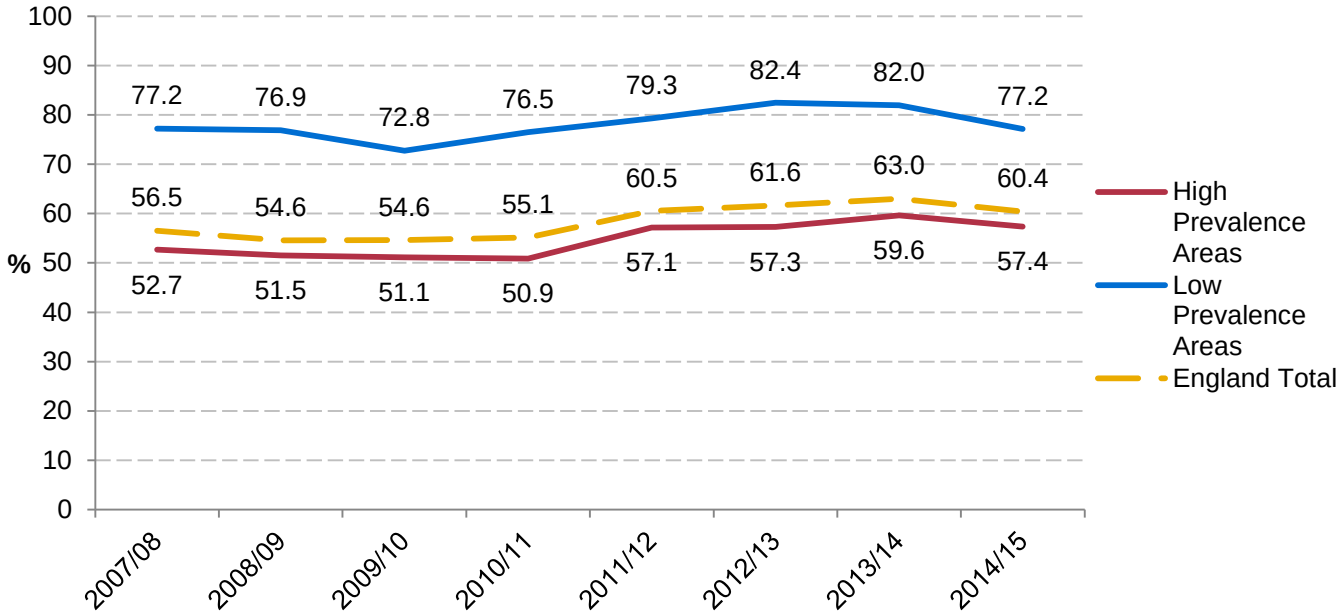
Figures shown differ from those previously reported as the exclusion criteria have been reviewed this year. Further exclusions were made where figures were provided for both number of father specimens requested and received, but where the number received was greater than the number requested.

Table AN-11. Uptake of father testing, 2012-15: England by region

Region	2012/13			2013/14			2014/15		
	Fathers requested	Fathers received	% uptake	Fathers requested	Fathers received	% uptake	Fathers requested	Fathers received	% uptake
East Midlands	1,199	821	68.47	1,234	902	73.10	970	741	76.39
East of England	571	427	74.78	570	382	67.02	611	436	71.36
London	6,218	3,154	50.72	7,705	4,201	54.52	7,225	3,646	50.46
North East	256	208	81.25	217	186	85.71	242	194	80.17
North West	1,101	740	67.21	904	595	65.82	1,082	719	66.45
South Central	763	521	68.28	691	570	82.49	899	625	69.52
South East Coast	725	543	74.90	665	496	74.59	610	393	64.43
South West	429	328	76.46	402	282	70.15	489	366	74.85
West Midlands	1,434	942	65.69	1,497	1,058	70.67	1,591	1,004	63.10
Yorkshire and The Humber	890	688	77.30	936	669	71.47	829	665	80.22
England total	13,586	8,372	61.62	14,821	9,341	63.03	14,548	8,789	60.41

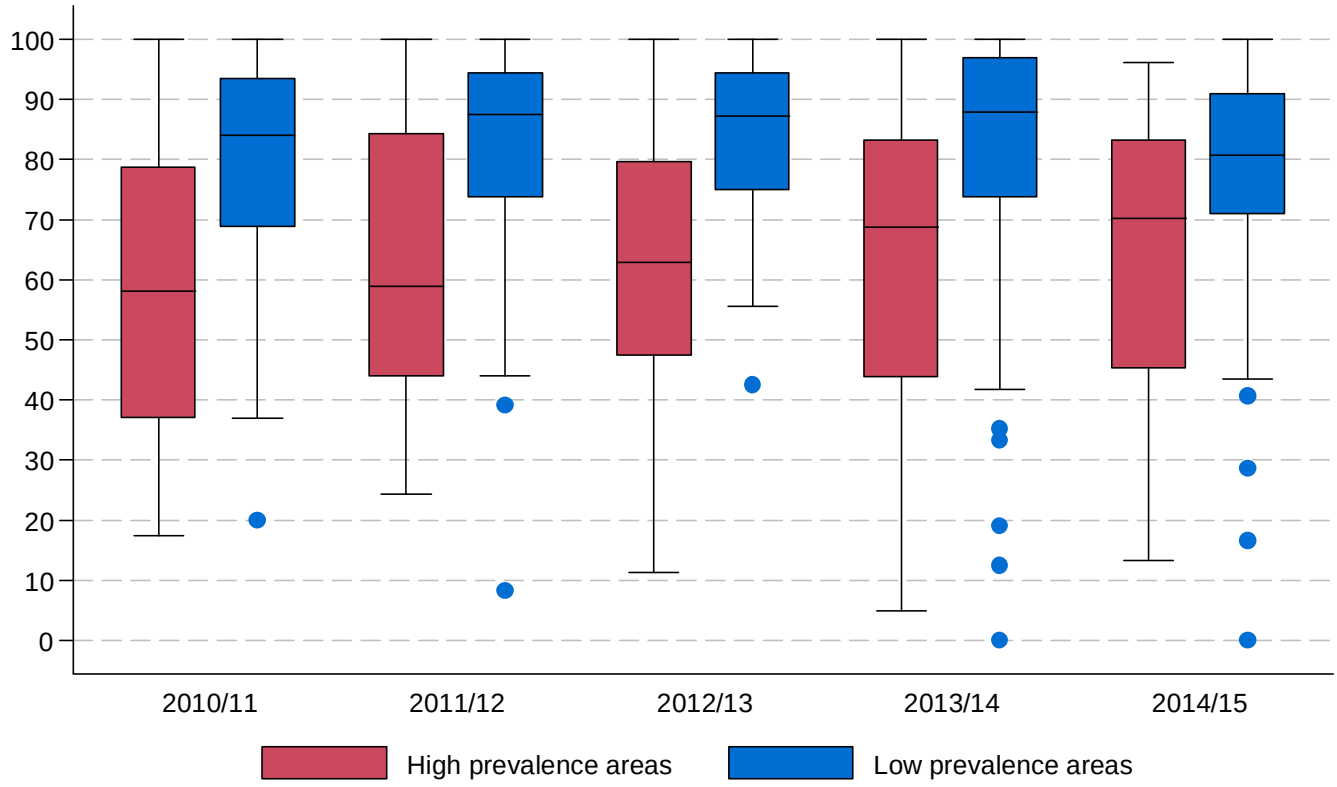
Exclusions based on missing or unavailable data, the proportion was greater than 100%, or there were no screen positive cases: 2012/13: 8; 2013/14: 11; 2014/15: 8.

Figure AN-6. Uptake of father testing, 2007-15: England by prevalence



Exclusions based on missing or unavailable data, the proportion was greater than 100%, or there were no screen positive cases: 2012/13: 8; 2013/14: 11; 2014/15: 8.

Figure AN-7. Variation in uptake of father testing, 2010-15: England by prevalence



Exclusions based on missing or unavailable data, the proportion was greater than 100%, or there were no screen positive cases: 2007/08: 23; 2008/09: 15; 2009/10: 12; 2010/11: 6; 2011/12: 8; 2012/13: 8; 2013/14: 11; 2014/15: 8.

‘High-risk’ couples are identified based on both mother and father results. The SCT programme requests breakdown data on mother and father results to identify the specific risk of an affected pregnancy. This information also allows us to separate out sickle cell and thalassaemia screen positive results.

Table AN-12 shows the breakdown data for 2014/15, showing the number of women reported with each haemoglobinopathy result, both as a total and broken down by the risk to the pregnancy, based on the results for the baby’s father. Not all laboratories were able to provide breakdown data, which means that not all screen positive women are included. Laboratories reported 14,354 screen positive women and 822 high-risk couples in 2014/15, but breakdown data was received for only 14,334 (99.9%) screen positive women and 809 (98.4%) high-risk couples. For comparison in the previous year breakdown data was received for 94% of screen positive women and 87% of high-risk couples, representing an improvement in data quality compared to 2013/14.

‘High-risk’ pregnancies are those represented by the dark orange boxes in the breakdown table in Appendix B: Antenatal data return form part 2 – breakdown of screen positive women.

Low-risk pregnancies are represented by the light orange boxes, and minimal-risk pregnancies are represented by the white boxes in the breakdown table.

Figure AN-8 shows the number of screen positive women, broken down by the risk to the pregnancy, as a percentage of the total number of screen positive women reported in Table AN-12. Of the 14,334 screen positive women reported in the breakdown data, 54% had a risk of a sickle cell affected baby, 33% had a risk of a beta thalassaemia affected baby, 8% had a risk of an alpha thalassaemia affected baby, and 5% had other haemoglobinopathy results which required testing of the baby’s father.

Table AN-12. Breakdown of pregnancy risk for screen positive women, 2014/15: England

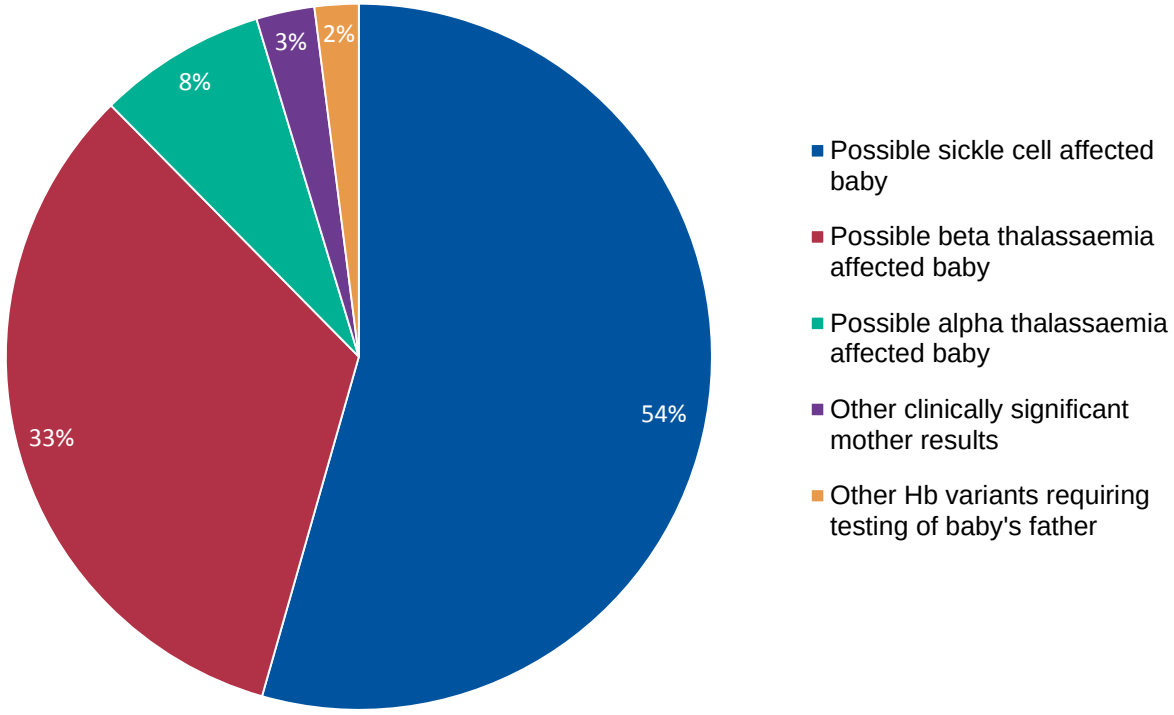
		Risk to pregnancy					Totals		
	Mother's screening result	High Risk	Low Risk	Minimal Risk	Father not a carrier	Father result not available	Total number of mothers with result	Total for group	Rate/1000 BBs received
Possible sickle cell affected baby	Hb S	564	8	101	2,497	2,787	5,957	7,801	10.98
	Hb D	*	-	53	498	159	714		
	Hb C	63	-	44	468	541	1,116		
	Hb O-Arab	*	*	*	9	*	14		
Possible beta thalassaemia affected baby	βThalassaemia	135	*	76	2,536	939	3,686	4,757	6.70
	δβ thalassaemia	*	*	*	35	17	54		
	Hb E	11	*	51	724	217	1,004		
	Hb Lepore	*	*	*	10	*	13		
Possible alpha thalassaemia affected baby	High risk alpha^{0}	24	-	25	518	538	1,105	1,105	1.56
Other clinically significant mother results	HPFH/Compound heterozygous/donor egg/bone marrow transplant	8	7	20	210	137	382	382	0.54
Other Hb variants requiring testing of baby's father	Other Hb variants requiring testing of baby's father	-	-	29	200	60	289	289	0.41
	Totals	809	18	400	7,705	5,402	14,334	14,334	20.18

Note: 'Mother's screening results' include both cases where the mother is a carrier and where she is affected by a condition

**Numbers less than five have been suppressed*

Not all laboratories were able to provide complete breakdown data for all screen positive women. For comparison, the total number of screen positive women reported by laboratories was 14,354 (99.9% included here) and 822 high risk couples (98.4% included here). The figure for rate per 1,000 booking bloods received is based on the number of booking bloods reported by laboratories with no exclusions made. The rates are therefore likely to be an under estimate.

Figure AN-8. Screen positive women broken down by risk to the pregnancy, 2014/15



Based on 14,334 of the 14,354 screen positive women reported by the laboratories in 2014/15.

3.7. Offer of screening early in pregnancy

One of the programme's aims is to support people to make informed choices during pregnancy. In order to offer informed choice, there are 2 aspects to antenatal screening. Firstly, pregnant women are offered antenatal screening for sickle cell and thalassaemia, and if they are screen positive then screening should be offered to the baby's father. If the couple are identified as being at high risk of having an affected pregnancy, they should be offered prenatal diagnostic (PND) testing which tests the fetus to identify whether or not it is affected by these conditions.

When offering informed choices, there are a number of aspects to take into account. Women/couples who are at high risk of being carriers may have strong beliefs that influence their decisions about having prenatal diagnosis testing or terminating the pregnancy and so they may wish to take these decisions privately before announcing the pregnancy. It is therefore important that screening is offered as early as possible in the pregnancy.

Programme standards set a target of prenatal diagnostic testing being completed by 12+6 weeks gestation. In order to allow time for the required tests of both the mother and the baby's father, the standards also set a target of antenatal screening of pregnant women by 10+0 weeks gestation.

Antenatal screening

The proportion of booking bloods tested by 10 weeks of gestation links to KPI ST2 (timeliness of testing) and with programme standard AP1. It is important to note that standard AP1 specifies an offer by 10 weeks, whereas this data identifies samples actually tested by 10 weeks. This means that these figures are using a stricter measure than that identified in the programme standards, as it is not currently possible for all maternity services to collect data on the offer of test.

Figures on gestation at antenatal screening are often dependent on completion of the FOQ to obtain gestational information. The numbers tested by 10+0 weeks gestation may therefore appear lower than they actually are where laboratories do not have this gestational information.

Table AN-13 shows the proportion of booking bloods that were tested by 10+0 weeks gestation broken down by high and low prevalence areas in the past 3 years. While previously laboratories have reported an increase in the proportion tested by 10+0 weeks, figures for 2014/15 appear similar to those for 2013/14. Aggregated figures show that low prevalence areas are reaching the 50% acceptable level for standard AP1, but high prevalence areas are not yet reaching this level.

The data indicates that in high prevalence areas where there is a greater risk of being screen positive as a carrier of sickle cell disease or thalassaemia, pregnant women are less likely to be offered screening before 10 weeks gestation (approximately 45% tested by 10 weeks in high prevalence areas compared to 54% in low prevalence areas). This could have an impact on equality and access to screening.

Figure AN-9 shows the variation in performance between laboratories in the past 5 years, broken down by prevalence. In each year the interquartile range (IQR) and the median value is higher for low prevalence areas than in high prevalence areas. The median value appears to have increased slightly each year, but the amount of variation between the highest and lowest performers appears to be similar each year for both high and low prevalence areas. While in 2014/15 the median value for low prevalence areas appears approximately the same as for 2013/14, the amount of variation between the highest and lowest performers has decreased.

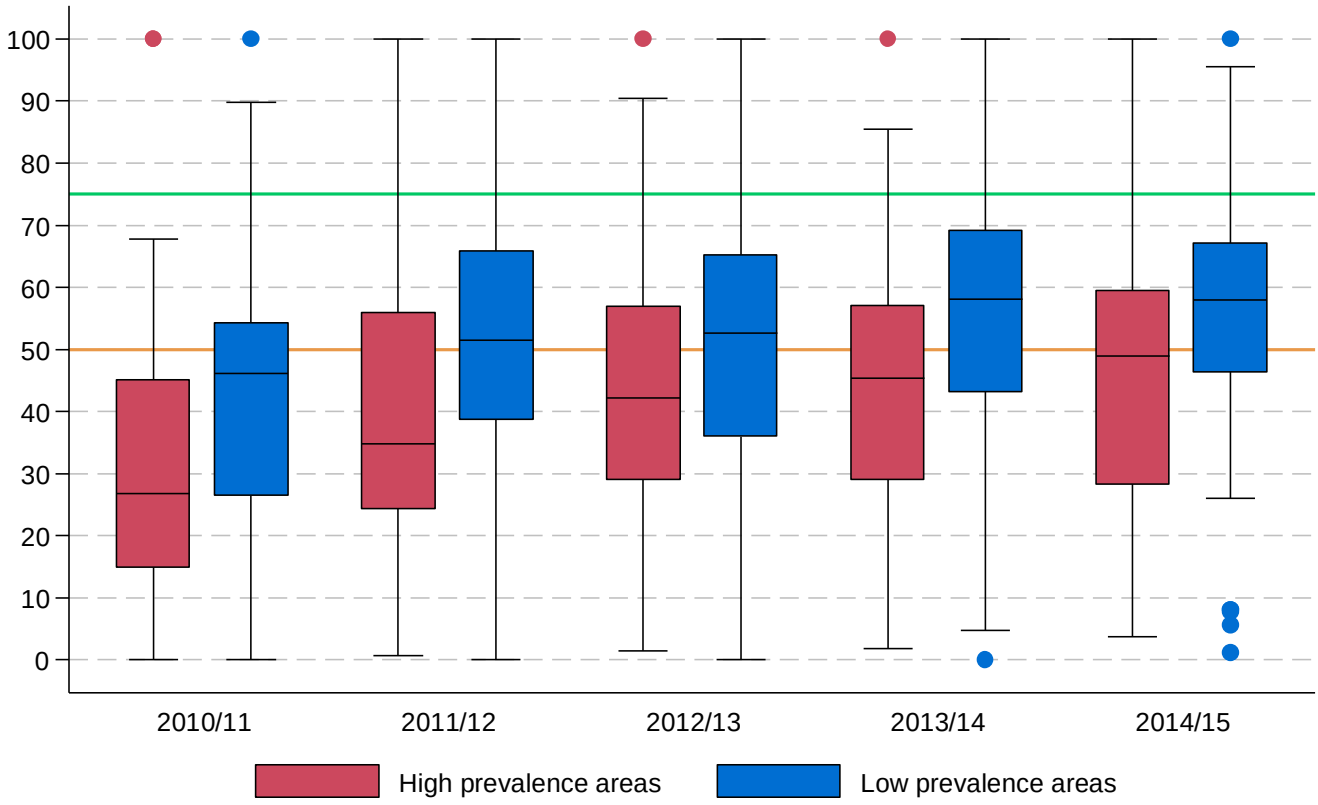
Figure AN-10 shows the proportion of antenatal booking bloods tested by 10+0 weeks by laboratory data return, broken down by region and by prevalence. Variation can be seen within regions for both high and low prevalence areas. This chart also shows that while nationally laboratories are not reaching the 50% acceptable level for standard AP1, there are individual laboratories that are exceeding the achievable level of 75%. This indicates that there is scope for sharing best practice between the highest and lowest performers for the 10+0 weeks standard.

Table AN-13. Antenatal booking bloods tested by 10+0 weeks gestation, 2012-15: England by prevalence

Prevalance	2012/13			2013/14			2014/15		
	Booking bloods (BBs) received	BBs tested by 10 wks	% of BBs	Booking bloods (BBs) received	BBs tested by 10 wks	% of BBs	Booking bloods (BBs) received	BBs tested by 10 wks	% of BBs
High prevalence areas	302,348	125,509	41.51	306,470	137,503	44.87	321,818	143,208	44.50
Low prevalence areas	267,547	136,205	50.91	281,377	153,774	54.65	271,875	145,906	53.67
Total England	569,895	261,714	45.92	587,847	291,277	49.55	593,693	289,114	48.70

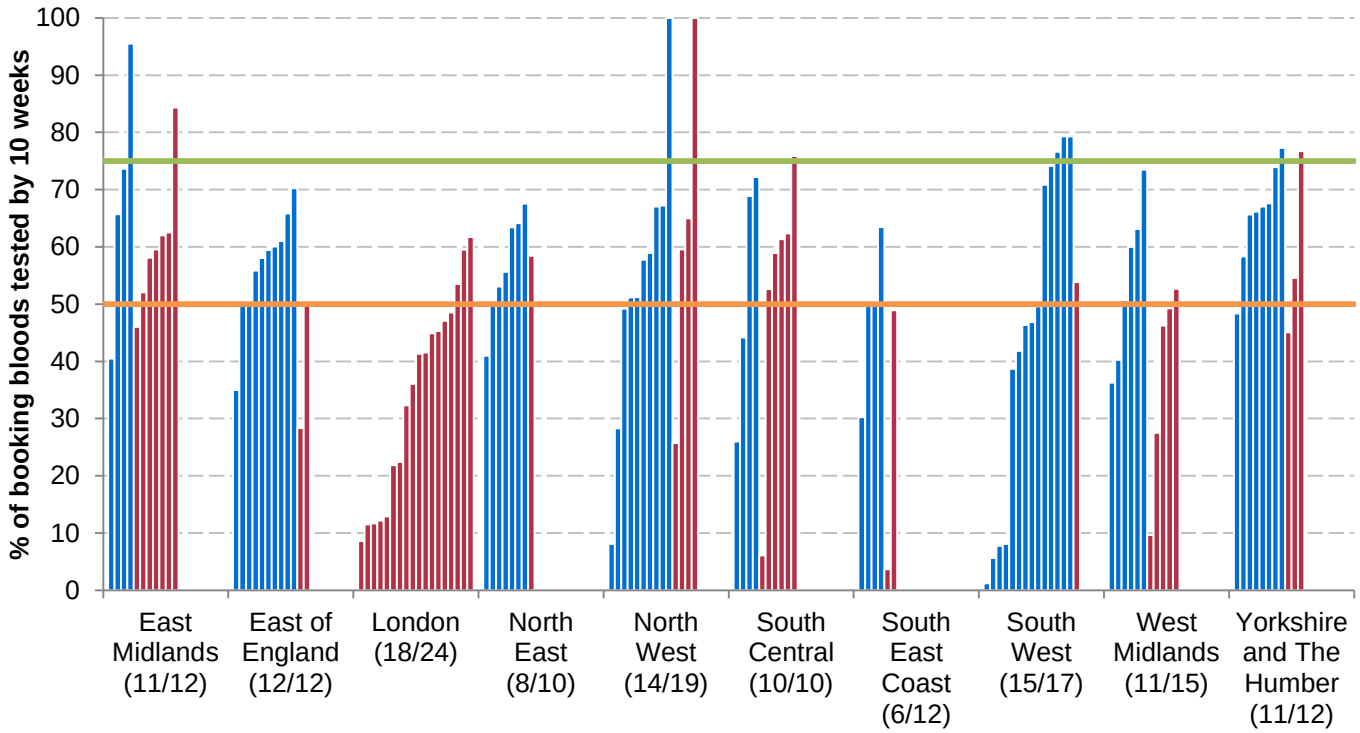
Exclusions based on missing or unavailable data for the data fields shown: 2012/13: 27; 2013/14: 25; 2014/15: 24.

