

Protecting and improving the nation's health

# Antenatal screening standards data report

1 April 2017 to 31 March 2018











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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.

#### www.gov.uk/phe/screening

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### **Foreword**

We are delighted that the antenatal screening teams in PHE have produced this joint antenatal annual standards data report. Antenatal screening covering 17 different conditions is offered to approximately 700,000 pregnant women in England every year.

This is the first time we report on all 3 population antenatal screening programmes together – the fetal anomaly screening programme (FASP), infectious diseases in pregnancy screening (IDPS) programme and sickle cell and thalassaemia (SCT) screening programme. We focussed on the woman's journey rather than individual screening programmes and in a way most meaningful to those who provide, commission and quality assure screening services. We hope you find this new format an improvement.

We'd like to thank everyone involved in collecting and collating the data, producing the report and most of all those from the NHS who deliver the screening services.

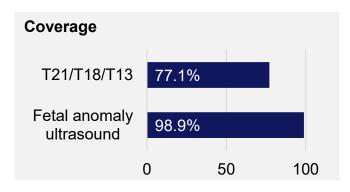


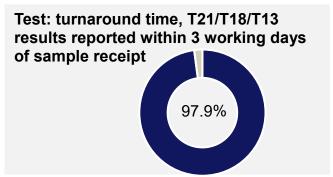
Radoslav Latinovic National Screening Data and Information Lead, Public Health England



**Professor Anne Mackie**Director of Screening, Public Health England

# FASP summary statistics 2017 to 2018





#### Referral

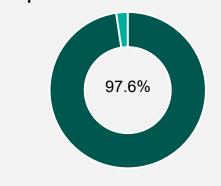


**97.4%** of women with higher chance results offered an appointment within 3 working days

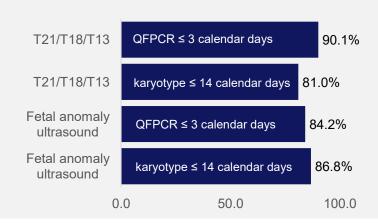
**81.5%** of women with a suspected/confirmed anomaly referred and seen locally within 3 working days

**88.2%** of women with a suspected/confirmed anomaly referred to tertiary fetal medicine and seen within 5 working days





### Diagnosis/intervention: test results issued

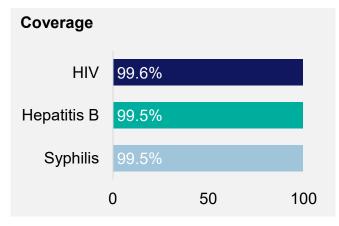


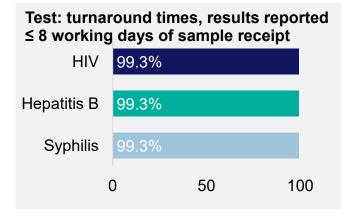
### **Test: performance**

The standardised screen positive rate (SPR) for T21/T18/T13 was 2.9%

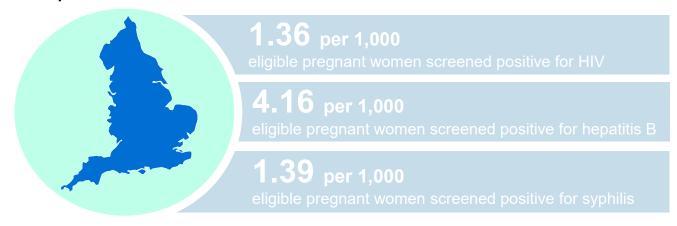
In 2016 to 2017, the crude detection rate (DR) was 82.1% (95% CI 78.8-85.1) for the combined test, and 66.3% (95% CI 56.0-75.3) for the quadruple test

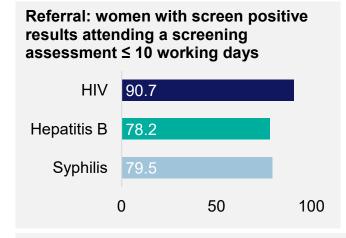
# IDPS summary statistics 2017 to 2018

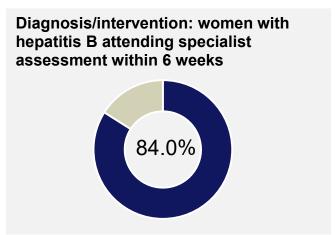




#### Screen positive rates





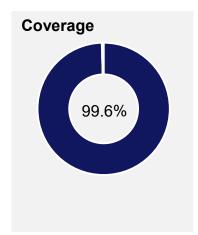


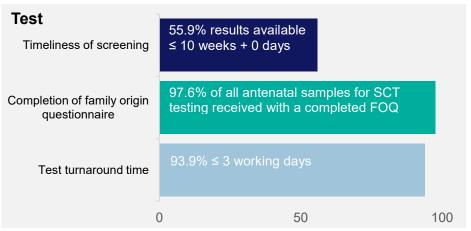
#### Intervention/treatment

98.9% of babies requiring hepatitis B vaccination received first dose ≤ 24 hours

**97.9**% of babies requiring immunoglobulin received it ≤ 24 hours

# SCT summary statistics 2017 to 2018

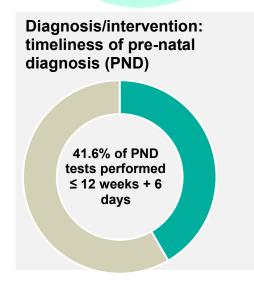


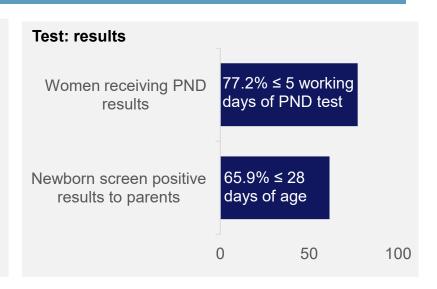


Referral

**38.2%** of women at risk of having an infant with sickle cell disease or thalassaemia offered PND ≤ 12 weeks +0 days

**53.2%** of couples at risk of having an infant with sickle cell disease or thalassaemia offered PND ≤ 12 weeks +0 days

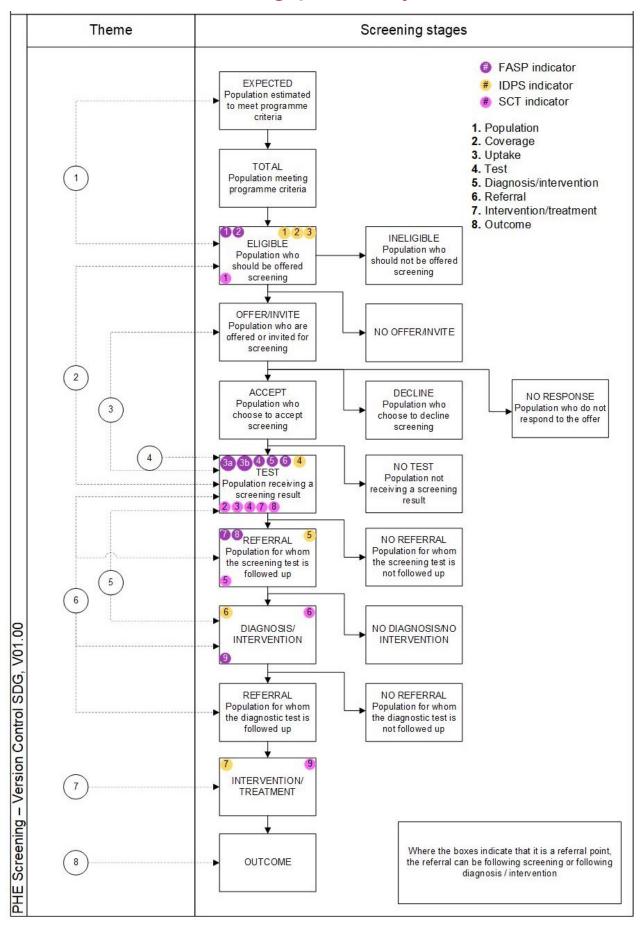




#### Intervention/treatment

**83.7%** newborn infants with a positive screening result were seen at a paediatric clinic or discharged for insignificant results ≤ 90 days of age

# Antenatal screening pathway



### Index of standards

How to use this index:

The code links to the full definition and the standard title is a bookmark to the relevant page within this report.

Code	Standard
FASP-S01	Coverage: T21/T18/T13 screening*
FASP-S02	Coverage: fetal anomaly ultrasound*
IDPS-S01	Coverage: HIV*
IDPS-S02	Coverage: hepatitis B*
IDPS-S03	Coverage: syphilis*
SCT-S01	Coverage: antenatal screening*
FASP-S03a	Test: screen positive rate T21/T18/T13 screening
FASP-S03b	Test: detection rate T21/T18/T13 screening
FASP-S04	Test: fetal anomaly ultrasound
FASP-S05	Test: turnaround time T21/T18/T13 screening
FASP-S06	Test: completion of laboratory request forms T21/T18/T13 screening*
IDPS-S04	Test: turnaround times HIV, hepatitis B, syphilis
SCT-S02	Test: timeliness of antenatal screening*
SCT-S03	Test: completion of family origin questionnaire (FOQ)*
SCT-S04	Test: turnaround time (antenatal screening)
SCT-S07	Test: timely reporting of prenatal diagnosis (PND) results to parents
SCT-S08	Test: reporting newborn screen positive results to parents
FASP-S07	Referral: time to intervention T21/T18/T13 screening
FASP-S08	Referral: time to intervention 18 <sup>+0</sup> to 20 <sup>+6</sup> fetal anomaly ultrasound
IDPS-S05	Referral: timely assessment of screen positive and known positive women
SCT-S05	Referral: timely offer of prenatal diagnosis (PND) to women at risk of having an infant with sickle cell disease or thalassaemia*

FASP-S09	Diagnosis/intervention: diagnostic tests fetal anomaly screening
IDPS-S06	Diagnosis/intervention: timely assessment of women with hepatitis B*
SCT-S06	Diagnosis/intervention: timeliness of prenatal diagnosis (PND)
IDPS-S07	Intervention/treatment: timely neonatal hepatitis B vaccination and immunoglobulin
SCT-S09	Intervention/treatment: timely follow-up, diagnosis and treatment of newborn infants with a positive screening result

<sup>\*</sup>Standards that are also KPIs. Standards are reported annually unless they are also KPIs, in which case they are usually reported on quarterly and annual figures are aggregated.

