Public Health England

Protecting and improving the nation's health

Newborn Blood Spot Screening Programme in the UK

Data collection and performance analysis 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 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 4 UK countries. PHE advises the government and the NHS so England has safe, high quality screening programmes that reflect the best available evidence and the UK NSC recommendations. PHE also develops standards and provides specific services that help the local NHS implement and run screening services consistently across the country.

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Executive summary

This report presents annual screening data for the NHS Newborn Blood Spot (NBS) Screening Programme for the financial year 1 April 2017 to 31 March 2018.

The aim of the report is to feedback performance against the national standards.

Each standard has an acceptable and an achievable threshold. The acceptable threshold is the lowest level of performance which screening services are expected to attain, and the achievable threshold represents the level at which the screening service is likely to be running optimally.

This year we have included recommendations for each standard based on the performance indicated by this year's data.

Child Health Records Departments (CHRDs) returned data for 196 out of 207 (94.7%) CCGs in England. Coverage measured at 17 days (CCG responsibility at birth) was reported to be 96.7% (above the 95% acceptable threshold). For movers in (see standard 1b for definition), coverage measured at 21 days was 90% in England. Whilst this was an improvement from last year's performance (87.1%), it is still under the acceptable threshold of 95%. The screening programme needs to explore this further to understand barriers, impact and interventions that could help improve coverage of movers in.

A total of 648,515 babies were screened in England (755,704 in UK). In England 84.1% of blood spot cards included the baby's NHS number on a bar-coded label, compared to 73.9% in 2016 to 2017. Although some regions are meeting the acceptable threshold (90%), no region is yet meeting the achievable threshold of 95%.

In England, 94.3% of samples were received by laboratories within 3 working days of collection although this ranges by screening region from 84.5% to 97.5%. Northern Ireland achieved 98% and Wales 82.3% The UK mean 93.8%, was just below the acceptable threshold of 95%.

In the UK, the reported number of screen positive babies for each condition were:

- 329 for cystic fibrosis (CF)
- 690 for congenital hypothyroidism (CHT)
- 255 for sickle cell disease (SCD)
- 113 for phenylketonuria (PKU)
- 67 for medium chain actyl co-enzyme deficiency (MCADD)
- 38 for the other 4 inherited metabolic diseases (IMDs)

Not all will have been confirmed to have the disorder in question.

100% of MCADD, MSUD, IVA and GA1 screen positive babies were clinically referred within 3 working days of sample receipt.

99.1% of PKU and 92.7% of CHT screen positive babies were clinically referred within 3 working days of sample receipt.

Blood spot quality continues to improve. Last year (2016 to 2017), England had an avoidable repeat rate of 2.9% and this year this has come down to 2.5%. Four out of the sixteen newborn screening laboratories reported avoidable repeat rate within the 2% acceptable threshold.

The acceptable standard (95% by 28 days) for timeliness of first appointment for CF screen positive babies with 2 mutations, was met in Northern Ireland, whilst for England and Scotland, it accounted for 93.1% and 91.3% of babies respectively. Though there were 9 CF screen positive babies with 2 mutations identified by the Welsh screening programme, age at first appointment was not reported for these 9 babies.

The acceptable standard (80% by 35 days) for timeliness of first appointment for CF screen positive babies with one or no mutations for England, Northern Ireland and Scotland, was 72.3%, 77.8% and 55.6% respectively. There was no age at first appointment reported for the 8 cases of CF screen positive babies with one or no mutations identified in Wales.

Northern Ireland and Scotland met the acceptable standard (100% by 14 days) for timeliness of first appointment for CHT screen positive babies detected on first sample. Wales met the acceptable standard (100% by 21 days) for timeliness of first appointment for CHT screen positive babies detected on second sample.

Recommendations

Standard 1a / KPI NB1: Coverage (CCG responsibility at birth) and Standard 1b / KPI NB4: Completeness of coverage (movers in)

Recommendation
Completeness can be improved in the Midlands and East and North Regions.
Responsibility
Commissioners of child health services.

Standard 2: Timely identification of babies with a null or incomplete result on the CHIS

Recommendation
Completeness of these returns is particularly poor with 72.6% of CCGs returning data. All of those that did return data met at least the acceptable threshold.
Responsibility
Commissioners of child health services.

Standard 3: Barcoded NHS number label is included on the blood spot card

Recommendation
Newborn screening laboratories should make efforts to report by maternity service as this is now a mandatory data field on the blood spot card. This will enable SQAS to monitor performance at maternity service level. This recommendation applies to standards 3 to 6.
Responsibility
Newborn screening laboratories.
Recommendation
Performance continues to rise. Support is still needed to make sure barcoded labels meet the recommended specification.
Responsibility
Providers of maternity services.

Standard 4: Timely sample collection

Recommendation
Sample collection on day 5 should be recommended and reinforced to increase performance against this standard. Babies undergoing transfusion can have the sample collected on days 6 to 8, but they are not excluded from this standard.

Responsibility
Providers of maternity services.

Standard 5: Timely receipt of a sample in the newborn screening laboratory

Recommendation
Support of new standard measuring 3 days within collection needs to be supported and communicated to improve performance.

Responsibility
Providers of maternity services.

Standard 6: Quality of the blood spot sample and Standard 7: Timely taking of a repeat blood spot sample

No recommendation.

Standard 9: Timely processing of CHT and IMD (excluding HCU) screen positive samples

Recommendation
Work to be done on how we measure receipt of sample.

Responsibility
Newborn screening laboratories

Standard 11: Timely entry into clinical care: All conditions

Recommendation
Data for 2017-18 is particularly poor.
Work must be done to improve the completeness of data for timely entry into care.
Communication processes must be improved to address this gap in reporting.

Responsibility
Newborn screening laboratories

Standard 12a: Timeliness of results to parents (CCG responsibility at birth) and Standard 12b: Timeliness of results to parents (movers in)

Recommendation
Completeness for standard 12 is poor. Work needs to be done in Midlands and East, North and South regions to improve completeness and data. The blood spot programme needs to work closely with SQAS in achieving a better data return and communicating the submission process widely.

Responsibility

Commissioners of child health services

Laboratory accreditation (standards 8 and 10) will be published by the United Kingdom Accreditation Service (UKAS).

Acknowledgements

The NHS Newborn Blood Spot (NBS) screening programme would like to thank all those who provided data to the annual collection, in particular the UK newborn screening laboratories and child health records departments (CHRDs) that submitted the 2017 to 2018 data.

Introduction

This report presents screening data and performance analysis for the UK's Newborn blood spot (NBS) screening programmes for the financial year 1 April 2017 to 31 March 2018. The UK National Screening Committee (UK NSC) recommends that all babies in the UK are offered NBS screening for sickle cell disease (SCD), cystic fibrosis (CF), congenital hypothyroidism (CHT) and 6 inherited metabolic diseases (IMDs): phenylketonuria (PKU), medium-chain acyl-CoA dehydrogenase deficiency (MCADD), maple syrup urine disease (MSUD), isovaleric acidaemia (IVA), glutaric aciduria type 1 (GA1) and homocystinuria (pyridoxine unresponsive) (HCU). The overall goal is to prevent ill health, disability and death through early diagnosis and effective intervention.

One of the objectives of the NHS NBS screening programme is to set national standards (see Table 1 and Figure 1). National standards are important to support the delivery and quality assurance of the screening programme and are used by local commissioners and quality improvement groups. The aim of this report is to feedback performance against the national standards. Providers, commissioners and the Screening Quality Assurance Service (SQAS) are encouraged to review this report to identify areas for improvement locally.

The newborn blood spot screening standards were revised in 2017 and this report reflects the new measures.

Table 1a: NBS standards (2017) Reporting focus and completeness

Standard	Reporting responsibility	Reporting process	Reporting focus	Completeness 2017/18 (UK)
Standard 1a: Completeness of coverage (CCG responsibility at birth). Collected as KPI NB1	CHRD	CCG	KPI quarterly submission	196/207 (94.7%)
Standard 1b: Completeness of coverage (movers in). Collected as KPI NB4	CHRD	CCG	KPI quarterly submission	196/207 (94.7%)
Standard 2: Timely identification of babies with a null or incomplete result recorded on the child health information system	CHRD	CCG	Annual data submission direct to NBS programme	170/207 (82.1%)
Standard 3: Barcoded NHS number is included on the blood spot card	Newborn screening laboratory	CHRD/CCG/Maternity unit (England), child health service (Northern Ireland), health board (Wales) or laboratory catchment area (Scotland)	Annual data submission direct to NBS programme	16/16 (100%)
Standard 4: Timely sample collection	Newborn screening laboratory	CHRD/CCG/Maternity unit (England), child health service (Northern Ireland), health board (Wales) or laboratory catchment area (Scotland)	Annual data submission direct to NBS programme	16/16 (100%)

Standard	Reporting responsibility	Reporting process	Reporting focus	Completeness 2017/18 (UK)
Standard 5: Timely receipt of a sample in the newborn screening laboratory	Newborn screening laboratory	CHRD/CCG/Maternity unit (England), child health service (Northern Ireland), health board (Wales) or laboratory catchment area (Scotland)	Annual data submission direct to NBS programme	16/16 (100%)
Standard 6: Quality of the blood spot sample	Newborn screening laboratory	CHRD/CCG/Maternity unit (England), child health service (Northern Ireland), health board (Wales) or laboratory catchment area (Scotland)	Annual data submission direct to NBS programme	16/16 (100%)
Standard 9: Timely processing of all CHT and IMD screen positive samples	Newborn screening laboratory	Annual data submission direct to NBS programme	Newborn screening laboratory	16/16 (100%)
Standard 11: Timely entry into clinical care**	Newborn screening laboratory	Annual data submission direct to NBS programme	Newborn screening labTE	PKU- 61.1% MCADD- 76.2% IVA – 75% GA1- 100% HCU- 66.7% MSUD- 50.0% CHT- 93.0% CF- 66.8%
Standard 12a: Timeliness of results to parents (CCG responsibility at birth)	CCG	CHRD	Annual data submission direct to NBS programme	165/207 (82.1%)
Standard 12b: Timeliness of results to parents (movers in)	CCG	CHRD	Annual data submission direct to NBS programme	117/207* (56.5%)

*29 CCGs received the wrong template for reporting and therefore we do not have a complete dataset for Standard 12. Some CCGs have returned separate data for standard 12 and 12b and some returned data as a whole for the previous version of the standard, which combined both parts a and b.

**Completeness of appointment data excludes babies clinically diagnosed and is shown as percentage of all screen positive babies that have an age at appointment reported.

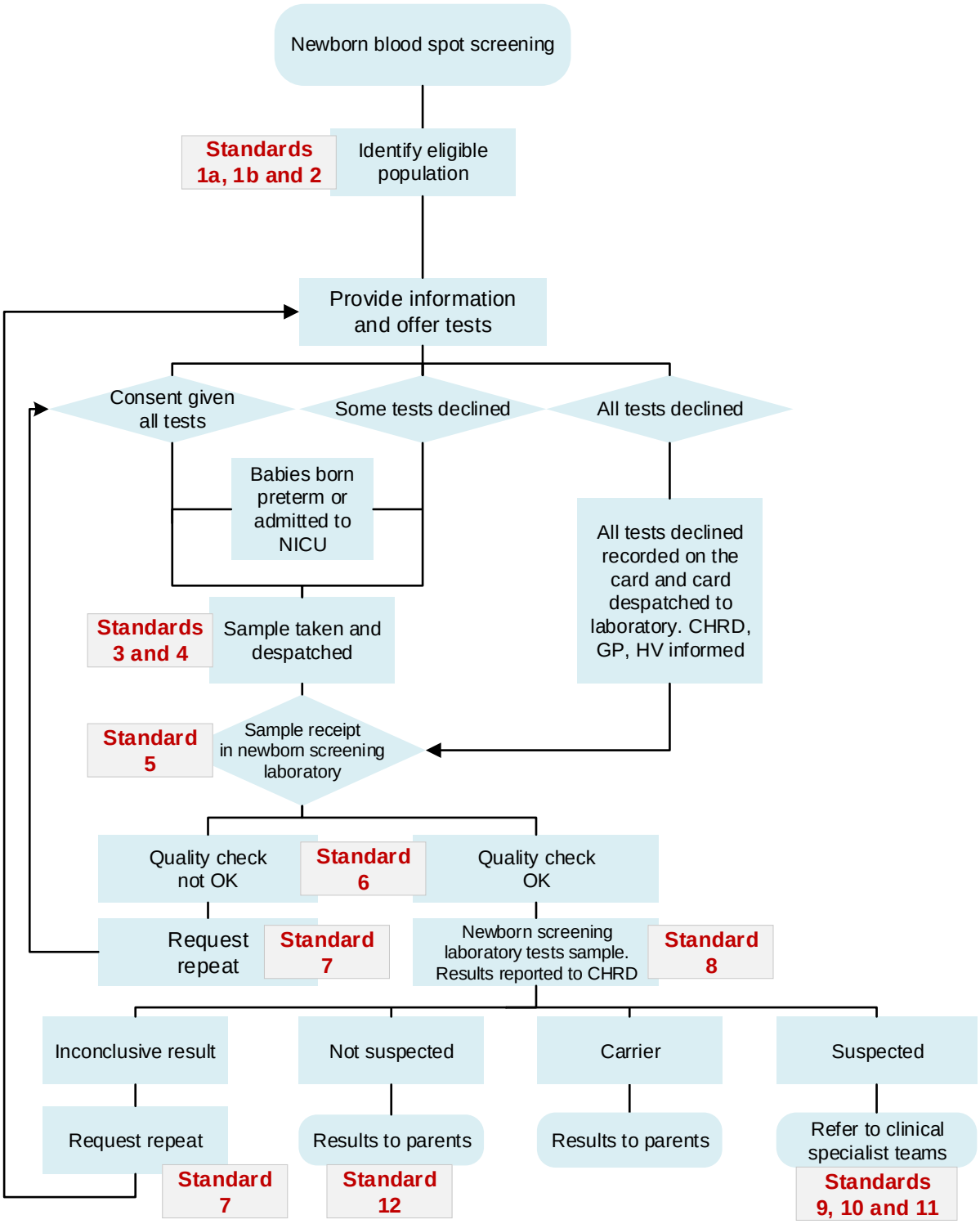
Standard 7 a, b and c (timely taking of a second blood spot sample) is not currently collected. Standard 8 (UKAS screening) and standard 10 (UKAS diagnosis) are part of UKAS accreditation and not included in this report.

Data are presented by financial year (1 April to 31 March) unless stated otherwise. The year '2017 to 2018' for example, refers to the financial year 1 April 2017 to 31 March 2018.

Table1b: Table of how newborn screening laboratories report standards data by:

Laboratory	Report standards data by:
Bristol	Maternity Services
Cambridge	Maternity Services
Great Ormond Street Hospital (GOSH)	Maternity Services
Leeds	Maternity Services
Liverpool	CCG
Manchester	Maternity Services
Newcastle	CCG
Oxford	CHRD
Portsmouth	CHRD
SE Thames	Maternity Services
Sheffield	CHRD
SW Thames	Maternity Services
West Midlands	CHRD
Northern Ireland	HSC Trust
Scotland	Country
Wales	Health Board

Figure 1: NBS standards mapped to a generic screening pathway



Analysis of screening performance

Overview of UK national screening figures

Number of babies tested and number of screen positive results.

Table 2: Number of UK babies tested and number of screen positive results for SCD, CF and CHT 1 April 2017 to 31 March 2018

Laboratory	SCD		CF		CHT	
	Number tested	Number of screen positives	Number tested	Number of screen positives	Number tested	Number of screen positives
Bristol	39,345	4	39,345	22	39,345	43
Cambridge	27,008	3	27,008	14	27,008	18
GOSH	121,488	79	121,488	34	121,488	127
Leeds	41,174	11	41,293	19	41,293	41
Liverpool	28,230	3	28,191	11	28,191	34
Manchester	53,098	15	52,992	26	53,335	49
Newcastle	31,562	5	31,075	17	31,075	36
Oxford	27,337	9	28,036	10	28,036	19
Portsmouth	36,834	4	34,578	14	35,032	37
SE Thames	57,919	49	55,711	19	55,990	40
Sheffield	68,612	15	67,705	30	68,119	68
SW Thames	51,143	35	51,050	14	51,050	38
West Midlands	67,924	21	68,553	32	68,553	63
England	651,674	253	647025	262	648,515	613
Northern Ireland	22,923	0	22,833	18	22,922	21
Scotland	52,552	2	52,552	32	52,552	37
Wales	31,715	2	31,653	17	31,715	19
UK total	758,864	257	754,063	329	755,704	690

Data source: Newborn screening laboratories

We would normally expect to see a lower number of babies tested for CF, than for the other conditions, as the screening test is not reliable, and therefore not undertaken, in babies over 8 weeks of age. This will apply to some movers in. This is reflected in data from 6 of the laboratories.

