



Public Health
England



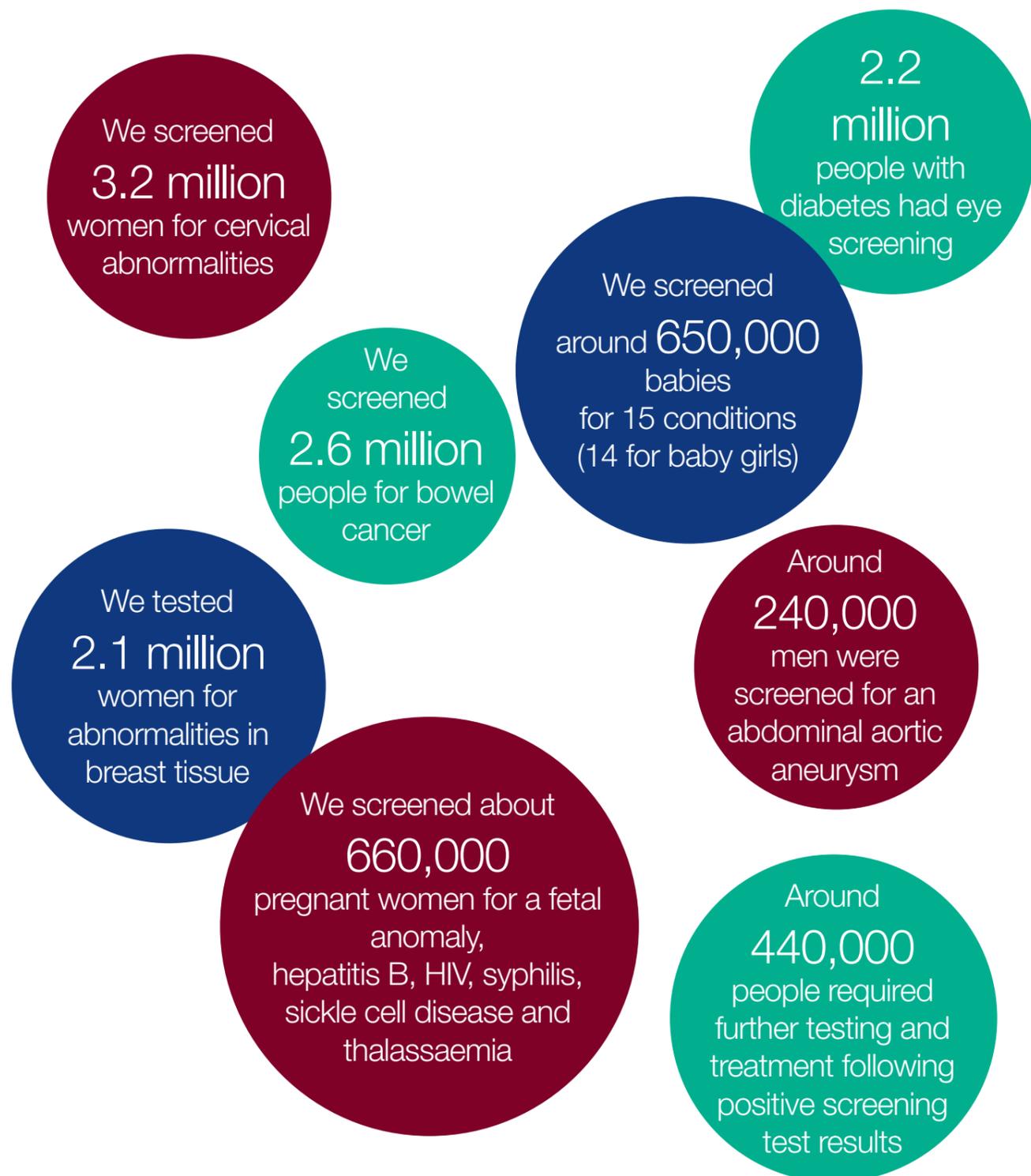
NHS Screening Programmes in England

1 April 2017 to 31 March 2018



The big picture

Between 1 April 2017 and 31 March 2018



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Foreword

Millions of people in England benefit from screening each year thanks to the hard work and expertise of Public Health England (PHE), NHS England, clinical and commissioning colleagues working together throughout the country.

Between 1 April 2017 and 31 March 2018, the NHS screening programmes screened 3.2 million women for cervical abnormalities, 2.6 million people for bowel cancer, 2.2 million people for diabetic eye disease, 2.1 million women for breast cancer, 660,000 pregnant women for a fetal anomaly, infectious diseases and genetic disorders, and more than 640,000 babies for 15 conditions, including sickle cell disease and cystic fibrosis.

As a result, we identified hundreds of thousands of individuals who needed further investigation or essential treatment.

Most of these people had not actively sought care and had no symptoms, which is why screening is such an important public health intervention.

We would like to thank all screening, commissioning and clinical colleagues for their patience and expertise this year in supporting the forthcoming introduction of:

- HPV primary screening in the cervical programme
- the new faecal immunochemical test in the bowel cancer programme
- non-invasive prenatal testing in antenatal screening
- risk-based screening intervals in the diabetic eye programme

These are 4 of our most complex programmes and millions of people will benefit from these changes when they are implemented.