### Introduction

This is the first report where we have combined the data for the 3 antenatal screening programmes. We hope that users will find this helpful as it presents the data by pathway themes (and we have mapped each standard to a point in the pathway) so the screening journey for the woman and the baby can be better understood. We also function as a family of programmes and we wanted to demonstrate this. We will be working to add data from the newborn screening programmes in the future.

We have come from a place where we did not have measurable standards for all screening programmes to a position where we have consistent and comparable standards, 11 of which are also key performance indicators. The data completeness and quality continues to improve year on year thanks to the hard work of providers; in many instances manual processes are required. This report would not be possible without their efforts and commitment.

### **Further information**

This report should be read in conjunction with the accompanying standards data tables for 2017 to 2018 for the FASP, IDPS and SCT programmes. Information about screening standards and service specifications are available for each programme.

For those standards that are also KPIs the annual data presented in this report is calculated by adding together all 4 quarters of KPI submissions. Screening services are only included where valid KPI submissions were made in all 4 quarters of 2017 to 2018.

The NHS population screening: checks and audits failsafe tools are referred to in recommendation 3.

Please contact the screening helpdesk if you would like further information on screening data by emailing phe.screeninghelpdesk@nhs.net

### Summary of recommendations and actions

As this is the first national report of the 3 antenatal screening programmes we have focused the recommendations on completeness of data. We have not explicitly made recommendations where the thresholds are not met but would expect screening services to put in place recovery plans to deliver rapid and sustained improvement to exceed the acceptable threshold and/or have agreed service improvement plans to meet the achievable threshold.

The recommendations throughout the report can be categorized into the following 4 themes (the recommendation number is a bookmark to the relevant page within this report):

### 1. Data completeness

Recommendation 1

Recommendation 4

Recommendation 5

Recommendation 7

Recommendation 8

Recommendation 9

Recommendation 10

Recommendation 12

Recommendation 14

Recommendation 16

Recommendation 21

Recommendation 23

Recommendation 24

### 2. Failsafe processes

Recommendation 2

Recommendation 3

#### 3. Performance

Recommendation 11

Recommendation 17

Recommendation 19

#### 4. Data quality/review

Recommendation 6

Recommendation 13

Recommendation 15

Recommendation 18

Recommendation 20

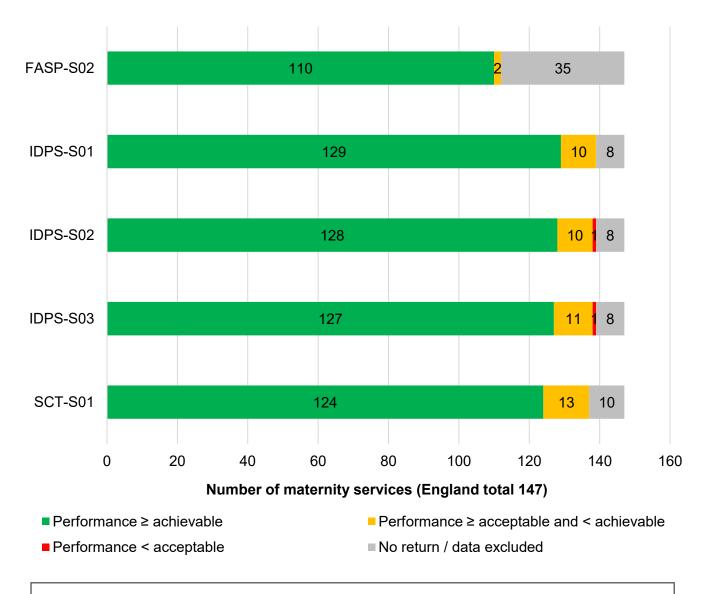
Recommendation 22

### Coverage

We measure coverage to provide assurance that screening is offered to the eligible population. Low coverage should be investigated as it may indicate:

- eligible women are not offered screening
- those offered screening are not accepting the test
- · the test is not completed for those accepting screening

Figure 1: Antenatal screening – coverage standards, performance against thresholds, England, 2017 to 2018

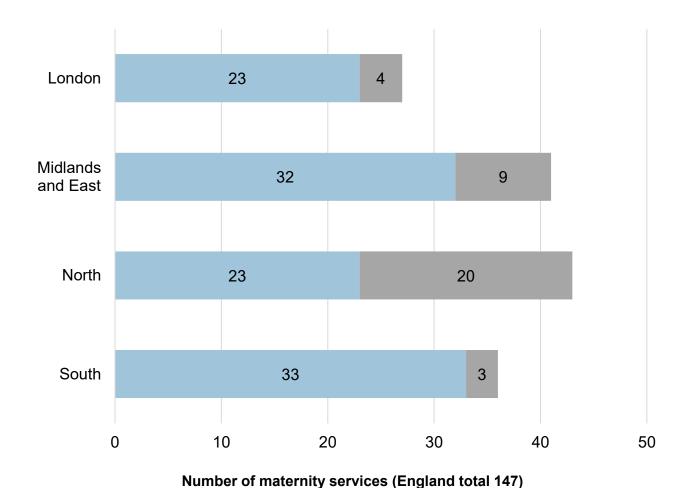


Performance thresholds: IDPS-S01, IDPS-S02, IDPS-S03 and SCT-S01: Acceptable > 95.0%

Acceptable: ≥ 90.0% Achievable: ≥ 95.0% Acceptable ≥ 95.0% Achievable ≥ 99.0%

Figure 2: FASP-S01: Coverage: T21/T18/T13 screening, completeness, 2017 to 2018

There is no intention to publish this standard by individual maternity service. Thresholds are not set for this standard, performance between providers should not be compared. FASP supports informed choice for women.



### Regional maternity service total

London = 27

Midlands and East = 41

North = 43

South = 36

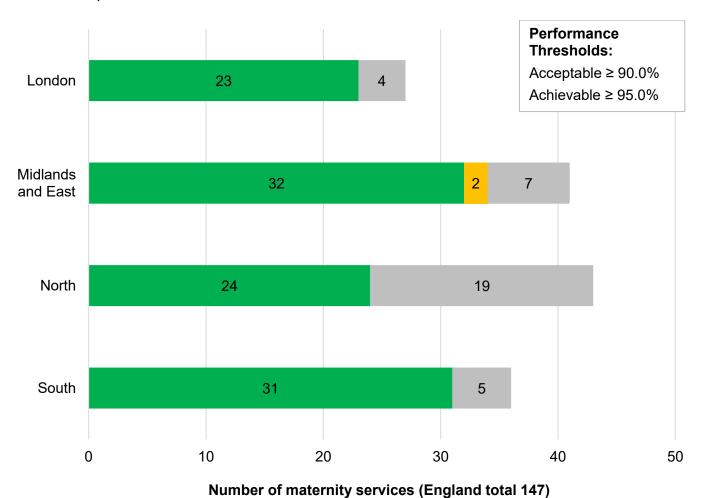
Data included

No return/data excluded

Table 1: FASP-S02: Coverage: fetal anomaly ultrasound, performance, 2017 to 2018

Region	Numerator	Denominator	Performance (%)
London	102,455	103,942	98.6
Midlands and East	136,323	137,666	99.0
North	79,518	80,510	98.8
South	114,350	115,179	99.3
England	432,646	437,297	98.9

Figure 3: FASP-S02: Coverage: fetal anomaly ultrasound, performance against thresholds, 2017 to 2018



### Regional maternity service total

London = 27

Midlands and East = 41

North = 43

South = 36

■ Performance ≥ achievable

Performance ≥ acceptable and < achievable

■ Performance < acceptable

■ No return / data excluded

Table 2: IDPS-S01: Coverage: HIV, performance, 2017 to 2018

Region	Numerator	Denominator	Performance (%)
London	146,195	146,414	99.9
Midlands and East	189,089	190,103	99.5
North	169,881	170,847	99.4
South	152,066	152,631	99.6
England	657,231	659,995	99.6

Figure 4: IDPS-S01: Coverage: HIV, performance against thresholds, 2017 to 2018

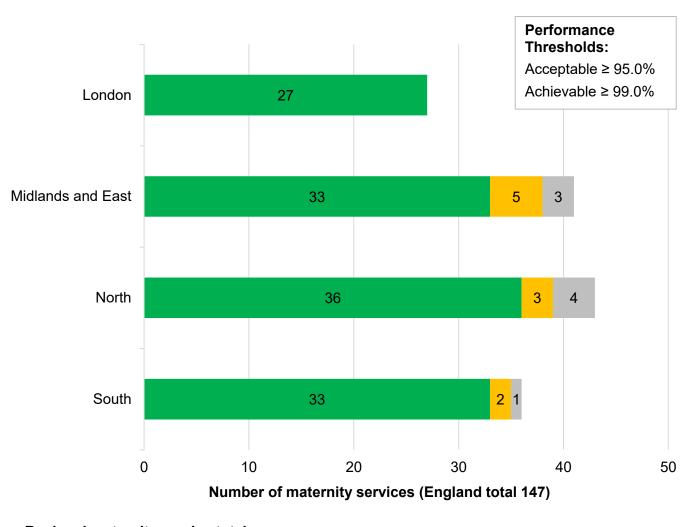
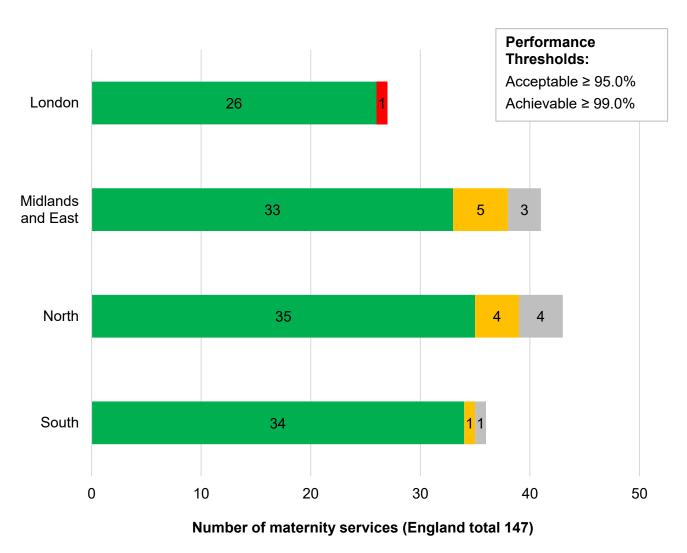