Figure AN-9. Variation in booking bloods tested by 10 weeks, 2010-15: England by prevalence



Exclusions based on missing or unavailable data: 2010/11: 62; 2011/12: 36; 2012/13: 27; 2013/14: 25; 2014/15: 24

Figure AN-10. Proportion of antenatal booking bloods tested by 10+0 weeks gestation by region, 2014/15: England by prevalence



Each bar represents one laboratory. Red bars represent high prevalence areas and blue bars represent low prevalence areas.
The reference line represents the 50% acceptable level for Programme Standard AP1.
The rate for the whole of England is 49%.
The numbers below the region represents how many of those Trusts for which data returns were received were able to provide complete data on booking bloods tested by 10 weeks, eg "4/10" shows that of the 10 returns received, 4 included complete data for both fields.
Excludes 27 laboratories where data on booking bloods tested by 10 weeks or the total number of booking bloods was missing or unavailable.

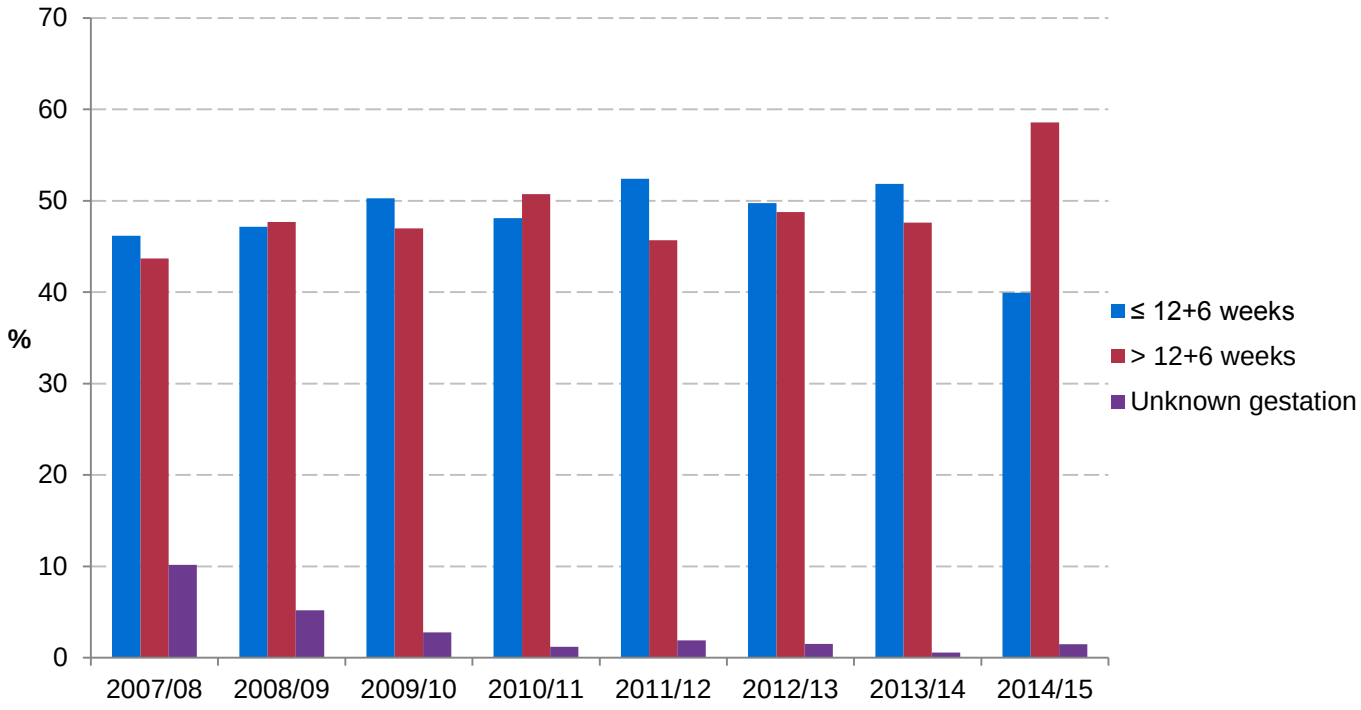
Prenatal diagnostic (PND) testing

Programme standard AO1b sets an acceptable level of 50% of all prenatal diagnoses to be performed by 12+6 weeks gestation and an achievable level of 75%. Table PND-1 shows the number and proportion of PND tests done before and after 12+6 weeks gestation in the 5-year period 2010-15 and Figure PND-1 shows the proportions since 2007/08. Prior to 2014/15 approximately half of PND tests were performed by 12+6 weeks gestation. However, in 2014/15 the proportion of tests performed by this gestation dropped to 40%. Tests performed in the 13th and 14th week of pregnancy have increased by 10%, while the proportion performed in or after the 15th week has remained at approximately 30%.

Table PND-1. Gestation at sample for PND, 2010-15: England

Gestation	2010/11		2011/12		2012/13		2013/14		2014/15	
	n	%	n	%	n	%	n	%	n	%
≤12+6 weeks	202	48.1	219	52.4	198	49.7	183	51.8	163	40.0
13+0 - 14+6 weeks	105	25.0	93	22.2	71	17.8	63	17.8	114	27.9
≥15+0 weeks	108	25.7	98	23.4	123	30.9	105	29.7	125	30.6
Unknown gestation	5	1.2	8	1.9	6	1.5	2	0.6	6	1.5
Total	420	100.0	418	100.0	398	100.0	353	100.0	408	100.0

Figure PND-1. Proportion of PND tests performed by gestation, 2007-15: England



3.8. Numbers tested and detected in prenatal diagnostic testing

Prenatal diagnostic (PND) testing should be offered to couples identified as 'high risk' in antenatal screening, and to women for whom the baby's father is not available for testing. Table PND-2 shows the number of PND tests performed each year by each of the PND laboratories. In 2014/15 there were 408 PND tests performed, representing an increase compared to the previous 2 years. Table PND-3 breaks these numbers down by region along with the proportion of all PNDs performed that were from each region. London has the highest numbers, with over half of all PND tests coming from that region each year.

Table PND-2. Number of PNDs performed, 2007-15: England by laboratory

PND laboratory	2007/08	2008/09	2009/10	2010/11	2011/12	2012/13	2013/14	2014/15
King's College Hospital	86	101	119	141	134	125	104	138
Oxford University Hospital	130	166	159	159	149	161	140	139
University College London Hospital	109	119	118	120	135	112	109	131
England total	325	386	396	420	418	398	353	408

Table PND-3. Number of PNDs performed, 2010-15: England by region

Region	2010/11		2011/12		2012/13		2013/14		2014/15	
	n	%	n	%	n	%	n	%	n	%
East Midlands	18	4.3	12	2.9	*	*	*	*	*	*
East of England	30	7.1	22	5.3	21	5.3	16	4.5	27	6.6
London	266	63.3	249	59.6	195	49.0	189	53.5	229	56.1
North East	*	*	*	*	*	*	*	*	*	*
North West	22	5.2	21	5.0	*	*	*	*	*	*
South Central	15	3.6	12	2.9	*	*	*	*	*	*
South East Coast	12	2.9	12	2.9	17	4.3	7	2.0	11	2.7
South West	11	2.6	*	*	*	*	*	*	*	*
West Midlands	16	3.8	21	5.0	*	*	5	1.4	*	*
Yorkshire and the Humber	16	3.8	11	2.6	*	*	*	*	*	*
Unknown Region	10	2.4	50	12.0	150	37.7	124	35.1	132	32.4
England total	420	100.0	418	100.0	398	100.0	353	100.0	408	100.0

**Numbers less than five have been suppressed*

Table PND-4 shows the number of affected, carrier, 'no abnormality detected' (NAD) and inconclusive or missing results, broken down by PND result or risk to pregnancy. Of the PND tests performed in 2014/15, 29% had affected results, 24% had NAD results, and 47% had carrier results.

Table PND-4. Breakdown of PND fetal results by condition, 2010-15: England

Fetal result	PND result/risk	2010/11		2011/12		2012/13		2013/14		2014/15	
		n	%	n	%	n	%	n	%	n	%
Affected	Sickle Cell	66	15.7	87	20.8	68	17.1	69	19.5	97	23.8
	Thalassaemia	29	6.9	14	3.3	17	4.3	19	5.4	20	4.9
	Other Hb variant	*	*	*	*	*	*	*	*	*	*
Carrier	Sickle Cell	170	40.5	139	33.3	160	40.2	115	32.6	144	35.3
	Thalassaemia	50	11.9	53	12.7	41	10.3	38	10.8	35	8.6
	Other Hb variant	*	*	14	3.3	12	3.0	10	2.8	12	2.9
NAD	Risk for Sickle Cell	79	18.8	63	15.1	52	13.1	77	21.8	84	20.6
	Risk for Thalassaemia	20	4.8	*	*	18	4.5	22	6.2	15	3.7
	Risk not known	*	*	35	8.4	26	6.5	*	*	*	*
Inconclusive/ result not known	All risks	*	*	*	*	*	*	*	*	*	*
Total		420	100.0	418	100.0	398	100.0	353	100.0	408	100.0

Sickle Cell' includes HbSS, HbAS, HbSC, HbS/beta thalassaemia, and HbS+other variant requiring clinical follow-up; 'Thalassaemia' includes both alpha and beta thalassaemias (grouped due to the small numbers of alpha thalassaemia cases) as well as HPFH results.

3.9. PND results by ethnicity

Table PND-5 shows the number of PND tests performed each year by mother's family origin (as reported to the laboratories) between 2010/11 and 2014/15. While in previous years African maternal family origins accounted for approximately half of PND tests performed each year, in 2014/15 these accounted for 70% of PND tests performed. This may, however, be partially attributed to an improvement in data quality, as the proportion with an unknown maternal family origin has decreased from approximately 20% each year to approximately 9%. The 'mixed/other' grouping includes combinations of family origins that do not fit into one single category.

Table PND-5. Number of PND tests by mother's ethnicity, 2010-15: England

Mother's family origin	2010/11		2011/12		2012/13		2013/14		2014/15	
	n	%	n	%	n	%	n	%	n	%
African	240	57.1	211	50.5	180	45.2	162	45.9	290	71.1
Caribbean	23	5.5	12	2.9	14	3.5	61	17.3	16	3.9
Indian	16	3.8	9	2.2	9	2.3	*	*	11	2.7
Pakistani	19	4.5	*	*	*	*	*	*	*	*
Cypriot/Mixed Cypriot	11	2.6	7	1.7	*	*	6	1.7	7	1.7
Other Asian	16	3.8	50	12.0	27	6.8	35	9.9	28	6.9
Southern & Other European	5	1.2	*	*	8	2.0	6	1.7	10	2.5
Middle Eastern	5	1.2	*	*	*	*	*	*	*	*
Mixed/Other	8	1.9	97	23.2	66	16.6	11	3.1	5	1.2
Not Known	77	18.3	23	5.5	84	21.1	61	17.3	36	8.8
Total	420	100.0	418	100.0	398	100.0	353	100.0	408	100.0

**Numbers less than five have been suppressed*

3.10. Pregnancy outcomes

One of the aims of antenatal screening for sickle cell and thalassaemia is to offer couples informed choice and the screening programme collects data on pregnancy outcomes following PND testing to assess what choices couples make following prenatal diagnosis. Table PND-6 shows the number of PND tests broken down by condition and by pregnancy outcome. It should be noted that there are a small number of alpha thalassaemia cases and so the percentages should be interpreted with caution.

Figure PND-2 shows the proportion of PND tests with an affected result where parents opted to either continue or terminate the pregnancy. This figure includes figures covering a 7-year period and excludes cases of miscarriage and where the pregnancy outcome was not known. Of the PND tests with an affected result, approximately 65% opted to terminate following a sickle cell affected diagnosis, 84% for a beta thalassaemia diagnosis, and 86% for an alpha thalassaemia diagnosis. As above, the alpha thalassaemia figures are based on small numbers and should be interpreted with caution.

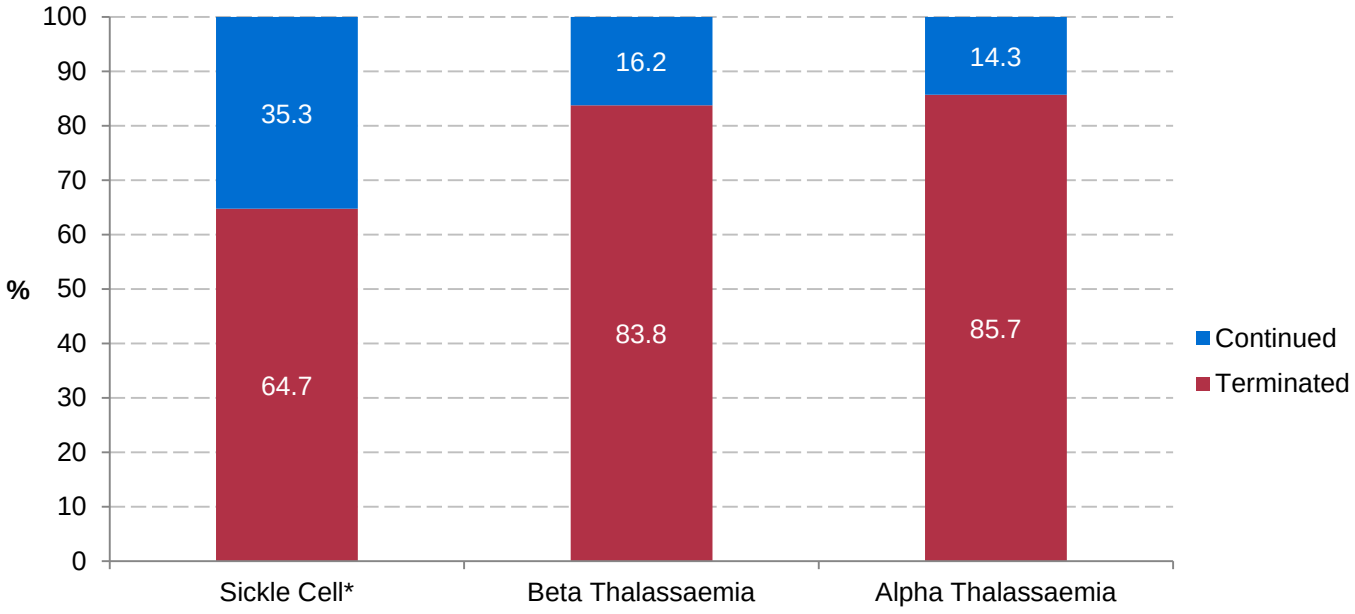
Table PND-6. Outcomes for pregnancies with affected fetal diagnoses at PND, 2012-15: England by condition

Condition	Pregnancy outcome	2012/13	2013/14	2014/15
		% of total identified with condition	% of total identified with condition	% of total identified with condition
Sickle Cell	Continued	17.6	17.4	26.8
	Terminated	41.2	44.9	38.1
	Not Known	38.2	37.7	35.1
Beta Thalassaemia	Continued	7.1	6.3	21.1
	Terminated	57.1	31.3	42.1
	Not Known	35.7	62.5	36.8
Alpha Thalassaemia	Continued	0.0	0.0	0.0
	Terminated	66.7	33.3	100.0
	Not Known	33.3	66.7	0.0
Total Affected (n)		85	89	118

Other haemoglobin variants and miscarriage outcomes have been excluded

**Numbers less than five have been suppressed*

Figure PND-2. Outcomes for pregnancies with 'affected' diagnosis at PND, 2008-15: England by condition



**The "Sickle Cell" category includes HbSS, HbSC, HbS/beta thalassaemia, and HbS+other variant requiring clinical follow-up.*

Excludes miscarriage outcomes and 257 cases where pregnancy outcome was not known.

Table PND-7 shows pregnancy outcomes for affected results by gestation at PND test covering a 7-year period.

Figure PND-3 shows the proportion of affected results where parents opted to terminate the pregnancy for all conditions by gestation, shown with 95% confidence intervals. This shows that of those who were tested by 12+6 weeks, 75% opted to terminate, compared to those tested after 15 weeks where this figures drops to 57%. This may indicate that the later in pregnancy that PND testing is performed, the less likely parents are to choose to terminate.

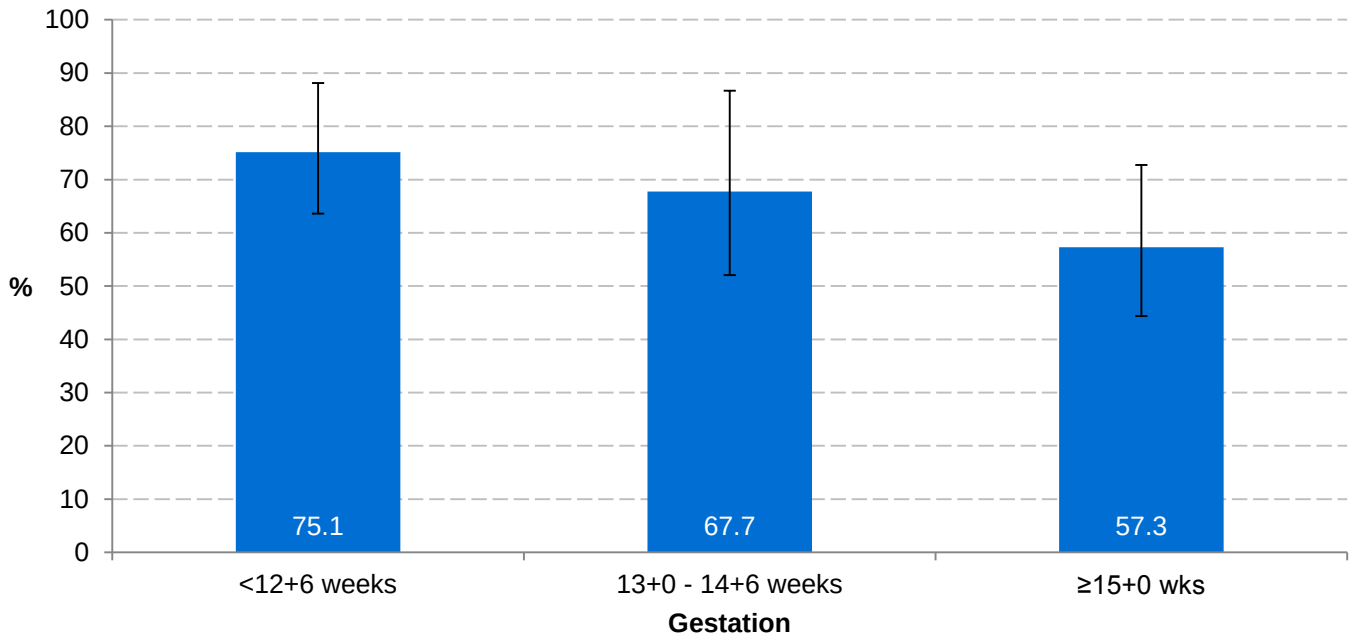
Table PND-7. Gestation at PND for affected results with a known outcome, 2008-15: England

		<12+6 weeks	13+0 - 14+6 weeks	≥15+0 wks
Condition	Outcome	n	n	n
Sickle Cell	Continued	37	27	48
	Terminated	100	50	58
Beta Thalassaemia	Continued	10	*	*
	Terminated	43	11	7
Alpha Thalassaemia	Continued	*	*	*
	Terminated	8	*	*

Excludes cases where the gestation at PND was unknown

**Numbers less than five have been suppressed*

Figure PND-3. Proportion of affected results where parents opted to terminate, grouped by gestation at PND for known pregnancy outcomes, 2008-15: England



**Excludes cases where the gestation at PND was unknown, and cases where the pregnancy outcome was unknown.*

4. Newborn screening data

4.1. Response rates and data quality

Response rate:

Data was received from all 13 newborn screening laboratories in England. We would like to thank all those involved in collecting and submitting this data to the screening programme.

Data quality:

Newborn laboratories report on 'results' which may differ from the number of babies tested. Data by region and by ethnicity are collected separately, which can lead to discrepancies when comparing the figures. Potential causes for these differences can include samples from outside of England being excluded in the regional data where these could be identified, but not in the ethnicity data.

Birth figures from the Office of National Statistics (ONS) offer a data quality check by comparing numbers of babies born with numbers of samples screened. ONS figures cover calendar years whereas the screening laboratory figures cover financial years, so these datasets do not exactly match. Other differences may be accounted for by declined screening tests, samples tested where their region was unknown (babies reported by the laboratories as 'out of region' or 'unknown region'), repeat tests, and babies who were born abroad who moved to England up to 1 year of age. However, comparing these 2 datasets shows these figures to be broadly similar, offering some data validation for the laboratory figures.

Table NB-1. Comparison of ONS birth figures and number of samples screened reported by newborn screening laboratories, 2014/15: England by region

Region	Data from newborn laboratories*	ONS figures†	Discrepancy (%)
East of England	69,407	71,855	3.41
East Midlands	48,552	53,170	8.69
London	130,203	127,399	-2.20
North East	26,378	28,456	7.30
North West	85,207	85,606	0.47
South East	102,797	102,406	-0.38
South West	57,798	58,403	1.04
West Midlands	69,740	70,123	0.55
Yorkshire and The Humber	65,328	64,078	-1.95
Unknown Region	6,022	-	-
England Total	661,432	661,496	0.01

**Data collected from the 13 newborn laboratories in England. This data covers the financial year 2014/15.*

†Data from ONS (Live Births by Area of Usual Residence 2014, available at http://www.ons.gov.uk/ons/rel/vsob1/births-by-area-of-usual-residence-of-mother--england-and-wales/index.html). This data covers the 2014 calendar year.