The screening programmes work well time again for very large numbers of babies, children and adults – identifying conditions early, preventing disease and saving thousands of lives.

UK screening programmes are world leading, which is why the issues that arose this year with failings in the arrangements for inviting women in the cervical and breast screening programmes were of such concern and why we worked so hard to put them right.

Screening should be equitable because we offer tests to all individuals in a population. However, we know inequalities exist in accessing screening, so reducing those inequalities is one of the

main aims of both PHE and NHS England.

Inside this report we have highlighted numerous examples of collaborative work involving ourselves and local authorities locally and nationally to identify and overcome barriers to screening.

For example, we have made use of national data to help identify and tackle inequalities in cervical screening (page 15). More than 1 in 4 women do not attend cervical screening when invited but we know that proportion is even higher for ethnic minority groups, lesbian and bisexual women and younger women. PHE Screening has worked with NHS Digital and Jo's Cervical Cancer Trust to create an interactive data tool

that helps providers identify potential barriers to cervical screening and plan initiatives to reduce inequalities.

People with a learning disability find it more difficult to access screening. This can be due to a lack of understanding, embarrassment or fear. On pages 16 and 17, we focus on our work to develop easy guides to screening for people with learning disabilities and anyone who struggles with written English.

Trans and non-binary people also often face barriers to screening. This can be because they do not know what screening they are eligible for, or because they are not invited because of the gender they are registered as with their GP.

We have addressed this issue by launching a new national leaflet (page 19) that includes important information for trans and non-binary people about bowel cancer, breast, cervical and AAA screening, including how to access additional support and advice.

These are just some of the examples of how we are working together to reduce inequalities. It is important people know what is on offer to

them so they can make the right decision for themselves about whether or not to be screened.

We will continue working together throughout 2019 and beyond to overcome these barriers and to ensure the NHS screening programmes reach everyone who could benefit from them.



Professor John Newton
Chief Knowledge Officer
Public Health England

What do we screen for?

NHS Abdominal Aortic Aneurysm Screening Programme

The NHS Abdominal Aortic Aneurysm (AAA) Screening Programme reduces premature deaths from ruptured AAAs among men aged 65 and over by up to 50% through early detection, appropriate follow-on tests and referral for potential treatment. It offers all men an ultrasound scan of the abdomen during the year they turn 65 while men over 65 who have not previously been tested can self-refer for screening.

NHS Bowel Cancer Screening Programme

The NHS Bowel Cancer Screening Programme detects bowel cancer at an early stage when treatment is more likely to be effective. Bowel cancer screening also detects polyps, which are not cancers but may develop into cancers over time. Polyps can be removed, reducing the risk of bowel cancer developing. A screening kit is offered to men and women aged 60 to 74 every 2 years. The kit is completed at home and posted to a laboratory for analysis. A one-off bowel scope screening test, using flexible sigmoidoscopy, for those aged 55, is also being implemented across England. This test uses a narrow, flexible video camera called a sigmoidoscope to look inside the rectum and bowel.

NHS Breast Screening Programme

The NHS Breast Screening Programme reduces the number of deaths from breast cancer by finding signs of disease at an early stage. Breast screening uses mammography (X-rays) to look for abnormalities in breast tissue. Women in England and Wales aged 50 to 70 are invited for breast screening every 3 years. Women over 70 can continue to have breast screening by making an appointment at their local screening unit every 3 years.

NHS Cervical Screening Programme

The NHS Cervical Screening Programme prevents cancer by detecting abnormalities of the cervix and referring for potential treatment. The programme uses liquid based cytology – still sometimes called a smear – to collect samples of cells from the cervix. These samples are examined in a laboratory to look for any abnormal changes in the cells, or in some cases the high risk strains of human papillomavirus (HPV) that cause the cells to change. Screening is offered every 3 years to all women aged 25 to 49 and every 5 years to those aged 50 to 64.

NHS Diabetic Eye Screening Programme

The NHS Diabetic Eye Screening Programme reduces the risk of sight loss in people with diabetes through the early detection, appropriate monitoring and referral for treatment of diabetic retinopathy, which is one of the biggest causes of blindness among people of working age. It offers screening every 12 months to all people with diabetes aged 12 and over.

NHS Fetal Anomaly Screening Programme

The NHS Fetal Anomaly Screening Programme offers the choice of screening for Down's syndrome, Edwards' syndrome, Patau's syndrome and a number of structural anomalies to all eligible women in England. The screening tests offered for Down's syndrome, Edwards' syndrome and Patau's syndrome vary depending on gestational age but screening can be offered up to 20 weeks of pregnancy. A fetal anomaly scan can be offered between 18 and 23 weeks of pregnancy. Screening is a choice and women may choose to end the screening pathway at any stage.

NHS Infectious Diseases in Pregnancy Screening Programme

The NHS Infectious Diseases in Pregnancy Screening Programme recommends screening for all pregnant women for hepatitis B, HIV and syphilis. The programme identifies women with hepatitis B, HIV or syphilis so they can be offered appropriate follow-on tests and treatments, substantially reducing the risk of passing on the infection to their babies.