Table 3: IDPS-S02: Coverage: hepatitis B, performance, 2017 to 2018

Region	Numerator	Denominator	Performance (%)
London	145,878	146,416	99.6
Midlands and East	189,128	190,103	99.5
North	169,944	170,860	99.5
South	152,084	152,631	99.6
England	657,034	660,010	99.5

Figure 5: IDPS-S02: Coverage: hepatitis B, performance against thresholds, 2017 to 2018

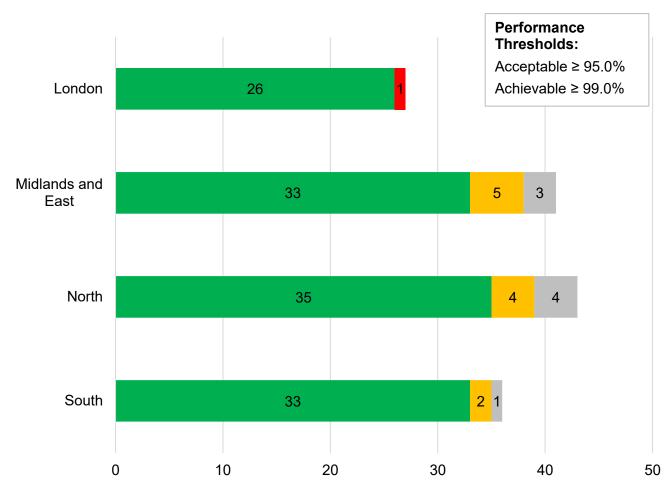


Regional maternity service total■ Performance ≥ achievableLondon = 27■ Performance ≥ acceptable and < achievable</td>Midlands and East = 41■ Performance < acceptable</td>North = 43■ Performance < acceptable</td>South = 36■ No return / data excluded

Table 4: IDPS-S03: Coverage: syphilis, performance, 2017 to 2018

Region	Numerator	Denominator	Performance (%)
London	145,868	146,413	99.6
Midlands and East	189,121	190,102	99.5
North	169,934	170,873	99.5
South	152,075	152,630	99.6
England	656,998	660,018	99.5

Figure 6: IDPS-S03: Coverage: syphilis, performance against thresholds, 2017 to 2018



Number of maternity services (England total 147)

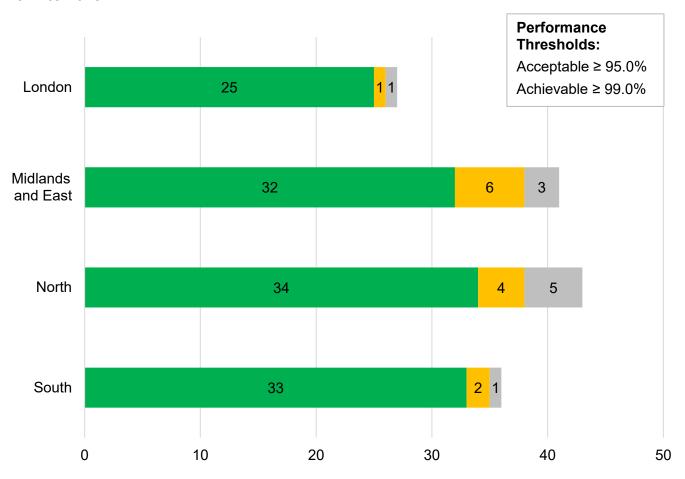
■ No return / data excluded



Table 5: SCT-S01: Coverage: antenatal screening, performance, 2017 to 2018

Region	Numerator	Denominator	Performance (%)
London	145,907	146,206	99.8
Midlands and East	189,080	190,189	99.4
North	164,762	165,630	99.5
South	151,903	152,505	99.6
England	651,652	654,530	99.6

Figure 7: SCT-S01: Coverage: antenatal screening, performance against thresholds, 2017 to 2018



Number of maternity services (England total 147)



London = 27

Midlands and East = 41

North = 43

South = 36

■ Performance ≥ achievable

■ Performance ≥ acceptable and < achievable</p>

■ Performance < acceptable

■ No return / data excluded

The number of providers that can submit good quality data is improving year on year. In 2016 to 2017 the number of providers that were unable to submit good quality data for FASP-S02, IDPS-S01 and SCT-S01 were 72, 21 and 24; this year (2017 to 2018) these have reduced to 35, 8 and 10 respectively. Eight providers were unable to submit data for both IDPS and SCT coverage. The North region has the greatest number of providers who were unable to submit data for FASP-S01 (20 providers) and FASP-S02 (19 providers).

Recommendation 1: Providers that are not yet submitting good quality data on coverage must have an action plan in place to enable them to do so (FASP-S01, FASP-S02, IDPS-S01, IDPS-S02, IDPS-S03, SCT-S01).

All regions had providers that did not submit data for FASP-S02. Joined up working is required across various health professionals and departments, such as maternity, ultrasound, or radiology services to do this. Data may be held on different information systems with no direct interface. Support from IT and audit departments is usually required to set up manageable systems for cross-referencing and correlating data that allows women who have accepted screening to be 'tracked' to confirm completion of screening.

Performance for IDPS and SCT coverage is good. One provider did not meet the acceptable coverage thresholds for hepatitis B and syphilis but this can be explained by organisational changes which had an impact on the data for one quarter.

Performance of FASP-S02 has also improved from 96.6% in 2016 to 2017 to 98.9% in 2017 to 2018. Whilst it is reassuring to see that performance is improving this does not negate the need for exception reporting to make sure providers account for all eligible women. We know from screening safety incidents that some eligible women miss the offer of screening or those accepting the offer do not always have the test completed.

Recommendation 2: Screening and immunisation leads should continue to monitor exception reports for coverage standards (FASP-S01, FASP-S02, IDPS-S01, IDPS-S03, SCT-S01).

Recommendation 3: Maternity providers should use the FASP/SCT/IDPS checks and audits for failsafe tools to improve quality and reduce risks in programme delivery (FASP-S01, FASP-S02, IDPS-S01, IDPS-S02, IDPS-S03, SCT-S01).

### **Test**

Timely analysis of the test is important in making sure women have their results or enter clinical services without delay.

3.5% 2.6% 3.0% 2.9% 2.3% 2.2% 2.2% 2.5% 2.0% 1.5% 1.0% 0.5% 0.0% 2013/14 2014/15 2015/16 2016/17 2017/18 --- Standardised screen positive rate

Figure 8: FASP-S03a: Test: screen positive rate T21/T18/T13 screening, England

The reference maternal age distribution changed, resulting in an increase in the screen positive rate. The reference range for this standard was revised from 2.3 to 2.8%.

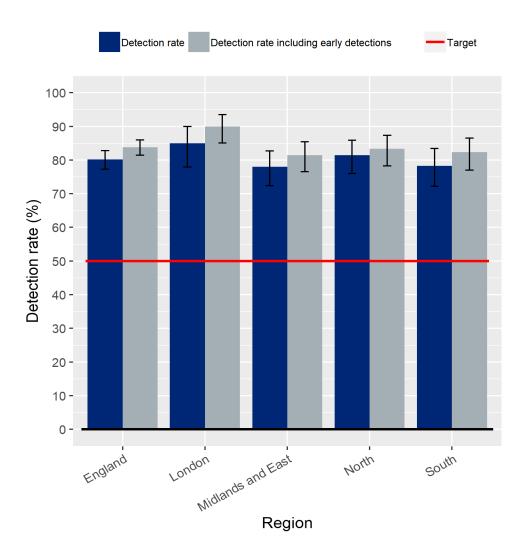
Table 6: FASP-S03b: Crude detection rates (%) and screening status (number): trisomy 21 by year, England, estimated delivery date (EDD) 2015 to 2016, to 2016 to 2017

	<b>3</b>	,
Crude detection rate (95% CI)	2015 to 2016	2016 to 2017
Combined test	81.9% (77.6-85.5)	82.1% (78.8-85.1)
Quadruple test	61.7% (47.4-74.2)	66.3% (56.0-75.3)
Programme	79.0% (74.8-82.6)	77.4% (74.1-80.4)

Public Health England launched The National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) in 2015. NCARDRS records people with congenital anomalies and rare diseases in England and is best placed to collect data on detection rates. This is vital for the ongoing monitoring and evaluation of the screening programme.

Maternal age adjusted targets for Down's syndrome screening were met for the combined test but not for the quadruple test.

Figure 9: FASP-S04: Test: fetal anomaly ultrasound. Detection rates with and without early detections (%) for serious cardiac conditions, EDD 2017 to 2018



Data from 95% of NHS maternity providers, for 5,321 babies with an expected date of delivery (EDD) between 1 April 2017 and 31 March 2018 shows detection rates were significantly above target for all cardiac conditions across England, with and without the inclusion of detections prior to 18<sup>+0</sup> weeks gestation.