4.2. Numbers screened and results

Coverage

Newborn blood spot screening standards 1a and 1b relate to the completeness of coverage in newborn screening[4]. Standard 1a represents coverage for babies born for whom the CCG is responsible for at birth and has an effective timeframe of a conclusive result for each of the conditions screened being recorded on the child health information system (CHIS) by 17 days of age. Standard 1b represents babies who 'moved in' to the CCG within their first year and has an effective timeframe of a conclusive result being recorded on the CHIS by 21 calendar days of movement in being recorded on the CHIS. The thresholds for both standards are 95% as an acceptable level and 99.9% as an achievable level.

Table NB-2 shows data collected by the newborn blood spot screening programme on coverage of newborn screening for babies who were the responsibility of the CCG at birth, both with and without the effective timeframe. This data shows that performance is close to the 95% acceptable level for this standard. This is comparable to similar data for KPI NB1 which shows coverage to be at 95.8% (see 5.2 Annual KPI data). Figure NB-1 shows trends in performance against standard 1a since 2010/11 using the effective timeframe, showing an improvement nationally each year, but some variation regionally. However, it is important to note when looking at these trends that while exclusions have been made in the 2014/15 figures based on missing data, this was not possible for data from previous years.

Table NB-2. Completeness of coverage for sickle cell screening (CCG responsibility at birth), 2014/15: England by region

Region	No. of babies born*	Babies tested (no timeframe)		No. of babies born	Babies tested and recorded on the CHIS at 17 days	
	n	n	%	n	n	%
East Midlands	47,098	46,965	99.7	47,098	44,158	93.8
East of England	61,514	61,199	99.5	61,514	59,305	96.4
London	84,693	83,305	98.4	88,927	85,300	95.9
North East	21,070	21,056	99.9	21,070	20,390	96.8
North West	69,795	69,611	99.7	73,007	69,813	95.6
South East	88,469	87,577	99.0	88,469	82,781	93.6
South West	49,157	49,048	99.8	49,157	43,837	89.2
West Midlands	56,926	56,140	98.6	56,926	55,340	97.2
Yorkshire and the Humber	53,286	53,239	99.9	53,286	48,562	91.1
Unknown region	43	43	100.0	43	42	97.7
England Total	532,051	528,183	99.3	539,497	509,528	94.4

**3 returns were excluded due to missing data.*

Data was received from CHRDs which accounted for 183 out of 211 CCGs.

Figure NB-1. Trends in completeness of coverage for sickle cell screening (CCG responsibility at birth), 2010-15: England by region

Exclusions have been made in the 2014/15 figures, but this was not possible for data from previous years.

Table NB-3 shows coverage of screening for babies who 'moved in' to the CCG in their first year both with and without the effective timeframe applied. The figures show that approximately 92% of babies who moved in during 2014/15 were tested, but when the 21-day effective timeframe is taken into account, this figure drops to 76%.

Figure NB-2 shows trends in performance against standard 1b since 2010/11. The 21-day timeframe is not applied in this chart as this timeframe was only introduced for 2014/15. As with standard 1a an improvement can be seen each year although in 2014/15 there appears to be a small decline. While in some years some regions appear to be reaching the acceptable level, nationally this level is not yet being met.

Table NB-3. Completeness of coverage for sickle cell screening ('movers-in'), 2014/15: England

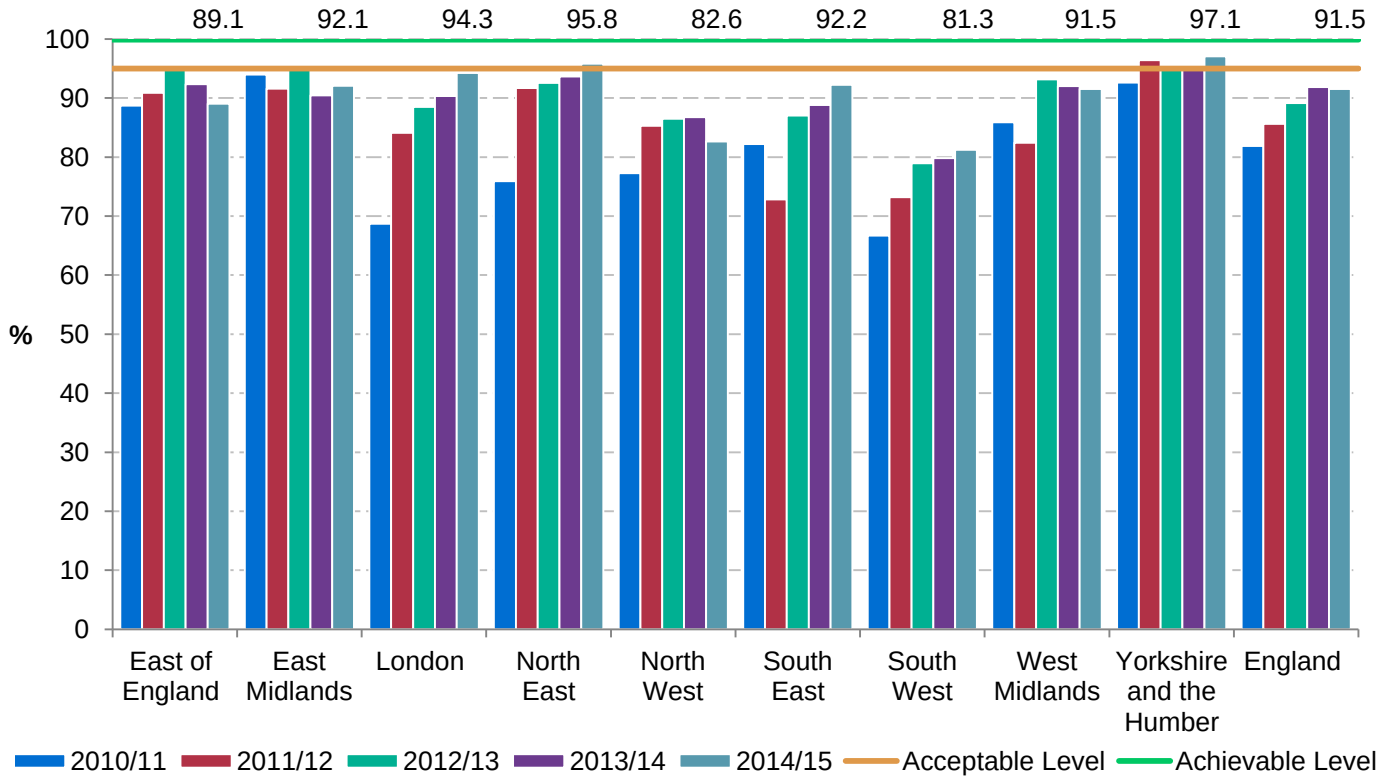
Region	No. of 'movers-in'*	Babies tested (no timeframe)		No. of 'movers-in'†	Babies tested and recorded on the CHIS ≤ 21 days of movement	
	n	n	%	n	n	%
East Midlands	1,203	1,013	92.6	1,203	775	64.4
East of England	2,973	2,670	89.8	2,973	2,428	81.7
London	8,958	8,448	94.3	7,607	5,750	72.2
North East	1,126	1,078	95.7	1,126	846	75.1
North West	3,367	2,767	82.2	3,413	2,675	78.4
South East	4,649	4,276	92.0	3,323	2,816	84.7
South West	1,387	1,120	80.7	1,387	659	47.5
West Midlands	1,372	1,260	91.8	931	594	63.8
Yorkshire and the Humber	3,374	3,273	97.0	2,979	2,564	86.1
Unknown region	2	2	100.0	-	-	-
England Total	28,411	25,907	91.5	24,942	19,107	75.5

**18 returns were excluded due to missing data.*

†40 returns were excluded due to missing data.

Data was received from CHRDs which accounted for 183 out of 211 CCGs.

Figure NB-2. Trends in completeness of coverage for sickle cell screening ('movers-in'), 2010-15: England



Exclusions have been made in the 2014/15 figures, but this was not possible for data from previous years.

Numbers screened

Laboratory data reports 661,432 samples screened in 2014/15, down from 668,117 in 2013/14. Of these 278 (one in 2,379 samples screened) were identified with significant conditions, and 8,942 (one in 74 samples screened) were identified with carrier results.

Table NB-4. Samples screened and newborn screening results, 2014/15: England by region

Region	Significant Conditions					Carriers					Total Screened		
	FS	FSC	FS-Other	FE	F-only	FAS	FAC	FAD	FAE	Other	Transfused	Declined	Normal+ Abnormal
East Midlands	9	*	*	*	*	259	49	53	32	*	88	*	48,552
East of England	7	9	*	*	*	415	108	49	88	*	55	174	69,407
London	101	45	*	8	*	3,070	634	221	396	5	432	185	130,203
North East	*	*	*	*	*	74	10	13	18	*	40	9	26,378
North West	18	*	*	*	*	514	78	79	91	*	133	120	85,207
South Central	10	*	*	*	*	344	77	51	59	*	42	119	51,181
South East Coast	6	*	*	*	*	230	49	38	61	*	256	83	51,616
South West	5	*	*	*	*	187	43	37	37	*	35	63	57,798
West Midlands	14	*	*	*	7	552	140	131	103	*	104	130	69,740
Yorkshire and the Humber	*	6	*	*	6	295	47	81	56	*	149	78	65,328
Unknown region	*	*	*	*	*	46	10	*	*	*	146	24	6,022
England Total	180	71	11	16	22	5,986	1,245	754	945	12	1,480	985	661,432

**Numbers less than five have been suppressed*

Significant conditions:

Significant conditions comprise FS, FSC, FS-other and FE results. Table NB-5 shows the number and rates of babies identified with a significant condition for each year since 2012/13.

In 2014/15 there were 278 babies identified with a significant condition, which equates to 0.42 per 1,000 babies screened or one in 2,379 babies screened. Rates range from 0.10 per 1,000 babies in the South West to 1.19 per 1,000 babies in London.

While newborn screening does not specifically test for beta thalassaemia major, F-only cases, which are probable beta thalassaemia affected babies, are identified as a by-product of screening for sickle cell disease. There are approximately 20-30 F-only cases identified each year, and in 2014/15 there were 22 cases reported.

Figure NB-3 shows the geographical prevalence of babies with screen positive results for significant conditions per 1,000 babies screened in 2014/15.

Table NB-5. Trends in the number of babies identified with significant conditions, 2012 - 15: England by region

Region	2012/13				2013/14				2014/15			
	n	Total screened	Rate/ 1000	1 in x	n	Total screened	Rate/ 1000	1 in x	n	Total screened	Rate/ 1000	1 in x
East Midlands	8	49,898	0.16	6,237	16	48,382	0.33	3,024	12	48,552	0.25	4,046
East of England	21	72,421	0.29	3,449	21	69,082	0.30	3,290	17	69,407	0.24	4,083
London	195	131,424	1.48	674	190	130,373	1.46	686	155	130,203	1.19	840
North East	*	*	0.03	28,966	*	*	0.07	13,948	*	*	0.19	5,276
North West	25	87,369	0.29	3,495	19	84,384	0.23	4,441	25	85,207	0.29	3,408
South Central	13	53,352	0.24	4,104	20	51,413	0.39	2,571	16	51,181	0.31	3,199
South East Coast	7	51,682	0.14	7,383	9	51,710	0.17	5,746	9	51,616	0.17	5,735
South West	7	59,938	0.12	8,563	8	57,940	0.14	7,243	6	57,798	0.10	9,633
West Midlands	21	72,559	0.29	3,455	20	70,773	0.28	3,539	15	69,740	0.22	4,649
Yorkshire and the Humber	11	69,613	0.16	6,328	13	67,820	0.19	5,217	14	65,328	0.21	4,666
Unknown region	*	*	0.37	2,739	*	*	0.12	8,344	*	*	0.66	1,506
England total	312	685,438	0.46	2,197	319	668,117	0.48	2,094	278	661,432	0.42	2,379

**Numbers of five or less have been suppressed*

Figure NB-3. Babies identified with a significant condition per 1,000 babies screened, 2014/15: England by region

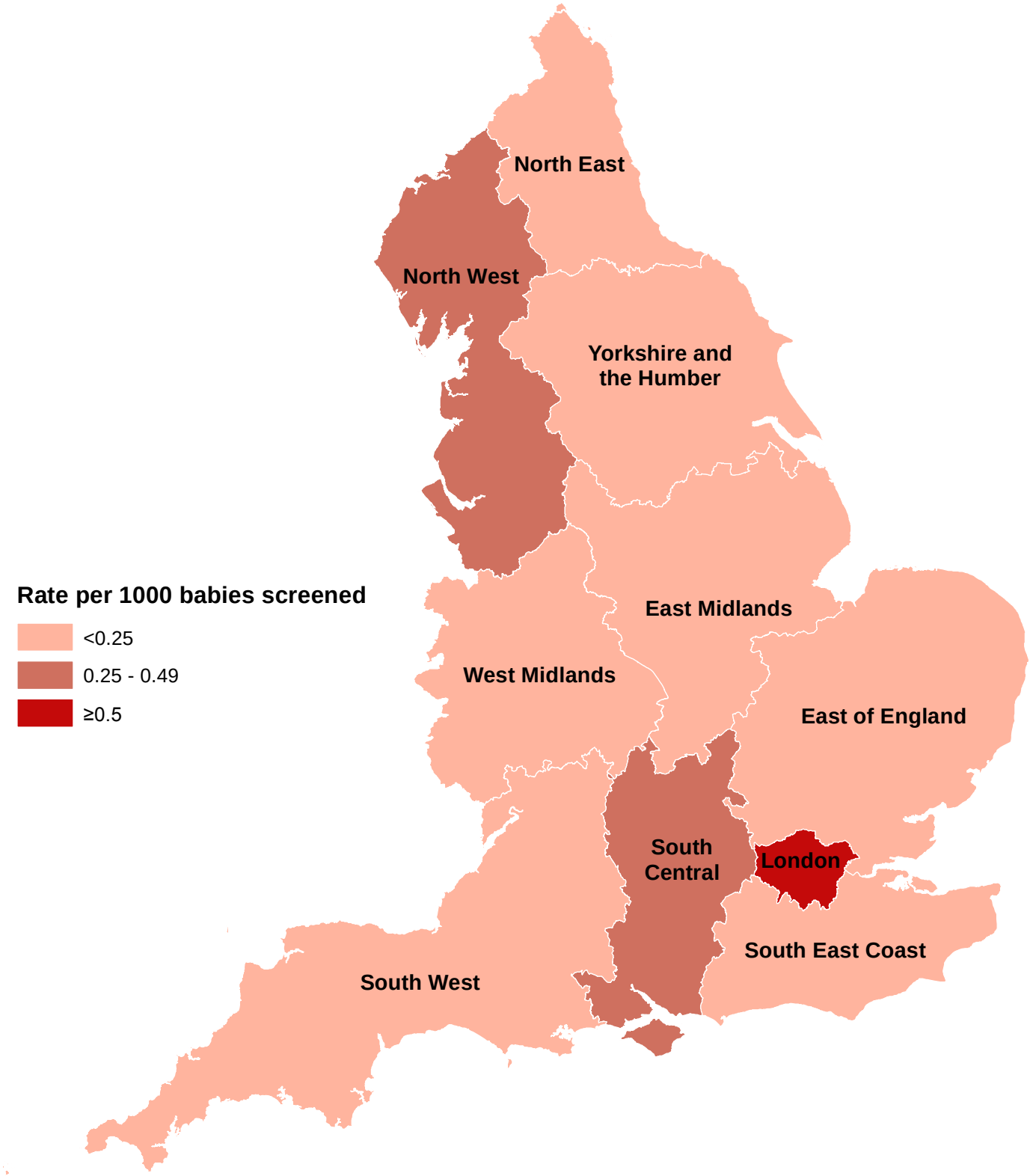
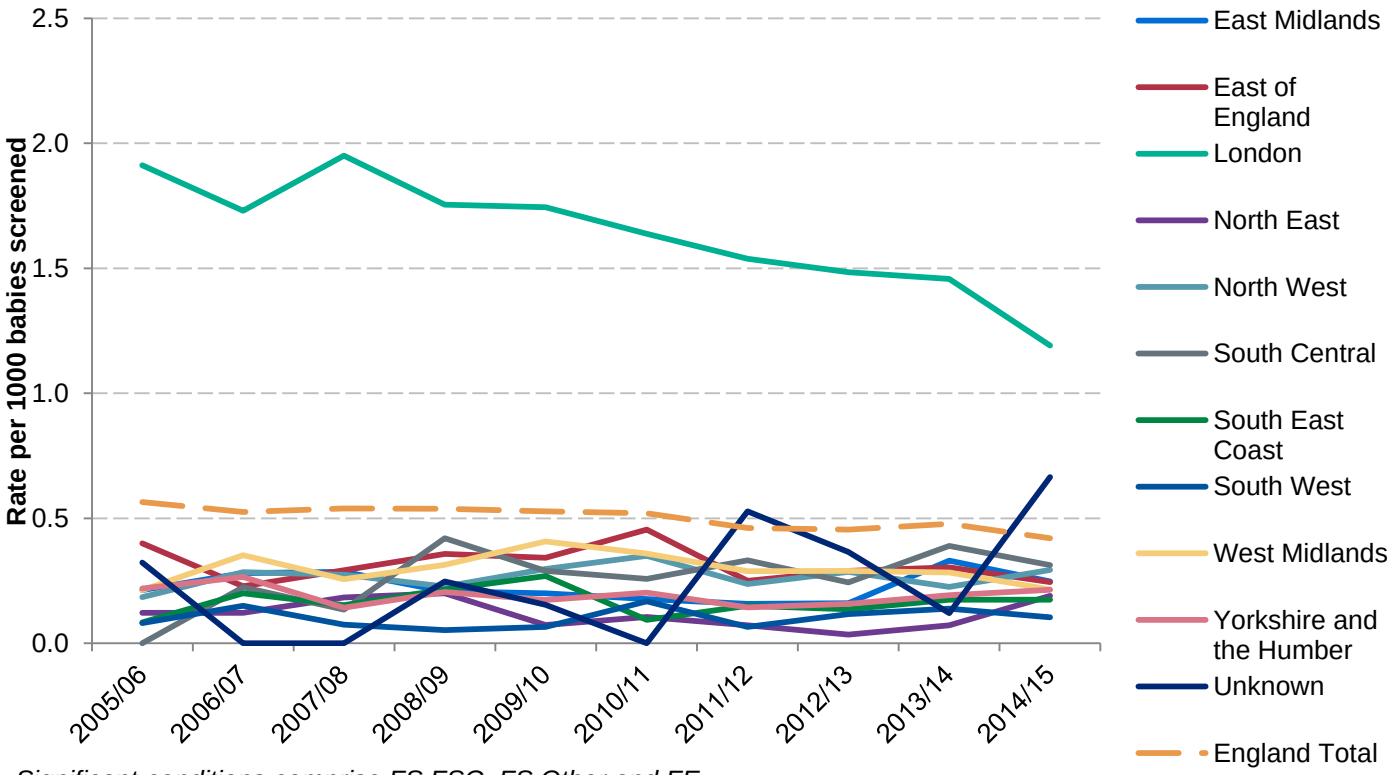


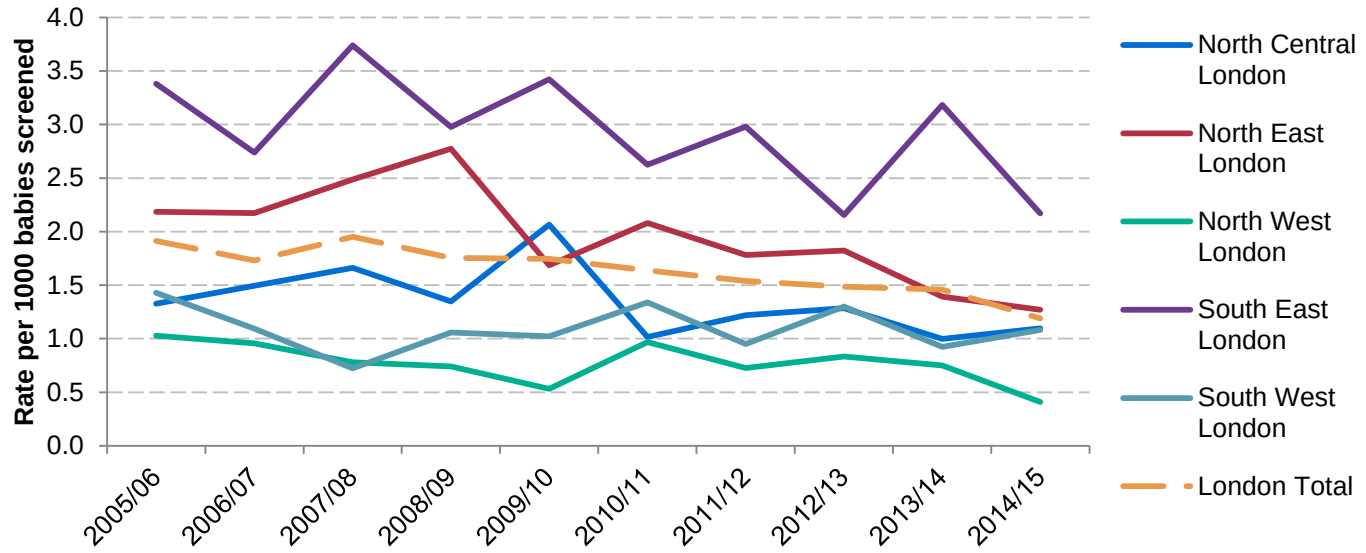
Figure NB-4 shows trends in rates of babies identified with a significant condition by region. There appears to be a decline in rates in London, but rates in London remain higher than those for other regions. Figure NB-6 compares the rates for London with the rest of England (including cases where the region is unknown) and Figure NB-5 shows a breakdown of rates in London by sector (pre-2006 SHAs). The rates for England remain at approximately 0.5 per 1,000 babies screened, but over time there appears to be a slight decline.