Note that a significant proportion of screen positive results will not be confirmed cases.

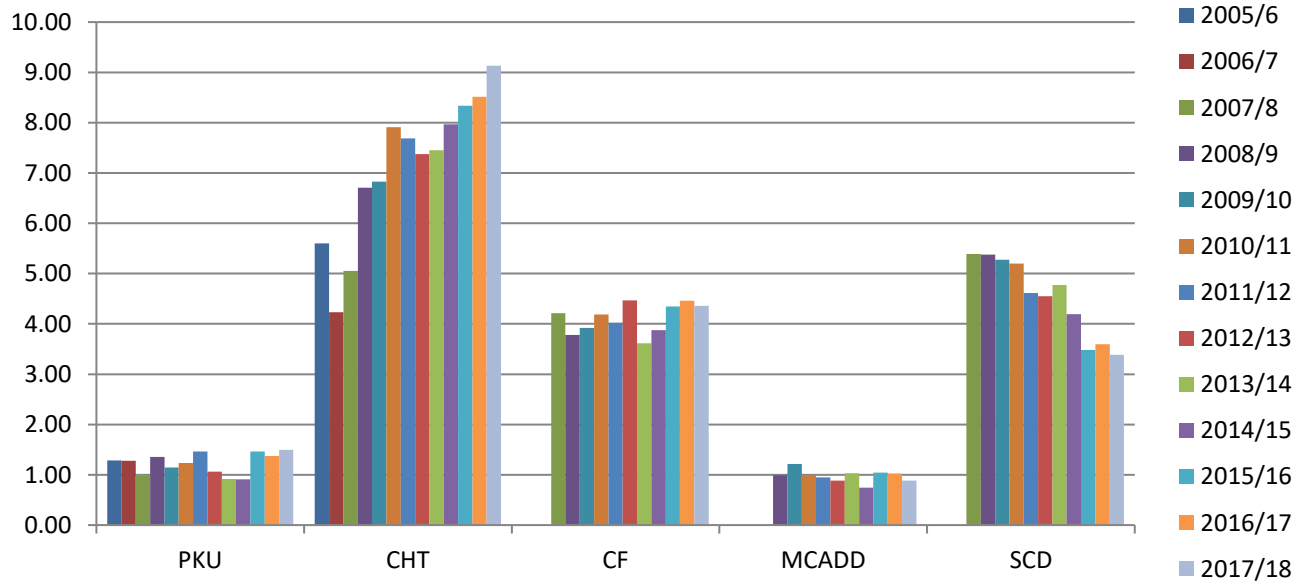
Table 3: Number of UK babies tested and number of screen positive results for IMDs 1 April 2017 to 31 March 2018

Laboratory	PKU		MCADD		MSUD, IVA, GA1, HCU	
	Number tested	Number of screen positives	Number tested	Number of screen positives	Number tested	Number of screen positives
Bristol	39,345	2	39,345	3	39,345	1
Cambridge	27,008	4	27,008	5	27,008	2
GOSH	121,488	9	121,488	10	121,488	7
Leeds	41,293	7	41,293	5	41,293	2
Liverpool	28,191	3	28,191	3	28,191	0
Manchester	53,335	5	53,335	7	53,335	5
Newcastle	31,075	7	31,075	2	31,075	0
Oxford	28,036	3	28,036	2	28,036	1
Portsmouth	35,032	7	35,032	2	35,032	0
SE Thames	55990	15	55,990	3	55,990	2
Sheffield	68,119	13	68,119	5	68,119	4
SW Thames	51,050	6	51,050	4	51,050	4
West Midlands	68,553	5	68,553	5	68,553	5
England	648,515	86	648515	56	648,515	33
Northern Ireland	22,922	7	22,922	3	n/a*	n/a
Scotland	52,552	16	52,552	4	52,552	5
Wales	31,715	4	31,715	4	31,715	0
UK total	755,704	113	755704	67	755,704	38

Data source: Newborn screening laboratories

*Northern Ireland do not screen for MSUD, IVA, GA1 or HCU.

Figure 2: Screen positive rate (per 10,000) for babies screened for PKU, CHT, CF, MCADD and SCD 2005 to 2018



Data source: Newborn screening laboratories

Data for SCD includes England only prior to 2015 to 2016.

It can be observed that the screen positive rate for CHT is rising and for SCD is falling. There is no evidence to explain these trends, there may be several confounding factors. The TSH cut off levels for CHT borderline samples is not the same across the country and therefore those laboratories using a lower cut off are reporting higher incidence of screen positive cases. When all laboratories use the same cut off level, incidence should stabilise, and a true screen positive rate can be measured.

Standard 1a / KPI NB1: Coverage (CCG responsibility at birth)

Description

The proportion of babies registered within the CCG both at birth and on the last day of the reporting period who are eligible for NBS screening and have a not suspected, suspected or carrier result recorded on the CHIS for each of the 9 conditions at less than or equal to 17 days of age.

Acceptable threshold

≥ 95.0% of eligible babies have a result for each of the 9 conditions recorded on the CHIS at less than or equal to 17 days of age.

Achievable threshold

≥ 99.0% of eligible babies have a result for the IMDs recorded on the CHIS at less than or equal to 17 days of age.

Achievable threshold

≥ 98.0% of eligible babies have a result for CF, CHT and SCD recorded on the CHIS at less than or equal to 17 days of age.

This standard is a Key Performance Indicator (KPI). PKU is used as a proxy for all conditions screened for, through newborn blood spot screening. More information on KPI definitions can be found on Gov.UK. The Newborn Blood Spot Failsafe Solution (NBSFS) now records ‘screening complete’ status which will enable coverage reporting for each condition in the future. Data on standards 1a and1b are collected as key performance indicators (KPIs); compiled from 4 quarterly returns. In the annual KPI data, providers are excluded where data has not been submitted for all 4 quarters in that year.

Table 4: Coverage of newborn screening measured against PKU: CCG responsibility at birth (born and registered population), 1 April 2017 to 31 March 2018: England and Northern Ireland

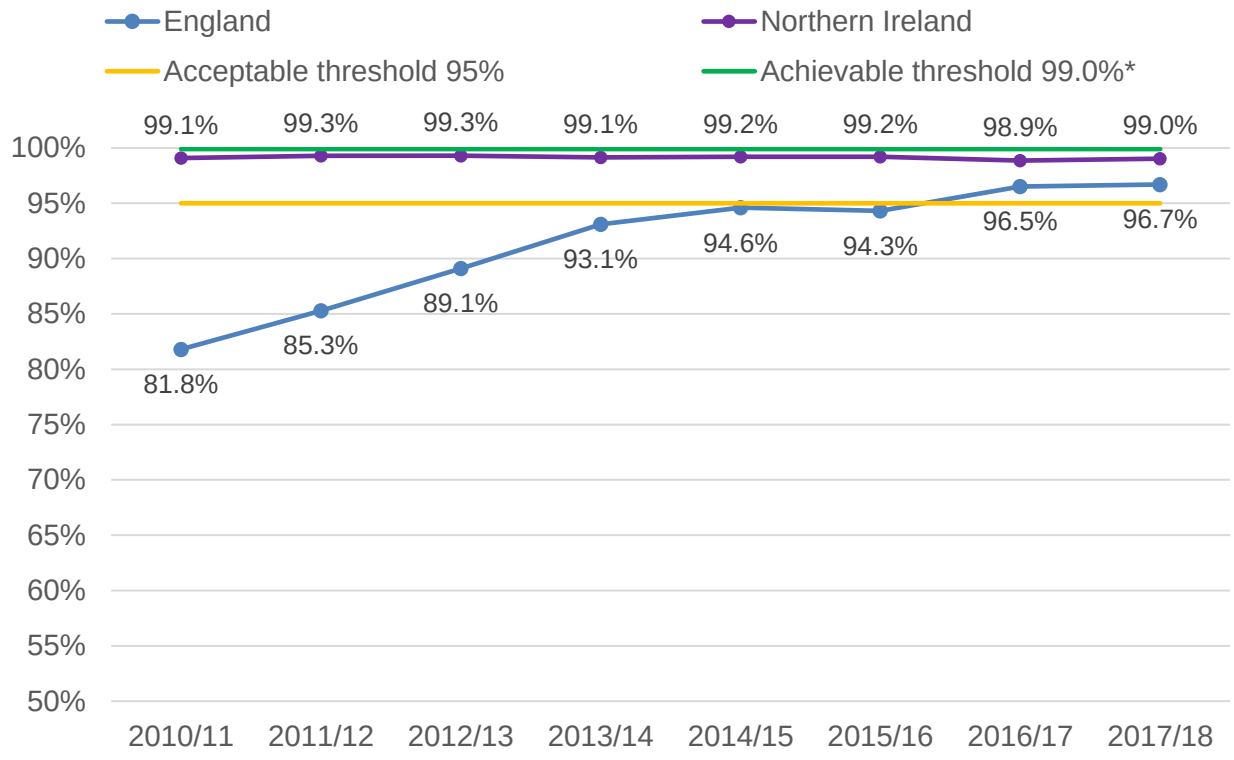
Region	Eligible babies	Tested babies	Coverage (%)
England	566,557	547,645	96.7
London	120,648	115,258	95.5
Midlands & East	150,642	145,850	96.8
North	152,468	147,623	96.8
South	142,799	138,914	97.3
Northern Ireland	22,568	22,362	99.0

Table 5: Completeness of data for coverage, England and Northern Ireland, 1 April 2017 to 31 March 2018

Completeness	Number of returns	No. of 'No returns'	% Complete
England	196	11	94.7
London	32	0	100.0
Midlands & East	55	6	90.2
North	59	5	92.2
South	50	0	100.0
Northern Ireland	1	0	100.0

Data source: national quarterly [annual aggregate] KPI data collection

Figure 3: Coverage of newborn screening measured using PKU: CCG responsibility at birth (born and registered population, measured at 17 days), 2010 to 2018



Data source: national quarterly [annual aggregate] KPI data and annual CHRD data collection received from Northern Ireland. Please note the y axis does not start at 0%

The achievable threshold was lowered from 99.9% to 99.0% in 2017 and subsequently this threshold was met by Northern Ireland in 2017-18. Performance against the standard continues to improve overall in England with all regions meeting the acceptable threshold. Completeness can be improved in the Midlands and East and North Regions.

Standard 1b / KPI NB4: Completeness of coverage (movers in)

Description

The proportion of all babies eligible for newborn blood spot (NBS) screening who have both:

- changed responsible clinical commissioning group (CCG), or have moved in from another UK country or abroad, in the reporting period
- a conclusive result for phenylketonuria (PKU) recorded on the child health information service system (CHISS) at less than or equal to 21 calendar days of notifying the child health department of movement in.

Acceptable threshold

≥ 95.0% of eligible babies have a result for each of the 9 conditions (or 5 conditions if not eligible for expanded screening) recorded on the CHIS at less than or equal to 21 calendar days of notifying the CHRD of movement in.

Achievable threshold

≥ 99.0% of eligible babies have a result for the IMDs recorded on the CHIS at less than or equal to 21 calendar days of notifying the CHRD of movement in.

Table 6. KPI NB-4. Coverage of newborn screening measured using PKU: movers in, 1 April 2017 to 31 March 2018: England

Regional summary	Eligible babies	Tested babies	Coverage (%)
England	42,834	38,550	90.0
London	10,160	8,981	88.4
Midlands & East	11,701	10,517	89.9
North	10,897	9,935	91.2
South	10,076	9,117	90.5

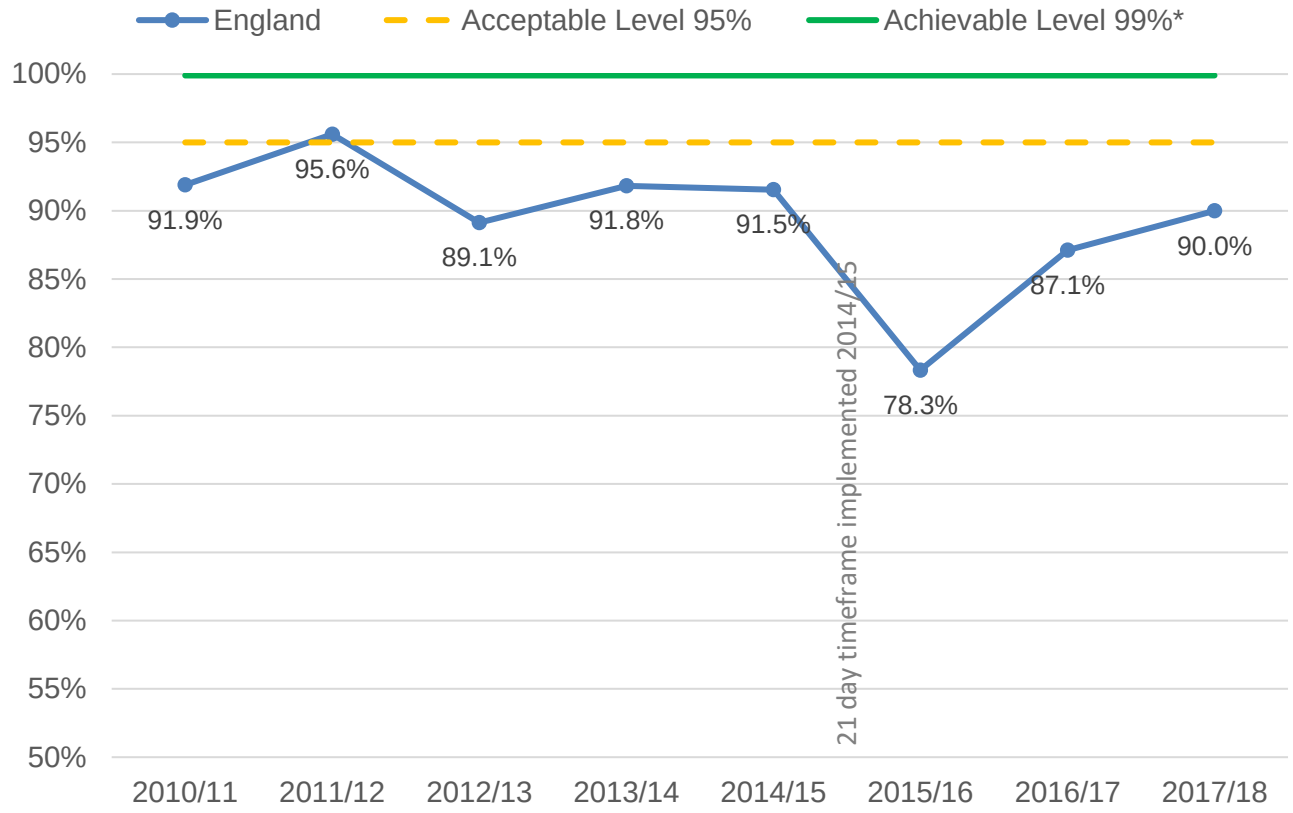
Table 7: Completeness of data for coverage, movers in, England and Northern Ireland, 1 April 2017 to 31 March 2018

Completeness	Number of returns	No. of 'No returns'	% Complete
England	196	11	94.7
London	32	0	100.0
Midlands & East	55	6	90.2
North	59	5	92.2
South	50	0	100.0

Data source: national quarterly [annual aggregate] KPI data collection

From 2010 to 2014, data was collected to measure coverage for movers in without applying an effective timeframe. Standard 1b introduces an effective timeframe of 21 calendar days; 2014 to 2018 data are presented with the timeframe in addition to year-on-year data without the timeframe. The introduction of the timeframe effected performance as seen in 2015/16 data but since this adjustment performance has risen yearly to 90%. Northern Ireland did not return data for babies tested within the timeframe for 2017 to 2018.