Recommendation 4: Laboratory providers and commissioners in areas not reporting should work with NCARDRS to improve notification and timely submission as required by service specification 16 (FASP-S03b, FASP-S04).

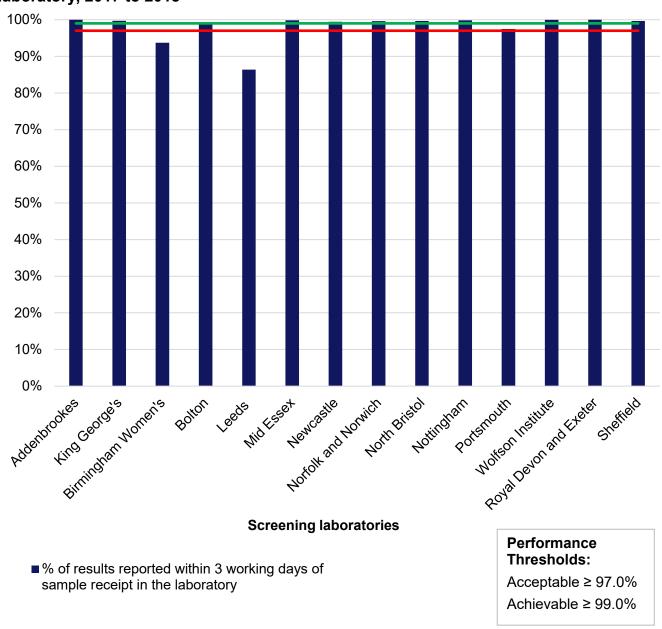


Figure 10: FASP-S05: Test: turnaround time T21/T18/T13 screening, performance by laboratory, 2017 to 2018

Six screening laboratories did not submit data; 3 of these have never submitted data despite this being a long-standing standard. Two laboratories submitting data did not meet the acceptable threshold.

Overall performance of those laboratories submitting data was 97.9% with 10 laboratories meeting the achievable threshold.

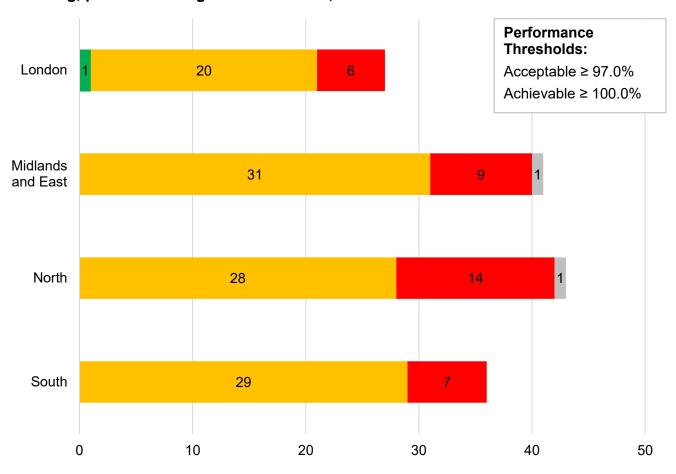
Recommendation 5: Commissioners of laboratory services must make sure that the service level agreements/sub contracts include the submission of data to PHE Screening as set out in service specification 16 (FASP-S05).

Table 7: FASP-S06: Test: completion of laboratory request forms T21/T18/T13 screening,

performance, 2017 to 2018

Region	Numerator	Denominator	Performance (%)
London	109,794	111,699	98.3
Midlands and East	144,604	148,134	97.6
North	110,027	112,890	97.5
South	122,844	126,400	97.2
England	487,269	499,123	97.6

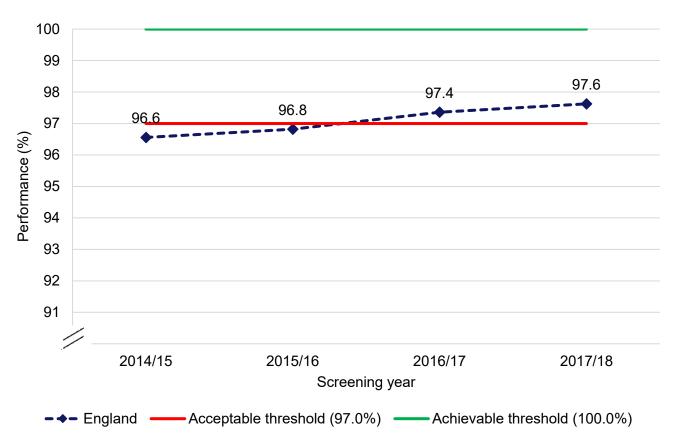
Figure 11: FASP-S06: Test: completion of laboratory request forms T21/T18/T13 screening, performance against thresholds, 2017 to 2018



Number of maternity services (England total 147)



Figure 12: FASP-S06: Test: completion of laboratory request forms T21/T18/T13 screening, performance trends, England, April 2014 to March 2018



Two providers did not submit data on this standard. Thirty-six of the providers submitting data did not meet the acceptable threshold, over a third of these were in the North region. One London provider submitting data met the achievable threshold. Although national performance has improved, performance seems to be plateauing.

Recommendation 6: NHS FASP should review this indicator to further drive quality improvement (FASP-S06).

# Table 8: IDPS-S04: Test: turnaround times HIV, hepatitis B, syphilis, performance, 2017 to 2018

IDPS-S04a: HIV

Region	Numerator	Denominator	Performance (%)
London	88,931	89,276	99.6
Midlands and East	165,316	166,409	99.3
North	142,053	143,349	99.1
South	142,928	144,147	99.2
England	539,228	543,181	99.3

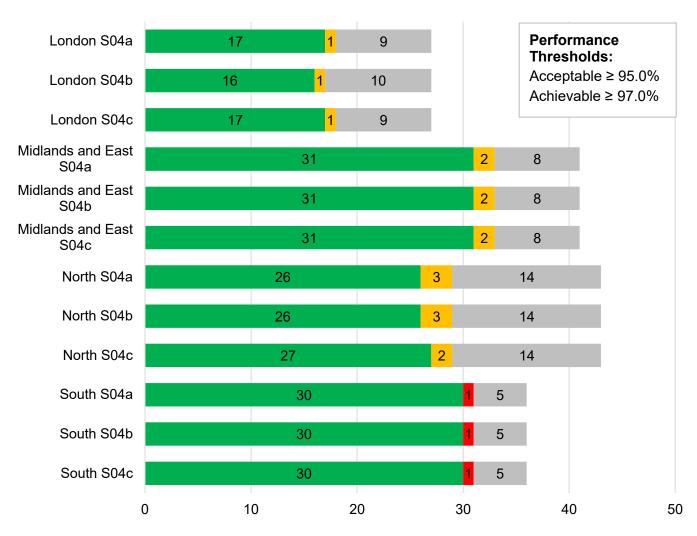
IDPS-S04b: hepatitis B

Region	Numerator	Denominator	Performance (%)
London	89,394	89,793	99.6
Midlands and East	165,399	166,480	99.4
North	141,931	143,301	99.0
South	143,072	144,265	99.2
England	539,796	543,839	99.3

IDPS-S04c: syphilis

Region	Numerator	Denominator	Performance (%)
London	90,047	90,386	99.6
Midlands and East	165,400	166,476	99.4
North	142,001	143,243	99.1
South	143,016	144,176	99.2
England	540,464	544,281	99.3

Figure 13: IDPS-S04: Test: turnaround times HIV, hepatitis B, syphilis, performance against thresholds, 2017 to 2018



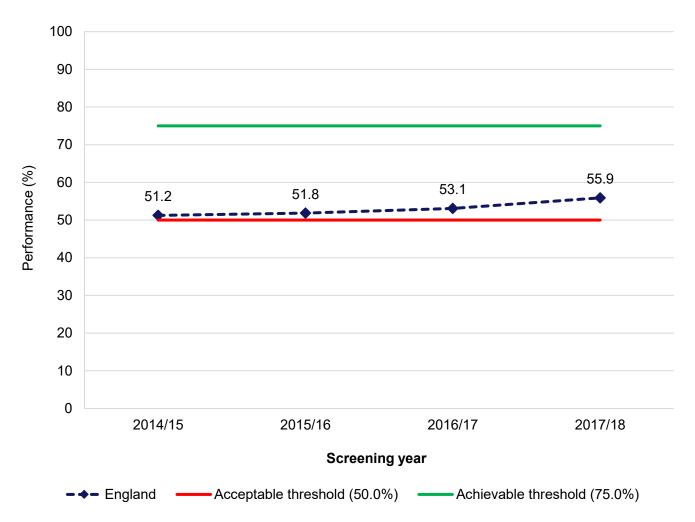
Number of maternity services (England total 147)



All regions had providers not submitting data with the North region having the largest proportion. The test turnaround time performance for all regions where data was submitted for HIV, hepatitis B and syphilis exceeded the achievable thresholds.

Recommendation 7: Commissioners of laboratory services must make sure that the service level agreements/sub contracts include the submission of data to PHE Screening as set out in service specification 15 (IDPS-S04).

Figure 14: SCT-S02: Test: timeliness of antenatal screening, performance trends, England, April 2014 to March 2018

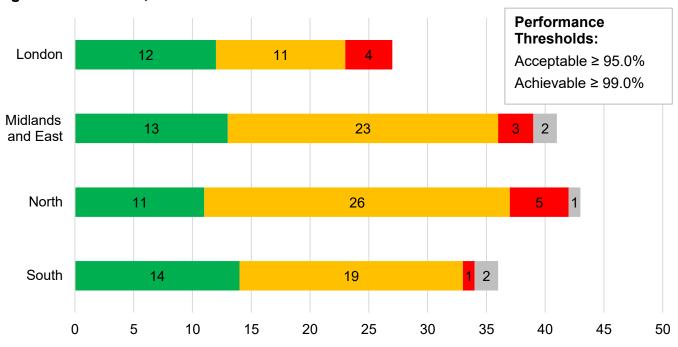


Due to inconsistencies in the way that SCT-S02 is reported we do not recommend that this standard is used to compare performance between maternity services. A regional comparison of performance against thresholds is therefore not presented in this report. However, the 4-year trend for England performance is shown above.