Figure NB-4. Trends in babies identified with a significant condition, 2005-15: England by region



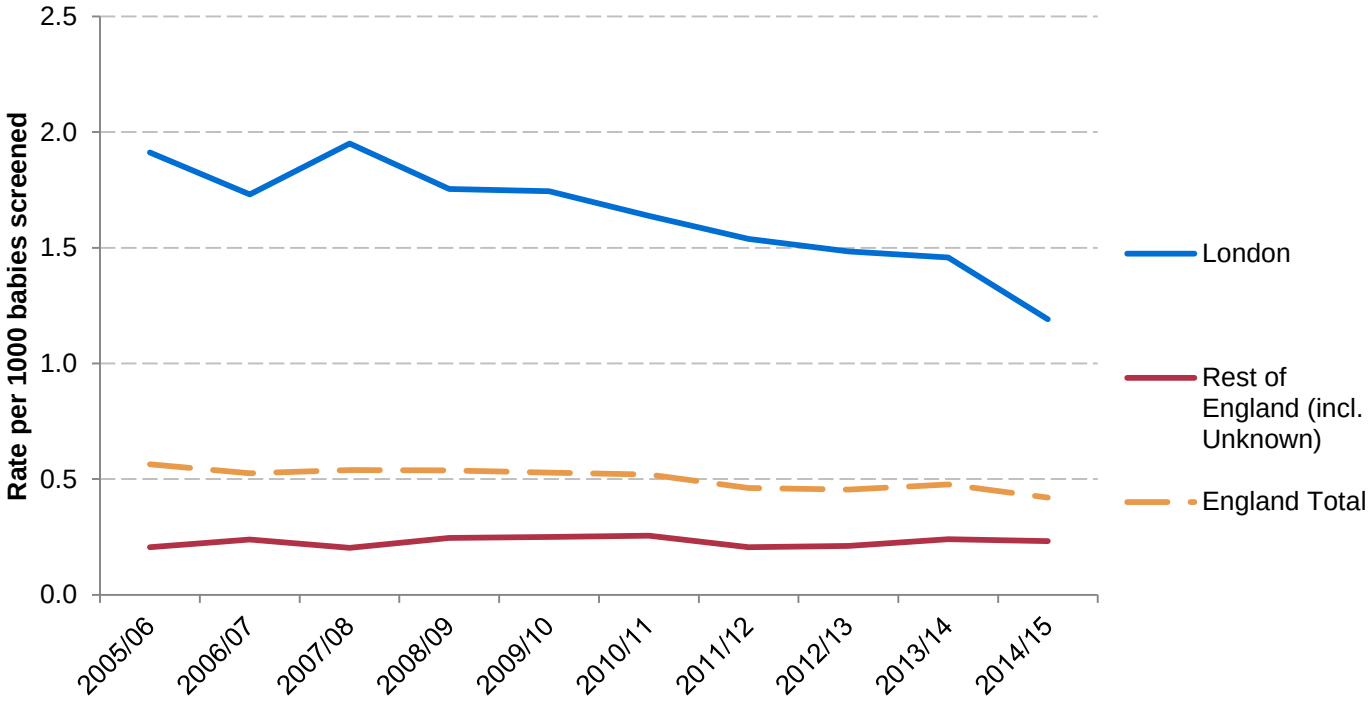
Significant conditions comprise FS,FSC, FS Other and FE.
**Bristol data for first half of 2005/06 not included and Oxford and Portsmouth data not included for whole of 2005/06; Oxford data starts from 1st July 2006; Transfused data from Manchester laboratory for 2009/10 not available.*

Figure NB-5. Trends in babies identified with a significant condition, 2005-15: London sectors (pre-2006 SHAs)



Significant conditions comprise FS,FSC, FS Other and FE.

Figure NB-6. Trends in babies identified with a significant condition, 2005-15: London and the rest of England



Significant conditions comprise FS,FSC, FS Other and FE.

Carriers:

Carrier results comprise FAS, FAC, FAD, FAE and other haemoglobin variants. There were 8,942 carrier results reported by the laboratories, which equates to 13.5 per 1,000 babies screened, or 1 in 74 babies screened. Carrier rates vary by region, ranging from 4.4 per 1,000 babies screened (one in 229 babies screened) in the North East to 33.2 per 1,000 babies screened (one in 30 babies screened) in London. National carrier rates appear steady at approximately 13.5 per 1,000 babies screened. Table NB-6 shows carrier numbers and rates for the last 3 years, broken down by region.

Figure NB-7 shows the geographical prevalence for carrier results per 1,000 babies screened in England in 2014/15.

Table NB-6. Trends in the number of babies identified with carrier results, 2012-15: England by region

Region	2012/13				2013/14				2014/15			
	n	Total Screened	Rate/ 1000	1 in x	n	Total Screened	Rate/ 1000	1 in x	n	Total Screened	Rate/ 1000	1 in x
East Midlands	444	49,898	8.90	112	383	48,382	7.92	126	395	48,552	8.14	123
East of England	706	72,421	9.75	103	629	69,082	9.11	110	660	69,407	9.51	105
London	4,679	131,424	35.60	28	4,410	130,373	33.83	30	4,326	130,203	33.23	30
North East	157	28,966	5.42	184	134	27,896	4.80	208	115	26,378	4.36	229
North West	665	87,369	7.61	131	721	84,384	8.54	117	762	85,207	8.94	112
South Central	564	53,352	10.57	95	481	51,413	9.36	107	532	51,181	10.39	96
South East Coast	357	51,682	6.91	145	369	51,710	7.14	140	378	51,616	7.32	137
South West	323	59,938	5.39	186	305	57,940	5.26	190	305	57,798	5.28	190
West Midlands	900	72,559	12.40	81	881	70,773	12.45	80	926	69,740	13.28	75
Yorkshire and the Humber	477	69,613	6.85	146	450	67,820	6.64	151	482	65,328	7.38	136
Unknown	96	8,216	11.68	86	87	8,344	10.43	96	61	6,022	10.13	99
England Total	9,368	685,438	13.67	73	8,850	668,117	13.25	75	8,942	661,432	13.52	74

Figure NB-7. Babies identified with a carrier result per 1,000 babies screened, 2014/15: England by region

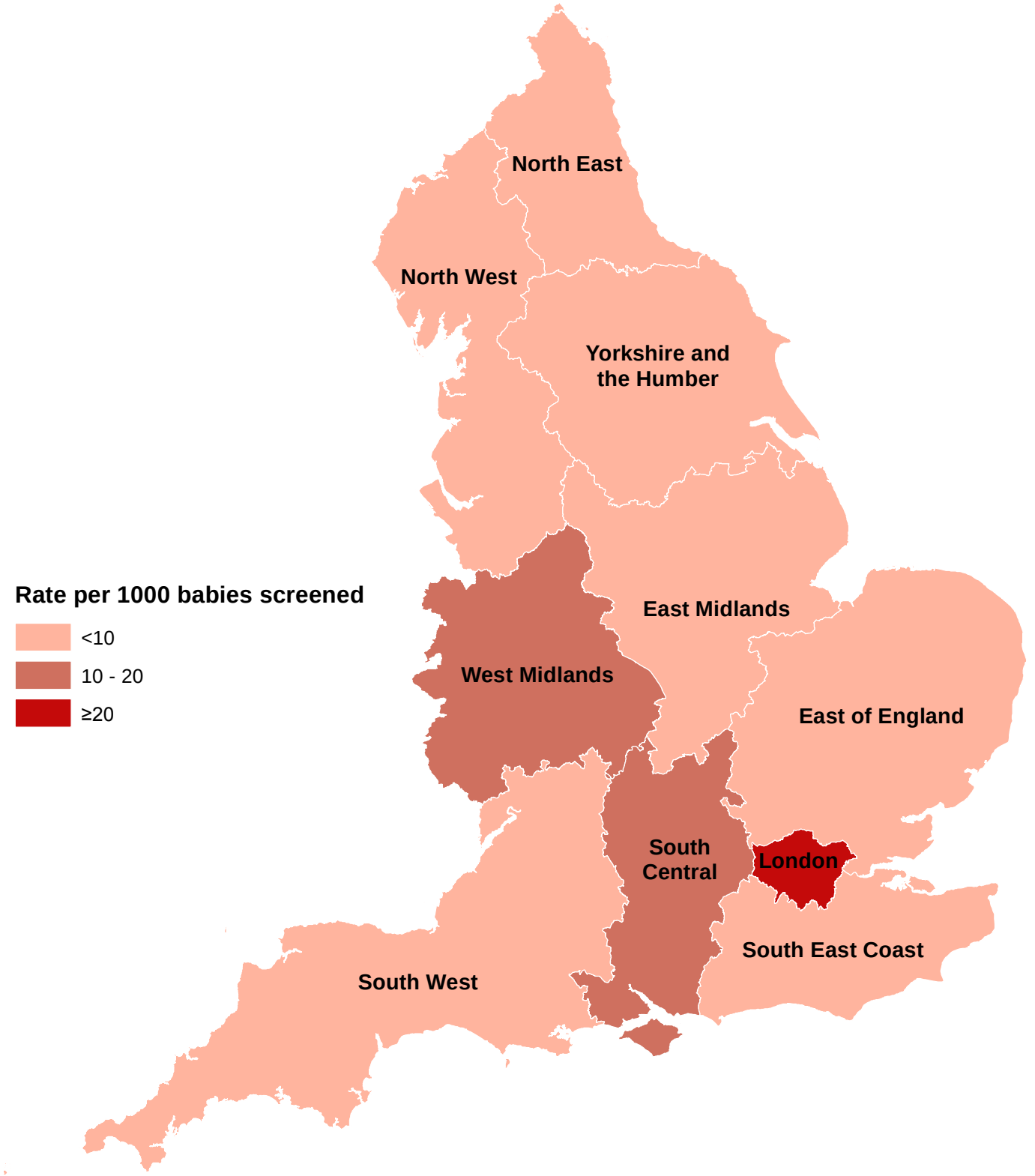
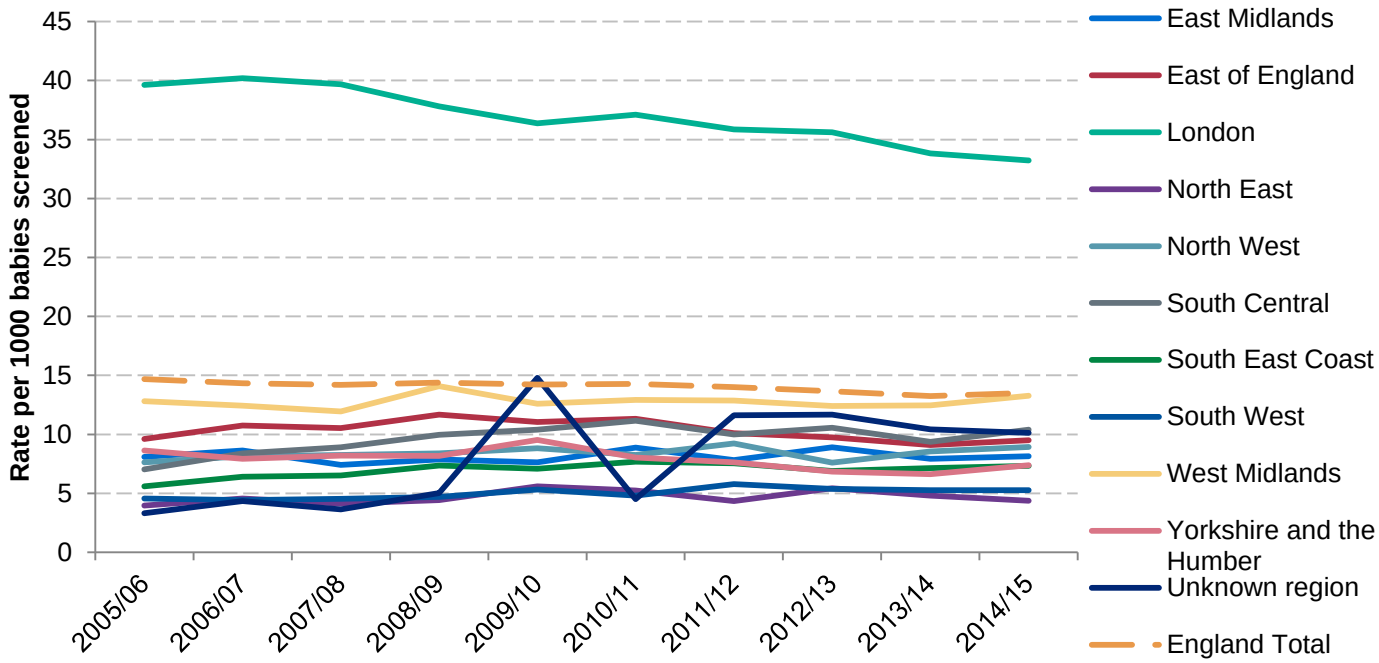


Figure NB-8 shows trends in rates of babies reported with a carrier results for England, broken down by region. As with the data on significant conditions, there appears to be a decline in London while the rates for the other regions appear more consistent. Figure NB-9 breaks down the rates for London by London sector (pre-2006 SHAs) and Figure NB-10 shows the rates by region excluding London.

Figure NB-8. Trends in babies identified as carriers, 2005-15: England by region



Carrier results comprise FAS, FAC, FAD, FAE and other carriers.
**Bristol data for first half of 2005/06 not included and Oxford and Portsmouth data not included for whole of 2005/06; Oxford data starts from 1st July 2006.*

Figure NB-9. Trends in babies identified as carriers, 2005-15: London sectors (pre-2006 SHAs)

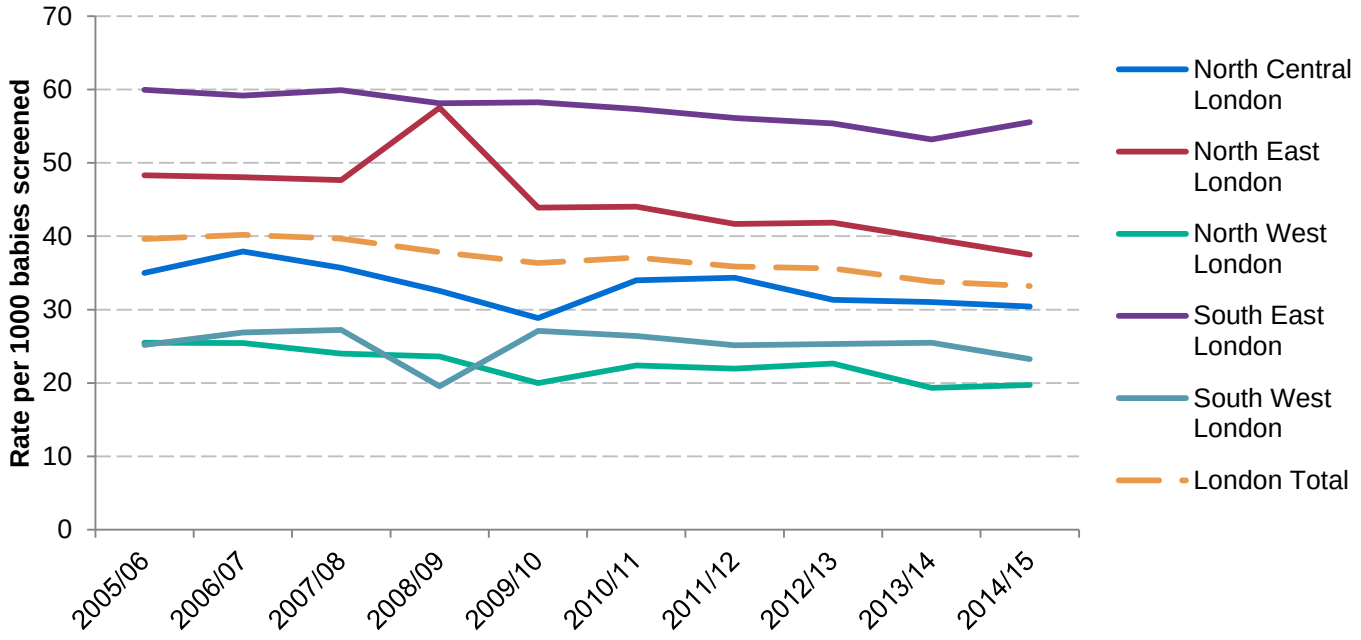
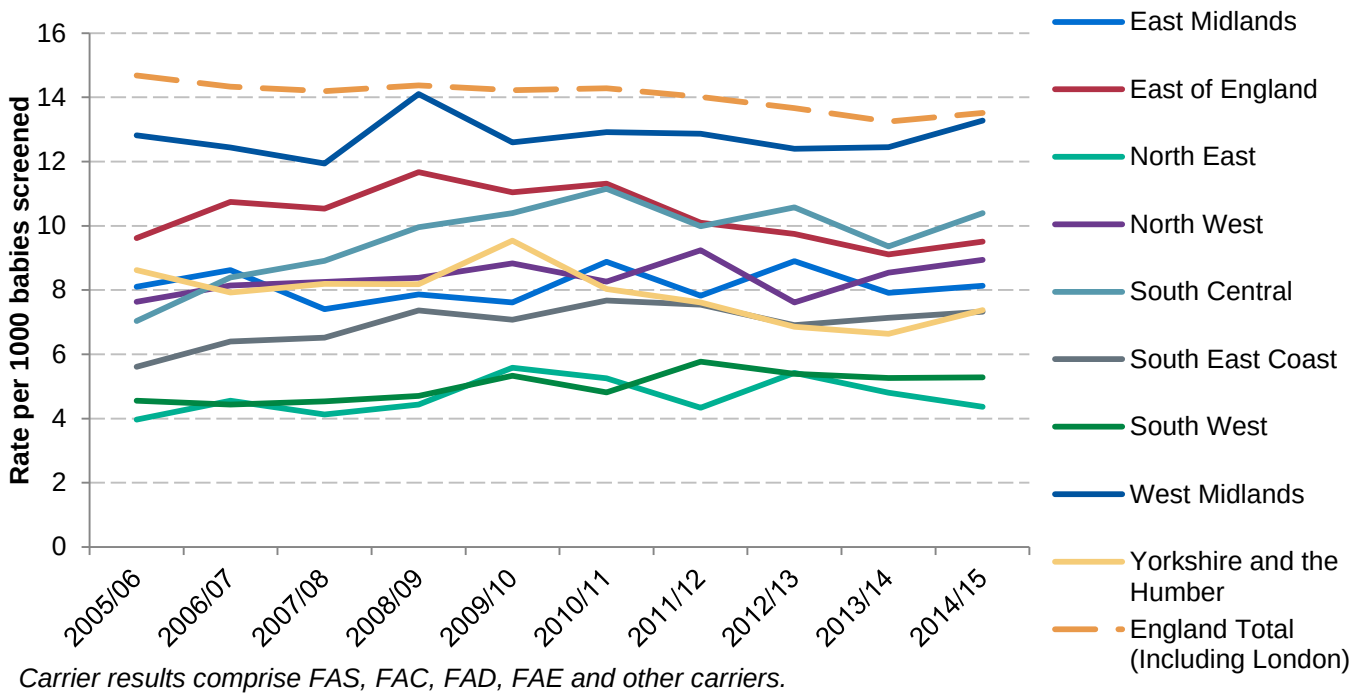


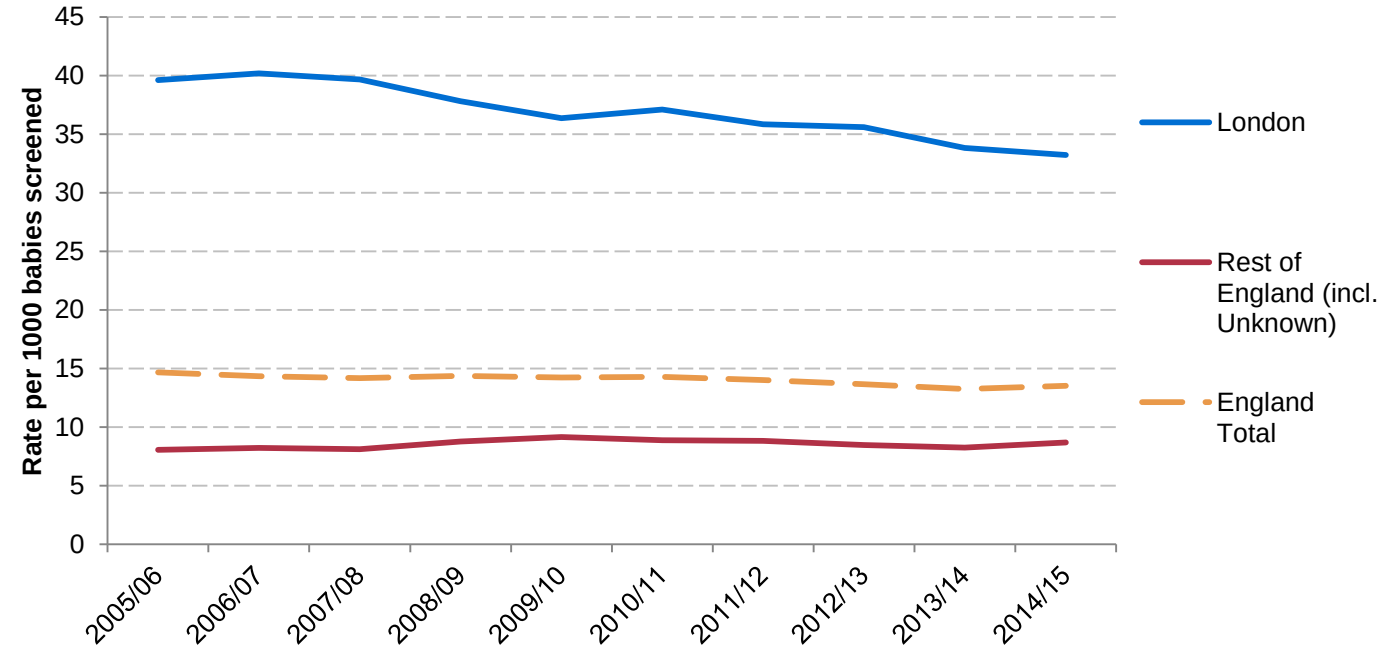
Figure NB-10. Trends in babies identified as carriers, 2005-15: England by region (excluding London)



Carrier results comprise FAS, FAC, FAD, FAE and other carriers.
**Bristol data for first half of 2005/06 not included and Oxford and Portsmouth data not included for whole of 2005/06; Oxford data starts from 1st July 2006.*

Figure NB-11 compares the rates for London to the rest of England (including babies with an unknown region). Carrier rates outside of London appear steady, ranging from approximately 8 to 9 per 1,000 babies screened, but there appears to be a decline in rates in London.

Figure NB-11. Trends in babies identified as carriers, 2015-15: London and the rest of England



Carrier results comprise FAS, FAC, FAD, FAE and other carriers.

4.3. Results by ethnicity

Newborn screening figures by ethnicity can differ slightly from the figures shown by region (see 4.1 Response rates and data quality). Numbers and rates for screen positive babies are shown in Table NB-7 and for carriers in Table NB-8 for a 3-year period. Babies who were reported as being black African in 2014/15 accounted for approximately 58% of babies identified with a significant condition, and for approximately 37% of carriers. The next largest group of babies identified was those reported as black Caribbean, for both significant conditions and carriers.