Figure 4: Completeness of coverage for PKU (movers in) 2010 to 2018



Data source: national quarterly [annual aggregate] KPI data collection

*Achievable threshold changed from 99.9% to 99% in 2017.
Please note the y axis does not start at 0%.

CHRD process data

Table 8: Receipt, recording and despatch of results by CHRDs 1 April 2017 to 31 March 2018 (reported per CCG)

Number of CHRDs that:													
Region / Country	receive results by hard copy		receive results by email		receive results by electronic messaging		receive results with status codes		record results using status codes		send letters directly to parents when 04* is reported on all conditions		total number of CCGs**
	n	%	N	%	n	%	n	%	n	%	n	%	n
London	0	0.0	32	100	0	0.0	32	100	32	100	32	100	32
Midlands and East	4	7.8	36	70.6	15	29.4	51	100	51	100	46	90.2	51
North	27	57.4	34	72.3	20	42.6	47	100	44	93.6	32	68.1	47
South	30	65.2	32	69.6	17	37.0	46	100	46	100	46	100	46
England	61	34.7	134	76.1	52	29.5	176	100	173	98.3	156	88.6	176
Northern Ireland†	1	100	0	0.0	1	100.0	1	100	1	100	0	0.0	1

Data source: CHRDs

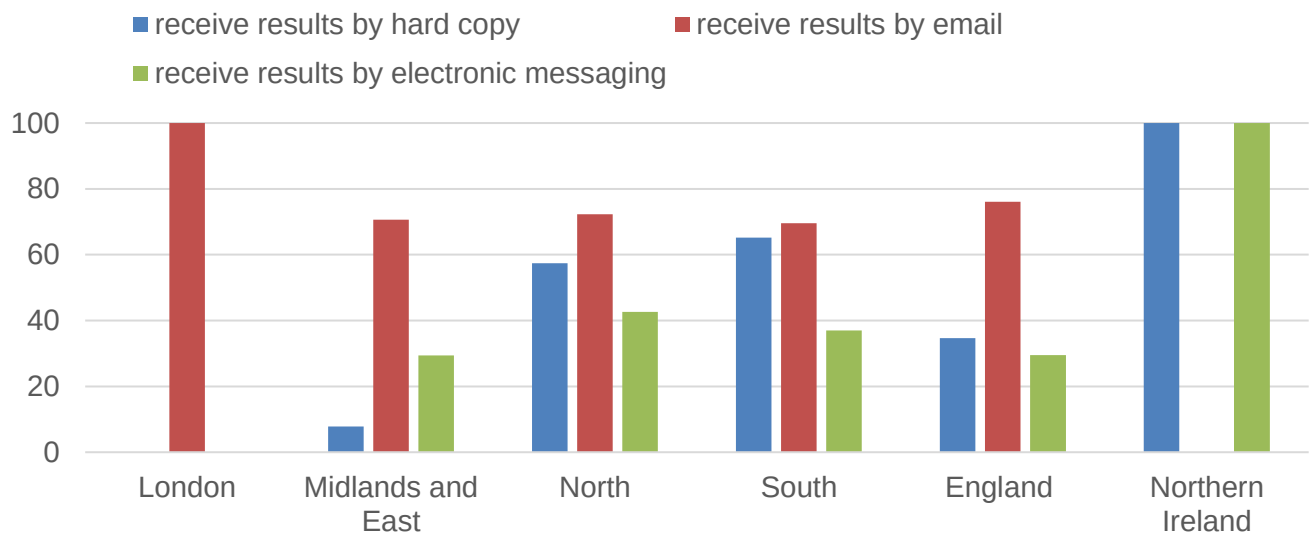
*Status code 04; condition screened for not suspected

**For which a return was received. For some CCGs more than one return was received

†Northern Ireland does not issue letters regarding results to parents. Results go to parents via the health visitor and a second set of results are inserted in the PCHR

The data highlights the multiplicity of methods by CHRDs receive results.

Figure 5: Percentage of CHRDs who receive results by hard copy, email and electronic messaging 2017 to 2018



Data source: CHRDs

Standard 2: Timely identification of babies with a null or incomplete result on the CHIS

Description

The NBS programme relies on regular checks of the CHIS to identify babies with a null or incomplete result within an effective timeframe. Reports are produced to identify these babies and action is taken to follow them up, according to local protocols.

Acceptable threshold

CHRD performs regular checks (ideally daily, minimum weekly) to identify babies ≥ 17 days and ≤ 364 days with a null or incomplete result.

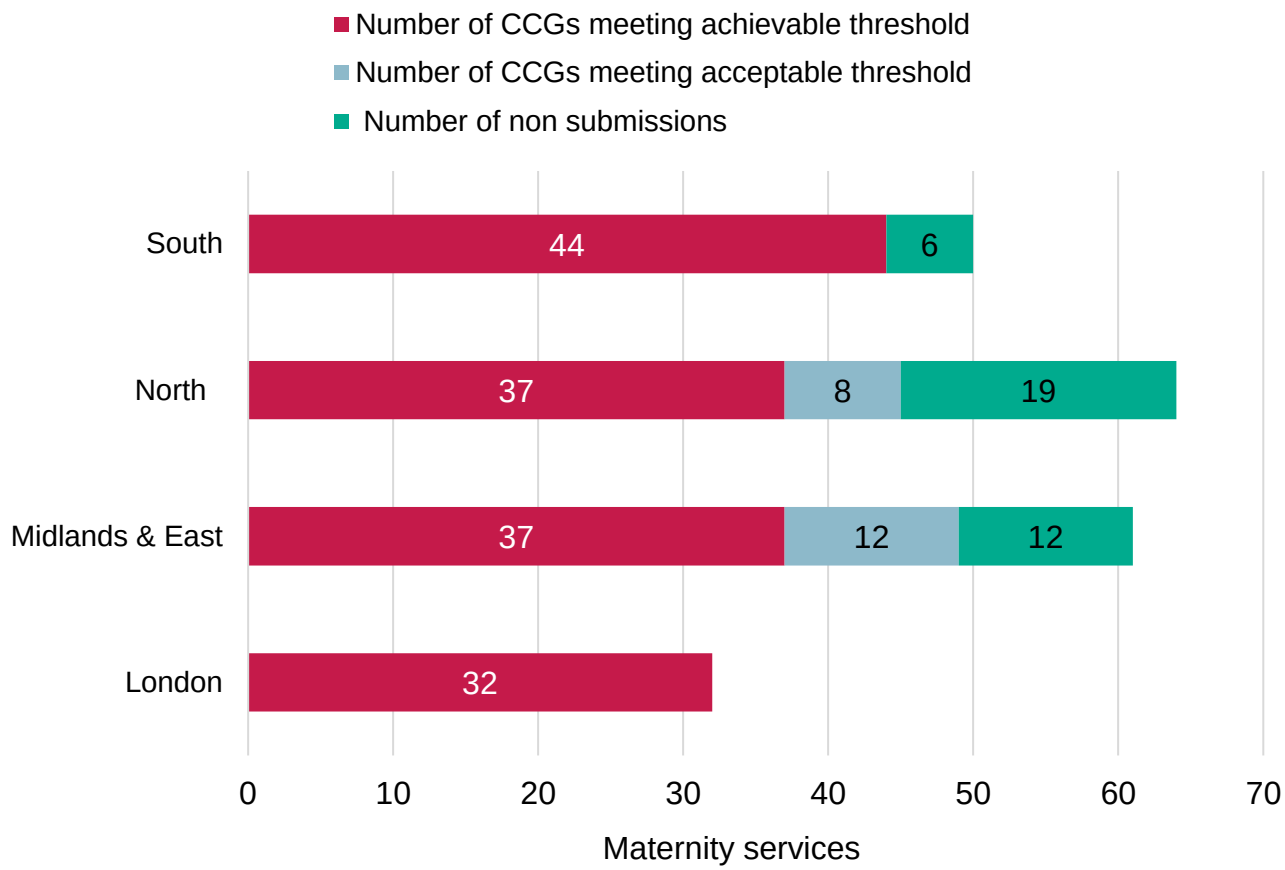
Achievable threshold

CHRD performs regular checks (ideally daily, minimum weekly) to identify babies ≥ 14 days and ≤ 364 days with a null or incomplete result.

Table 9: Number and percentage of CHRDs that search for missing results at 17 days, 14 days, 1 April 2017 to 31 March 2018

Completeness	Number of returns	No. of 'No returns'	% Complete
England	196	11	94.7
London	32	0	100.0
Midlands & East	55	6	90.2
North	59	5	92.2
South	50	0	100.0

Figure 6: Number of CHRDs that search for missing results at 17 days, 14 days, 1 April 2017 to 31 March 2018



Completeness of these returns is particularly poor with 72.6% of CCGs returning data. All of those that did return data met at least the acceptable threshold.

The Newborn Blood Spot Failsafe Solution (NBSFS) alerts maternity sites and CHRDs of babies born in England who have not been offered screening. It is unclear whether CHRDs checking NBSFS are reporting this as their process for identifying missing results. NBSFS does not receive notification of babies born outside England, so regular checks of the CHIS are still required.

Standard 3: Barcoded NHS number label is included on the blood spot card

Description

Use of the NHS number on the baby's blood spot card is mandatory in England. Use of a barcoded NHS number label will reduce the risk of an inaccurate NHS number on the blood spot card which would require a repeat sample to be taken.

Acceptable threshold

≥ 90.0% of blood spot cards are received by the laboratory with the baby's NHS number on a barcoded label.

Achievable threshold

≥ 95.0% of blood spot cards are received by the laboratory with the baby's NHS number on a barcoded label.

Table 10: Use of the bar-coded label 1 April 2017 to 31 March 2018, England

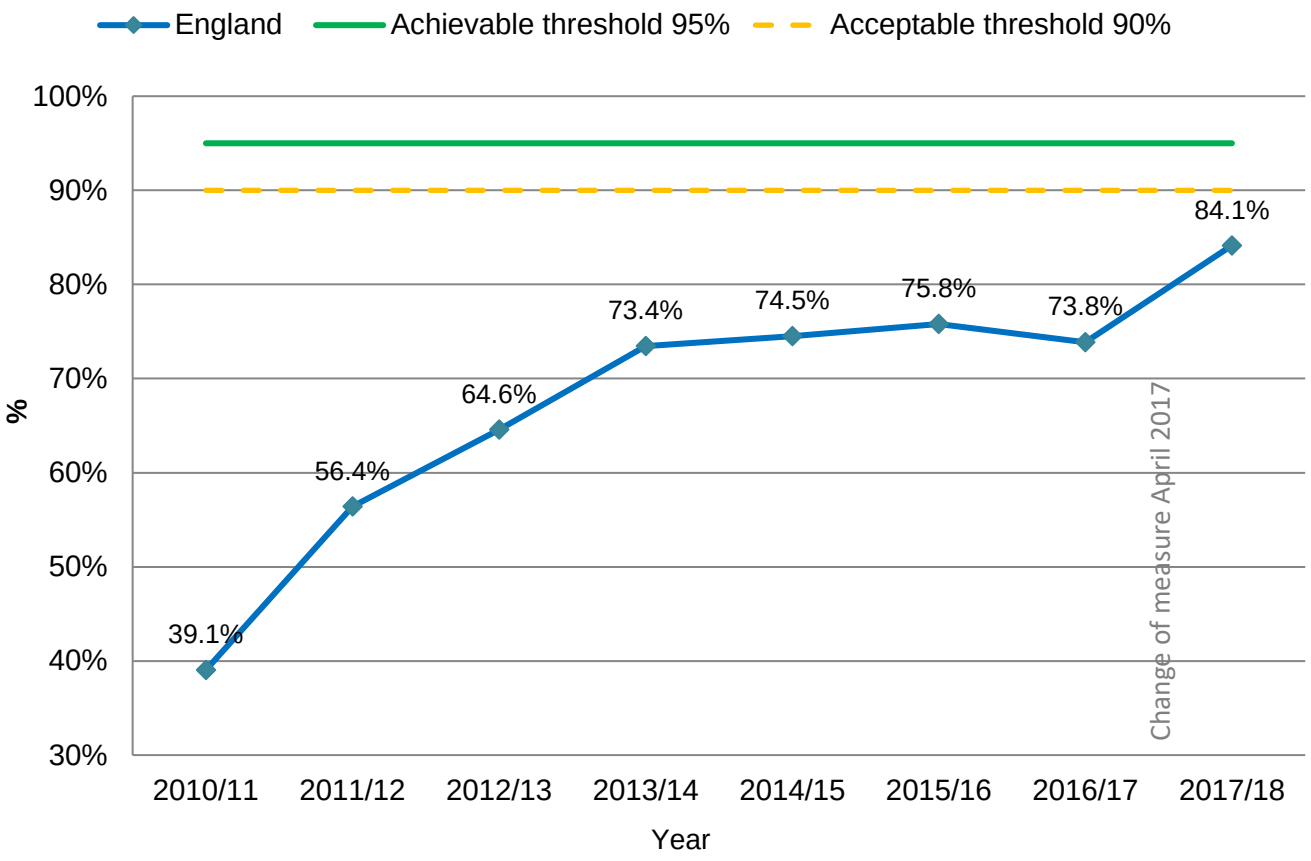
Regional summary	Denominator	Numerator	Performance (%)
Bristol	37,950	34,780	91.6%
Cambridge	29,651	27,400	92.4%
GOSH	125,483	104,754	83.5%
Leeds	43,516	32,033	73.6%
Liverpool	29,844	23,253	77.9%
Manchester	53,757	45,106	83.9%
Newcastle	33,150	27,175	82.0%
Oxford	29,699	22,607	76.1%
Portsmouth	32,884	26,975	82.0%
SE Thames	57,979	51,273	88.4%
Sheffield	72,059	62,183	86.3%
SW Thames	52,880	47,240	89.3%
West Midlands	71,872	59,597	82.9%
England	670,724	564,376	84.1%

Data source: Newborn screening laboratories

*Use of Health and Care number (equivalent to NHS number) in Northern Ireland is not mandatory

'Out of area' samples have been removed from this data.

Figure 7: Percentage of blood spot cards including a bar-coded NHS number (or UK equivalent) 2010 to 2018, England



Data source: Newborn screening laboratories

Both Wales and Scotland do not currently use bar coded label, but both reported 98.8% of samples received in the lab were complete with NHS number.

The increase in performance in 2017/18 can be attributed to bar coded label becoming a standard in 2017. Previously, NHS number was the acceptable measure, bar coded label was the achievable measure.

Standard 4: Timely sample collection

Description

It is essential to take the blood spot sample promptly to give each screen positive baby the best possible chance of receiving early treatment. The health professional responsible for taking the blood sample should adhere to the guidelines for newborn blood spot sampling to ensure a valid sample is taken.

Acceptable threshold

Equal to or greater than 90% of first samples taken on day 5.

Achievable threshold

Equal to or greater than 95% of first samples taken on day 5.