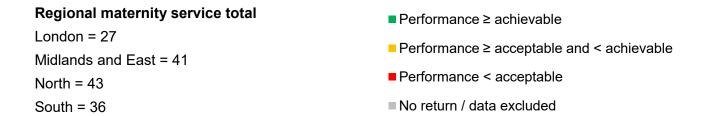
Table 9: SCT-S03: Test: completion of family origin questionnaire (FOQ), performance, 2017 to 2018

Region	Numerator	Denominator	Performance (%)
London	140,282	144,347	97.2
Midlands and East	198,035	202,906	97.6
North	182,509	187,205	97.5
South	146,144	148,955	98.1
England	666,970	683,413	97.6

Figure 15: SCT-S03: Test: completion of family origin questionnaire (FOQ), performance against thresholds, 2017 to 2018



Number of maternity services (England total 147)



The thresholds for SCT-S03 were changed in 2015 to 2016. Five providers did not submit data, despite this being a long-standing indicator. Of those providers submitting data 13 did not meet the acceptable threshold. Thirty-five percent of those that submitted data met the achievable threshold.

Recommendation 8: Commissioners of laboratory services must make sure that the service level agreements/sub contracts include the submission of data to PHE Screening as set out in service specification 18 (SCT-S03).

Table 10: SCT-S04: Test: turnaround time (antenatal screening), performance, 2017 to 2018

Region	Numerator	Denominator	Performance (%)
London	79,594	87,860	90.6
Midlands and East	152,432	163,173	93.4
North	163,584	170,585	95.9
South	63,770	67,432	94.6
England	449,458	478,846	93.9

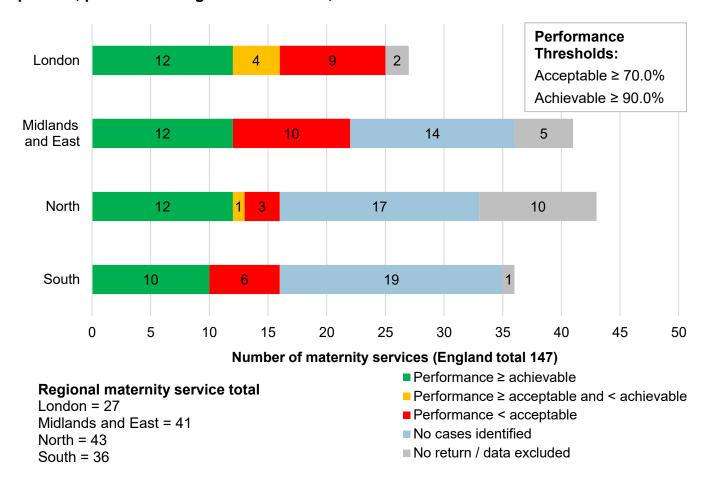
SCT-S04 is a new standard. 93.9% of tests were turned around in 3 working days. The way antenatal screening laboratories are set-up varies considerably across the country. In some areas large centralised laboratories perform screening for several providers, this is particularly common in London. Due to this variation, a graphical presentation of performance against thresholds is not shown in this report. Performance for individual screening laboratories is shown in the accompanying data tables.

Recommendation 9: Commissioners of laboratory services must make sure that the service level agreements/sub contracts include the submission of data to PHE Screening as set out in service specification 18 (SCT-S04).

Table 11: SCT-S07: Test: timely reporting of prenatal diagnosis (PND) results to parents, performance, 2017 to 2018

Region	Numerator	Denominator	Performance (%)
London	173	214	80.8
Midlands and East	24	53	45.3
North	35	40	87.5
South	52	61	85.2
England	284	368	77.2

Figure 16: SCT-S07: Test: timely reporting of prenatal diagnosis (PND) results to parents, performance against thresholds, 2017 to 2018



This is a small number standard and it should be noted that all regions except London had providers with no cases in 2017 to 2018. There were 18 providers that did not submit data, 10 of these are in the North region. All regions had providers that did not meet the acceptable threshold. No region met the achievable threshold and Midlands and East did not meet the acceptable threshold.

Recommendation 10: Providers that are not yet submitting good quality data must have an action plan in place to enable them to do so (SCT-S07).

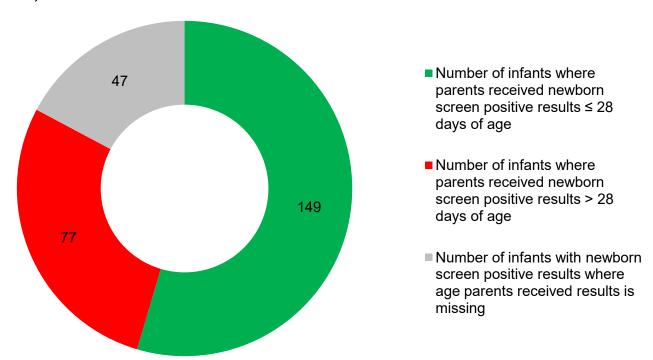
Recommendation 11: Commissioners need to review reasons for low performance in the Midlands and East region (SCT-S07).

Table 12: SCT-S08: Test: reporting newborn screen positive results to parents, perfor-

mance, England, 2017 to 2018

Numerator	Denominator	Performance (%)	Exclusions from the denominator due to missing data
149	226	65.9	47

Figure 17: SCT-S08: Test: reporting newborn screen positive results to parents, England, 2017 to 2018



This is the first year of data collection on this standard, and we have identified data quality issues with the submitted data. Therefore, only England level data is shown, and this must be interpreted with caution, as it may not be reflective of true performance. We also do not have enough information on 47 infants to determine performance for this standard. We will review the methods of data collection and the standard definition to improve data quality and completeness in future.

Recommendation 12: Providers and commissioners in areas not reporting should work with NCARDRS to improve notification and timely submission as required by service specification 18 (SCT-S08).

Recommendation 13: NHS SCT should review the standard definition and data source (SCT-S08).

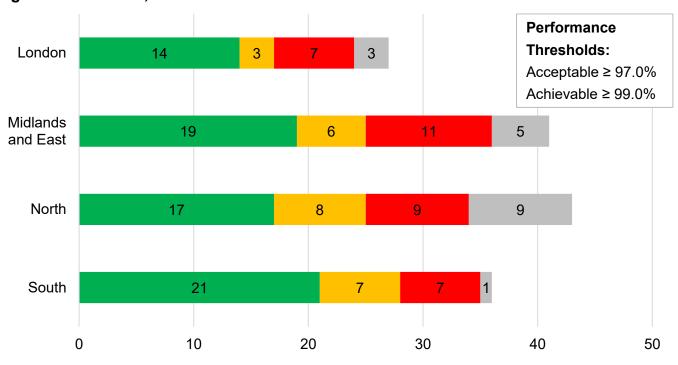
### Referral

These standards give us assurance that women with higher chance/screen positive results have a timely opportunity to discuss their results and further options with an appropriately trained health professional.

Table 13: FASP-S07: Referral: time to intervention T21/T18/T13 screening, performance, 2017 to 2018

-0.1. 00 -0.10				
Region	Denominator	Numerator	Performance (%)	
London	3,003	2,934	97.7	
Midlands and East	3,693	3,589	97.2	
North	2,678	2,599	97.1	
South	3,648	3,556	97.5	
England	13,022	12,678	97.4	

Figure 18: FASP-S07: Referral: time to intervention T21/T18/T13 screening, performance against thresholds, 2017 to 2018



Number of maternity services (England total 147)

Regional maternity service totalPerformance ≥ achievableLondon = 27Performance ≥ acceptable and < achievable</td>Midlands and East = 41Performance < acceptable</td>North = 43No return / data excluded

This is a long-standing indicator so it is disappointing that 18 providers did not submit data. The North region had the greatest number of non-submitting providers. Thirty-four of the providers submitting data did not meet the acceptable threshold; about a third of these are in the Midlands and East. Just over half of providers submitting data met the achievable threshold. No region met the achievable threshold.

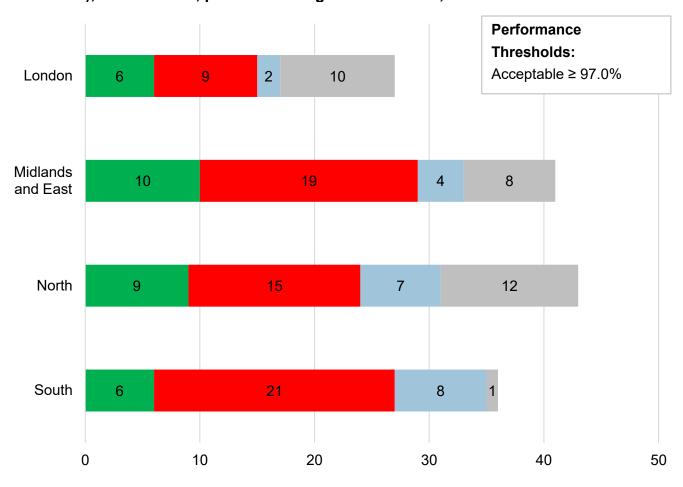
Recommendation 14: Providers that are not yet submitting good quality data must have an action plan in place to enable them to do so (FASP-S07).