Table NB-7. Numbers of babies identified with significant conditions, 2012-15: England by ethnicity

Ethnic Category	2012/13				2013/14				2014/15			
	n	Total Screened	Rate/ 1000	1 in x	n	Total Screened	Rate/ 1000	1 in x	n	Total Screened	Rate/ 1000	1 in x
A - White British	5	434,514	0.01	86,903	5	413,538	0.01	82,708	*	*	*	*
B - White Irish	*	*	*	*	*	*	*	*	*	*	*	*
C - Any other White background	*	*	*	*	*	*	*	*	*	*	*	*
D - White and Black Caribbean	8	7,803	1.03	975	10	8,042	1.24	804	9	8,514	1.06	946
E - White and Black African	*	*	*	*	5	5,080	0.98	1,016	8	5,085	1.57	636
F - White and Asian	*	*	*	*	*	*	*	*	*	*	*	*
G - Any other mixed background	*	*	*	*	8	13,404	0.60	1,676	*	*	*	*
H - Indian	*	*	*	*	*	*	*	*	*	*	*	*
J - Pakistani	*	*	*	*	*	*	*	*	*	*	*	*
K - Bangladeshi	9	9,856	0.91	1,095	8	9,166	0.87	1,146	9	8,992	1.00	999
L - Any other Asian background	*	*	*	*	*	*	*	*	*	*	*	*
M - Black Caribbean	30	7,402	4.05	247	32	6,163	5.19	193	26	5,533	4.70	213
N - Black African	196	22,244	8.81	113	191	22,770	8.39	119	163	21,918	7.44	134
P - Any other Black background	17	4,838	3.51	285	25	3,233	7.73	129	23	3,282	7.01	143
R - Chinese	*	*	*	*	*	*	*	*	*	*	*	*
S - Any other ethnic category	10	18,615	0.54	1,862	5	14,234	0.35	2,847	*	*	*	*
Z - Not stated	24	43,490	0.55	1,812	19	42,863	0.44	2,256	18	38,342	0.47	2,130
England Total	311	686,893	0.45	2,209	319	669,437	0.48	2,099	279	663,134	0.42	2,377

**Numbers less than five have been suppressed*

Table NB-8. Number of babies identified with carrier results, 2012-15: England by ethnicity

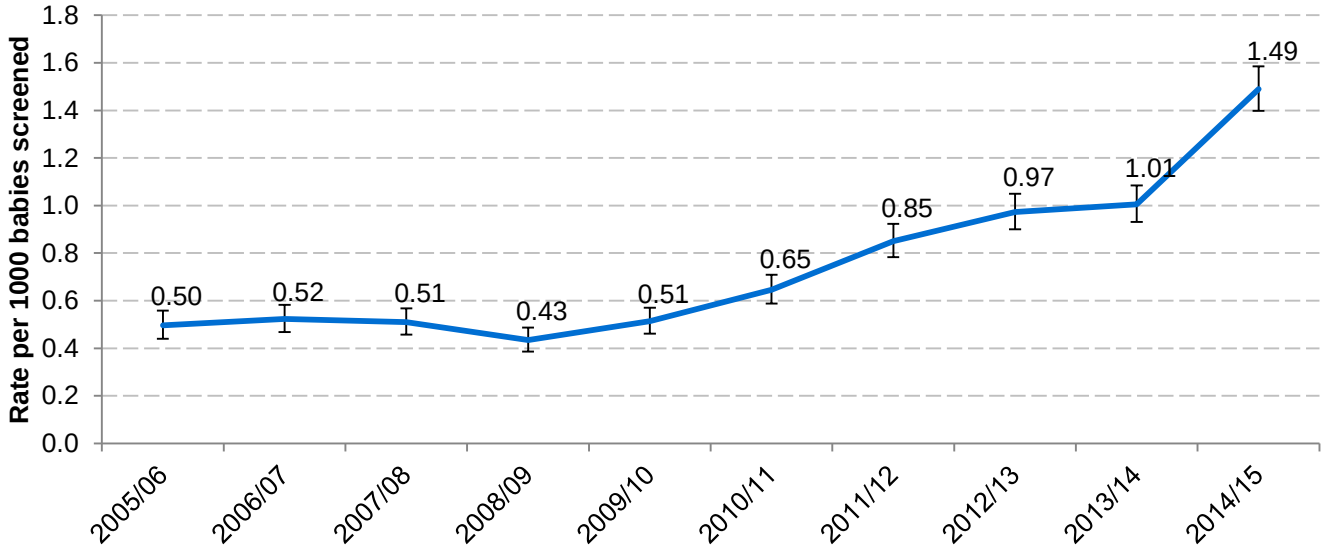
Ethnic Category	2012/13				2013/14				2014/15			
	n	Total screened	Rate/ 1000	1 in x	n	Total screened	Rate/ 1000	1 in x	n	Total screened	Rate/ 1000	1 in x
A - White British	762	434,514	1.75	570	609	413,538	1.47	679	607	403,379	1.50	665
B - White Irish	*	*	1.74	574	*	*	13.09	76	*	*	2.01	497
C - Any other White background	139	49,386	2.81	355	158	57,664	2.74	365	184	64,497	2.85	351
D - White and Black Caribbean	457	7,803	58.57	17	506	8,042	62.92	16	554	8,514	65.07	15
E - White and Black African	359	4,348	82.57	12	384	5,080	75.59	13	482	5,085	94.79	11
F - White and Asian	146	10,495	13.91	72	139	8,545	16.27	61	144	8,740	16.48	61
G - Any other mixed background	352	10,735	32.79	30	395	13,404	29.47	34	483	15,586	30.99	32
H - Indian	314	21,560	14.56	69	262	21,149	12.39	81	225	20,832	10.80	93
J - Pakistani	293	27,855	10.52	95	305	27,595	11.05	90	308	26,851	11.47	87
K - Bangladeshi	420	9,856	42.61	23	468	9,166	51.06	20	437	8,992	48.60	21
L - Any other Asian background	158	8,078	19.56	51	147	10,868	13.53	74	190	12,125	15.67	64
M - Black Caribbean	843	7,402	113.89	9	750	6,163	121.69	8	712	5,533	128.68	8
N - Black African	3,483	22,244	156.58	6	3,369	22,770	147.96	7	3,301	21,918	150.61	7
P - Any other Black background	412	4,838	85.16	12	391	3,233	120.94	8	388	3,282	118.22	8
R - Chinese	*	*	7.34	136	*	*	3.42	292	*	*	2.29	436
S - Any other ethnic category	495	18,615	26.59	38	245	14,234	17.21	58	234	13,980	16.74	60
Z - Not stated	746	43,490	17.15	58	693	42,863	16.17	62	684	38,342	17.84	56
England Total	9,411	686,893	13.70	73	8,857	669,437	13.23	76	8,945	663,134	13.49	74

**Numbers less than 30 have been suppressed*

4.4. Declined screening tests

In 2014/15 there were 985 declined screening tests, which equates to 1.5 per 1,000 babies screened. Figure NB-12 shows the rate per 1,000 babies screened since 2005 and shows an increase in the rate of declines over time.

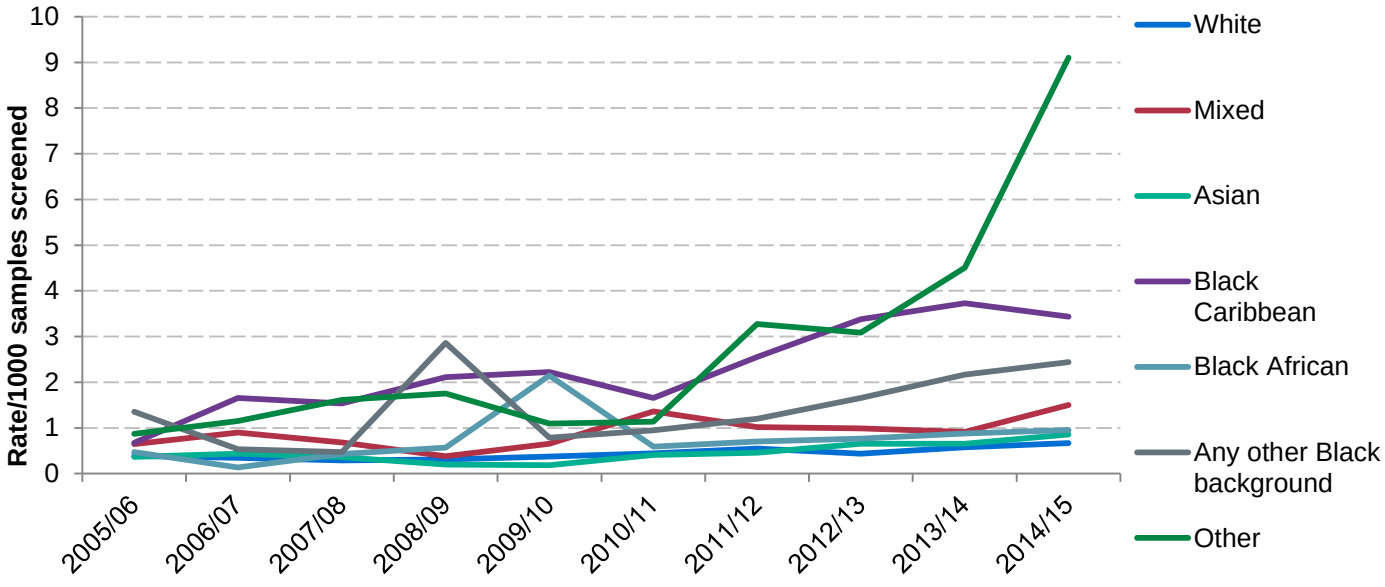
Figure NB-12. Declined screening for sickle cell disease, 2005-15: England



Bristol data for first half of 2005/06 not included and Oxford and Portsmouth data not included for whole of 2005/06; Oxford data starts from 1st July 2006.

Figure NB-13 breaks down the figures on declines by reported ethnic category. While there appears to be an increase across all ethnic categories, the largest increase is in the 'other' category which comprises Chinese, 'any other ethnic category' and 'not stated' ethnic categories.

Figure NB-13. Declined screening for sickle cell disease by ethnic category, 2005-15: England



4.5. Post-transfusion testing

Routine techniques are not suitable for testing samples from transfused babies as transfused red cells can survive up to 120 days in circulation. It is therefore important that pre-transfusion samples are taken in accordance with newborn blood spot sampling guidelines. The programme introduced a pre-transfusion sample policy in 2008 which requires that blood spots should be taken for SCD screening prior to blood transfusion[5].

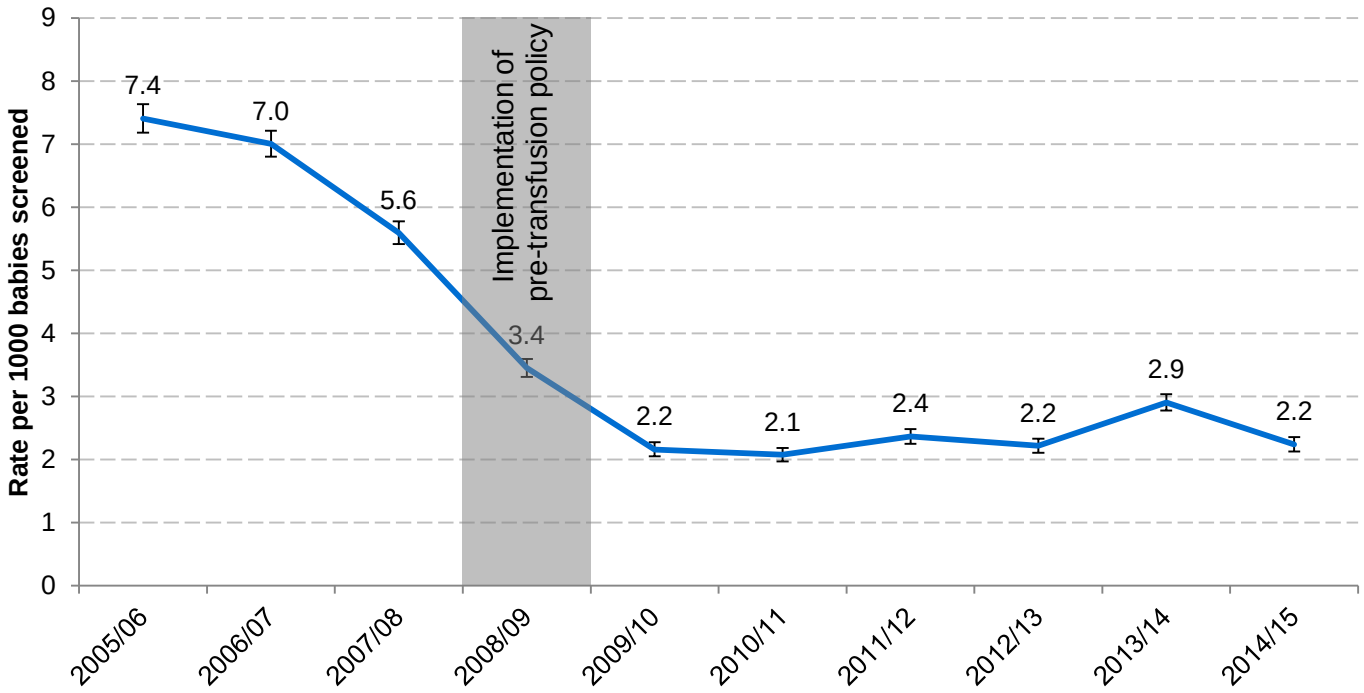
Table NB-9 shows the number and rates of post-transfusion samples between 2012 and 2015. In 2014/15 there were 1,480 post-transfusion samples reported by the laboratories, which equates to 2.24 per 1,000 babies screened. Since the programme implemented its pre-transfusion policy, rates have dropped to approximately 2.2 per 1,000 babies screened, shown in Figure NB-14. The increase in 2013/14 appears to be due to one region, shown in Figure NB-15, but it should also be noted that numbers for post-transfusion samples for 2013/14 exclude data from the Great Ormond Street Hospital (GOSH) laboratory as figures on post-transfusion samples were not included on their data return.

Table NB-9. Post-transfusion samples, number and rate per 1,000 babies screened, 2012-15: England by region

Region	2012/13			2013/14			2014/15		
	n	Total Screened	Rate/ 1000	n	Total Screened	Rate/ 1000	n	Total Screened	Rate/ 1000
East Midlands	89	49,898	1.78	94	48,382	1.94	88	48,552	1.81
East of England	96	72,421	1.33	22	69,082	0.32	55	69,407	0.79
London	368	131,424	2.80	522	130,373	4.00	432	130,203	3.32
North East	44	28,966	1.52	36	27,896	1.29	40	26,378	1.52
North West	137	87,369	1.57	137	84,384	1.62	133	85,207	1.56
South Central	42	53,352	0.79	33	51,413	0.64	42	51,181	0.82
South East Coast	199	51,682	3.85	619	51,710	11.97	256	51,616	4.96
South West	34	59,938	0.57	30	57,940	0.52	35	57,798	0.61
West Midlands	182	72,559	2.51	115	70,773	1.62	104	69,740	1.49
Yorkshire and the Humber	133	69,613	1.91	96	67,820	1.42	149	65,328	2.28
Unknown region	195	8,216	23.73	236	8,344	28.28	146	6,022	24.24
England total	1,519	685,438	2.22	1,940	668,117	2.90	1,480	661,432	2.24

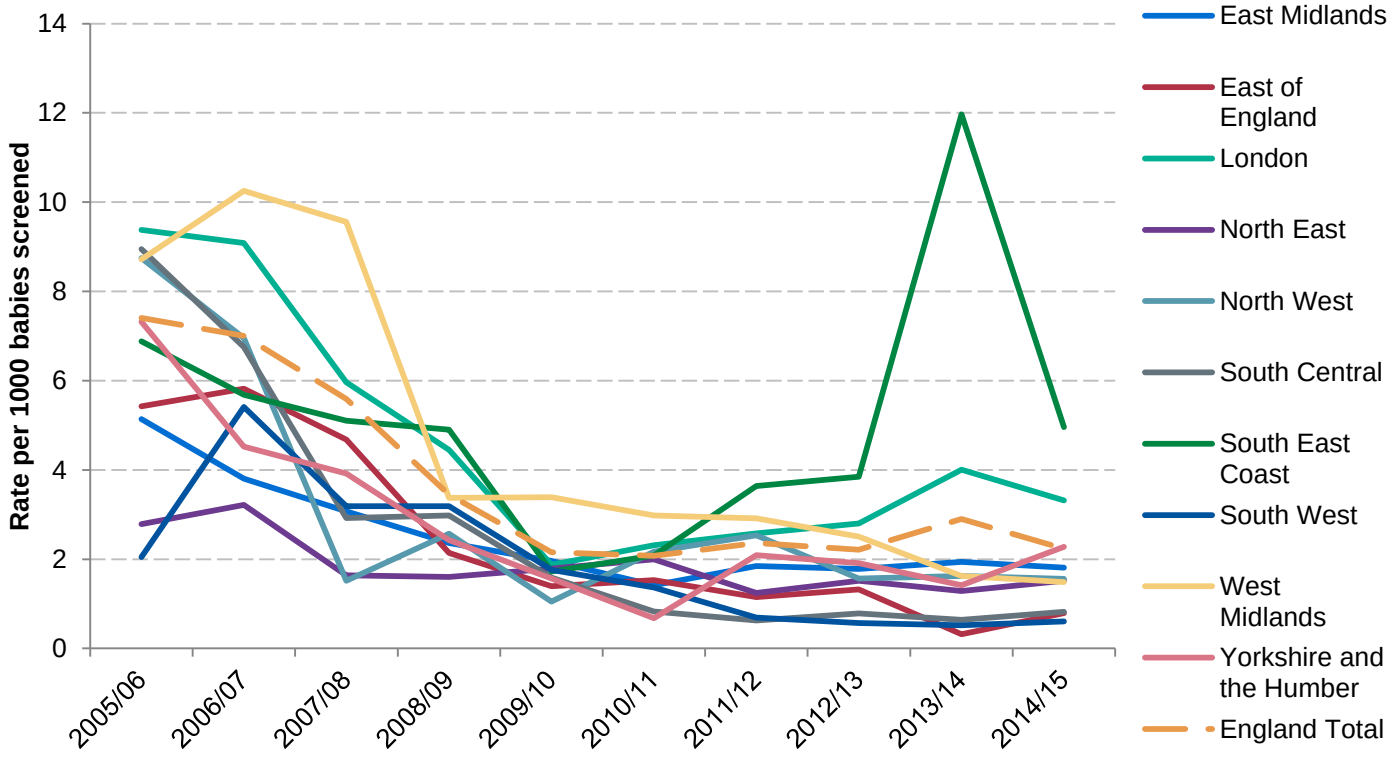
**Transfusion data for GOSH for 2013/14 not separated out from the 'normal+abnormal' figure and so not included here.*

Figure NB-14. Post-transfusion samples, rate per 1,000 babies screened, 2005-15: England



Bristol data for first half of 2005/06 not included and Oxford and Portsmouth data not included for whole of 2005/06; Oxford data starts from 1st July 2006;
Transfused data from Manchester laboratory for 2009/10 not available; Transfusion data for GOSH for 2013/14 not separated out from the 'normal+abnormal' figure and so not included here.

Figure NB-15. Post-transfusion samples, rate per 1,000 babies screened, 2005-15: England by region



Where it is not possible to take a pre-transfusion sample, DNA testing is required to mitigate the risk of a missed baby[5]. DNA testing is provided by laboratories at King's College Hospital and Sheffield Children's Hospital, and the figures from these laboratories are shown in Table NB-10. Numbers of specimens received by the DNA laboratories appear to be lower than the number of post-transfusion samples reported by the newborn screening laboratories, with 1,123 specimens received by the DNA laboratories in 2014/15 compared to 1,480 post-transfusion samples reported by the newborn laboratories. In the 6-year period since DNA testing for transfused babies started there have been 6 positive homozygous cases identified through DNA testing.

Table NB-10. Numbers detected through DNA testing for transfused babies, 2009-15: England

	2009/10†	2010/11	2011/12	2012/13	2013/14	2014/15	Total
Total Specimens received	493	1,674	1,520	1,343	1,160	1,123	7,313
Number of Negative results (HbS not detected)	483	1,650	1,497	1,319	1,140	1,106	7,195
Number of Positive Heterozygotes	10	24	21	21	20	16	112
Number of Positive Homozygotes	*	*	*	*	*	*	6
Number of Results pending	*	*	*	*	*	*	*
Number rejected due to lack of identifiers	*	*	*	*	*	*	*

†*2009/10 data is for Q3 and Q4 only*
**Numbers less than five have been suppressed*

4.6. Laboratory processes and entry into care

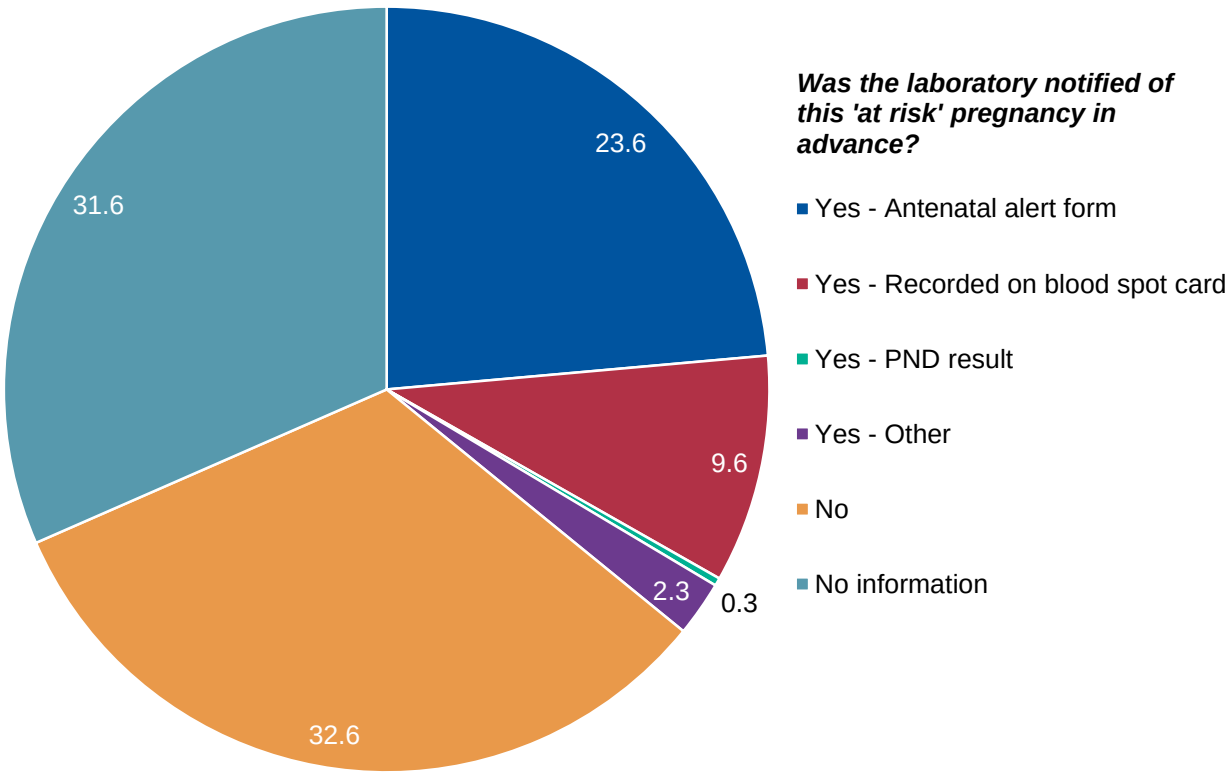
The SCT screening programme expanded the data fields requested from the newborn laboratories for 2014/15 to collect data on laboratory processes and timeliness of entry into care. These additional fields are consistent with those collected for other conditions screened for in newborn blood spot screening.