NHS Newborn and Infant Physical Examination Programme

The NHS Newborn and Infant Physical Examination Programme uses a detailed physical examination to screen newborn babies and infants for problems with their eyes, heart, hips or testes. Screening helps ensure early detection and diagnosis of several conditions. This enables early intervention and treatment to reduce the chance of long-term disability.

NHS Newborn Blood Spot Screening Programme

The NHS Newborn Blood Spot Screening Programme screens newborn babies for 9 rare but serious conditions: phenylketonuria (PKU), congenital hypothyroidism (CH), sickle cell disease (SCD), cystic fibrosis (CF), medium-chain acyl-CoA dehydrogenase deficiency (MCADD), maple syrup urine disease (MSUD), isovaleric acidaemia (IVA), glutaric aciduria type 1 (GA1) and homocystinuria (HCU). The programme uses a heel prick test to collect spots of blood which are tested to find babies who have any of the conditions. Babies who test positive can then be treated early, improving their health and, in some cases, preventing severe disability or even death.

NHS Newborn Hearing Screening Programme

The NHS Newborn Hearing Screening Programme offers a hearing screening test for babies during the first few weeks of their lives to find those who are born with hearing loss. These children and their families can then be offered the right support, treatment and information as early as possible, helping them reach their full educational and social potential.

NHS Sickle Cell and Thalassaemia Screening Programme

The NHS Sickle Cell and Thalassaemia (SCT) Screening Programme uses a questionnaire about family origin and, if necessary, offers blood tests to screen pregnant women for 2 serious inherited blood conditions – sickle cell disease and thalassaemia major. People who have these conditions need specialist care throughout their lives. The SCT programme helps find those at risk and gives parents time to consider the options available. It also means babies who have either condition can be given the best support and treatment from the very start.

2017 to 2018 screening data

NHS Abdominal Aortic Aneurysm (AAA) Screening Programme	
Eligible for screening (2017 to 2018 cohort ⁱ)	285,693
Offered screening	284,116
Tested (2017 to 2018 cohort ⁱ)	229,956
Coverage (2017 to 2018 cohort ⁱ)	80.5%
Tested (self-referrals)	10,677
Coverage (self-referrals)	97.1%
AAAs detected (cohort)	2,323
Incidence (cohort)	1.01%
AAAs detected (self-referrals)	384
Incidence (self-referrals)	3.60%
Men on surveillance at end of year	15,151
Referrals to surgery	809
Elective AAA repairs	609
Deaths from elective repairs	7
Ruptures	18
Deaths from rupture	18

ⁱ Men registered with a GP in England and born between 1 April 1952 and 31 March 1953.

Data source: AAA SMarT **Data extracted:** 10 July 2018

NHS Breast Screening Programme (provisional data)	
Number of women tested (all ages)	2,138,448
Uptake of screening (all ages)	70.0%
Screening round length (50 to 70 year olds) ⁱ	90.6%

ⁱ % of women aged 50 to 70 invited within 36 months of previous screening, or previous invitation if did not attend.

NHS Digital is responsible for publishing official statistics for the NHS Breast Screening Programme. NHS Digital has allowed the Screening Quality Assurance Service (SQAS) to publish this provisional data for 1 April 2017 to 31 March 2018 based on in-house analysis, prior to official publication expected February 2019. Please note that it is possible these SQAS figures will be different to the validated official statistics. Number of tests and uptake are based on screening records held for women of all ages. Screening round length is based on women aged 50 to 70 only, by definition.

NHS Diabetic Eye Screening Programme	
Eligible people with diabetes known to programme	3,297,294
Offered screening (routine digital screening)	2,700,774
Tested (routine digital screening)	2,232,797
Uptake	82.7%
New registrations to programmes	274,211
Urgent referrals (R3A)	8,782
Routine referrals (R3SM1, R2M1, R2M0, R1M1)	54,893

Data source: programme performance reports and quarter 4 quarterly submission. **Collected:** July 2018. Data is provisional and subject to change. R1 = Background retinopathy; R2 = Pre-proliferative retinopathy; R3A = Active proliferative retinopathy; R3S = stable treated proliferative retinopathy; M0 = No maculopathy; M1 = Maculopathy.

2017 to 2018 screening data

NHS Bowel Cancer Screening Programme (gFOBt) ⁱ	
Number of people invited ⁱⁱ	4,478,437
Number of people adequately screened ⁱⁱⁱ	2,579,831
Number of people definitively gFOBt abnormal ^{iv}	41,095
Uptake ^v	57.61%
Positivity ^{vi}	1.59%
Number of people diagnosed with cancer ^{vii}	2,962
Number of people diagnosed with high risk adenomas ^{vii}	3,717
Number of people diagnosed with intermediate risk adenomas ^{vii}	4,772
Number of people diagnosed with low risk adenomas ^{vii}	7,289
Number of people diagnosed with abnormal findings ^{vii} ^{viii}	9,524
Number of people with a normal diagnostic outcome	5,063

This data relates to the invited population only. Episodes which originate from requests for screening or attendance at programme surveillance tests are excluded.

ⁱ gFOBt is the guaiac faecal occult blood test used in the bowel cancer screening programme.