Table 14: FASP-S08a: Referral: time to intervention 18<sup>+0</sup> to 20<sup>+6</sup> fetal anomaly ultrasound,

local referral, performance, 2017 to 2018

Region	Numerator	Denominator	Performance (%)
London	956	988	96.8
Midlands and East	1,582	2,081	76.0
North	728	984	74.0
South	1,690	2,029	83.3
England	4,956	6,082	81.5

Figure 19: FASP-S08a: Referral: time to intervention 18<sup>+0</sup> to 20<sup>+6</sup> fetal anomaly ultrasound), local referral, performance against threshold, 2017 to 2018



Number of maternity services (England total 147)

Regional maternity service total London = 27

Midlands and East = 41

North = 43South = 36 Performance < acceptable</li>No cases identifiedNo return / data excluded

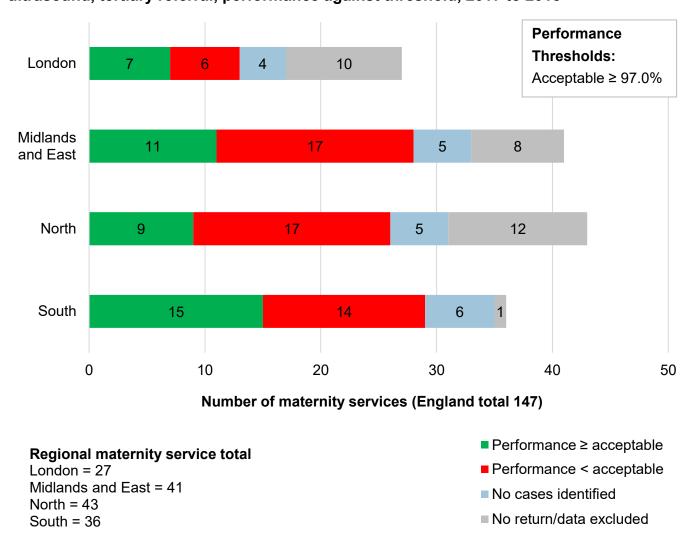
■ Performance ≥ acceptable

Table 15: FASP-S08b: Referral: time to intervention 18<sup>+0</sup> to 20<sup>+6</sup> fetal anomaly ultrasound,

tertiary referral, performance, 2017 to 2018

Region	Numerator	Denominator	Performance (%)
London	542	575	94.3
Midlands and East	1,095	1,240	88.3
North	843	990	85.2
South	914	1,045	87.5
England	3,394	3,850	88.2

Figure 20: FASP-S08b: Referral: time to intervention 18<sup>+0</sup> to 20<sup>+6</sup> fetal anomaly ultrasound, tertiary referral, performance against threshold, 2017 to 2018



No region met the acceptable threshold for FASP-S08a or S08b. There are concerns about data quality and some submissions were excluded where it was clear that some providers were using the same denominator for a and b. The acceptable threshold is not met for England.

Recommendation 15: Maternity providers should work with their regional SQAS to map their referral pathways to make sure local and tertiary referrals are reported in the correct part of the standard (FASP-S08a and FASP-S08b).

### Table 16: IDPS-S05: Referral: timely assessment of screen positive and known positive women, performance, 2017 to 2018

IDPS-S05a: HIV

Region	Numerator	Denominator	Performance (%)
London	298	312	95.5
Midlands and East	198	215	92.1
North	143	167	85.6
South	105	126	83.3
England	744	820	90.7

IDPS-S05b: hepatitis B

Region	Numerator	Denominator	Performance (%)
London	802	1,034	77.6
Midlands and East	467	580	80.5
North	365	459	79.5
South	275	369	74.5
England	1,909	2,442	78.2

IDPS-S05c: syphilis

:=:			
Region	Numerator	Denominator	Performance (%)
London	230	279	82.4
Midlands and East	189	234	80.8
North	149	211	70.6
South	85	97	87.6
England	653	821	79.5

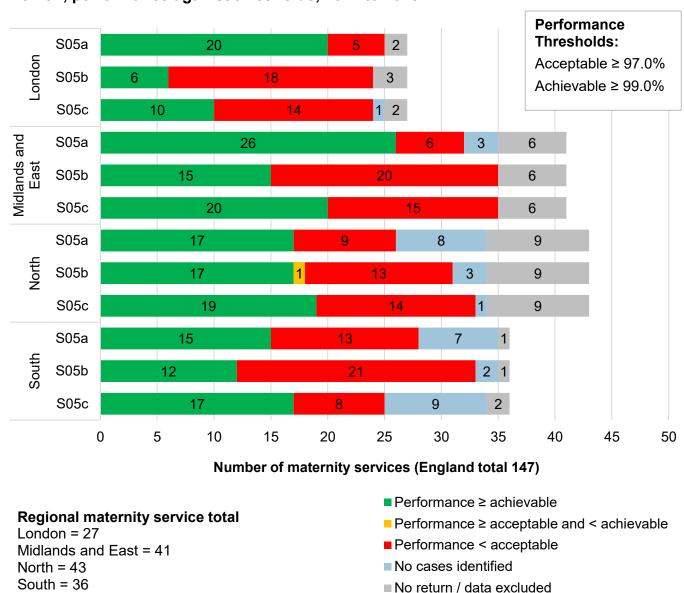


Figure 21: IDPS-S05: Referral: timely assessment of screen positive and known positive women, performance against thresholds, 2017 to 2018

No region met the acceptable threshold for IDPS-S05a, S05b or S05c. The performance for those submitting data shows that HIV performs markedly better than hepatitis B and syphilis. This likely reflects long established pathways for HIV. Nineteen providers did not submit data for at least one part of the standard; the North and Midlands and East regions had the greatest number of non-submitting providers.

Recommendation 16: Providers that are not yet submitting good quality data must have an action plan in place to enable them to do so (IDPS-S05).

Recommendation 17: Providers should review their pathways for hepatitis B and syphilis to achieve timely assessment by the screening team (IDPS-S05b and IDPS-S05c).

Table 17: SCT-S05: Referral: timely offer of prenatal diagnosis (PND) to women (a) or couples (b) at risk of having an infant with sickle cell disease or thalassaemia, performance, 2017 to 2018

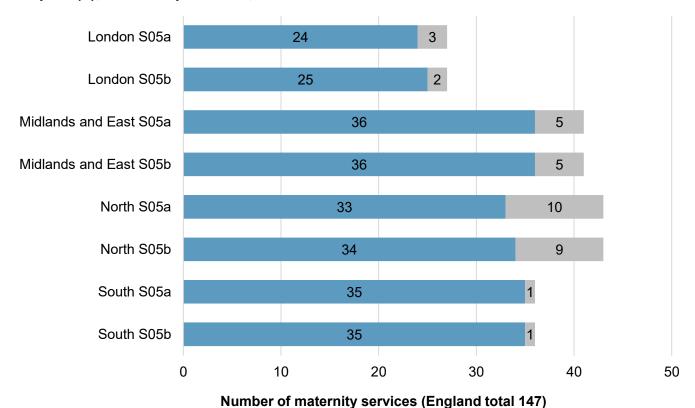
SCT-S05a: The proportion of at risk women offered PND by 12 weeks + 0 days gestation

Region	Numerator	Denominator	Performance (%)
London	410	1,252	32.7
Midlands and East	154	421	36.6
North	290	529	54.8
South	71	221	32.1
England	925	2,423	38.2

SCT-S05b: The proportion of at risk couples offered PND by 12 weeks + 0 days gestation

Region	Numerator	Denominator	Performance (%)
London	222	459	48.4
Midlands and East	100	190	52.6
North	121	187	64.7
South	58	105	55.2
England	501	941	53.2

Figure 22: SCT-S05: Referral: timely offer of prenatal diagnosis (PND) to women at risk of having an infant with sickle cell disease or thalassaemia, at risk women (a) and at risk couples (b), data completeness, 2017 to 2018



, ,

#### Regional maternity service total

London = 27 Midlands and East = 41 North = 43 South = 36

■ Data included

■ No return / data excluded

This standard was collected for the first time in 2017 to 2018, and performance thresholds have not yet been set. The above figure presents the data completeness for this standard.

This standard is now a key performance indicator so data will be collected every 3 months. New KPIs are not published in the first year of data collection. This time is used to improve the data quality and completeness, by revising the definition, adding clarity and/or setting thresholds as required. After this time PHE Screening will review the data with the aim of publishing it from the following year. We have identified data quality issues in 2017 to 2018, therefore the submitted data may not reflect true performance. Performance between regions should not be compared. Nineteen providers did not submit data/had data excluded for at least one part of the standard, the North region had the greatest number of non-submitting providers.

Recommendation 18: NHS SCT to analyse the KPI data and review the definition (SCT-S05).

Recommendation 19: Maternity providers should use the SCT pre-natal diagnosis audit tool (available through the phe.screeninghelpdesk@nhs.net) to improve quality and reduce risks in programme delivery (SCT-S05).

#### Diagnosis/intervention

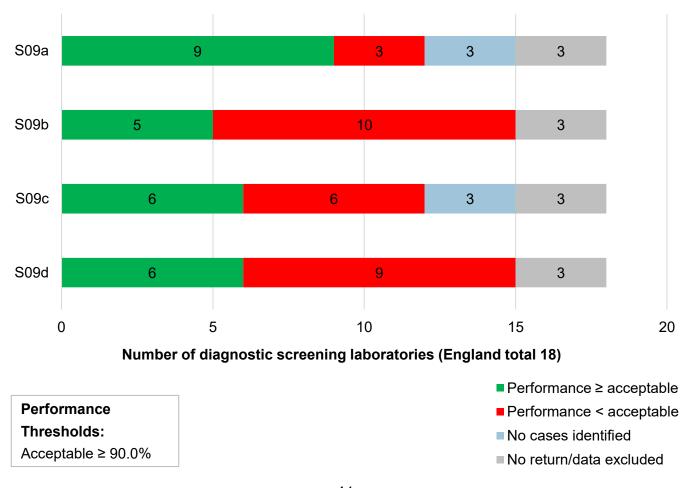
These standards provide assurance that women with screen positive/higher chance results or known to have a condition, who wish to have a diagnostic procedure or intervention have these in a timely manner.