Data was provided for all screen positive babies, although 2 cases were reported as 'FS' in the regional data and as 'FS other' in the breakdown data. One additional case from a private hospital was excluded from the regional data but it was not possible to exclude it from the breakdown data, so there are 301 cases included (including F-only cases) compared to 300 in the regional data. While all screen positive babies were accounted for, completeness of data for each varied between laboratories.

Links between antenatal and newborn screening

Laboratories were asked to identify whether they were informed of each 'at-risk' pregnancy in advance of receiving the blood spot card. For approximately a third of screen positive cases the laboratory was notified in advance, for a third the laboratory was not notified in advance, and a third had no information given. Figure NB-16 shows the proportion of screen positive babies where the laboratory was notified in advance of newborn screening, and for those where there was a notification, the method of notification.

Figure NB-16. Proportion of screen positive babies where the laboratory was notified in advance of newborn screening, 2014/15



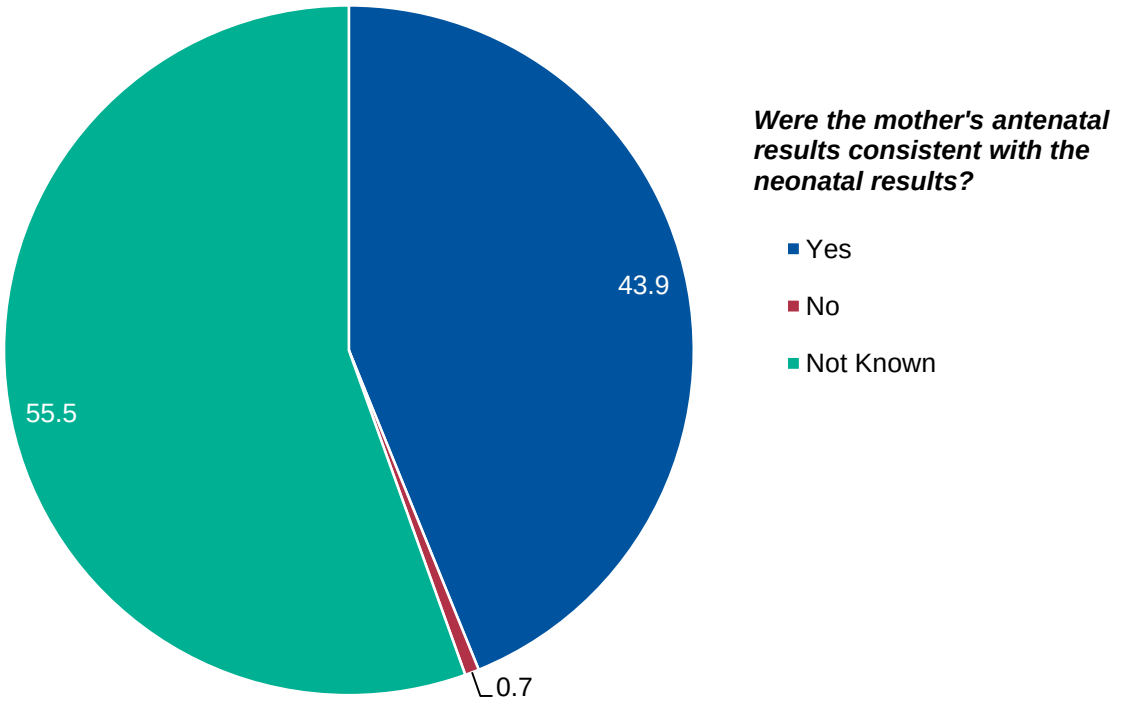
In addition to notifications of 'at-risk' pregnancies, the programme also requested data on whether antenatal screening results were available at the time of testing the newborn sample. Table NB-11 shows the number and proportion of screen positive babies where the mother's and father's antenatal screening results were recorded on the blood spot card to aid the interpretation of results. Approximately 21% of screen positive babies had their mother's results recorded, and approximately 16% had their father's results recorded on the blood spot card. The lower proportion of fathers' results recorded compared to mothers' results may link to cases where the father was not available for antenatal screening. Approximately 20% of screen positive babies had no information given regarding whether antenatal results were recorded on the blood spot card.

Table NB-11. Screen positive results where antenatal results were available at the time of testing, 2014/15

Were the antenatal results recorded on blood spot card?	Yes		No		Not Known		Total
	n	%	n	%	n	%	
Mother's antenatal results recorded	63	20.9	181	60.1	57	18.9	301
Father's antenatal results recorded	48	15.9	194	64.5	59	19.6	301

To examine the effectiveness of the antenatal screening test, the programme asked whether the mother's results were consistent with the neonatal results for screen positive babies. Figure NB-17 shows that less than 1% of screen positive neonatal results were not consistent with the antenatal results, and that for approximately 56% no information was given.

Figure NB-17. Consistency of antenatal and neonatal screening results (%), 2014/15



Timeliness of clinical referral

Newborn Blood Spot (NBS) Screening Programme standard 4 (timely sample collection) is for the sample to be taken on day 5 and in exceptional circumstances between day 5 and day 8 (day of birth is day zero). This standard has a 95% acceptable threshold and 99% achievable threshold. Standard 5 (timely receipt of a sample in the newborn screening laboratory) sets an acceptable threshold for 99% of samples to arrive in the laboratory within 4 working days of sample collection and an achievable threshold for 99% of samples to arrive in the laboratory within 3 working days.

Sickle Cell and Thalassaemia (SCT) Screening Programme standard NP3 (timely communication of positive screening results) requires 90% of sickle cell disease results to be communicated to parents by 4 weeks of age.

Table NB-12 shows the timeliness figures for newborn babies identified with a significant condition or with F-only results which are probable beta thalassaemia affected cases. Clinical referral is the process in which newborn laboratories refer screen positive infants directly to the clinician for confirmatory testing, diagnosis, and treatment/intervention. Figure NB-21 includes age at clinical referral alongside age at first visit to a paediatrician for screen positive babies. The lowest age at clinical referral reported was 2 days and the highest age reported was 360 days, with a median of 16 days of age at clinical referral. This suggests that standard NP3 is both realistic and achievable.

Table NB-12. Timeliness of reporting affected newborn results, 2014/15: England by laboratory

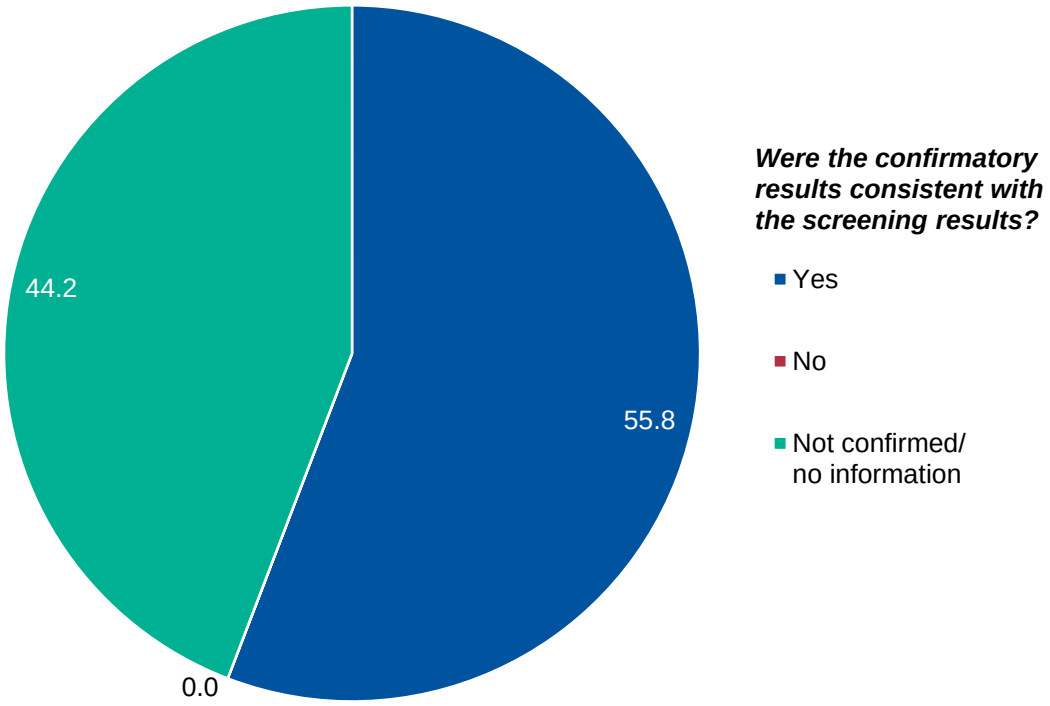
Laboratory	No. of screen positives	Sample ≤8 days		Sample received by lab within 4 days		Clinical referral by 28 days		Time between sample taking and clinical referral (days)†		
	n	n	%	n	%	n	%	Min	Max	Median
Bristol	*	*	*	*	*	*	*	5	5	5
Cambridge	*	*	*	*	*	*	*	16	22	19
GOS & CMH	94	92	97.9	75	79.8	93	98.9	6	31	10
Leeds	14	13	92.9	13	92.9	13	92.9	3	21	9
Liverpool	*	*	*	*	*	*	*	4	11	5.5
Manchester	22	20	90.9	21	95.5	20	90.9	7	27	10
Newcastle	5	5	100.0	5	100.0	5	100.0	1	4	3
Oxford	13	13	100.0	11	84.6	10	76.9	9	27	13.5
Portsmouth	7	7	100.0	6	85.7	7	100.0	10	15	13
Sheffield	19	19	100.0	17	89.5	19	100.0	10	21	15
South East Thames	64	61	95.3	53	82.8	60	93.8	3	72	9
South West Thames	33	32	97.0	27	81.8	32	97.0	8	20	13
West Midlands	22	22	100.0	20	90.9	21	95.5	6	24	13
England Total	301	292	97.0	255	84.7	288	95.7	1	72	10

This includes F-only cases, which are likely beta thalassaemia affected babies
†Excludes 2 cases where the age at clinical referral given was smaller than the age at sample.
**Numbers less than five have been suppressed*

Consistency of results

As a measure of the effectiveness of newborn screening, the programme asked whether the confirmatory results were consistent with the screening results. This involves taking a second sample from the baby and comparing these results with the screening result. Figure NB-18 shows that approximately 56% of screen positive babies had consistent confirmatory results, none had inconsistent results, and approximately 44% of the samples were reported as either not confirmed or no information was provided.

Figure NB-18. Consistency of newborn and confirmatory results (%), 2014/15

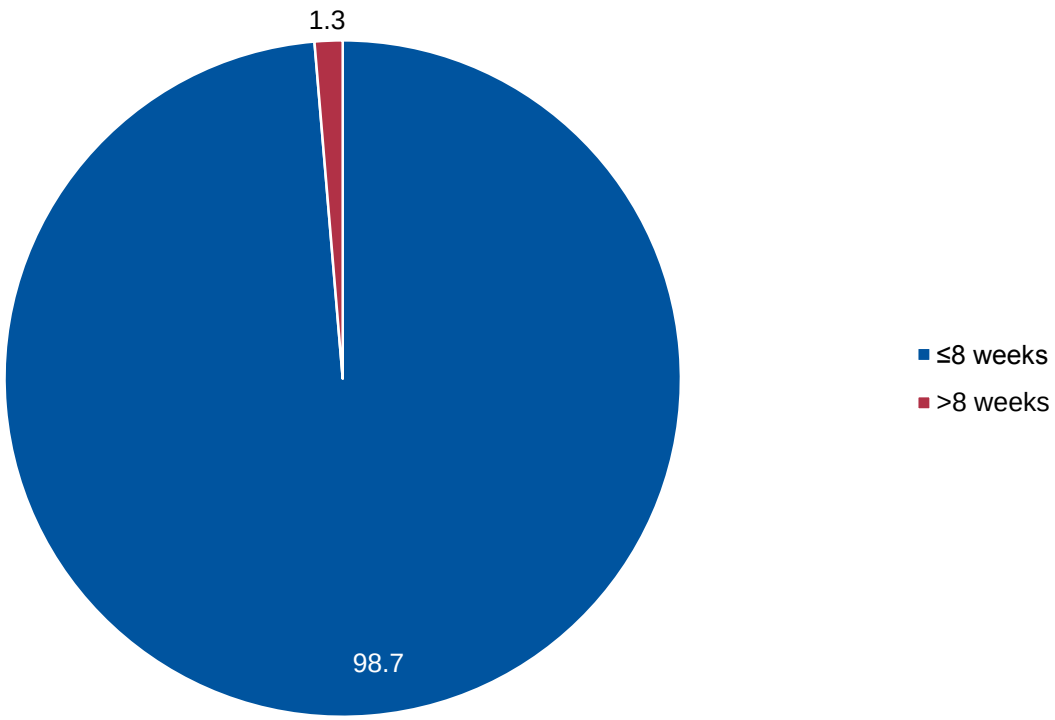


Age at first visit to specialist health team or local health team

SCT programme standard NP4 is for babies identified with positive screening results to be referred by 8 weeks to a designated healthcare professional and to attend a local clinic by 3 months of age. The thresholds for both of these timeframes is set at 90% for the acceptable level and 95% for the achievable level.

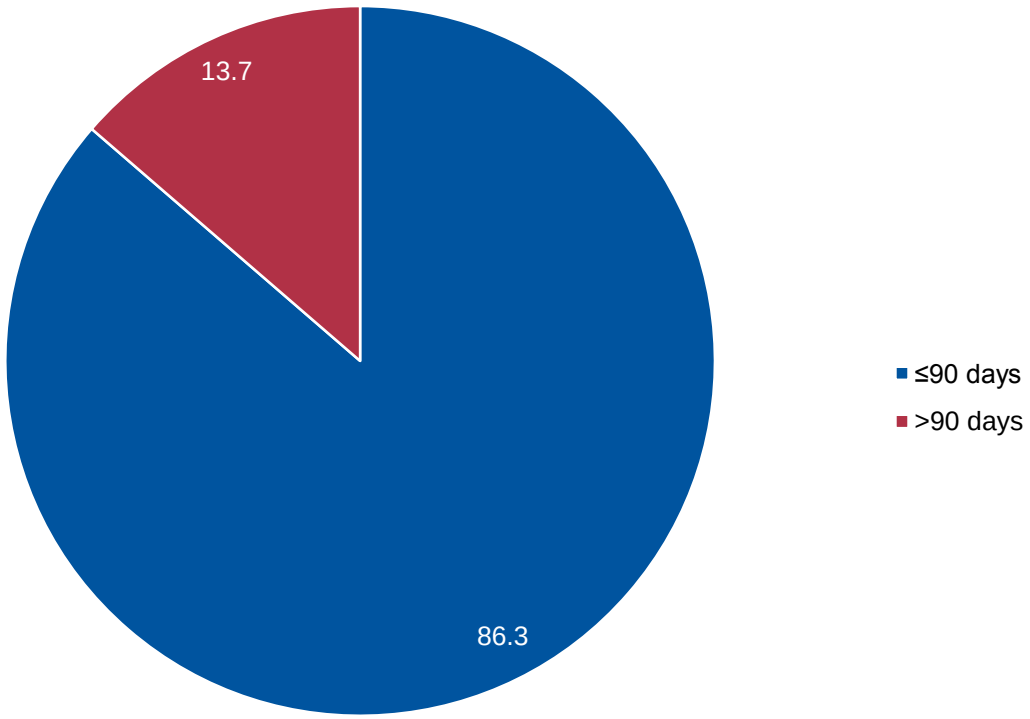
Figure NB-19 shows the age of screen positive babies in 2014/15 at the time of initial clinical referral excluding babies for whom no information was submitted, and shows that approximately 99% of screen positive babies received their initial clinical referral by 8 weeks of age. This shows that the achievable threshold for age at first visit is being met. Figure NB-20 shows the age of screen positive babies at their first visit to paediatrician at a specialist health team (SHT) or a local health team (LHT) excluding the 96 babies for whom no information was submitted, and shows that approximately 86% of screen positive babies are seen by a paediatrician by 3 months of age (using 90 days to represent 3 months).

Figure NB-19. Age of screen positive babies at time of initial referral to specialist services (%), 2014/15



Excludes one baby for whom no information was submitted.

Figure NB-20. Age of screen positive babies at first visit to paediatrician at SHT or LHT (%), 2014/15

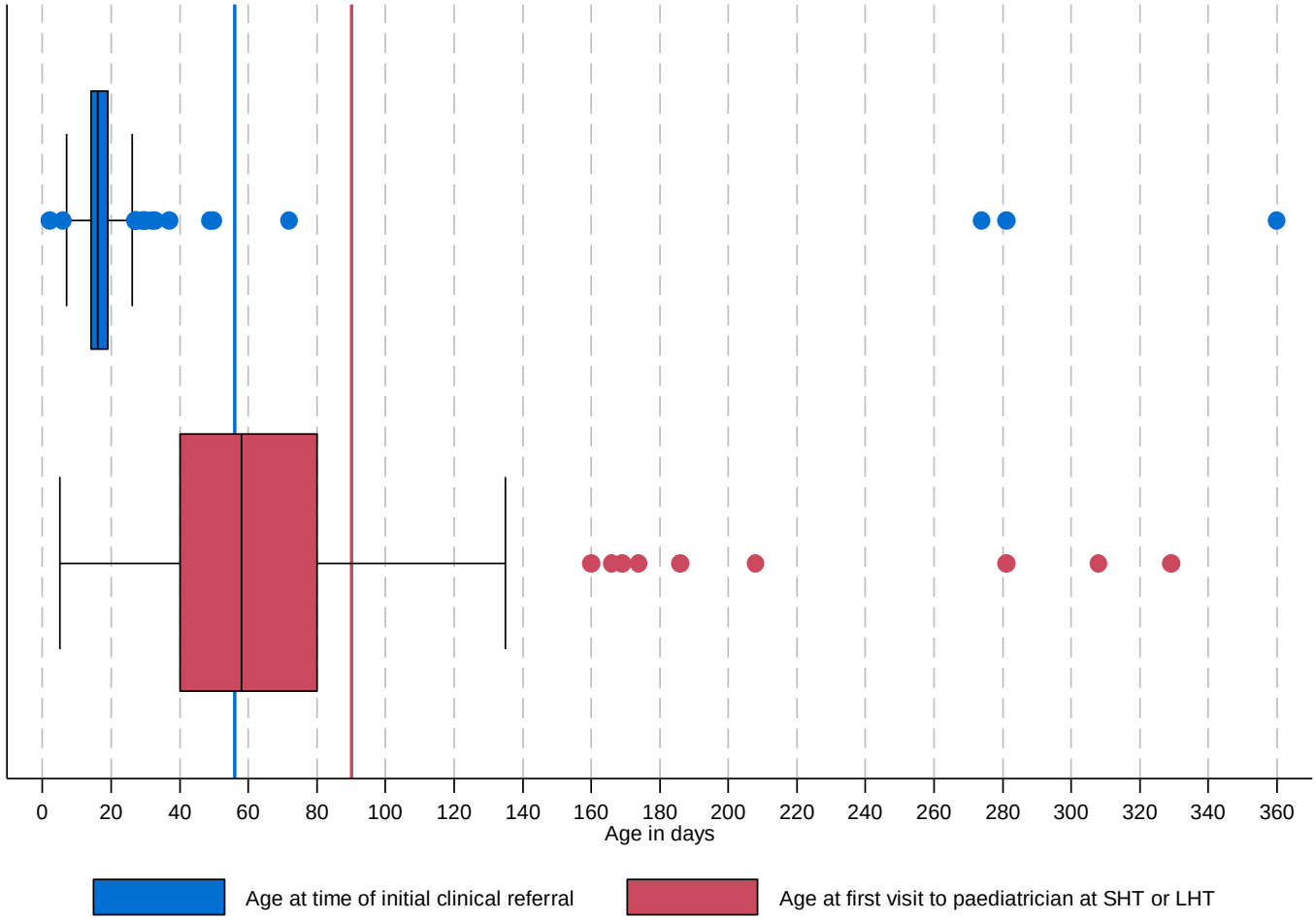


Excludes 96 babies for whom no information was submitted.

Figure NB-21 shows the variation in the age at time of initial clinical referral and at first visit to a paediatrician at a specialist health team or local health team. The blue reference line represents the 8 week standard for initial clinical referral and the red reference line represents the 3 month standard for first visit to a paediatrician (using 90 days to represent 3 months). Excluding the outliers all babies are receiving clinical referral by 8 weeks of age, with a median of 16 days.

The whole of the interquartile range (representing half of the values) is below the 90 day threshold for the standard for first visit to a paediatrician by 3 months of age, but there are babies in the upper quartile of age who are older than 90 days at first visit to a paediatrician. The median age at first visit is 58 days.

Figure NB-21. Variation in age at time of initial clinical referral and at first visit to paediatrician at SHT or LHT, 2014/15



5. Key performance indicators (KPIs)

5.1. Background to the KPIs

The Sickle Cell and Thalassaemia Screening Programme has 3 antenatal KPIs and shares one newborn KPI with the Newborn Blood Spot Screening Programme. Newborn KPIs NB1 and NB2 are also relevant to SCT screening.

For more information on KPI data collection and reporting, please see https://www.gov.uk/government/collections/nhs-screening-programmes-national-data-reporting.

KPI Code	KPI Description	Acceptable level	Achievable level
ST1	The proportion of pregnant women eligible for antenatal sickle cell and thalassaemia screening for whom a conclusive screening result is available at the day of report (the day on which data to support an audit or performance return are collated)	≥95.0%	≥99.0%
ST2	The proportion of women having antenatal sickle cell and thalassaemia screening for whom a conclusive screening result is available by 10 weeks' gestation	≥50.0%	≥75.0%
ST3	The proportion of antenatal sickle cell and thalassaemia samples submitted to the laboratory which are supported by a completed Family Origin Questionnaire (FOQ)	≥90.0%	≥95.0%
NB1	The proportion of babies registered within the CCG both at birth and on the last day of the reporting period who are eligible for newborn blood spot screening and have a conclusive result recorded on the Child Health Information System within an effective timeframe. For this KPI, PKU is used as a proxy for all tests and the test must be completed by 17 days of age.	≥95.0%	≥99.9%
NB2	The percentage of babies from whom it is necessary to take a repeat blood sample due to an avoidable failure in the sampling process.	≤2.0%	≤0.5%
NB3	The proportion of newborn blood spot screening results which are screen negative for all five conditions, available for communication to parents within 6 weeks of birth	95.0%	98.0%

5.2. Annual KPI data

Overview

Performance for each of the KPIs is broken down by quarter in Table KPI-1. The annual figures are then broken down by region for each KPI in the following sections.