ⁱⁱ One invite sent per screening subject episode. A subject can have multiple episodes during their 'bowel cancer screening lifetime'. Number of people invited does not include requests for screening such as over-age self-referrals, later responders or opt back-in episodes.

ⁱⁱⁱ Of those invited, the number reaching a definitive gFOBt outcome of either 'normal' or 'abnormal' from potentially multiple gFOB test kits. Subjects can receive and return more than one test kit within an episode.

^{iv} Of those invited and adequately screened, the number reaching a definitive gFOBt outcome of 'abnormal' from potentially multiple gFOB test kits. People who reach a definitive outcome of gFOBt abnormal are then referred for a colonoscopy fitness assessment.

^v Percentage of people adequately screened (ⁱⁱⁱ) out of those invited (ⁱ) for gFOBt screening. No adjustment is made for undelivered letters and/or test kits.

^{vi} Percentage of people with a definitive gFOBt outcome of 'abnormal' (^{iv}) out of those who were adequately screened (ⁱⁱⁱ) via gFOBt screening. Positivity is calculated from the invited (ⁱ) population only. No adjustment is made for undelivered letters and/or test kits.

^{vii} The episode outcomes presented here are for the invited (ⁱ) population only (for the specified fiscal year). Specifically, those invited (ⁱ) who were found to be definitively gFOBt abnormal (^{iv}), who went on to have a diagnostic test (one or more) within the episode. It is important to note that episode outcomes are calculated from the findings of potentially multiple endoscopic / radiological tests within the episode. A patient can only have one episode outcome per episode.

^{viii} Abnormal findings can be for:

- non-neoplastic diagnosis (such as diverticular disease, haemorrhoids, inflammatory bowel disease)
- non-adenomatous polyp (such as hyperplastic, inflammatory, Peutz-Jeghers polyp)
- non-adenomatous polyp and non-neoplastic diagnosis
- people who have polyps seen at a radiological test only, so no histological confirmation is possible

NHS Bowel Cancer Screening Programme data is extracted from the Bowel Cancer Screening IT system (BCSS), using the reporting tool OBIEE. Data extracted 3 September 2018.

2017 to 2018 screening data

NHS Cervical Screening Programme	
Ages 25 to 64	
Number of eligible women	14,933,811
Number of women invited for screening in year	4,457,953
Number of women tested	3,181,762
Coverage	71.4%
Number of screen positive women	176,561

All data is from the 'Cervical Screening Programme: England, Statistics for 2017-18' bulletin, published by NHS Digital on 27 November 2018. Eligible population is the registered female population minus any women ceased for clinical reasons (for example, after a hysterectomy).

Coverage is the percentage of eligible women who were screened adequately within the previous 3.5 years for women aged 25 to 49 and within 5.5 years for women aged 50 to 64. Number of screen positive women equals the number of adequate tests minus the number of negative samples.

NHS Infectious Diseases in Pregnancy Screening Programme	
HIV	
Eligible women ⁱ	659,995
Tested women ⁱ	657,231
Coverage (%) ⁱ	99.6%
Women declining ⁱ	0.2%
Results reported within 8 working days ⁱⁱ	98.9%
Number of positive results ⁱⁱ	812
Screen positive women attending specialist assessment within 10 working days ⁱⁱ	91.2%
Hepatitis B	
Eligible women	660,010
Tested women	657,034
Coverage (%)	99.5%
Women declining (%) ⁱ	0.2%
Results reported within 8 working days ⁱⁱ	98.9%
Number of positive results ⁱⁱ	2,479
Women with hepatitis B (new positive/high infectivity) seen within 6 weeks (%) ⁱ	84.0%
Screen positive women attending specialist assessment within 10 working days ⁱⁱ	78.7%
Syphilis	
Eligible women ⁱ	660,018
Tested women ⁱ	656,998
Coverage (%) ⁱ	99.5%
Women declining (%) ⁱ	0.2%
Results reported within 8 working days ⁱⁱ	99.0%
Number of positive results ⁱⁱ	824
Screen positive women attending specialist assessment within 10 working days ⁱⁱ	79.9%

ⁱ Figures based on key performance indicator (KPI) data. Exclusions made where completed data was not submitted for all 4 quarters.

ⁱⁱ Figures based on annual standards data. Exclusions were made when data was incomplete or missing, not where trusts could not account for their whole cohort. Data provisional as of 21 November 2018

2017 to 2018 screening data

NHS Newborn and Infant Physical Examination Programme	
Number of eligible babies	535,462
Number of eligible babies tested	504,389
Coverage %	94.24%
Number of babies who have a positive screening test on newborn physical examination and undergo assessment by specialist hip ultrasound within 2 weeks of age	680
Timely assessment %	7.24%
Abnormalities suspected (hips)	9,389
Referrals (hips) with abnormalities suspected (hips)	9,041
Referrals (hips) with risk factors (hips)	40,357
Abnormalities suspected (eyes)	1,089
Referrals (eyes) with abnormalities suspected (eyes)	892
Abnormalities suspected (heart)	8,973
Referrals (heart) with abnormalities suspected (heart)	7,820
Bilateral abnormalities suspected – testes	1,437
Referrals (testes) with bilateral abnormalities suspected – testes	1,083

Data source: NIPE SMART/PMS **Data extracted:** 2 November 2018 A number of Trusts are still not using the NIPE SMART IT system to its optimum level. In general, data input for screening and coverage looks to be in line with submitted coverage (NP1) KPIs but accurate recording of some screen positive cases, referral for hips in particular and recording of outcomes remains a challenge. The NIPE programme has undertaken a number of quality improvement initiatives in order to support more accurate data collection (particularly in relation to capturing post-referral outcomes). Babies born before a site's go-live date are excluded from the data.