Table 11: Day of first sample collection 1 April 2017 to 31 March 2018*

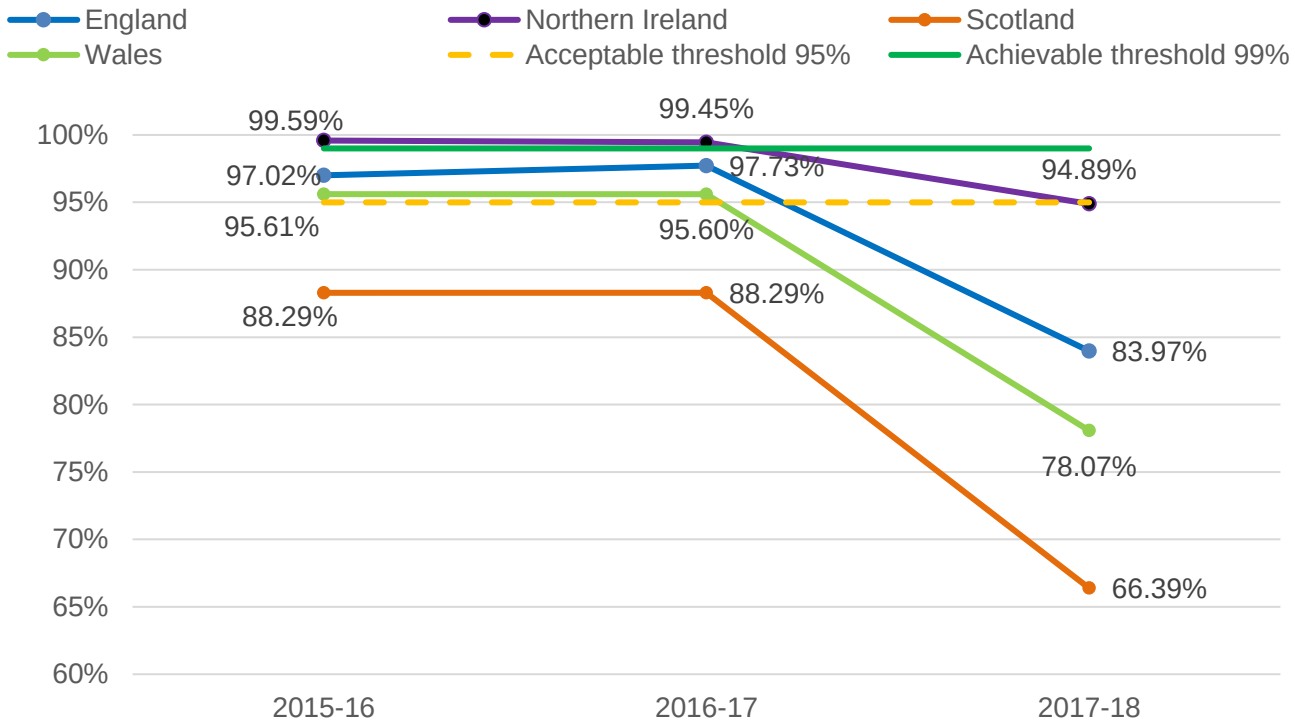
Laboratory	Total number of samples	Number of samples taken on day 5	% of samples taken on day 5
Bristol	35,139	29,482	83.9%
Cambridge	26,906	24,892	92.5%
GOSH	123,507	92,812	75.1%
Leeds	40,895	33,100	80.9%
Liverpool	28,534	24,895	87.2%
Manchester	50,394	43,676	86.7%
Newcastle	31,075	26,758	86.1%
Oxford	25,725	22,406	87.1%
Portsmouth	31,660	28,629	90.4%
SE Thames	55,917	46,915	83.9%
Sheffield	67,727	55,193	81.5%
SW Thames	50,973	43,359	85.1%
West Midlands	67,282	61,727	91.7%
England total	635,734	533,844	84.0%
Northern Ireland	22,953	21,780	94.9%
Scotland†	52,494	34,850	66.4%
Wales	31,603	24,674	78.1%
UK Total	742,784	615,148	82.8%

Data source: Newborn screening laboratories

*For the purposes of this standard, day of birth is taken as day 0. Pre-transfusion samples are excluded from the denominator and numerator.

†Scotland accept samples to be taken on or before day 4 without asking for repeat. In 2017 to 2018 21.5% of samples were received on or before day 4. If these are included, the percentage (%) will be higher.

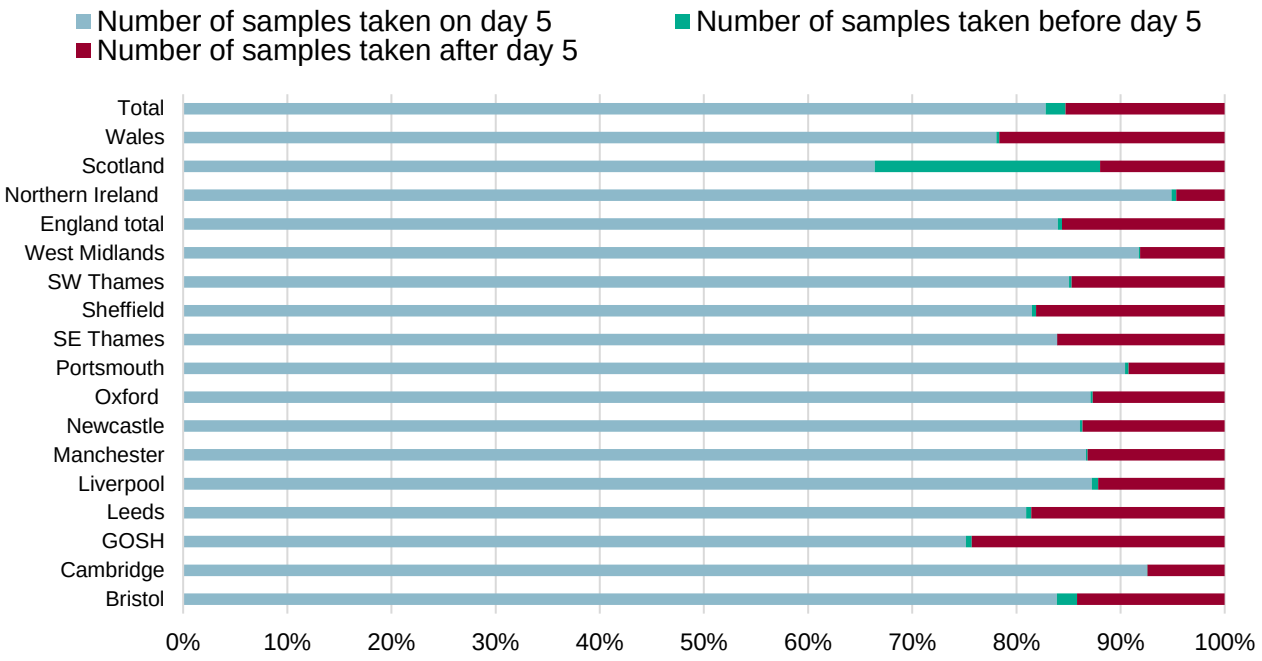
Figure 8: Percentage of samples taken day 5-8, 2015 to 2017 and on day 5, 2015 to 2018



Data source: Newborn screening laboratories

Prior to 2017, the standard measured sample collection day 5 to 8. The number of blood spots taken on day 5 has increased in all countries but has yet to meet the acceptable threshold in England, Scotland or Wales.

Figure 9: Percentage of samples taken before, on and after day 5, 2017 to 2018



Data source: Newborn screening laboratories
Scotland do not measure day 4 as too early for sample collection and therefore have a large proportion of samples taken on day 4.

Standard 5: Timely receipt of a sample in the newborn screening laboratory

Description

All samples must arrive within the screening laboratory as soon as possible after the sample has been taken. This enables the laboratory to analyse the sample at the earliest opportunity and also reduces the risk of sample deterioration due to prolonged despatch.

Acceptable threshold

≥ 95.0% of all samples received less than or equal to 3 working days of sample collection.

Achievable threshold

≥ 99.0% of all samples received less than or equal to 3 working days of sample collection.

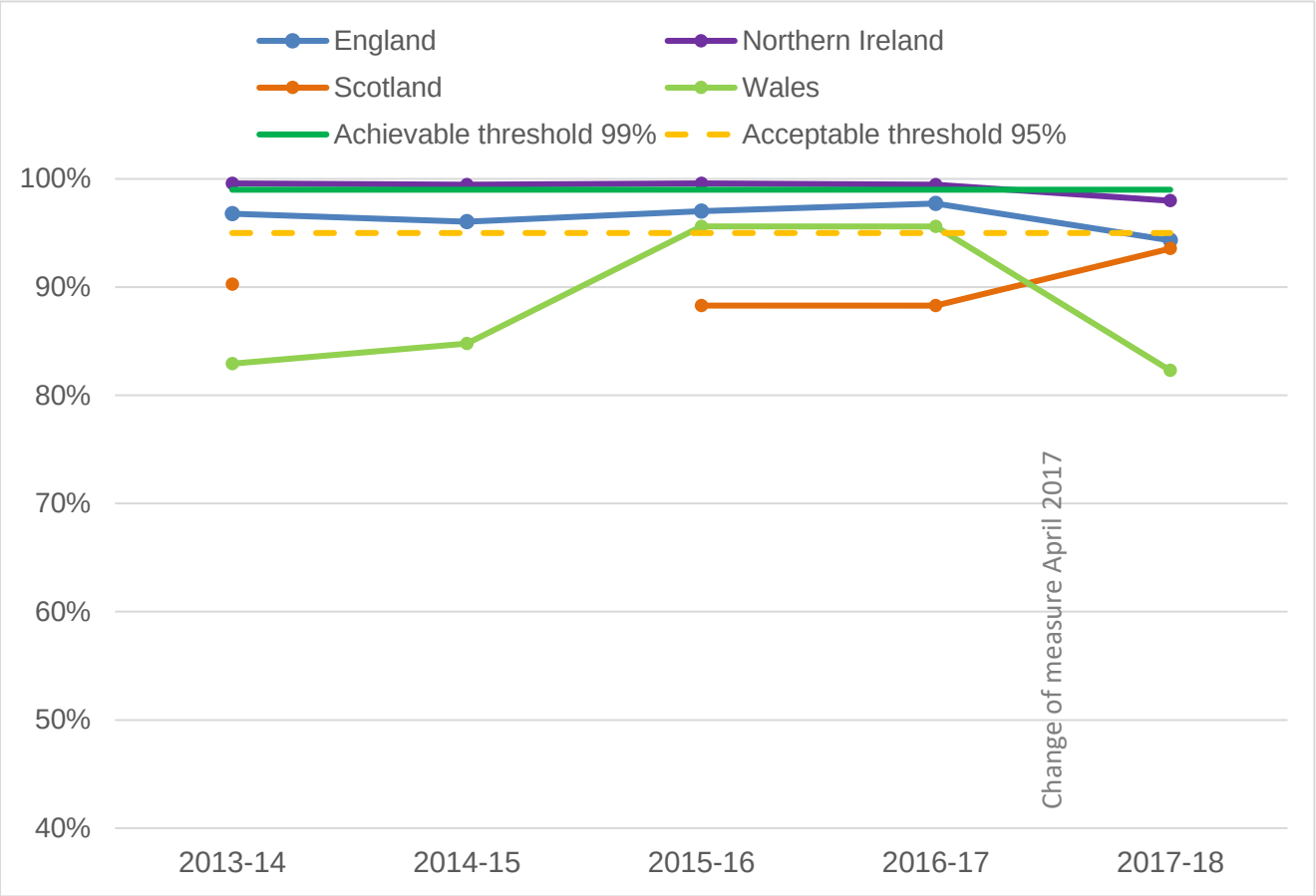
Table 12: Number of working days taken to receive sample 1 April 2017 to 31 March 2018

Laboratory	Samples received within 3 working days	
	n	%
Bristol	32,082	84.5%
Cambridge	26,697	96.5%
GOSH	118,258	94.5%
Leeds	39,928	91.8%
Liverpool	29,220	97.9%
Manchester	51,350	97.6%
Newcastle	31,061	93.9%
Oxford	25,427	85.6%
Portsmouth	31,195	95.4%
SE Thames	55,446	95.6%
Sheffield	66,183	92.5%
SW Thames	51,745	97.9%
West Midlands	70,022	97.5%
England total	628,614	94.3%
Northern Ireland	24,712	98.0%
Scotland	49,113	93.6%
Wales	29,036	82.3%
UK total	731,475	93.8%

Data source: Newborn screening laboratories

'Out of area' samples have been removed from this data.

Figure 10: Number of samples received in 4 working days, 2013 to 2017 and 3 working days of sample being taken, 1 April 2017 to 31 March 2018



Data source: Newborn screening laboratories
Please note the Y axis does not begin at zero.

In April 2017 the standard was changed from measuring samples received in the lab within 3 (achievable threshold) and 4 (acceptable threshold) to measuring all samples received within 3 working days of sample collection.

Standard 6: Quality of the blood spot sample

Description

Good quality blood spot samples are vital to ensure that babies with rare but serious conditions are identified and treated early.

Good quality samples should be obtained first time to prevent the need for avoidable repeats. Avoidable repeat samples can cause anxiety for parents, distress to babies and delays in the screening process. They are also a waste of resources.

A good quality blood spot sample is one that:

- is taken at the right time
- has all data fields completed to enable identification of the baby, analysis and reporting of results
- contains sufficient blood to perform all tests (each circle filled and evenly saturated by a single drop of blood that soaks through to the back of the blood spot card
- is not contaminated
- arrives in the laboratory in a timely manner

Acceptable threshold

Avoidable repeat rate is ≤ 2.0%.

Achievable threshold

Avoidable repeat rate is ≤ 1.0%.

New consensus guidelines on quality blood spot were introduced in April 2015 following which the percentage of avoidable repeats predictably rose. They have since improved. Four out of the sixteen newborn screening laboratories reported avoidable repeat rate within the 2% acceptable threshold.

Figure 11: Avoidable repeat request rates for UK countries 2012 to 2018

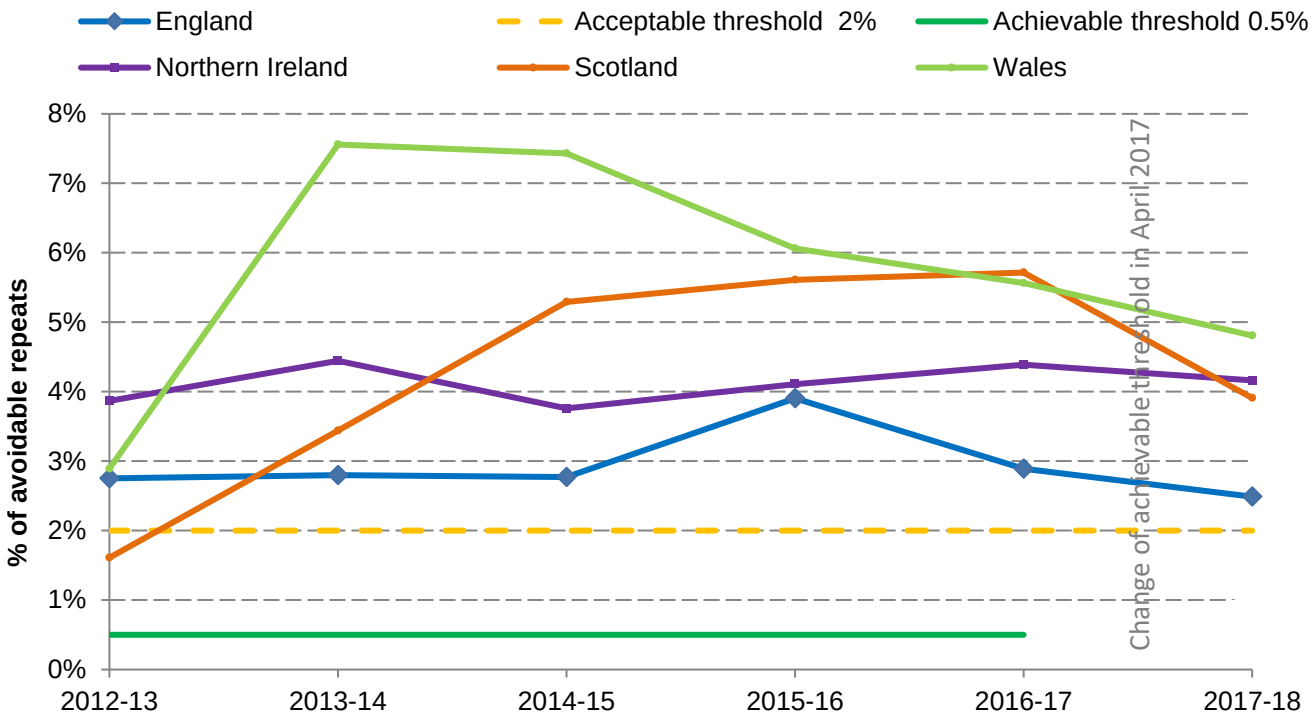


Table 13: Avoidable repeat request rates 1 April 2017 to 31 March 2018

Laboratory	First samples received/babies tested	Repeat (second or subsequent) samples requested by the laboratory because the previous sample was:						Avoidable repeat request rate
		taken when the baby was too young*		insufficient		unsuitable		
	n	n	%	n	%	n	%	%
Bristol	35,138	67	0.19%	265	0.75%	599	1.7%	2.65%
Cambridge	26,985	23	0.09%	159	0.59%	231	0.9%	1.53%
GOSH	123,598	223	0.18%	725	0.59%	2415	2.0%	2.72%
Leeds	41,293	198	0.48%	914	2.21%	594	1.4%	4.13%
Liverpool	29,844	50	0.17%	520	1.74%	83	0.3%	2.19%
Manchester	53,335	90	0.17%	621	1.16%	606	1.1%	2.47%
Newcastle	31,075	57	0.18%	372	1.20%	326	1.0%	2.43%
Oxford	28,036	54	0.19%	170	0.61%	302	1.1%	1.88%
Portsmouth	31,836	81	0.25%	188	0.59%	320	1.0%	1.85%
SE Thames	55,917	150	0.27%	322	0.58%	719	1.3%	2.13%
Sheffield	68,217	105	0.15%	740	1.08%	1262	1.7%	2.92%
SW Thames	51,005	91	0.18%	279	0.55%	856	1.7%	2.40%
West Midlands	67,333	85	0.13%	1110	1.65%	155	0.2%	2.00%
England total	643,612	1274	0.20%	6385	0.99%	8468	1.3%	2.51%
Northern Ireland	23,072	104	0.45%	857	3.71%	0	0.0%	4.17%
Scotland	52552	69	0.13%	946	1.80%	1040	2.0%	3.91%
Wales	31603	62	0.20%	573	1.81%	884	2.8%	4.81%
UK total	750839	1509	0.20%	8761	1.17%	10392	1.4%	2.75%

Data source: Newborn screening laboratories

*Not all English laboratories ask for a repeat when the first sample was taken on or before day 4.