Table KPI-1. Quarterly KPI performance, 2014/15: England

KPI	Q1			Q2			Q3			Q4			Total for year*		
	Num	Denom	%	Num	Denom	%	Num	Denom	%	Num	Denom	%	Num	Denom	%
ST1	146,925	149,003	98.6	154,372	156,668	98.5	162,788	165,248	98.5	167,728	169,466	99.0	578,425	585,120	98.9
ST2	83,754	177,151	47.3	86,090	166,801	51.6	87,662	171,785	51.0	89,855	180,808	49.7	334,423	652,702	51.2
ST3	165,347	174,426	94.8	167,308	175,372	95.4	168,827	177,736	95.0	178,765	184,584	96.8	655,220	684,315	95.7
NB1	137,709	144,450	95.3	140,530	145,745	96.4	146,800	153,857	95.4	129,019	134,477	95.9	467,392	487,742	95.8
NB2	3,896	151,844	2.6	4,176	162,078	2.6	4,599	162,837	2.8	4,412	150,519	2.9	16,869	616,023	2.7
NB3	140,943	141,894	99.3	142,474	143,395	99.4	150,466	151,077	99.6	131,367	131,764	99.7	477,416	479,641	99.5

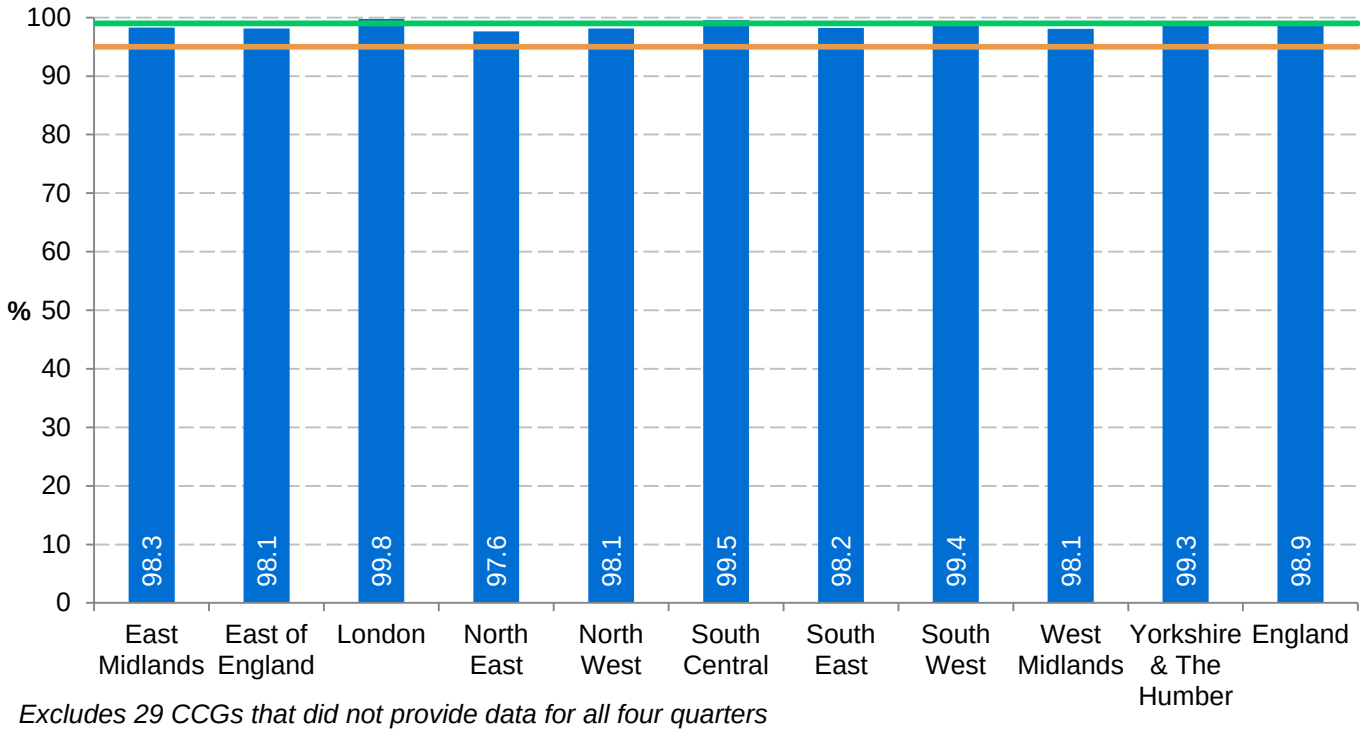
**The total excludes Trusts/CCGs that did not submit data for all four quarters*

Figure KPI-1 and Figure KPI-2 show that for KPI ST1 all regions are reaching the acceptable level for KPI ST1, and that 4 regions are reaching the achievable level and indicates that in regions where the median performance is higher there is also less variation between trusts. Figure KPI-3 and Figure KPI-4 indicate that early testing (KPI ST2) is lowest in London and in the West Midlands, which are also the 2 regions with the highest proportion of screen positive women and carrier babies (see *3.2 Numbers screened and detected in antenatal screening* and *4.2 Numbers screened and results*). Figure KPI-5 and Figure KPI-6 show completion of the FOQ (KPI ST3) to be high with all regions at or exceeding the achievable level. London has the most variation in performance, but the majority appear to be above the acceptable level for this standard.

Figure KPI-7shows that 4 of the 10 regions are not reaching the acceptable level for KPI NB1, and that no region as a whole is reaching the achievable level. As with KPI ST1, Figure KPI-8 indicates that there is less variation in regions which are achieving higher median levels of coverage with the exception of the North West. Figure KPI-9 and Figure KPI-10 show that all regions with the exception of the North West are above the 2.0% acceptable level for KPI NB2, and that no region is below the 0.5% achievable level. Figure KPI-11 and Figure KPI-12 show the interquartile range (IQR) for all regions to be above the 98% achievable level for KPI NB3 and the IQR of all regions except London is above 99%.

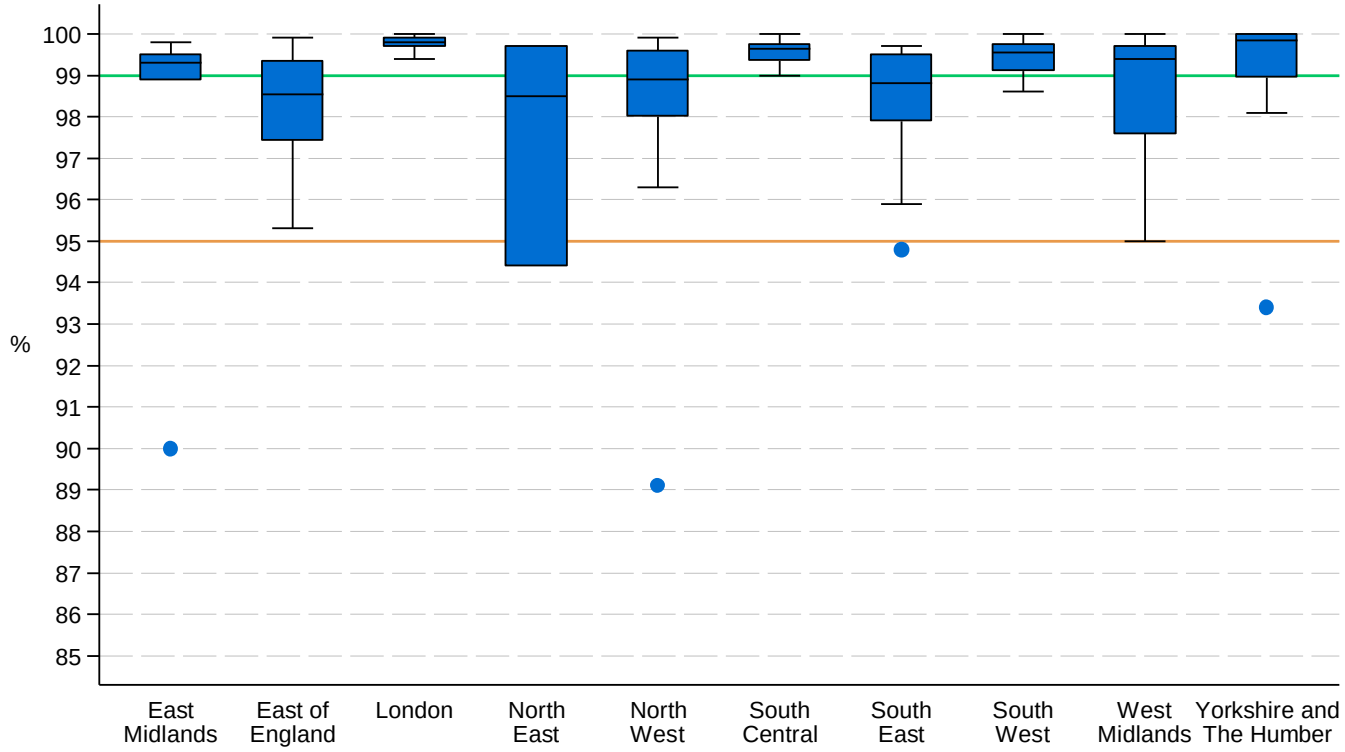
ST1: Coverage (antenatal)

Figure KPI-1. Antenatal coverage (KPI ST1), 2014/15: England by region



Excludes 29 CCGs that did not provide data for all four quarters

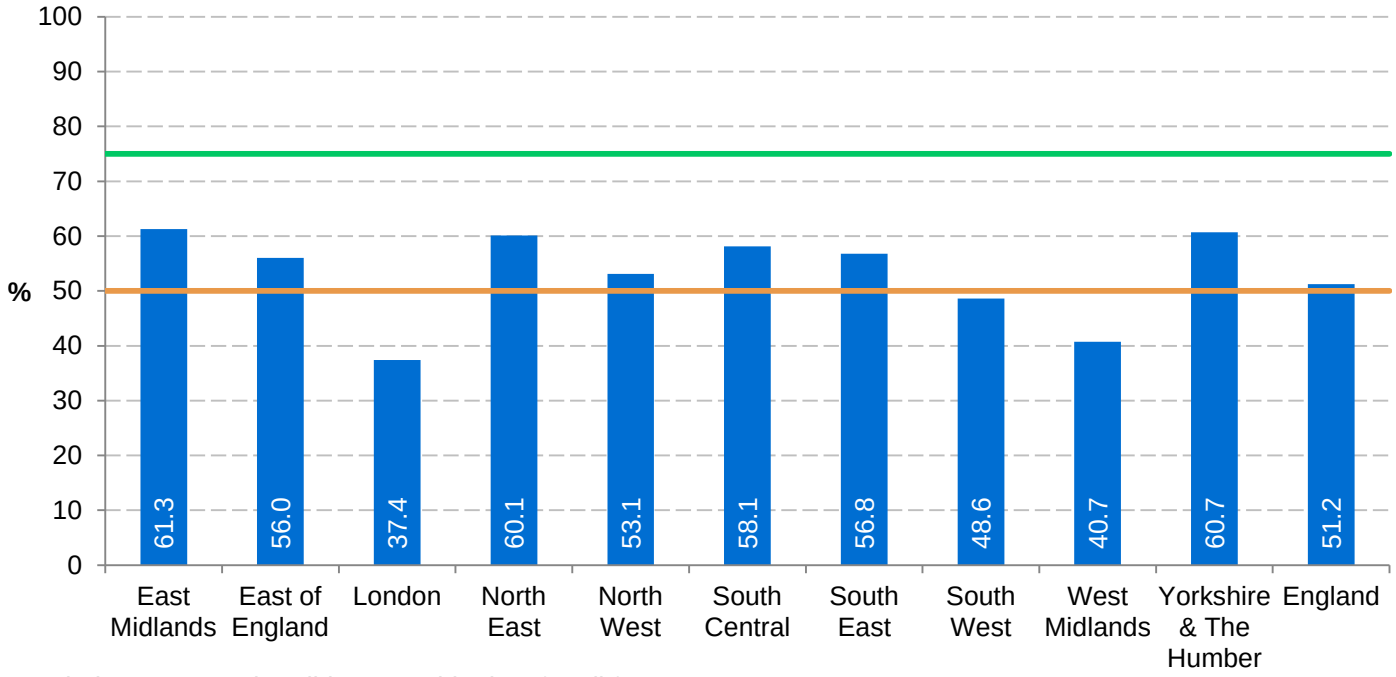
Figure KPI-2. Variation in antenatal coverage (KPI ST1), 2014/15: England by region



Excludes 29 trusts that did not provide data for all four quarters

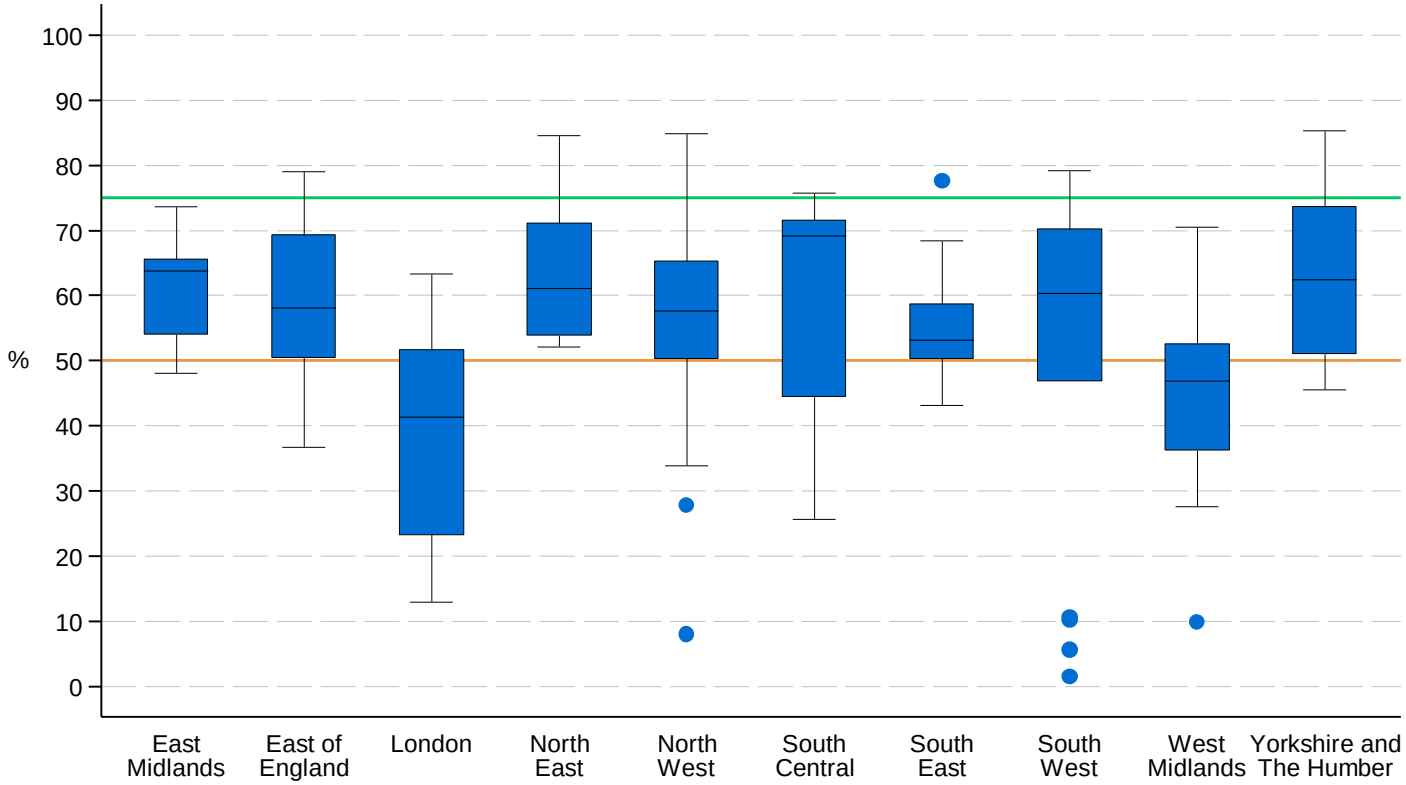
ST2: Timeliness of antenatal screening

Figure KPI-3. Timeliness of antenatal screening (KPI ST2), 2014/15: England by region



Excludes 16 trusts that did not provide data for all four quarters.

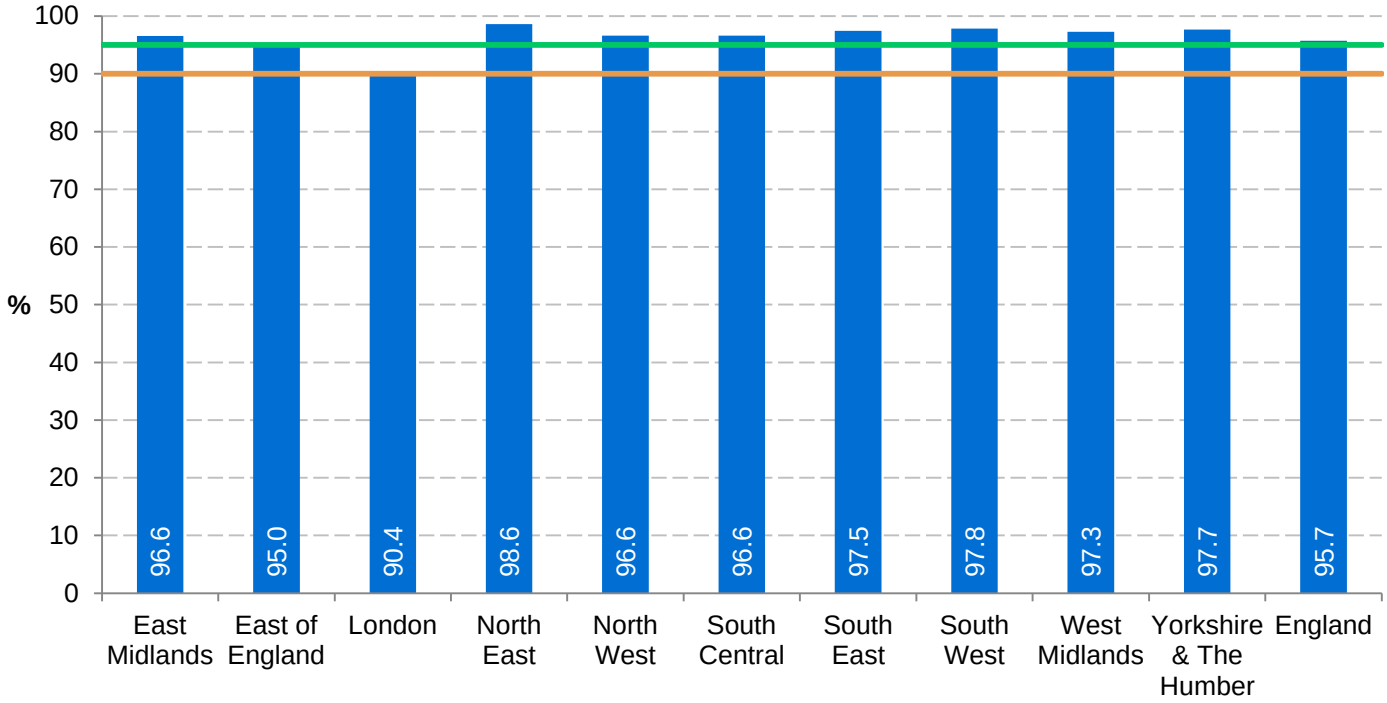
Figure KPI-4. Variation in timeliness of antenatal screening (KPI ST2), 2014/15: England by region



Excludes 16 trusts that did not provide data for all four quarters

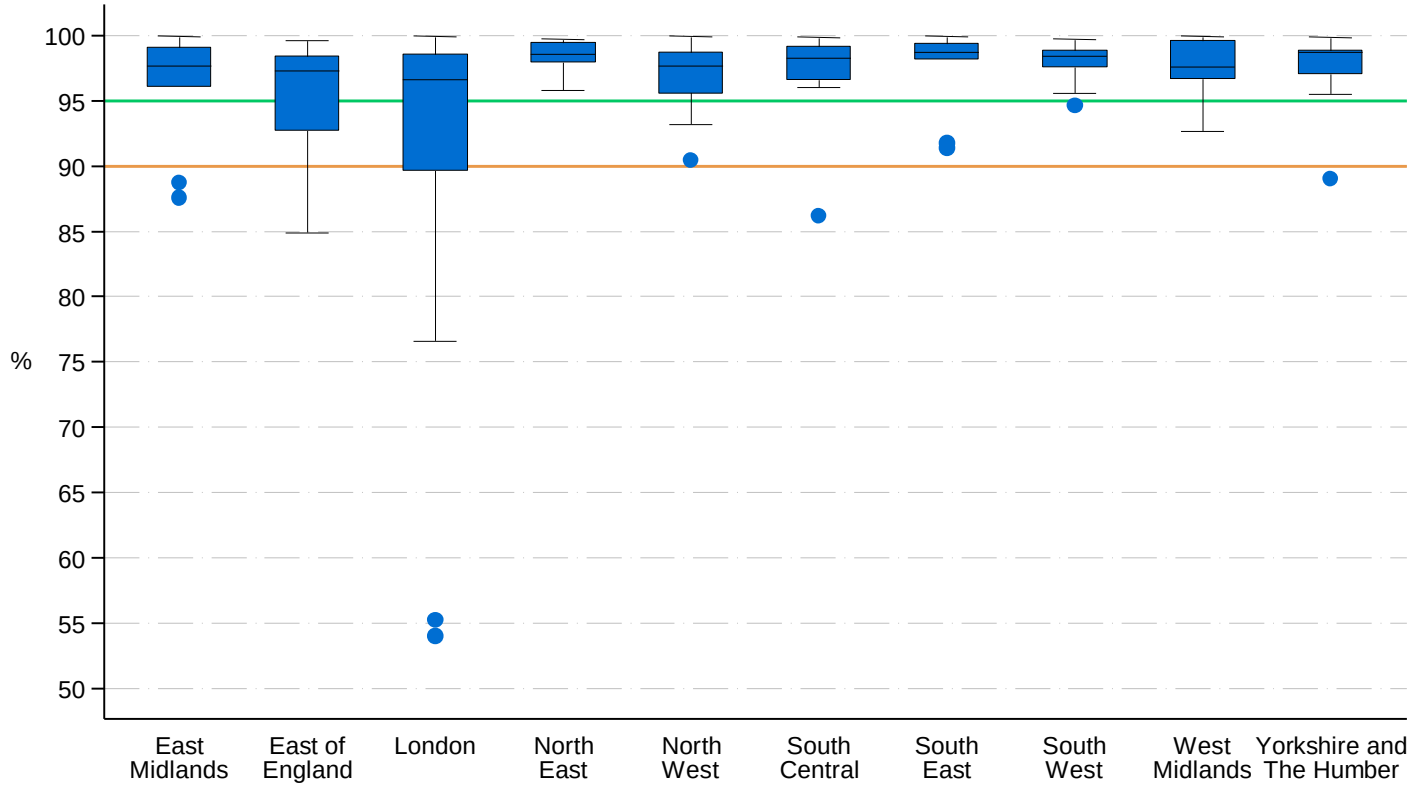
ST3: Completion of the FOQ

Figure KPI-5. Completion of the FOQ (KPI ST3), 2014/15: England by region



Excludes 11 trusts that did not provide data for all four quarters.