NHS Fetal Anomaly Screening Programme	
Number of tests performed	519,864
Number of women at higher chance	15,036
Number of sonographers going through DQASS ⁱ	2,440
DQASS % red flags	1.1%
DQASS % red4 flags	1.9%
DQASS % amber flags	33.5%
DQASS % green flags	60.7%
DQASS % no flags	2.8%

ⁱ DQASS is the Down's syndrome Screening Quality Assurance Support Service. Flags are assigned to a dataset of nuchal translucency (NT) and crown rump length (CRL) measurements. Flags indicate bias of the dataset. Green flag: NT bias ≤ 0.10mm. Amber flag: NT bias 0.11mm - 0.40mm. Red flag: NT bias > 0.40mm. Red4 flag: assigned if fewer than 25 paired measurements over 4 cycles. No flag: trainee sonographer has < 25 paired measurements.

2017 to 2018 screening data

NHS Newborn Blood Spot Screening Programme			
Cystic fibrosis		MCADD	
Babies tested	647,025	Babies tested	648,515
Total screened positive (incl. babies clinically diagnosed before screening)	262	Babies screened positive (excludes 4 babies clinically diagnosed before screening)	52
Screened positive 1st sample (excludes 31 babies clinically diagnosed before screening)	135	Babies for whom we have age at appointment data	41
Babies for whom we have age at appointment data	103	Screened positive and 1st appt within 17 days	41
Screened positive 1st sample and 1st appt within 28 days	95	IVA	
Screened positive 2nd sample (excludes 4 babies clinically diagnosed before screening)	92	Babies tested	648,515
Babies for whom we have age at appointment data	64	Babies screened positive (excludes 1 baby clinically diagnosed before screening)	12
Screened positive 2nd sample and 1st appt within 35 days	47	Babies for whom we have age at appointment data	10
Carriers detected by the screening pathway	146	Screened positive and 1st appt within 17 days	10
CHT		GA1	
Babies tested	648,515	Babies tested	648,515
Total screened positive (incl. babies clinically diagnosed before screening)	613	Babies screened positive (excludes 1 baby clinically diagnosed before screening)	5
Screened positive 1st sample (excludes 11 babies clinically diagnosed before screening)	326	Babies for whom we have age at appointment data	4
Babies for whom we have age at appointment data ⁱ	295	Screened positive and 1st appt within 17 days	4
Screened positive 1st sample and 1st appt within 17 days	284	HCU	
Screened positive 2nd sample (excludes 8 babies clinically diagnosed before screening)	268	Babies tested	648,515
Babies for whom we have age at appointment data ⁱⁱ	224	Babies screened positive (excludes 1 baby clinically diagnosed before screening)	4
Screened positive 2nd sample and 1st appt within 24 days	208	Babies for whom we have age at appointment data	3
PKU		Screened positive and 1st appt within 17 days	2
Babies tested	648,515	MSUD	
Babies screened positive (excludes 5 babies clinically diagnosed before screening)	86	Babies tested	648,515
Babies for whom we have age at appointment data	60	Babies screened positive	9
Screened positive and 1st appt within 17 days	59	Babies for whom we have age at appointment data	5
		Screened positive and 1st appt within 17 days	5
		Coverage	
		% of babies tested and recorded on the Child Health Information System at 17 days	90.0%

ⁱ excludes 12 pre-term babies.

ⁱⁱ excludes 26 pre-term babies.

Data provisional. Every attempt has been made to provide the most correct, up to date information. however, data is incomplete and may be subject to further change/update as and when follow-up of missing information is received.

2017 to 2018 screening data

NHS Newborn Hearing Screening Programme	
Eligible babies	639,913
Eligible babies for whom the screening process is complete by 3 months corrected age	635,562
% eligible babies for whom the screening process is complete by 3 months corrected age	99.3%
% eligible babies for whom the screening process is complete by 4 weeks corrected age (hospital programmes-well babies, NICU babies) or by 5 weeks corrected age (community programmes-well babies). (NH1) ⁱ (standard 1, target ≥ 97%)	98.5%
% eligible babies for whom the screen is declined	0.06%
Well baby referrals from OAE 1 hospital model (standard 2, target ≤30%)	23.4%
Well baby referrals from OAE 1 community model (standard 2, target ≤15%)	15.0%
Babies referred for diagnostic audiological assessment ⁱⁱ	15,772
% referred for diagnostic audiological assessment from hospital model (standard 3, target ≤3%)	2.5%
% referred for diagnostic audiological assessment from community model (standard 3, target ≤1.6%)	1.8%
% babies with a no clear response result in one or both ears or other result that require an immediate onward referral for audiological assessment who are offered audiological assessment within the required timescale. ⁱⁱⁱ (standard 4, target ≥97%)	96.7%
% babies with a no clear response result in one or both ears or other result that require an immediate onward referral for audiological assessment who receive audiological assessment within the required timescale. (NH2) ⁱⁱⁱ (standard 5, target ≥90%)	88.6%
Babies with a confirmed hearing impairment in both ears by 6 months of age ^{iv}	501

Figures exclude babies born or currently in Wales.