Table 18: FASP-S09: Diagnosis/intervention: diagnostic tests fetal anomaly screening, 2015 to 2018

Standard	England performance (%)		
	2015/16	2016/17	2017/18
9a – QFPCR* testing for higher chance T21/T18/T13	97.1	89.8	90.1
9b - Karyotype testing for higher chance T21/T18/T13	82.1	82.7	81.0
9c – QFPCR* testing for fetal anomaly ultrasound	91.3	84.0	84.2
9d - Karyotype testing for fetal anomaly ultrasound	82.2	86.2	86.8
Number of submissions	15/18	16/18	15/18

<sup>\*</sup>Quantitative Fluorescence-Polymerase Chain Reaction

Figure 23: FASP-S09: Diagnosis/intervention: diagnostic tests fetal anomaly screening, 2015 to 2018



The Association of Clinical Genomic Science (ACGS) collects this data on behalf of NHS FASP. Standards FASP-S09a and S09b measure the turnaround times for results from either QF-PCR or karyotype following a higher chance screening result for Down's syndrome, Edwards' syndrome and Patau's syndrome.

An increasing number of diagnostic laboratories report that they are more likely to perform a micro-array than karyotype following an unexpected finding at the fetal anomaly scan. It should be noted that the NHS FASP standards and service specification recommends karyotype.

There were 3 genomic laboratories that did not submit data. Several laboratories did not meet the acceptable threshold.

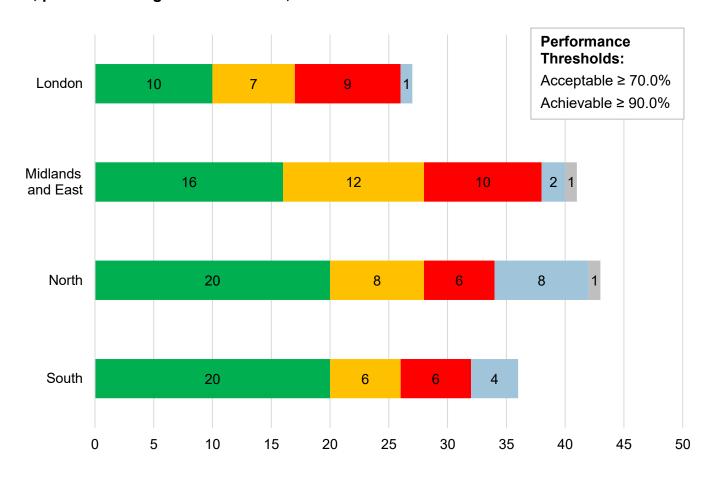
Recommendation 20: NHS FASP will review the ACGS updated professional guidance and produce a paper on microarray to discuss possible changes with the UK NSC evidence team (FASP-S09).

Recommendation 21: The ACGS should work with genomic laboratories to achieve complete data submission for all laboratories (FASP-S09).

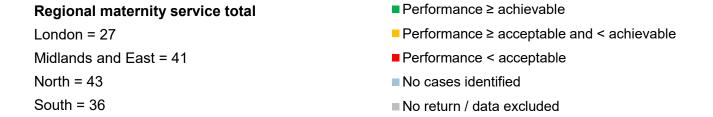
Table 19: IDPS-S06: Diagnosis/intervention: timely assessment of women with hepatitis B. performance, 2017 to 2018

2, por tormanoo, 2011 to 2010					
Region	Numerator	Denominator	Performance (%)		
London	278	352	79.0		
Midlands and East	308	366	84.2		
North	218	248	87.9		
South	141	159	88.7		
England	945	1,125	84.0		

Figure 24: IDPS-S06: Diagnosis/intervention: timely assessment of women with hepatitis B, performance against thresholds, 2017 to 2018



Number of maternity services (England total 147)



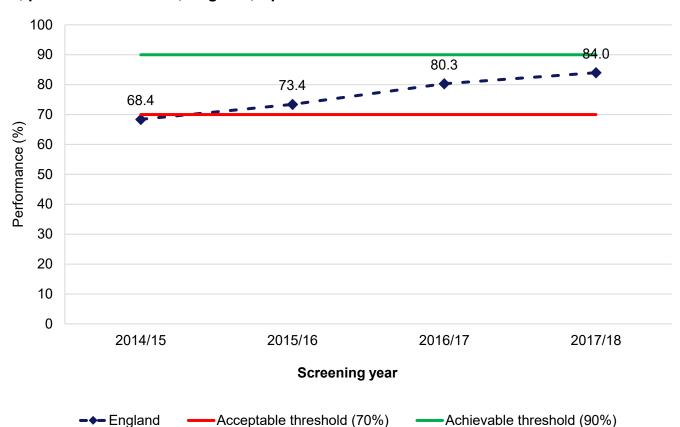


Figure 25: IDPS-S06: Diagnosis/intervention: timely assessment of women with hepatitis B, performance trends, England, April 2014 to March 2018<sup>^</sup>

^ Since 2016 to 2017, IDPS-S06 counts only women with hepatitis B who are either **newly diagnosed** or known positive with **high infectivity** markers.

There were 2 providers that did not submit data, these are no longer providing services. All regions met the acceptable threshold. The London region had the highest proportion of providers not meeting the acceptable threshold.

Nationally there is a steady improvement in performance since 2014 to 2015, noting that the definition changed in 2016 to 2017.

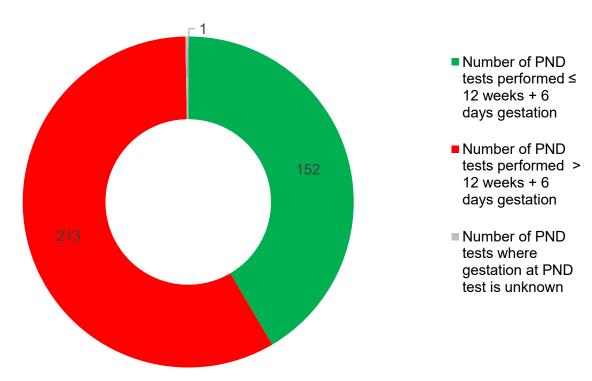
Table 20: SCT-S06: Diagnosis/intervention: timeliness of prenatal diagnosis (PND),

**England, 2017 to 2018** 

Numerator	Denominator	Performance (%)	Exclusions from the denominator due to missing data
152	365	41.6	1

The numerator relates to PND fetal samples that are taken ≤ 12 weeks + 6 days gestation

Figure 26: SCT-S06: Diagnosis/intervention: timeliness of prenatal diagnosis (PND), England, 2017 to 2018



This standard was collected at the national level for the first time in 2017 to 2018 from NCARDRS and the prenatal diagnostic (PND) laboratories. We will review the data from the PND laboratories to report by maternity service in future.

Recommendation 22: NHS SCT should analyse the data and review the definition and data source (SCT-S06).

#### Intervention/treatment

These standards provide assurance that babies who require treatment receive it in a timely manner.

### Table 21: IDPS-S07: intervention/treatment: timely neonatal hepatitis B vaccination and immunoglobulin, performance, 2017 to 2018

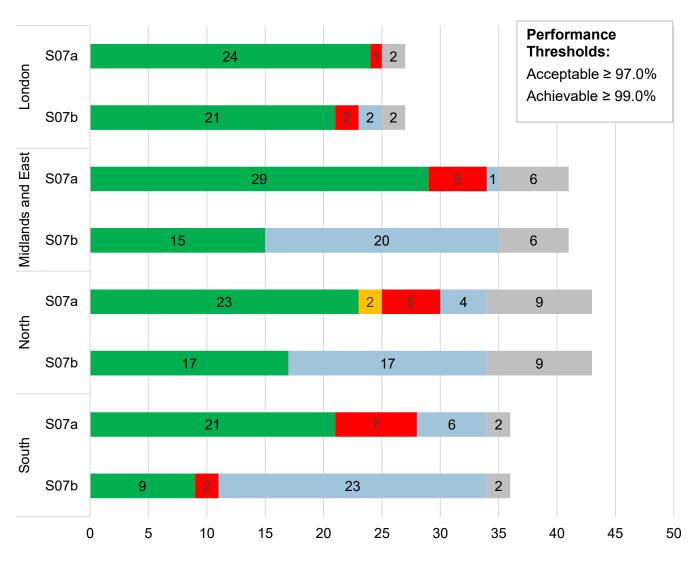
IDPS-S07a: vaccination

Region	Numerator	Denominator	Performance (%)
London	954	955	99.9
Midlands and East	477	483	98.8
North	335	343	97.7
South	284	292	97.3
England	2,050	2,073	98.9

IDPS-S07b: immunoglobulin

Region	Numerator	Denominator	Performance (%)	
London	86	88	97.7	
Midlands and East	36	36	100.0	
North	40	40	100.0	
South	24	26	92.3	
England	186	190	97.9	

Figure 27: IDPS-S07: intervention/treatment: timely neonatal hepatitis B vaccination (a) and immunoglobulin (b), performance against thresholds, 2017 to 2018



Number of maternity services (England total 147)



There were 19 providers that did not submit data for at least one part of IDPS-S07. The North region had the highest number of non-submitters. The number of data returns excluded this year has reduced improving the quality of the data. The London region had the highest number of babies requiring treatment and exceeded the achievable threshold for vaccination.

Recommendation 23: Commissioners should work with providers to make sure data is submitted (IDPS-S07).