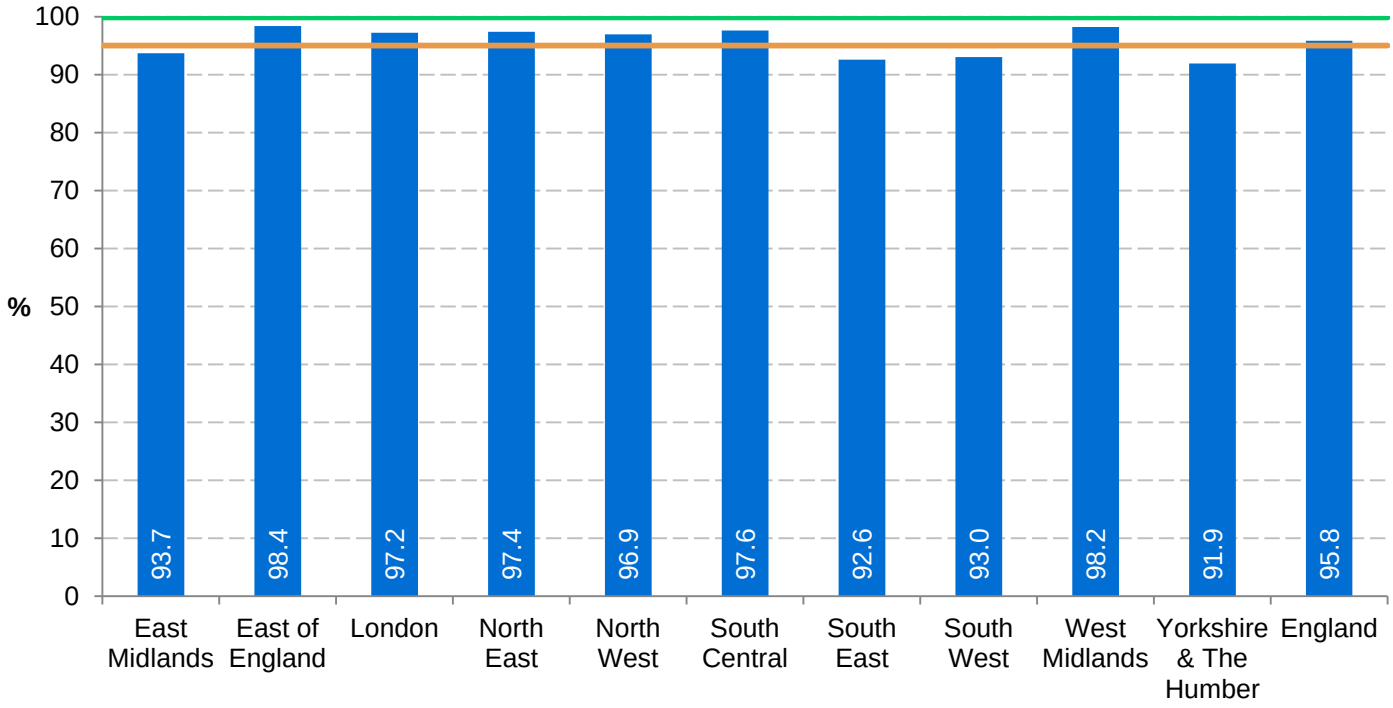
Figure KPI-6. Variation in completion of the FOQ (KPI ST3), 2014/15: England by region



Excludes 11 trusts that did not provide data for all four quarters

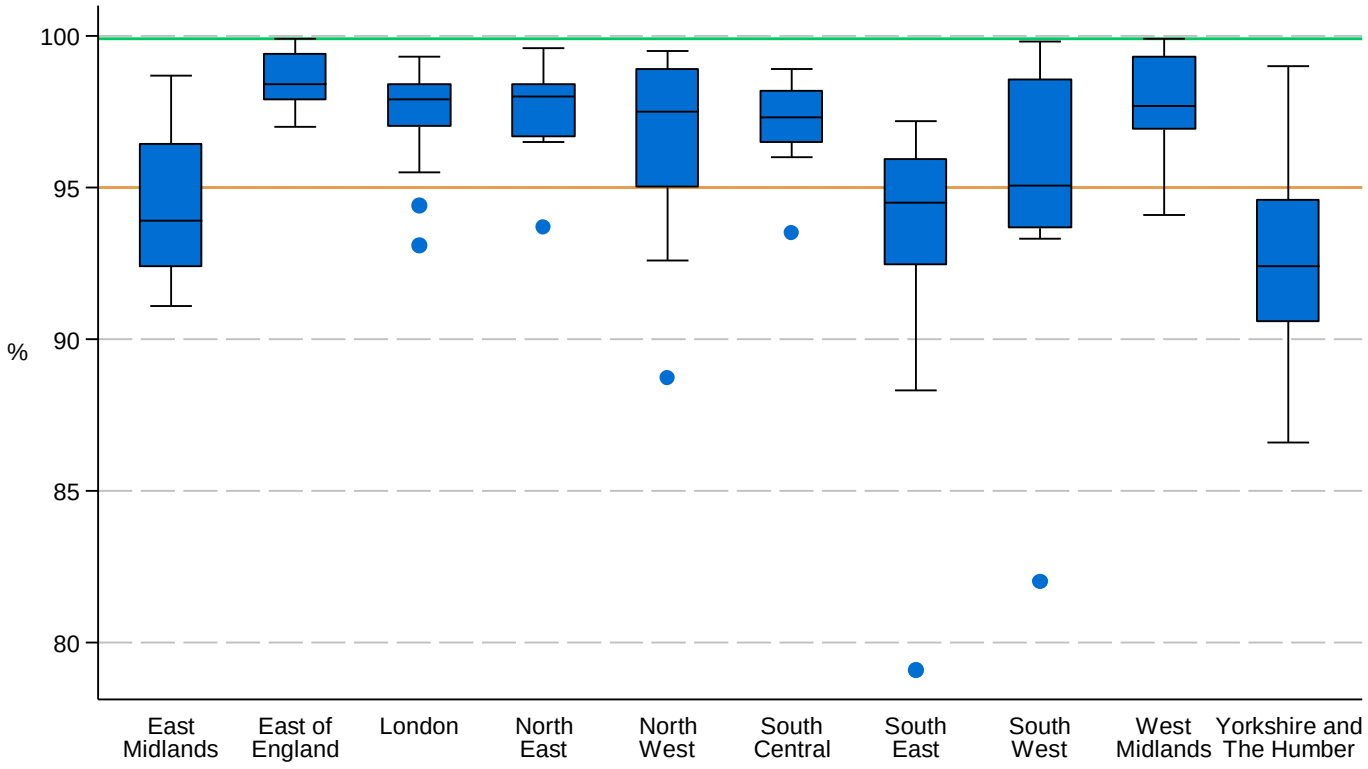
NB1: Coverage for the born and resident population (newborn)

Figure KPI-7. Newborn coverage (KPI NB1), 2014/15: England by region



Excludes 47 CCGs that did not provide data for all four quarters.

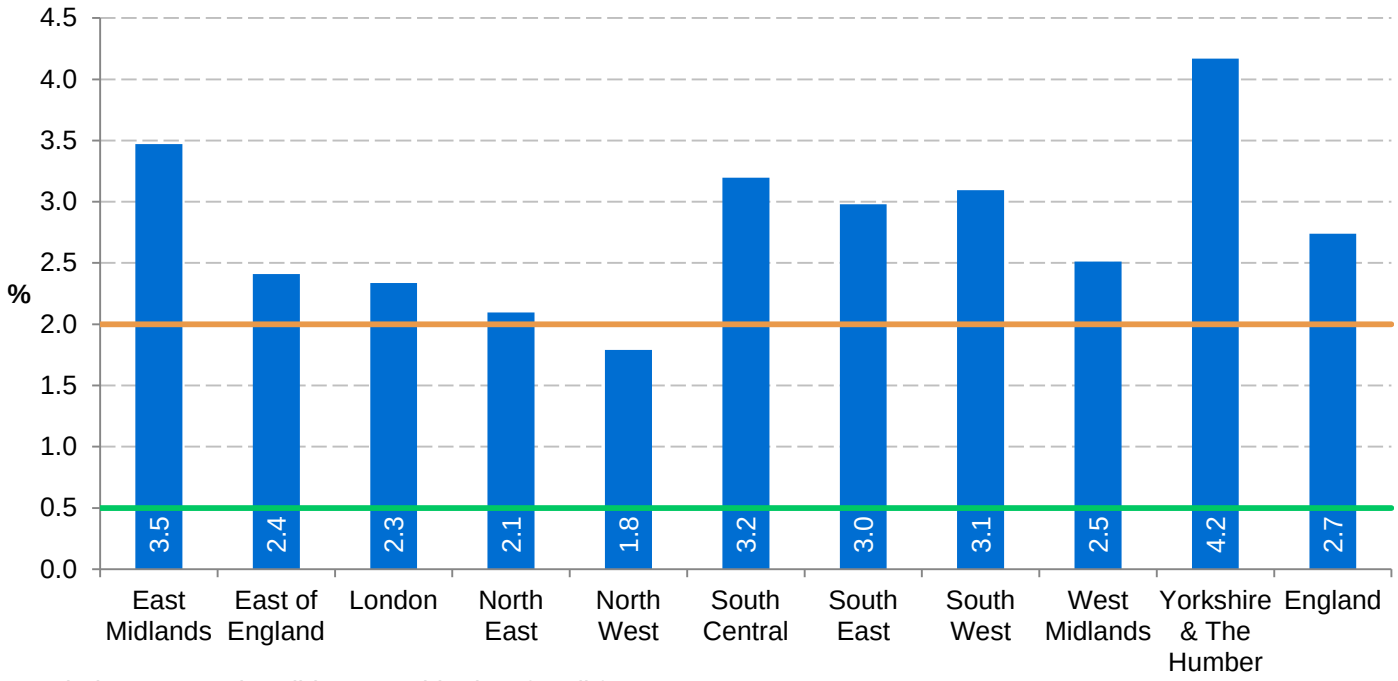
Figure KPI-8. Variation in newborn coverage (KPI NB1), 2014/15: England by region



Excludes 47 CCGs that did not provide data for all four quarters

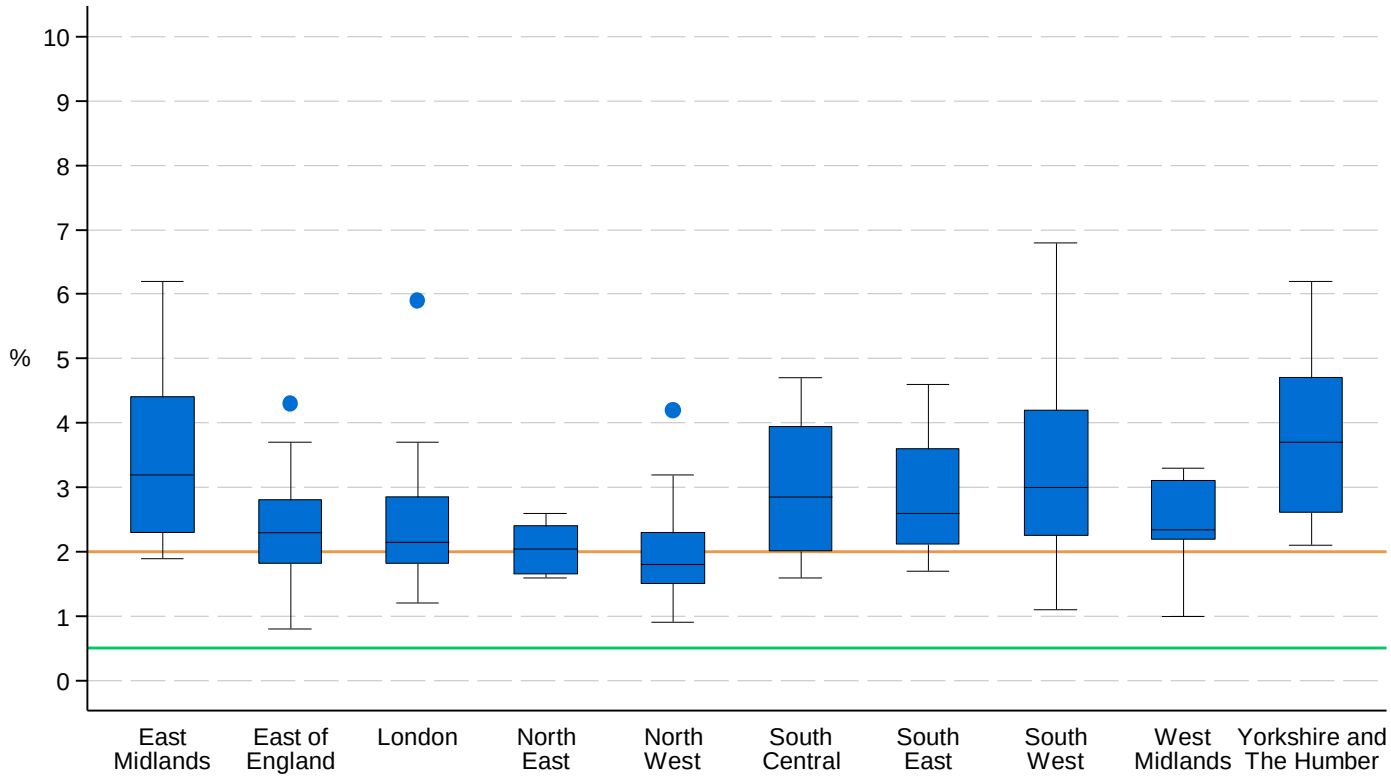
NB2: Avoidable repeats

Figure KPI-9. Newborn avoidable repeats (KPI NB2), 2014/15: England by region



Excludes 9 trusts that did not provide data for all four quarters.

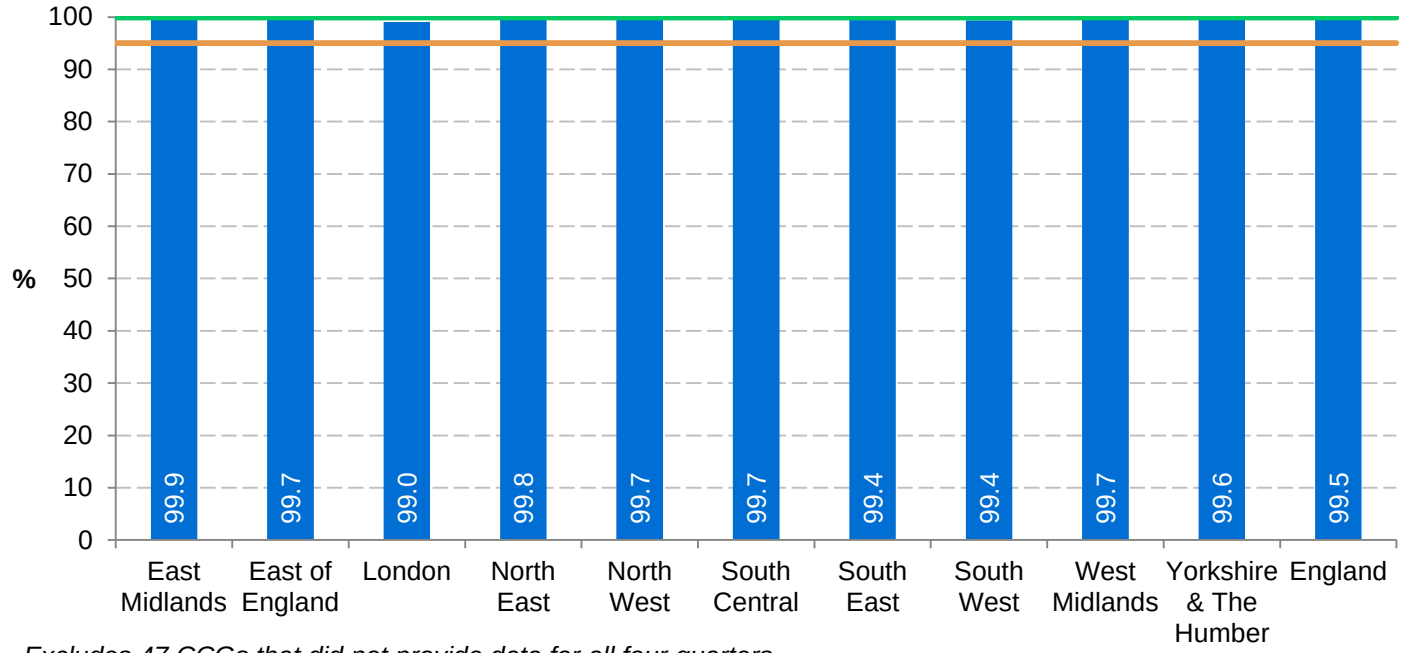
Figure KPI-10. Variation in newborn avoidable repeats (KPI NB2), 2014/15: England by region



Excludes 9 trusts that did not provide data for all four quarters

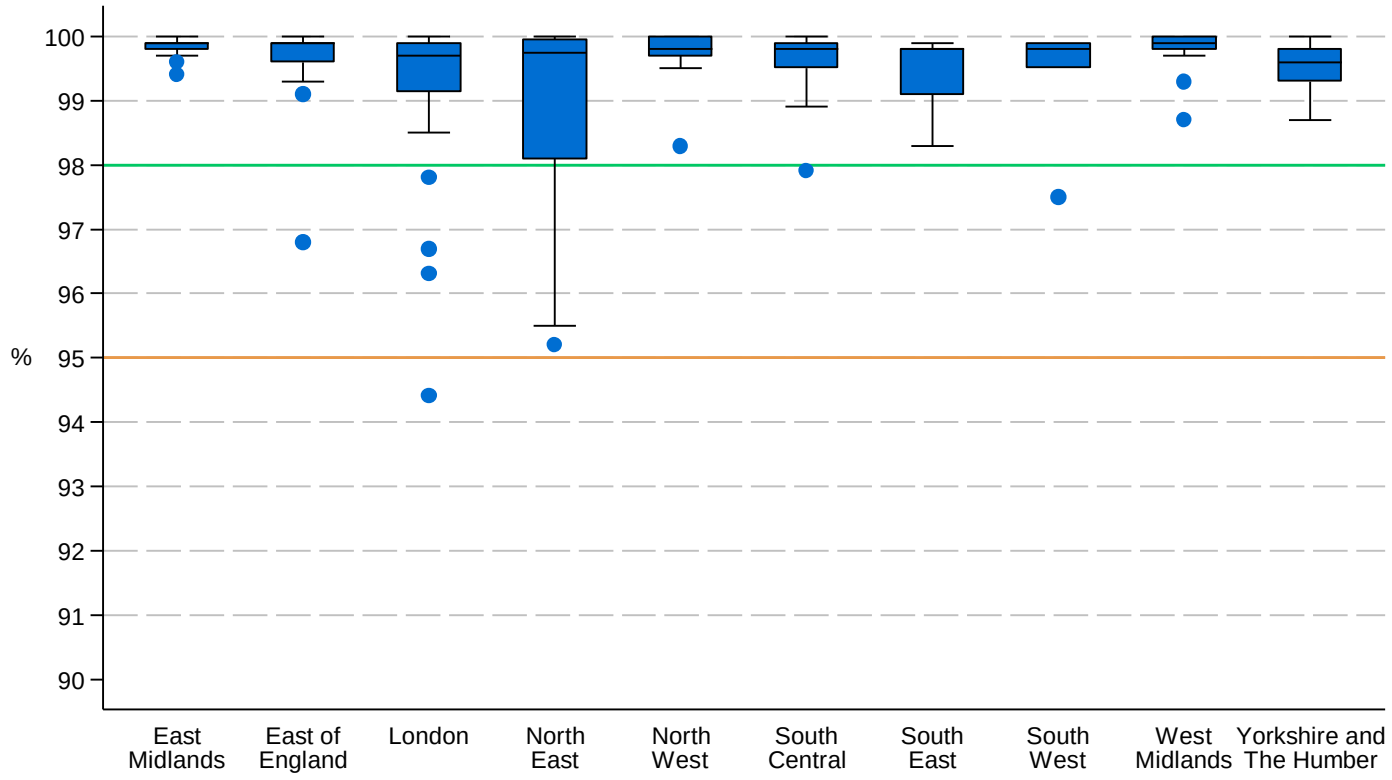
NB3: Timeliness of reporting screen negative results

Figure KPI-11. Timeliness of reporting screen negative newborn results (KPI NB3), 2014/15: England by region



Excludes 47 CCGs that did not provide data for all four quarters.

Figure KPI-12. Variation in timeliness of reporting screen negative newborn results (KPI NB3), 2014/15: England by region



Excludes 35 CCGs that did not provide data for all four quarters

6. Appendices

Appendix A: Update on the Newborn Outcomes Project: an evaluation of the linked antenatal and newborn screening programme

Universal newborn screening for sickle cell disease and beta thalassaemia has been available in England since 2005.

In September 2010, the NHS Sickle Cell and Thalassaemia Screening Programme started a project to assess the outcomes of the linked antenatal and newborn screening programme. We are collecting identifiable data on babies, or children under age 5, with sickle cell disorders or beta thalassaemia. This project will assess:

- the health of babies or children affected with sickle cell disease or thalassaemia
- timely entry to care and start of treatment of affected babies or children
- a review of the mother's antenatal screening history

The main rationale for the project is to reduce early mortality from invasive pneumococcal sepsis by ensuring that all affected babies with sickle cell disease are in clinical care and receiving the standard treatment. The programme currently has approval to collect named data without consent. We are collecting anonymised data alongside this data to assess its viability as a long-term exit strategy for the project, to provide assurance that all babies who need clinical care are receiving it. There is also an expectation that clinicians will enrol every newborn with sickle cell disease and clinically significant beta thalassaemia onto the National Haemoglobinopathy Registry if parents give consent, which may provide an alternative exit strategy.

Between 1 April 2014 and 31 March 2015 there were 263 screen positive babies born in England. Of these:

- 229 babies had confirmed sickle cell disease of which 83% were seen in clinic by 3 months
- 24 babies had confirmed beta thalassaemia of which 96% were seen in clinic by 3 months
- 10 cases had an unconfirmed diagnosis

Babies were excluded from this cohort if they were presented with a clinically insignificant diagnosis, they had migrated or were born abroad, and any deaths which were not ascribed to sickle cell disease.

Data collection has been a lengthy and protracted process. This has been in part due to manual processes and varying numbers of babies across the country (with the greatest number in London), and in part due to differing methods used for notification to specialist and community centres. The process needs to be streamlined and simplified to avoid duplication of requests.

Data collection forms for this project are available at https://www.gov.uk/government/publications/newborn-outcomes-project-data-collection-templates. The clinician is expected to complete the relevant clinical data and return it to the project administrator using nhs.net email, to ensure confidentiality.

For more information about this project please see https://www.gov.uk/guidance/newborn-outcomes-project-definition-and-implementation.

Appendix B: Antenatal data return form part 2 – breakdown of screen positive women

		Father's test result													
		Hb S	βThal	db thal	Hb Lepore	Hb D	Hb C	Hb E	Hb O-Arab	HPFH	High risk alpha0	Compound Hetero-zygous	Other	Not a carrier	Father result not available
Mother's test result	Hb S														
	βThal														
	db thal														
	Hb Lepore														
	Hb D														
	Hb C														
	Hb E														
	Hb O-Arab														
	HPFH														
	High risk alpha0														
	Compound Heterozygous														
	Egg donor/bone marrow transplant														

References

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