ⁱ excludes babies currently less than 90 days corrected age and deceased babies.

ⁱⁱ immediate referrals from the screen, includes incompletes who require a referral.

ⁱⁱⁱ excludes babies currently less than 30 days corrected age and deceased babies.

^{iv} this figure is subject to change as further data is provided.

Source for NHSP data – eSP/S4H/PMS 5 November 2018.

NHS Sickle Cell and Thalassaemia Screening Programme	
Antenatal screening	
Eligible women ⁱ	654,530
Tested women ⁱ	651,652
Coverage ⁱ	99.6%
Women declining (%) ⁱ	0.2%
Women tested by 10 weeks (%) ⁱ	55.9%
ⁱ Based on KPI data. Exclusions made where completed data was not submitted for all 4 quarters.	
Prenatal diagnostic (PND) testingⁱ	
PNDs performed	373
Affected fetal results	95
Carrier results	185
Normal results	93
Newborn screeningⁱ	
Screen positive babies ⁱ	252
Carrier results ⁱ	8,127

ⁱ Data provisional as of 21 November 2018

Powerful data helps providers identify

The 4 UK nations joined forces this year to develop guidance and resources to help tackle inequalities in access to abdominal aortic aneurysm (AAA) screening. AAA screening is an individual choice but data shows that some groups find it more difficult to access screening than others.

Analysis of NHS AAA Screening Programme data in England showed a strong link between social deprivation and lower screening uptake rates. The study, published in the European Journal of Vascular and Endovascular Surgery, looked at data from nearly 600,000 men invited for screening over 2 years.

It found uptake was only 65% in the most deprived 10% of the population compared to 84% in the least deprived. In contrast, the most deprived were twice as likely to have an aneurysm compared to the least deprived.

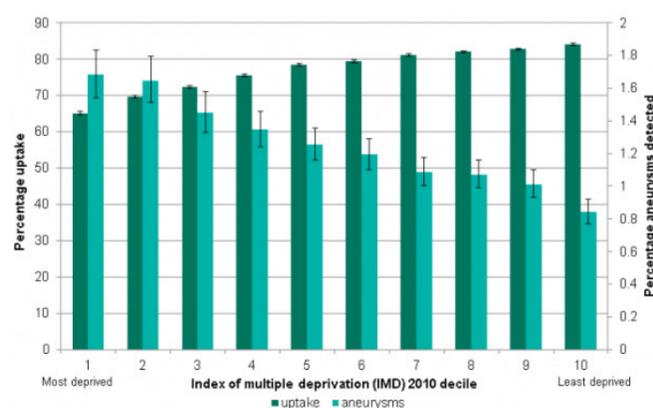
The study also concluded that local factors are the most important determinants of uptake, so solutions to improve uptake must be designed at local, not national, level.

The link between deprivation and lower uptake provided the motivation for us to develop new UK-wide guidance on reducing barriers to AAA screening attendance.

In developing these resources, we built on the work of the 4 nations AAA inequalities project which published a **paper on factors that influence screening attendance and recommendations to increase awareness and accessibility**.

The new guidance, being published on GOV.UK, will help providers and other stakeholders to:

- identify inequalities
- reduce inequalities
- share examples of best practice
- highlight initiatives that have not worked so well



Bar chart from the AAA screening inequalities study showing the link between deprivation and both screening uptake and prevalence of aneurysms

ABDOMINAL AORTIC ANEURYSM SCREENING

In tackling inequalities you first need to identify if they exist. To do this you need good data. In October 2017, we launched a **deprivation and ethnicity report for local AAA screening providers** that shows where inequality of uptake occurs in local services.

Alongside this we also produced:

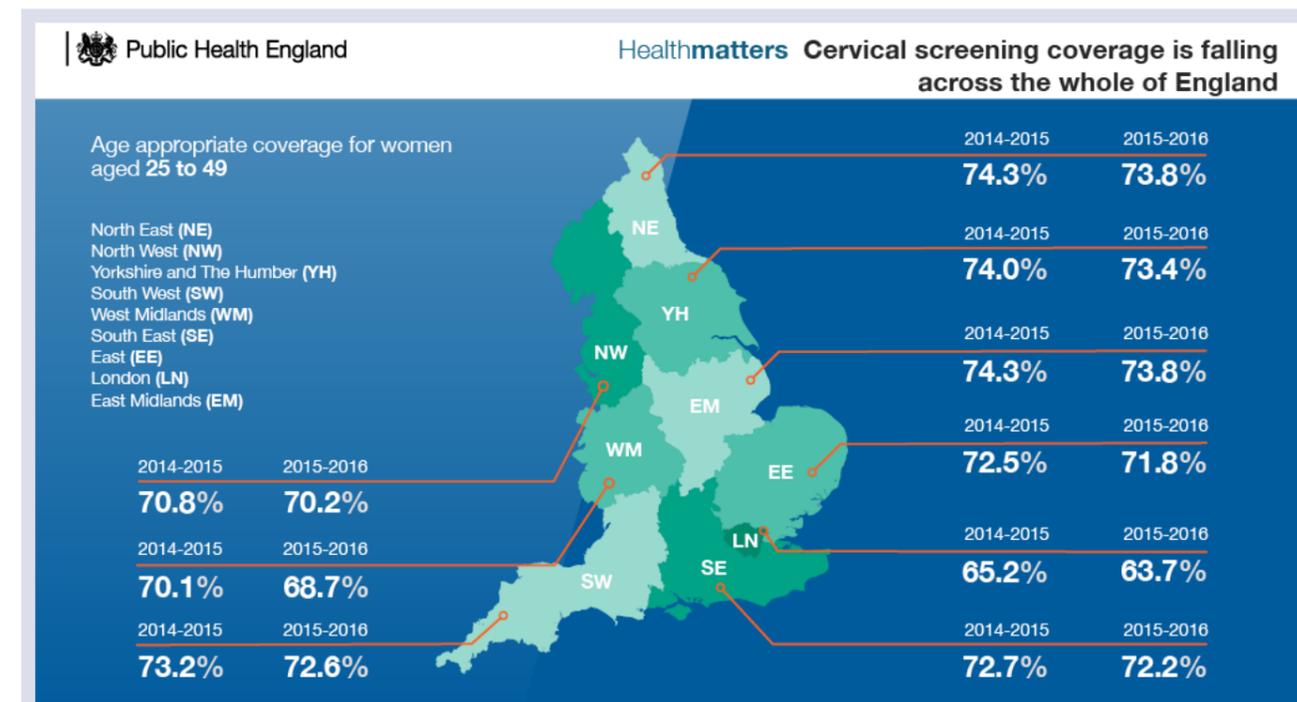
- a reporting tool to help analyse the data
- 4 videos that explain how to use and understand both the report and reporting tool

Good quality data is a powerful tool. Over time we will look to develop and improve the data in the report – for example data on prison populations.

We encourage providers, commissioners and quality assurance teams to work together and make the best use of all these resources. We are also urging providers to share examples of best practice via the PHE Screening blog.

We can then make sure we are all doing everything we can to tackle inequalities in AAA screening.

and tackle barriers to attendance



Attending cervical screening increases the chances of detecting abnormalities that could develop into cervical cancer. So it is important screening is accessible to all women who want to be screened.

Coverage – the proportion of women eligible for cervical screening aged 25 to 64 years who are screened adequately – has been falling steadily over the past decade. More than 1 in 4 women do not attend when invited.

We know there are many barriers that may prevent women attending. These include:

- embarrassment about having a smear test
- worry about the outcome of the test
- cultural or language barriers
- no female sample takers being available
- inconvenient appointment times

Frequent non-attenders include women over 50, younger eligible women, women from ethnic minority groups, lesbian and bisexual women.

We have worked with NHS Digital and Jo's

CERVICAL SCREENING

Cervical Cancer Trust to create an **interactive data coverage tool**. This tool presents data in an accessible way at local authority, clinical commissioning group (CCG) and GP practice level. The data helps providers:

- identify potential barriers to screening
- plan local initiatives and set priorities in relation to cervical screening
- evaluate initiatives aimed at reducing inequalities in a timely way

CCGs can use the interactive tool to investigate screening coverage for their practices and take action to improve coverage and compare with neighbouring CCGs. Local authorities can use the tool to make sure screening continues to be provided through sexual health services as well as GP practices so that the cervical screening needs of their local communities are met.

More information on making cervical screening more accessible was published in an edition of **PHE's Health Matters**.

‘Easy’ way to make screening more accessible for people with learning disabilities

Reducing inequalities is one of the main aims of Public Health England.

Many people decide not to be screened and that is entirely their choice. The decision to have – or not have – a screening test is one that only the person involved can and should make.

We know, however, that people with a learning disability find it more difficult to access screening.

They are less likely to attend screening for a variety of reasons, including a lack of understanding, embarrassment and fear.

Reducing inequalities is not about forcing or even encouraging people to be screened if they do not want it. It is about addressing any barriers that mean people cannot engage with an offer of screening or participate when they might like to.

A significant barrier for people with a learning disability can be the wording and format of the information we give them when we invite them.

Under the Accessible Information Standard, we have a legal obligation to:

- make screening equitable for people who have a disability or sensory loss
- make sure people receive information which they can access and understand

That is why we have been developing easy guides on screening for people with learning disabilities and anyone who struggles with written English.

The easy guides are based on our standard information but we have made the content easier to read by using



BREAST SCREENING AND BOWEL CANCER SCREENING

shorter sentences and easier words. We use photos and other artwork to illustrate each important message.

Local providers can download and print off the easy guides from GOV.UK for anyone who requires information in a more accessible format.