New consensus guidelines on quality blood spot were introduced in April 2015 following which the percentage of avoidable repeats predictably rose. They have since improved. Three out of the sixteen newborn screening laboratories reported avoidable repeat rate within the 2% acceptable threshold.

Figure 12: Breakdown of unsuitable samples for UK 1 April 2017 to 31 March 2018

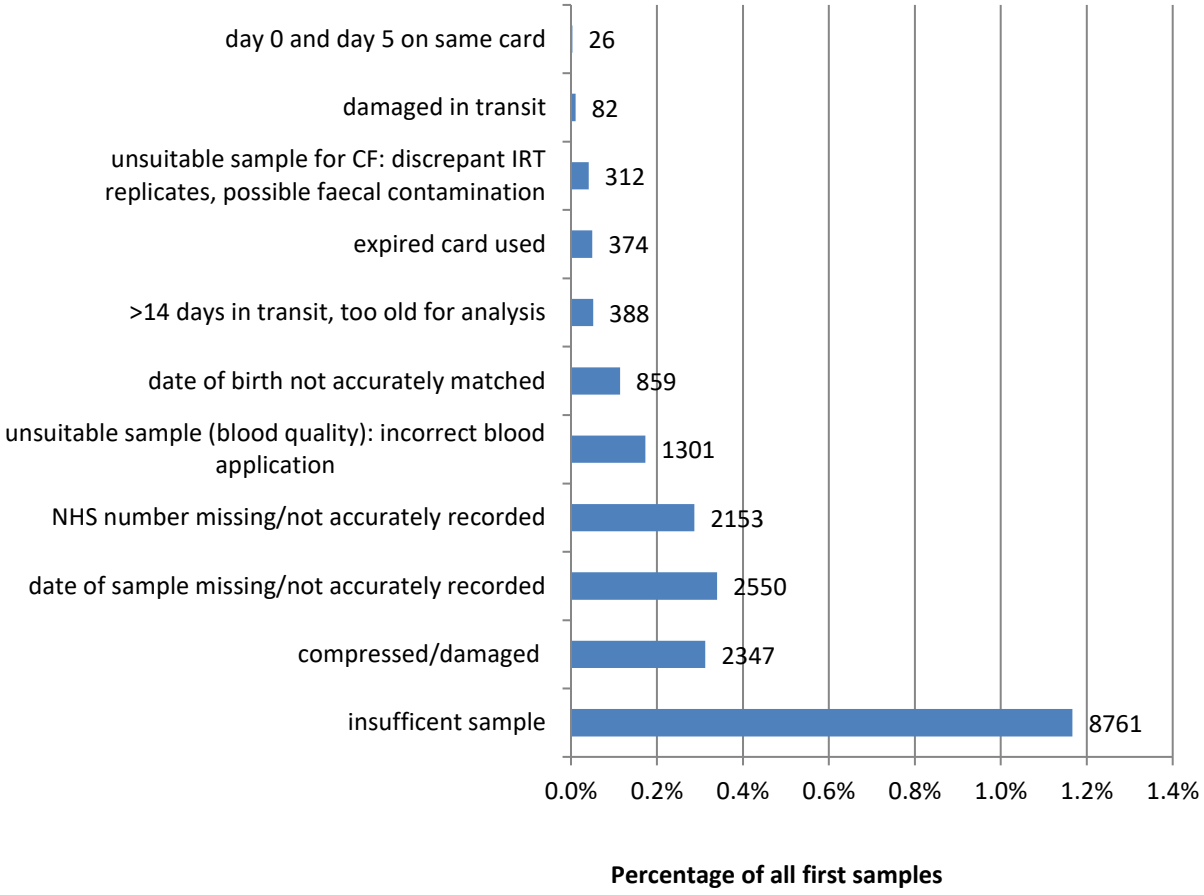


Figure 12 shows that the majority of unsuitable samples are due to insufficient blood. However, over 5,000 babies required a repeat blood spot test to be taken due to missing or incorrect information being recorded on the card. This is unacceptable and further efforts must be made to eradicate these avoidable errors. See programme resources including a new eLearning module ‘Newborn blood spot sample’ accessible here.

Standard 7: Timely taking of a repeat blood spot sample

Description

Timely taking of a second blood spot sample is vital to maximise accuracy of the screening test and ensure that clinical referral and treatment targets are met.

7a: CF

Acceptable threshold

≥ 95% of second blood spot samples taken on day 21 to day 24 (this allows for day 21 to fall on a weekend when a special visit is not warranted).

Achievable threshold

≥ 70% of second blood spot samples taken on day 21.

7b: CHT borderline

Acceptable threshold

≥ 95.0% of second blood spot samples taken as defined.

Achievable threshold

≥ 99.0% of second blood spot samples taken as defined.

7c: CHT preterm

Acceptable threshold

≥ 95% of second blood spot samples taken as defined.

Achievable threshold

≥ 70% of second blood spot samples taken as defined.

Laboratory information management systems do not currently support collection of data for this standard.

Standard 9: Timely processing of CHT and IMD (excluding HCU) screen positive samples

Description

Timely processing of all screen positive samples is vital to ensure that health benefits are achieved by reducing morbidity/mortality.

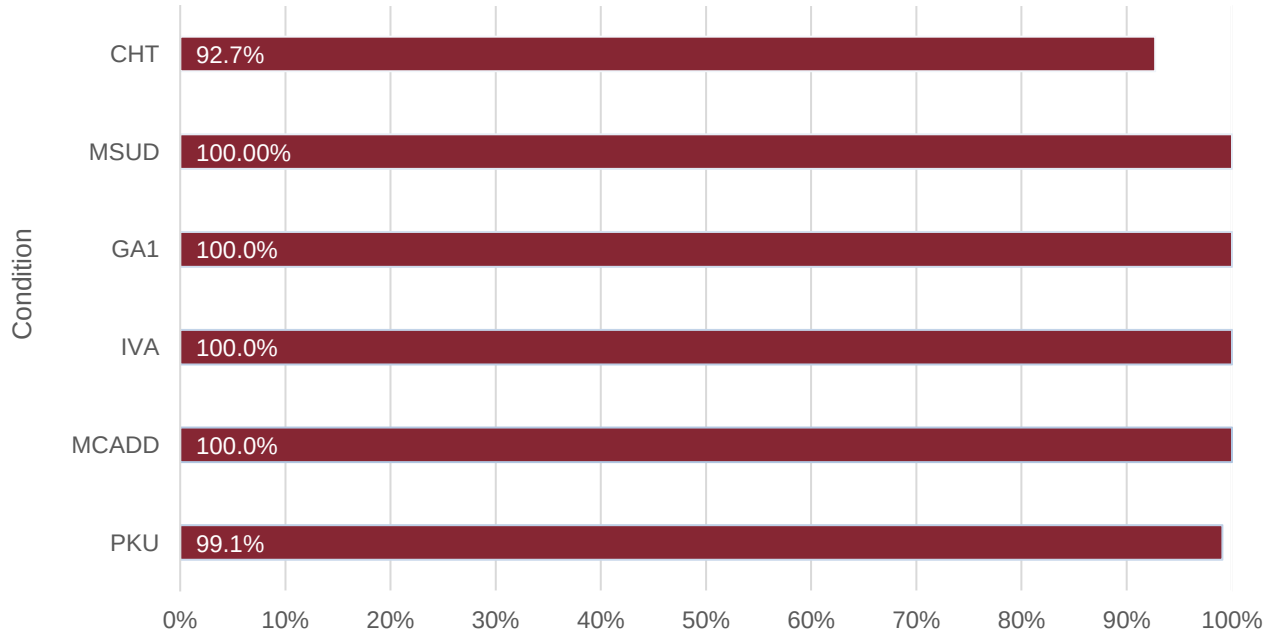
To facilitate high quality and timely intervention in those who wish to participate.

The proportion of CHT and IMD (excluding HCU) screen positive results available and clinical referral initiated within 3 working days of sample receipt by the screening laboratory.

Acceptable threshold

100% of babies with a positive screening result (excluding HCU) have a clinical referral initiated within 3 working days of sample receipt by screening laboratory.

Figure 13: Percentage of babies with a CHT and IMD (excluding HCU) positive screening result referred within 3 working days, UK, 1 April 2017 to 31 March 2018



Standard 11: Timely entry into clinical care

Sickle cell disease

Newborn screening for sickle cell disease (SCD) saw approximately 650,000 newborn babies screened for SCD in England in 2017 to 2018 and approximately 758,000 for the whole of UK. Of those screened in England, 253 babies were identified with significant conditions* (0.39 per 1000 screened) and approximately 8,150 babies were identified as carriers* (12.53 per 1000 screened).

There has been a decline in the rate of babies screening positive for significant SCD conditions in England, which has been driven by decreases in London, particularly in the years up to 2015 to 2016. Over the last 3 years the rates in London have stabilised, and the rates in the rest of England remain steady. The rates of babies with carrier results have also decreased in England in the years up to 2017 to 2018, and this is again due to decreases seen in London.

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 1 April 2017 to 31 March 2018 there were 25 F-only cases in England.

Rates of declines for newborn screening for SCD continue to rise and are now at approximately 2.8 per 1,000 babies screened. The reason for this increase is not clear, but it may be due to improved reporting of declines or declines for mover-in babies who are older babies and may have been tested elsewhere. Although rates of declines are not collected for the other conditions screened, this pattern of declines is unlikely to be confined to just screening for SCD.

The SCT programme has 2 screening standards relating to newborn screening for SCD. Screening standard 8 (SCT-S08) collects the proportion of parents receiving newborn screen positive results at less than or equal to 28 days of age. In 2017 to 2018 the England performance for this standard was 65.1%, which is below the acceptable threshold of 90%. Screening standard 9 (SCT-S09) collects the proportion of newborn infants with a positive screening result who are seen at a paediatric clinic or discharged for insignificant results by 90 days of age. Performance for this standard in England in 2017 to 2018 was 82.7%, which is below the acceptable threshold of 90%.

* Significant conditions comprise FS, FSC, FS-other and FE results. Carrier results comprise FAS, FAC, FAD, FAE and other haemoglobin variants.

Information provided by the NHS Sickle Cell and Thalassaemia Screening Programme.

CF – screen positive babies with 2 cystic fibrosis transmembrane conductance regulator (CFTR) mutations

Description

A baby in whom CF is suspected should have their first clinical appointment by 28 days of age.

Acceptable threshold

≥ 95% of babies attend first clinical appointment by 28 days of age.

Achievable threshold

≥ 100% of babies attend first clinical appointment by 28 days of age.

Table 14: Timeliness of appointment and outcome for CF screen positive babies with 2 mutations 1 April 2017 to 31 March 2018

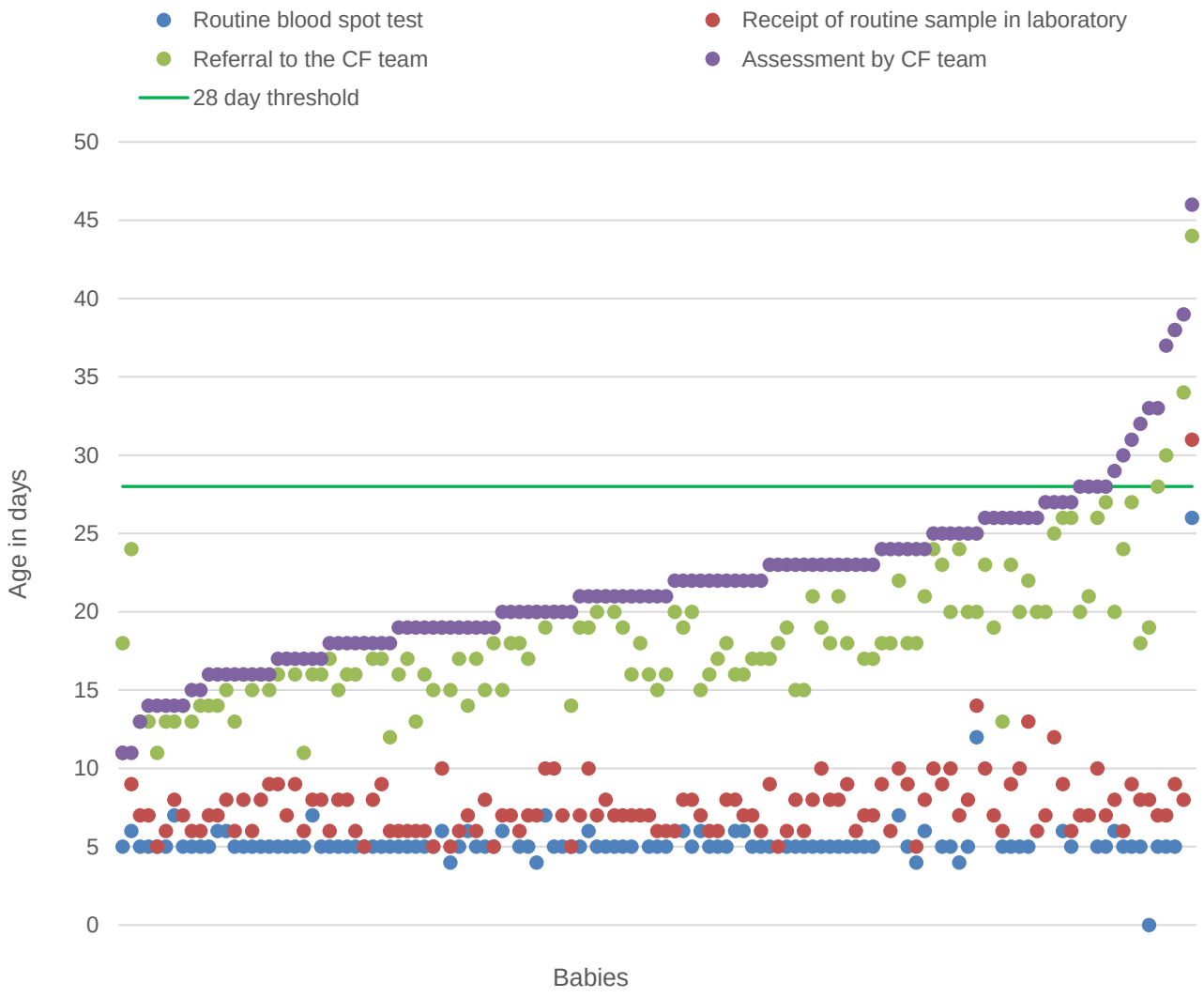
	England	Northern Ireland	Scotland	Wales
Number of CF screen positive babies with 2 mutations	160	8	20	9
Number diagnosed before screening (excluded from following age data)	31	1	3	0
Number of babies with age at first appointment reported	102	7	16	0
Number seen ≤ 28 days (% of known data)	95 (93.1%)	7	13 (81.3%)	N/A
All babies mean age at first appointment	22 days	22	24	N/A
All babies median age at first appointment	21 days	22	23	N/A
Age range at first appointment	11-39 days	21-23 days	11-46 days	N/A
Number of babies with age at first appointment not reported	27	0	1	9
Outcome (out of ALL babies screened positive with 2 mutations. Includes number diagnosed before screening)				
Confirmed	127	8	18	9
CF SPID	10	0	1	0
Excluded	0	0	0	0
Not reported	23	0	1	0

Data source: Newborn screening laboratories

Note that different screening and diagnostic protocols are followed in the UK.