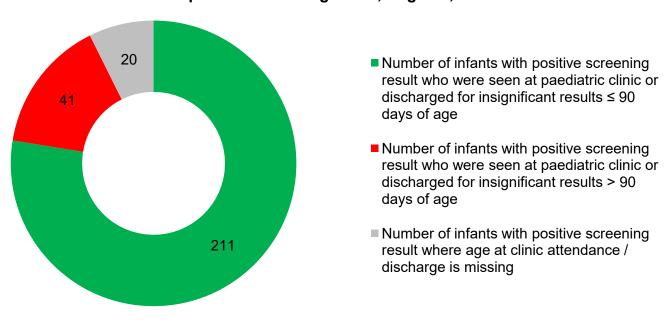
Table 22: SCT-S09: Timely follow-up, diagnosis and treatment of newborn infants with a

positive screening result, performance, 2017 to 2018

Region*	Numerator	Denominator	Performance (%)	Exclusions from the denominator due to missing data
London	121	150	80.7	11
Midlands and East	47	52	90.4	2
North	24	29	82.8	2
South	18	20	90.0	1
Unknown	1	1	100.0	4
England	211	252	83.7	20

<sup>\*</sup> Region relates to the region of the haemoglobinopathy centre (medical) in which the infant was seen or referred to and thus may not reflect the infant's region of residence.

Figure 28: SCT-S09: Intervention/treatment: timely follow-up, diagnosis and treatment of newborn infants with a positive screening result, England, 2017 to 2018



This is the first year of data collection on this standard. We do not have enough information on 20 infants to determine performance, but as this standard gets embedded we expect the completeness of data to improve. Only the Midlands and East and South regions met the acceptable threshold of  $\geq 90.0\%$ .

Recommendation 24: Providers and commissioners in areas not reporting should work with NCARDRS to improve notification and timely submission as required by service specification number 18 (SCT-S09).

# Infectious diseases in pregnancy screening programme: screen positive rates

The data collection for IDPS-S05: referral: timely assessment of screen positive and known positive women includes the collection of the breakdown of women who screen positive. These breakdowns are shown below. Please note that due to data exclusions the absolute numbers reported here may differ from those reported elsewhere.

Table 23: Breakdown of women who screen positive for HIV, England, 2017 to 2018

Breakdown of screen positives		% of total
Newly screened positive women	94	11.3
Previously known positive women, not re-tested	116	14.0
Previously known positive women, re-tested in this pregnancy		74.7
Total screen positive women	829	100.0

Known false positives were excluded from the above.

The above includes data submitted by 130/147 maternity services in England.

Table 24: Breakdown of women who screen positive for hepatitis B, England, 2017 to 2018

Breakdown of screen positives	n	% of total
Newly screened positive women	581	22.9
Previously known positive women, not re-tested	56	2.2
Previously known positive women, re-tested in this pregnancy	1,895	74.8
Total screen positive women	2,532	100.0

The above includes data submitted by 130/147 maternity services in England.

Table 25: Breakdown of women who screen positive for syphilis, England, 2017 to 2018

Breakdown of screen positives	n	% of total
Newly diagnosed requiring treatment	230	27.5
Previously diagnosed requiring treatment	86	10.3
Previously diagnosed not requiring treatment	474	56.8
Other treponemal infections	42	5.0
Unknown	3	0.4
Total screen positive women	835	100.0

The above includes data submitted by 129/147 maternity services in England.

Screen positive rates are calculated as the total number of screen positive women (newly positive or previously known diagnosed) per 1,000 women tested.

Rates for the three infections are calculated using a combination of data from:

- standards 1, 2, 3, on coverage to provide numbers tested and
- standard 5 to provide the number of screen positive women.

Data are only included if trusts provided completed data for both standards. This means that the absolute numbers reported here are lower than those reported for individual standards.

Please note that the below screen positive rates are based upon two separate data collections relating to the number of women who were booked for antenatal care in the reporting period and subsequently tested (including women who were known positives and not retested), and the number of women with screen positive results/known positive status reported in the reporting period. The two cohorts of women may therefore differ slightly, and the below should therefore be interpreted with caution.

For HIV and hepatitis B the number of screen positive women is the total number of women who screen positive during antenatal screening which comprises: women newly diagnosed and those previously diagnosed. Previously known diagnosed women may not be retested in the pregnancy, but will still appear in the women tested and screen positive women totals.

All women are offered screening for syphilis in every pregnancy regardless of history of previous infection. For syphilis, the number of screen positive women is the total number of women who screen positive during antenatal screening. This will include women who are later found to have a treponemal infection that is not syphilis.

For all infections, the rates are calculated based on the total number of women tested.

Table 26: Screen positive rates for HIV in pregnant women, England, 2017 to 2018

		Screen pos	osed women		
			Rate/1,000		Rate/1,000
Region (returns	Women		women		women
included/expected)	tested	n	tested	n	tested
London (25/27)	140,721	312	2.22	26	0.18
Midlands and East	167,351	217	1.30	28	0.17
(34/41)					
North (32/43)	145,529	164	1.13	21	0.14
South (34/36)	144,790	123	0.85	18	0.12
England (125/147)	598,391	816	1.36	93	0.16

<sup>†</sup> Known false positive results are not included in the number of screen positives.

Table 27: Screen positive rates for hepatitis B in pregnant women, England, 2017 to 2018

		Screen pos	itive women	Newly diagn	osed women
			Rate/1,000		Rate/1,000
Region (returns	Women		women		women
included/expected)	tested	n	tested	n	tested
London (25/27)	140,397	1,085	7.73	233	1.66
Midlands and East	167,386	599	3.58	149	0.89
(34/41)					
North (32/43)	145,576	444	3.05	102	0.70
South (34/36)	144,808	358	2.47	91	0.63
England (125/147)	598,167	2,486	4.16	575	0.96

Table 28: Screen positive rates for syphilis in pregnant women, England, 2017 to 2018

				syphi	onfirmed ilis positive vomen‡	v re	en positive vomen, equiring eatment
Region (returns included/expected)	Women	3	Rate/1,000 women	3	Rate/1,000 women	2	Rate/1,000 women
London (25/27)	tested 140,392	n 279	tested 1.99	n 275	tested 1.96	n 109	tested 0.78
Midlands and East (34/41)	167,379	245	1.46	234	1.40	98	0.59
North (32/43)	145,581	205	1.41	178	1.22	59	0.41
South (33/36)	137,988	93 0.67		0.67 93 0		47	0.34
England (124/147)	591,340	822	1.39	780	1.32	313	0.53

<sup>‡</sup>Confirmed syphilis positive excludes women who are found to have a treponemal infection that is not syphilis.

# Sickle cell and thalassaemia screening programme: screen positive rates

The sickle cell and thalassaemia screening programme collects annual data from antenatal screening laboratories. This data is used to determine the proportion of pregnant women who screen positive for significant haemoglobinopathy conditions or carrier states for significant haemoglobinopathy conditions. When women screen positive, testing of the biological father is recommended. Based on the results of both parents, it can be determined whether the pregnancy is at risk of a haemoglobin disorder. The table below presents the proportion of women that screened positive, and the proportion of the screen positive women that were found to be in an at risk couple i.e. a couple where there is a 1 in 4 chance or higher of the fetus being affected by a serious haemoglobin disorder. At risk couples are those where the mother and father results are represented by the dark orange boxes in the breakdown table in Appendix A.

Please note that data returns are only included in Table 29 if data for the number of samples, the number of screen positive women and the number of at risk couples could all be accepted. Data returns are based upon the maternity provider served by the laboratory. The number and proportion of at risk couples shown in Table 29 is likely to be an underestimate due to couples where the baby's biological father's status is unknown.

Table 29: Numbers screened and proportion of screen positive women and at risk couples, antenatal sickle cell and thalassaemia screening, England, 2017 to 2018

	Antenatal screening samples		n positive en (Scr+)	At risk	couples
Region (returns			% of		
included/expected)	n	n	samples	n	% of Scr+
London (21/26)	118,904	5,538	4.66	334	6.03
Midlands and East	199,254	3,402	1.71	169	4.97
(36/39)					
North (35/41)	174,185	2,236	1.28	114	5.10
South (35/38)	148,046	1,602	1.08	81	5.06
England (127/144)	640,389	12,778	2.00	698	5.46

The sickle cell and thalassaemia screening programme also collects annual data from newborn screening laboratories. This data is used to determine the rate of infants with significant conditions and carrier results identified through newborn blood spot screening. Significant conditions comprise FS, FSC, FS-other and FE results. Carrier results comprise FAS, FAC, FAD, FAE and other haemoglobin variants. Data presented is from all thirteen newborn screening laboratories in England.

Table 30: Numbers and rates of significant conditions and carrier results, newborn blood

spot screening for sickle cell disease, England, 2017 to 2018

Region	Babies tested		gnificant Inditions	Carriers		
	n	n	Rate/1,000 babies screened	n	Rate/1,000 babies screened	
London	129,967	139	1.07	3,673	28.26	
Midlands and East	191,340	56	0.29	2,185	11.42	
North	169,140	35	0.21	1,165	6.89	
South	146,255	14	0.10	977	6.68	
Unknown region	14,084	9	0.64	152	10.79	
England	650,786	253	0.39	8,152	12.53	

Region is based upon maternity unit, clinical commissioning group or child health record department of the baby. The geography used differs according to the submitting laboratory. Data is based upon samples received into newborn screening laboratories in 2017 to 2018, apart from for Portsmouth laboratory where data is based on samples from babies born in 2017 to 2018. For two laboratories in England, data provided is based upon samples rather than babies tested.

## **Appendix**

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

								Father's t	est 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
	Hb S														
	βThal														
	db thal														
	Hb Lepore														
art	Hb D														
estres	Hb C														
Mother's test result	Hb E														
Mot	Hb O-Arab														
	HPFH														
	High risk alpha0														
	Compound Heterozygous														
	Egg donor/bone marrow transplant														