Figures 14 and 15 show the various pathway points of each screen positive baby. Each vertical row of points represents one baby.

Figure 14: age in days of screen positive babies with 2 mutations at time of first sample, receipt in laboratory, referral and assessment, UK



CF – screen positive babies with one or no mutations

Description

A baby in whom CF is suspected should have their first clinical appointment by 35 days of age.

Acceptable threshold

80% of babies attend first clinical appointment by 35 days of age.

Achievable threshold

100% of babies attend first clinical appointment by 35 days of age.

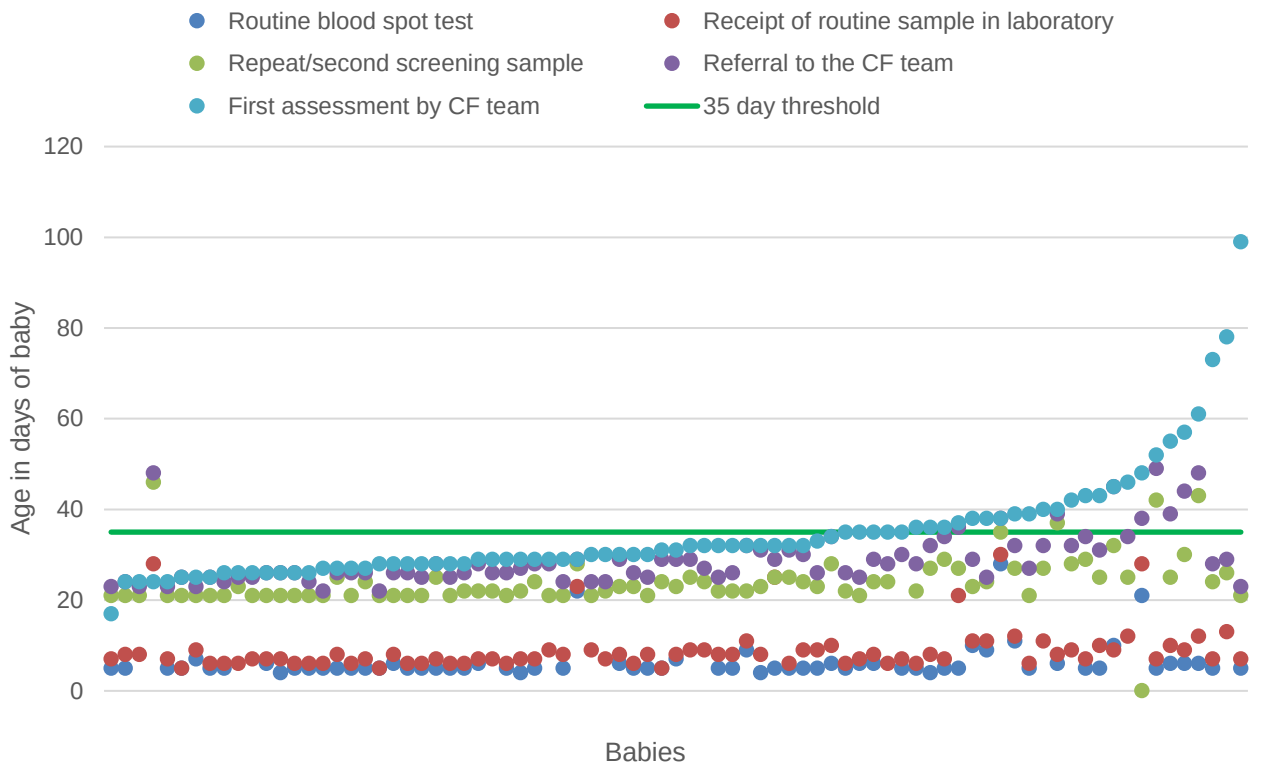
Table 15: Timeliness of appointment and outcome for CF screen positive babies with one or no mutations 1 April 2017 to 31 March 2018

	England	Northern Ireland	Scotland	Wales*
Number of CF screen positive babies with one or no mutations	102	10	9	8
Number diagnosed before screening (excluded from following age data)	4	0	0	0
Number of babies with age at first appointment reported	65	9	9	0
Number seen ≤ 35 days (% of known data)	47 (72.3%)	7 (77.8%)	5 (55.6%)	0
All babies mean age at first appointment	36	31	35	0
All babies median age at first appointment	31	29	32	0
Age range at first appointment	24-104 days	26-39 days	26-57 days	0
Number of babies with age at first appointment not reported	33	1 (R.I.P)	0	8
Outcome (out of ALL babies screened positive with 1 or 0 mutations. Includes number diagnosed before screening)				
Confirmed	25	3	1	0
CF SPID	2	0	0	0
Excluded	31	6	7	8
Baby died	1	1	0	0
Not reported	36	0	1	0
Carrier	7	0	0	0
Other				0

Data source: Newborn screening laboratories

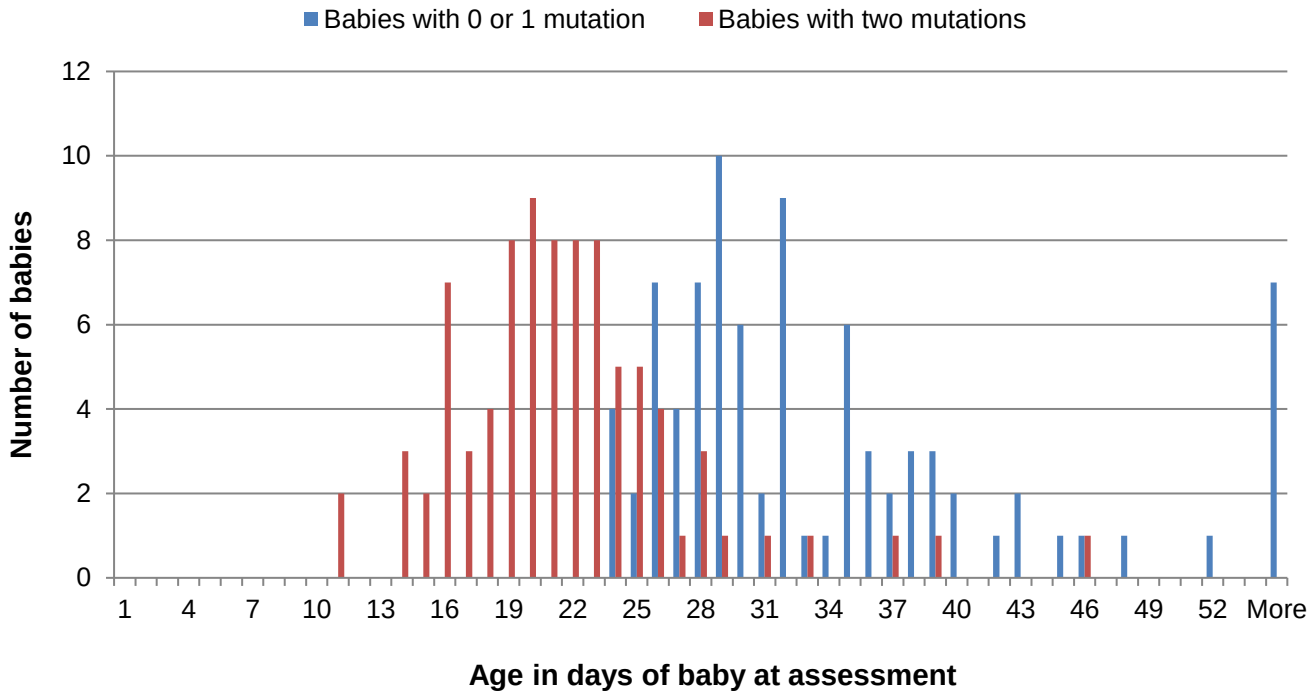
*Wales data does not include 0 mutations.

Figure 15: Age in days of babies screened positive for CF with one or no mutations, at time of first sample, second sample, referral and assessment, UK



Data source: Newborn screening laboratories

Figure 16: CF screen positive babies comparing 2 with one or no mutations 1 April 2017 to 31 March 2018, UK: Age in days at time of first appointment



The X axis stops at 54 days. Eight babies received an appointment after this age.

CF screen positive data 2007 to 2018

Table 16: CF screen positive data 2007 to 2018

Laboratory	Rate of CF screen positives 2007 to 2018
	Rate per 10,000
Bristol	5.84
Cambridge	4.30
GOSH	2.75
Leeds	4.11
Liverpool	5.50
Manchester	3.75
Newcastle	4.64
Oxford	2.77
Portsmouth	3.97
SE Thames	3.67
Sheffield	4.46
SW Thames	3.21
West Midlands	3.86
England total	3.88
Northern Ireland	6.23
Scotland	5.55
Wales	5.77
UK total	4.14

Data source: Newborn screening laboratories

CHT – screen positive babies detected on first sample (not including preterm babies)

Description

A baby in whom CHT is suspected on the first sample should attend their first clinical appointment by 14 days of age.

Acceptable level

100% by 14 days of age.

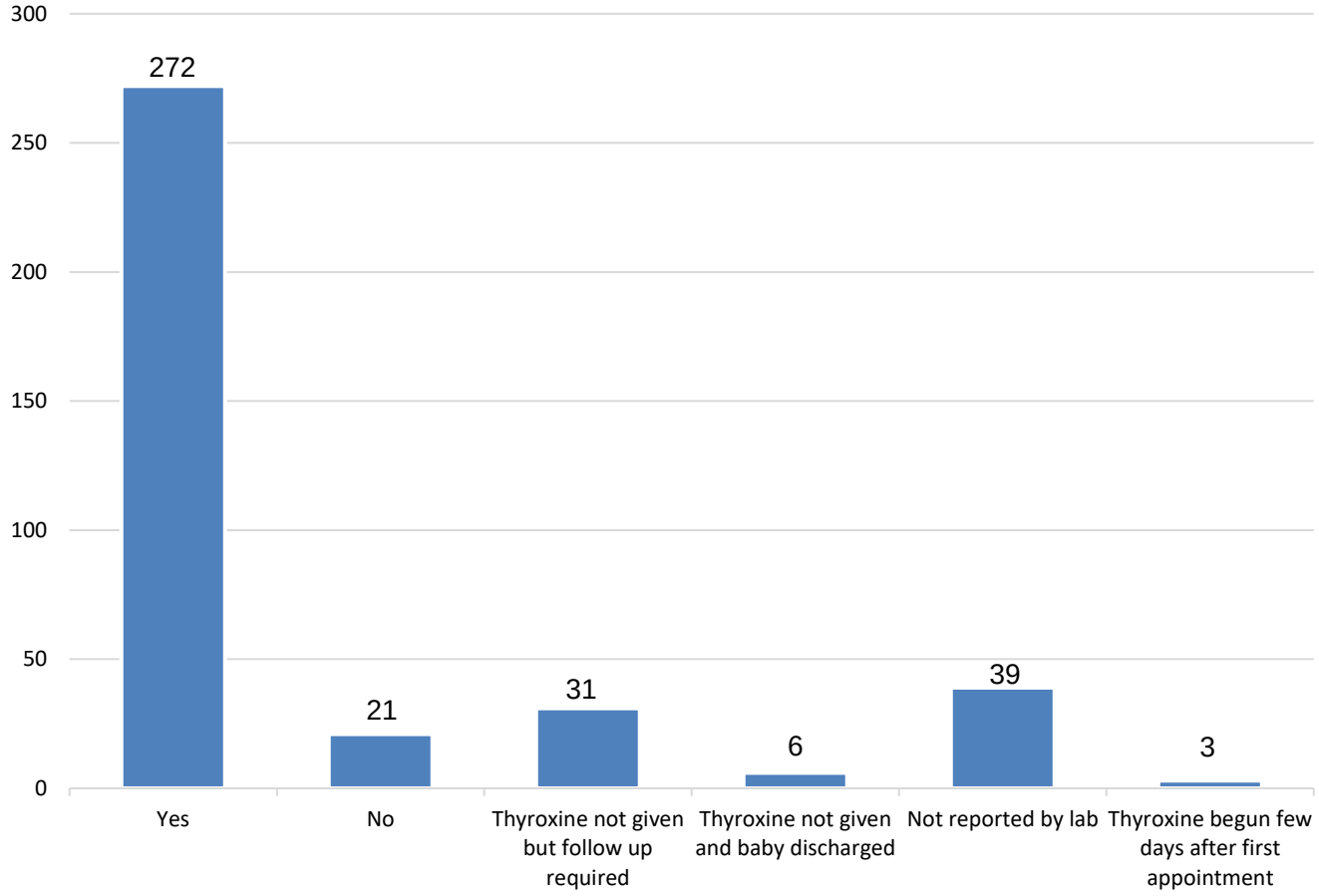
Table 17: Timeliness of appointment and treatment outcome for CHT screen positive babies detected on first sample 1 April 2017 to 31 March 2018

	England	Northern Ireland	Scotland	Wales
Number of CHT screen positive babies detected on first sample	326	11	24	14
Number diagnosed before screening (excluded from following age data)	11	0	0	0
Number of babies with age at first appointment reported	296	11	24	13
Number seen ≤ 14 days standard (% of known data)	265 (89.5%)	11 (100%)	24 (100%)	11 (84.6%)
All babies mean age at first appointment	13 days	10 days	11 days	12 days
All babies median age at first appointment	11 days	10 days	11 days	12 days
Age range at first appointment	6-376 days	8-11 days	7-14 days	09-15 days
Number of babies with age at first appointment not reported	19	0	0	1
Inpatient	2	0	0	0
Other*	0	0	0	1

Data source: Newborn screening laboratories

*One baby indicated as “DECLINE; mother refused to bring child, GP had to treat at home”.

Figure 17: Treatment outcome for CHT screen positive babies, UK, 'Are babies treated with Thyroxine?'



CHT – screen positive babies detected on second sample (not including preterm babies)

Description

A baby in whom CHT is suspected on a repeat blood spot sample that follows a borderline TSH should have their first clinical appointment by 21 days.

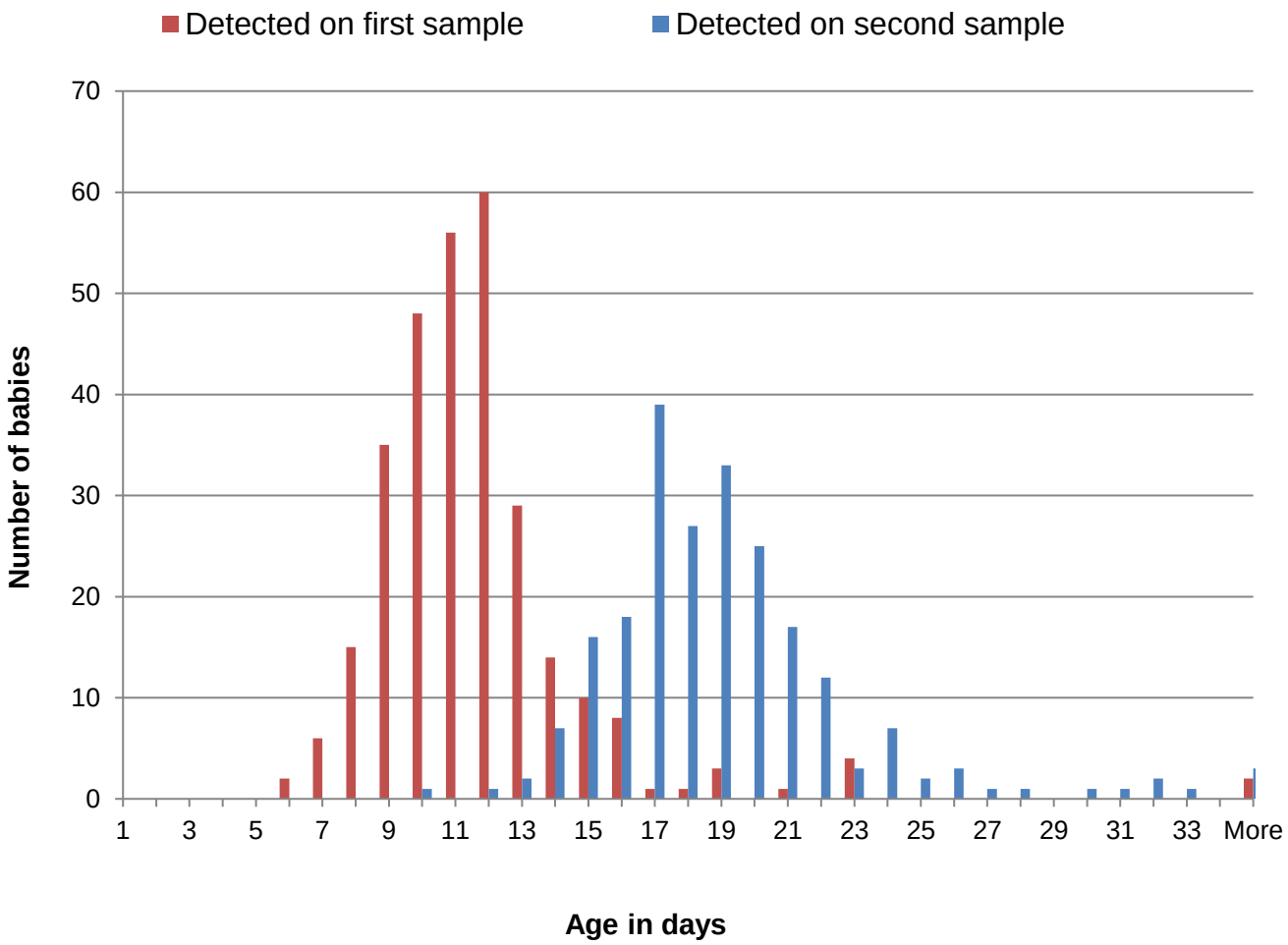
Acceptable threshold

100% by 21 days of age.

Table 18: Timeliness of appointment and treatment outcome for CHT screen positive babies detected on second sample 1 April 2017 to 31 March 2018

	England	Northern Ireland	Scotland	Wales
Number of CHT screen positive babies detected on second sample	241	10	12	3
Number diagnosed before screening (excluded from following age data)	5	1	0	0
Number of babies with age at first appointment reported	223	9	11	3
Number seen ≤ 21days standard (% of known data)	186 (83.0%)	7 (77.8%)	8 (72.7%)	3 (100%)
All babies mean age at first appointment	19	16	20	20
All babies median age at first appointment	19	16	19	19
Age range at first appointment	10-46 days	14-39 days	15- 27 days	19-21 days
Number of babies with age at first appointment not reported	13	0	1	0
Inpatient	2	0	0	0

Figure 18: Age in days of CHT screen positive babies (not including preterm babies) detected on first and second sample at time of first appointment 1 April 2017 to 31 March 2018, England only



Data source: Newborn screening laboratories

CHT – screen positive preterm babies (born at less than 32 weeks)

Data on CHT preterm babies will be further analysed in detail separately.

CHT results depending on use of national or local borderline cut-off level

CHT is the only screening protocol in which a borderline result necessitates a second sample before a conclusive result can be achieved. The national borderline cut-off level is 10 mU/L. Some laboratories use a local cut-off level.

Table 19: CHT borderline results depending on use of national or local cut-off level 1 April 2017 to 31 March 2018

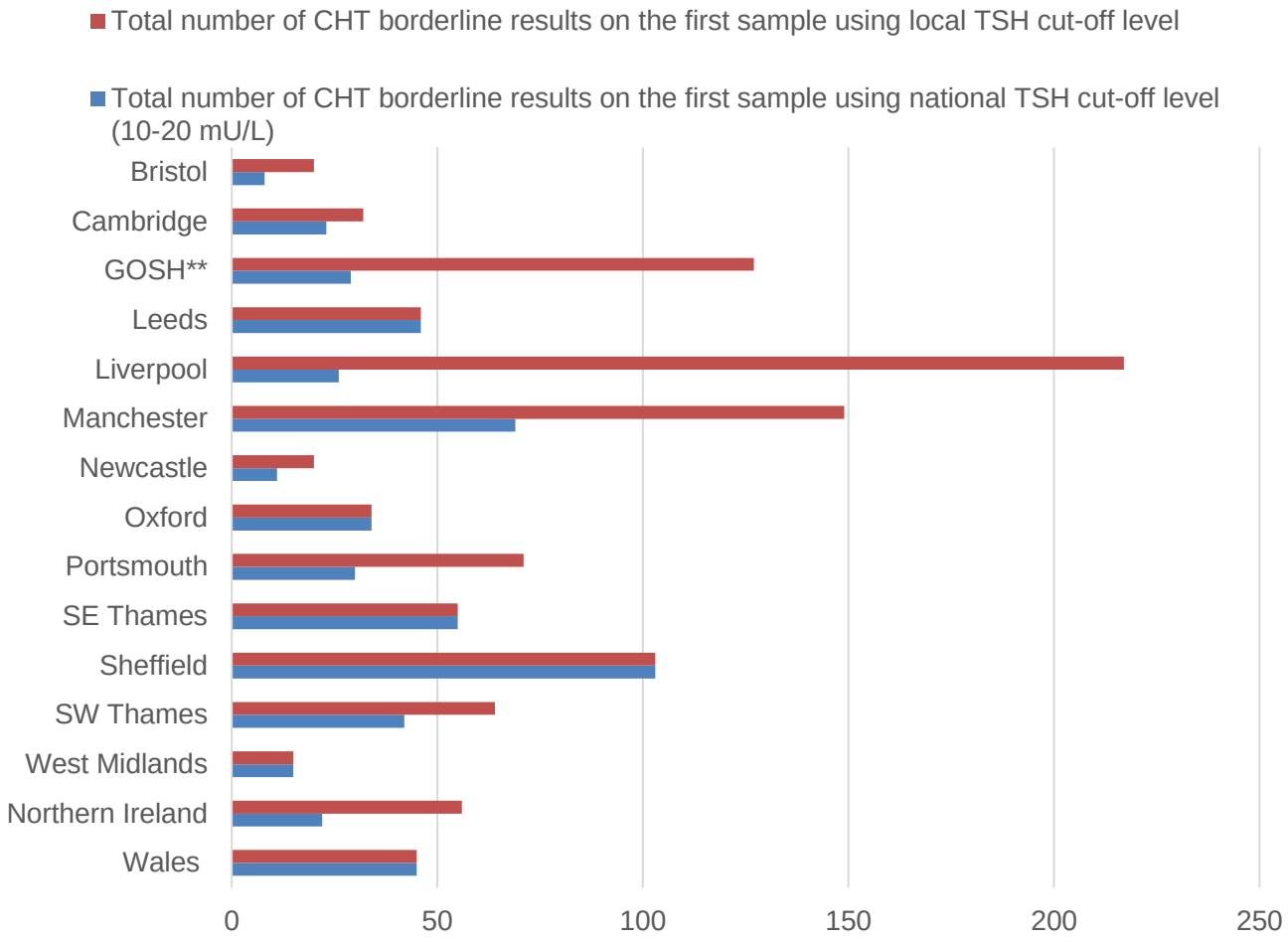
Laboratory	What TSH* cut-off levels do you use to determine a positive screen for CHT (mU/L)?	What TSH cut-off levels do you use to determine a borderline screen for CHT (mU/L)?	Total number of CHT borderline results on the first sample using national TSH cut-off level (10-20 mU/L)	Total number of CHT borderline results on the first sample using local TSH cut-off level
Bristol	18	5.5	8	20
Cambridge	18 (GSP)	9 (GSP)	23	32
GOSH**	18 (GSP)	8 (GSP)	29	127
Leeds	20	10	46	46
Liverpool	20	5	26	217
Manchester	20	8	69	149
Newcastle	20	6	11	20
Oxford	20	10	34	34
Portsmouth	20	8	30	71
SE Thames	20	10 (Q1- Q3) 8 (Q4)	55	55
Sheffield	18 (GSP)	9 (GSP)	103	103
SW Thames	20	10 until 01/01/18. 8 from 01/12/17-31/03/18	42	64
West Midlands	20	10	15	15
England total	n/a	n/a	507	855
Northern Ireland	20	8	22	56
Scotland	20	8	not completed	not completed
Wales	20	10	45	45

Data source: Newborn screening laboratories

*Thyroid stimulating hormone (TSH).

**Note that GSP (Genetic Screening Processor) cut-offs are equivalent to national cut-offs.

Figure 19: CHT borderline results depending on use of national or local cut-off level 1 April 2017 to 31 March 2018



Data source: Newborn screening laboratories

CHT screen positive data 2007 to 2018

Table 20: CHT screen positive data 2007 to 2018

Laboratory	Rate of CHT screen positives 2007 to 2018 Rate per 10,000
Bristol	6.62
Cambridge	6.84
GOSH	10.93
Leeds	7.15
Liverpool	10.60
Manchester	7.83
Newcastle	8.37
Oxford	6.75
Portsmouth	5.66
SE Thames	5.86
Sheffield	6.15
SW Thames	6.26
West Midlands	7.78
England total	7.74
Northern Ireland	7.26
Scotland	5.08
Wales	6.77
UK total	7.51

Data source: Newborn screening laboratories

PKU

Description

A baby in whom PKU is suspected should attend their first clinical appointment by 14 days of age.

Acceptable level

100% by 14 days of age.

Table 21: Timeliness of appointment and outcome for PKU screen positive babies 1 April 2017 to 31 March 2018

	England	Northern Ireland	Scotland	Wales
Number of PKU screen positive babies	86	7	16	4
Number clinically diagnosed before screening (excluded from following age data)	5	0	0	0
Number of babies with age at appointment reported	55	7	0	4
Number seen ≤ 14 days (% of known data)	51 (92.7%)	7 (100%)	n/a	3 (75%)
All babies mean age at appointment	10	9	n/a	12
All babies median age at appointment	10	9	n/a	11
Age range at first appointment	7-21 days	7-11 days	n/a	10-15 days
Number of babies with age at appointment not reported	26	0	16	0

Data source: Newborn screening laboratories

Figure 20: Treatment outcome for PKU screen positive babies 1 April 2017 to 31 March 2018, UK

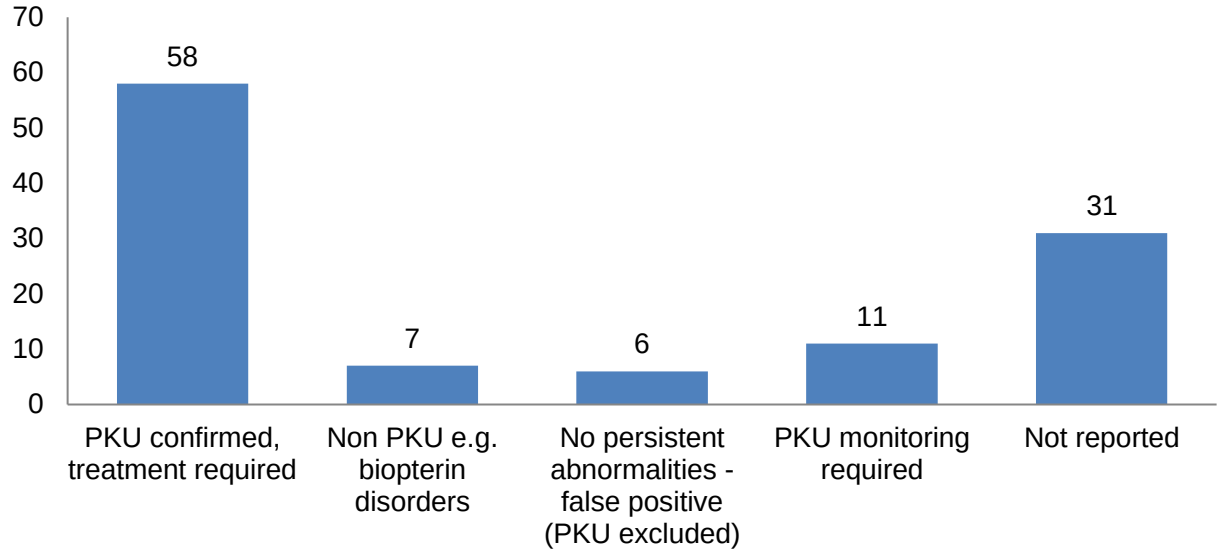
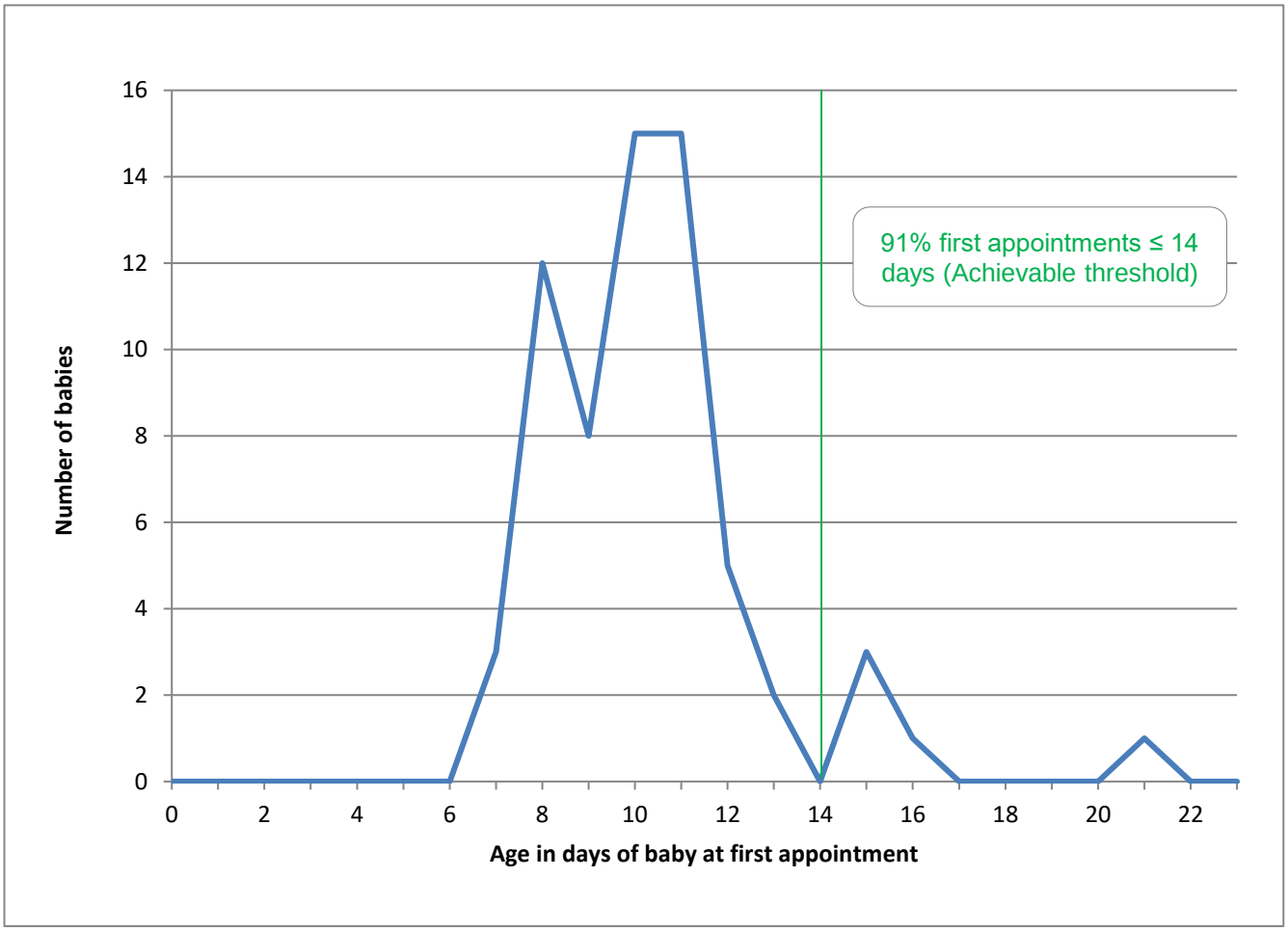


Figure 21: age at first appointment for PKU screen positive babies 1 April 2017 to 31 March 2018, UK



Data source: Newborn screening laboratories

Table 22: PKU screen positive data 2007 to 2018

Laboratory	Rate of PKU screen positives 2007 to 2018
	Rate per 10,000
Bristol	0.80
Cambridge	1.77
GOSH	0.90
Leeds	1.23
Liverpool	1.16
Manchester	1.49
Newcastle	1.39
Oxford	0.89
Portsmouth	0.79
SE Thames	1.14
Sheffield	1.56
SW Thames	0.75
West Midlands	0.92
England total	1.11
Northern Ireland	2.69
Scotland	1.59
Wales	1.70
UK total	1.22

Data source: Newborn screening laboratories

MCADD screen positive data 2017 to 2018

Description

A baby in whom MCADD is suspected should attend their first clinical appointment by:

Acceptable level

100% by 17 days of age.

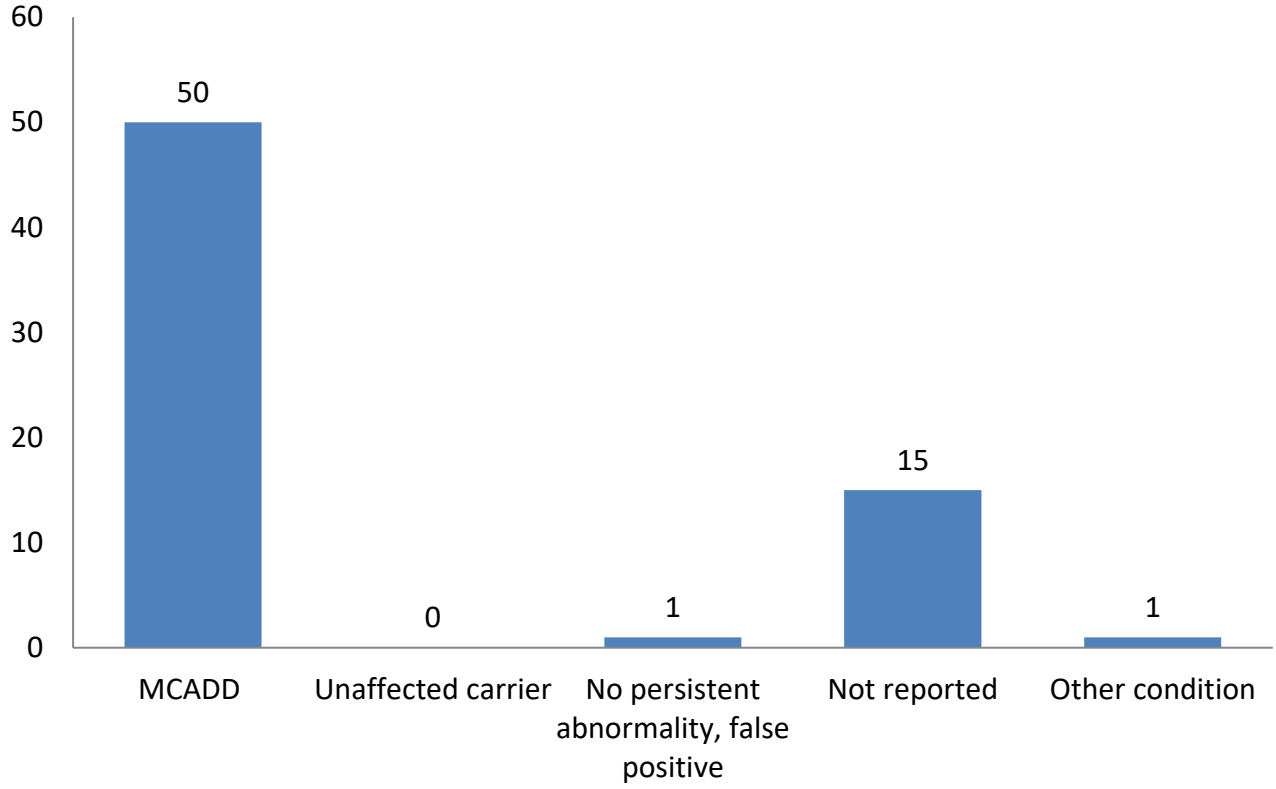
Achievable level

100% by 14 days of age.

Table 23: Timeliness of appointment and outcome for MCADD screen positive babies 1 April 2017 to 31 March 2018

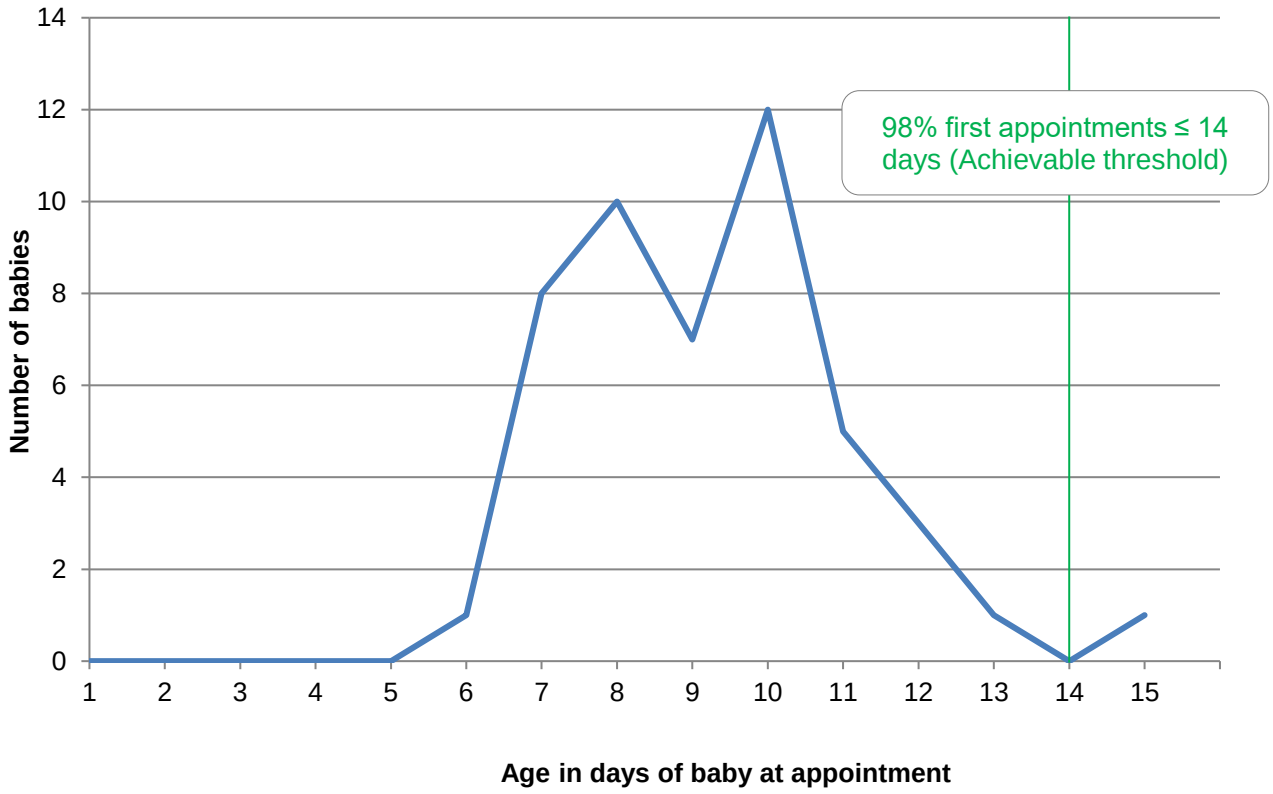
	England	Northern Ireland	Scotland	Wales
Number of MCADD screen positive babies	56	3	4	4
Family history (early testing excluded from following age data)	4	0	0	0
Number of babies with age at appointment reported	41	3	0	4
Number seen ≤ 14 days	40	3	Not reported	4
Number seen ≤ 17 days	41	3	Not reported	4
All babies mean age at appointment	9	7	Not reported	10
All babies median age at appointment	9	8	Not reported	10
Age range at first appointment	7-15 days	6-8 days	Not reported	10-11 days
Number of babies with age at appointment not reported	11	0	4	0

Figure 22: Treatment outcome for MCADD screen positive babies, 1 April 2017 to 31 March 2018, UK



Data source: Newborn screening laboratories

Figure 23 UK: age at first appointment for MCADD screen positive babies 1 April 2017 to 31 March 2018



Data source: Newborn screening laboratories

The biochemical data reported for MCADD was incomplete and therefore unable to map to the MCADD 2017/18 algorithm.

MCADD screen positive data 2008 to 2018

Table 24: MCADD screen positive data 2008 to 2018

Laboratory	Rate of MCADD screen positives 2008 to 2017
	Rate per 10,000
Bristol	0.82
Cambridge	1.35
GOSH	0.72
Leeds	1.42
Liverpool	1.03
Manchester	1.16
Newcastle	1.00
Oxford	1.22
Portsmouth	1.03
SE Thames	0.73
Sheffield	1.47
SW Thames	0.82
West Midlands	0.84
England total	1.00
Northern Ireland	1.17
Scotland	0.38
Wales	0.98
UK total	0.97

Data source: Newborn screening laboratories

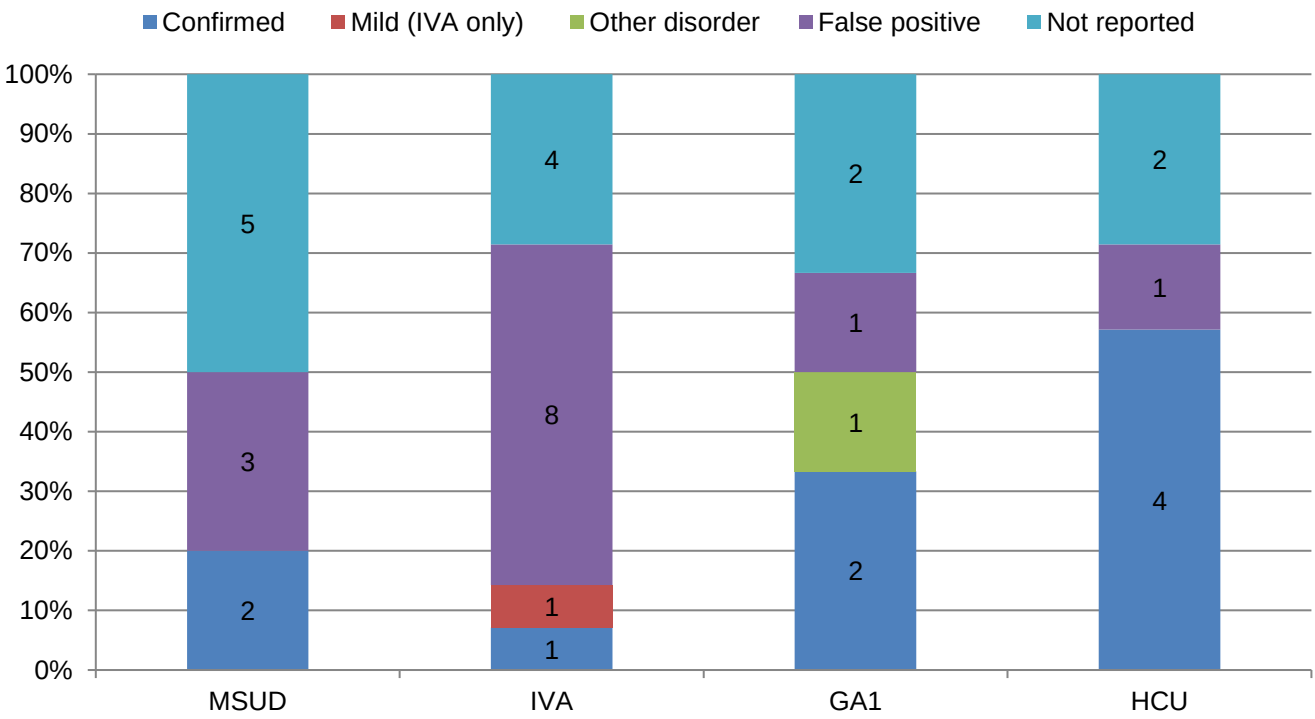
MSUD, IVA, GA1 and HCU screen positive data 2017 to 2018

Table 25: UK: Timeliness of appointment and outcome for MSUD, IVA, GA1 and HCU screen positive babies 1 April 2017 to 31 March 2018

	MSUD	IVA	GA1	HCU
Number of screen positive babies	10	14	6	7
Family history (early testing)	0	0	1	1
Number of babies with age at first appointment reported	5	9	4	4
Number seen ≤ 14 days	5	9	4	2
Number seen ≤ 17 days2	5	9	4	3
All babies median age at first appointment (in days)	9	10	10	15
Age range at first appointment (in days)	8-14	10-13	8-12	13-24
Number of babies with age at first appointment not reported	5	5	1	2
Outcome (includes number diagnosed before screening)				
Confirmed	2	1	2	4
Mild (IVA only)	n/a	1	n/a	n/a
Other disorder	0	0	1	0
False positive	3	8	1	1
Not reported	5	4	2	2

Data source: Newborn screening laboratories

Figure 24. Outcomes for MSUD, IVA, GA1 and HCU, UK, 1 April 2017 to 31 March 2018



Standard 12a: Timeliness of results to parents (CCG responsibility at birth)

Description

The proportion of babies with a not suspected result for each of the conditions for whom a not suspected results letter was despatched directly to parents by the CHRD within 6 weeks of birth.

Acceptable threshold

100% of babies with a not suspected result for each of the conditions for whom a not suspected results letter was despatched directly to parents by the CHRD within 6 weeks of birth.

Table 26: Timeliness of results to parents, England 1 April 2017 to 31 March 2018

Regional summary	Numerator	Denominator	Performance
England	458,947	468,844	97.9
London	110,226	111,405	98.9
Midlands & East	145,930	146,435	99.7
North	87,789	88,979	98.7
South	115,002	122,025	94.2

Table 27: standard 12a, completeness of data, England 1 April 2017 to 31 March 2018

Regional summary	Number of non-submissions	Number with no data	No. complete returns	% complete returns
England	36	6	165	82.1
London	0	0	32	100.0
Midlands & East	12	0	49	80.3
North	19	6	39	67.2
South	5	0	45	90.0

Data source: CHRDs

Standard 12b: Timeliness of results to parents (movers in)

Description

The proportion of babies with a not suspected result for each of the conditions screened for whom a not suspected results letter was despatched directly to parents by the CHRD within 6 weeks of notification of movement in.

Acceptable threshold

100% of babies with a not suspected result for each of the conditions for whom a not suspected results letter was despatched directly to parents by the CHRD within 6 weeks of notification of movement in.

Table 28: Timeliness of results to parents, movers in, England 1 April 2017 to 31 March 2018

Regional summary	Numerator	Denominator	Performance
England	19,074	20,833	91.6
London	6,380	7,060	90.4
Midlands & East	7,629	8,175	93.3
North	2,934	3,057	96.0
South	2,131	2,541	83.9

Table 29: Completeness of data, movers in, England 1 April 2017 to 31 March 2018

Regional summary	Number of non-submissions	Number with no data	No. complete returns	% complete returns
England	37	53	117	56.5
London	0	1	31	97.0
Midlands & East	12	14	35	57.4
North	19	17	28	43.8
South	6	21	22	44.9

Twenty-nine CHRDs completed the wrong template containing only standard 12a. Therefore, the data for this standard cannot be used for quality assurance as the data is inconsistent across areas.

Completeness for standard 12 is poor. Work needs to be done in Midlands and East, North and South regions to improve completeness and data. The blood spot programme needs to work closely with SQAS in achieving a better data return and communicating the submission process widely.