This year, we developed and published new breast screening and bowel scope screening easy guides with the help of PHE Screening’s easy read expert group.

This is the group that previously helped us put together easy read versions of the **Screening tests for you and your baby easy guides** and the **AAA screening easy guide**.

It brings together experts with a broad range of skills and experiences, including:

“ *The workshops have all included experts by experience and involve a broad range of people. Everyone brings something different.* ”

- learning disability nurses
- PHE Screening national programme teams
- local screening providers
- commissioners
- health professionals
- patient organisations
- experts by experience

The input of service users with learning

that is being rolled out across England for people aged 55 where a thin, flexible tube with a camera at the end is used to look inside the bowel for small growths called polyps that could eventually turn into cancer if they are not removed.

Our new easy guide includes:

- why the NHS offers bowel scope screening
- what to expect on the day of the test
- the possible benefits and risks

It follows the same structure as a film developed by Leicestershire Partnership Trust and Lincolnshire community learning disabilities teams to help explain bowel scope screening in simple terms. It also uses still images from the film.

Our expert group has included Sharon Ashby and Deborah Rees, who work as screening liaison nurses for adults with learning disabilities in Cornwall.

They said: “Being part of the PHE Screening expert group workshops has been great because we are passionate about reducing the inequalities experienced by people with learning disabilities.

“The workshops have all included experts by experience and involve a broad range of people, which is great because everyone brings something different.”

Many challenges remain, including how to identify who needs accessible information because of a learning disability at the screening invitation stage.

This requires GPs and learning disability teams to share information appropriately with screening services.

disabilities – our ‘experts by experience’, is particularly important – reinforcing the principle of ‘nothing about us without us’.

They help make sure the PHE Screening easy guides are clear, concise and unambiguous, and meet the needs of the people who will use them.

The new **easy guide to breast screening** explains:

- why the NHS offers breast screening
- what to expect on the day of the test
- the possible benefits and risks of accepting the offer of screening

It builds on excellent work by a variety of groups across the country and incorporates images that also feature in the Leicestershire, Northamptonshire and Rutland Breast Screening Group leaflet.

The new **easy guide to bowel scope screening** explains the screening test

Setting clear, high standards ensures safety and quality

We publish national standards for all 11 NHS population screening programmes.

Every local screening provider has to report data against these standards in order to help us make sure screening is safe and of high quality. This process also highlights inequalities and identifies areas of services we can improve both locally and nationally.

Screening standards provide:

- reliable and timely information about the quality of a screening programme
- data at local, regional and national level
- quality measures across the screening pathways

We know that screening is extremely effective at detecting diabetic retinopathy.

Between 1 April 2017 and 31 March 2018:

- 2,700,774 people with diabetes were offered diabetic eye screening
- 2,232,797 people were screened
- 63,675 people were referred for follow-up tests or treatment

We use national standards to make sure diabetic eye screening (DES) continues to improve. This year, we launched **revised DES standards** after conducting a review of the previous version and changing the screening software so that providers can report against the new measures.

The review was carried out by a group that included representatives from the national programme team, screening quality assurance service (SQAS) and clinical professionals. We consulted on the proposed standards with both internal and external stakeholders before they were reviewed by the PHE screening data group.



Screening is extremely effective at detecting diabetic retinopathy

DIABETIC EYE SCREENING

During the review, we focused on agreeing new process standards that we could use to prompt action to improve local screening services.

Following the review, we:

- removed or amended standards that could not be measured
- removed standards that could be measured through other routes
- removed a number of interim standards that related to the structure of the programme and are included in the **diabetic eye screening service specification**

Guidance is available for commissioners on how they can continue to monitor standards related to the structure of the programme.

We also introduced:

- new standards for the slit lamp biomicroscopy, digital surveillance and pregnancy pathways so that we can monitor the performance of these aspects of the screening service
- a standard looking at repeat non-attenders to help providers address inequalities by targeting some of our hardest to reach groups

Improving awareness for trans people

This year, PHE Screening launched a new resource for people who are trans or non-binary (any gender that is not exclusively male or female) as part of our commitment to make screening accessible and inclusive for all eligible populations.

Trans people are more likely to report not being in good health, being disabled or having a long-term illness.

Many have had experiences that suggest that being trans has affected their access to mainstream healthcare services. As a result, some trans people have developed a lack of trust in healthcare professionals.

In addition, screening and treatment, which can involve discussing body parts and intimate examinations, can be distressing for some trans people.

Inequalities may exist because individuals:

- do not know which screening programmes they are eligible for
- are not invited for screening because of the gender they are registered as with their GP

For example, individuals registered as male may not be called for cervical and breast screening, even though they might benefit from it.

Our new leaflet helps to address these issues. It explains who we invite for breast screening, bowel cancer screening, cervical screening and abdominal aortic aneurysm screening.

It includes important information about all

INFORMATION AND PUBLICATIONS

4 screening processes and how to access additional support and advice.

The leaflet has been very well received by trans communities and healthcare professionals alike.

The LGBT Foundation was one of the first organisations to ask for hard copies. Andrew Gilliver, of the LGBT Foundation's Pride in

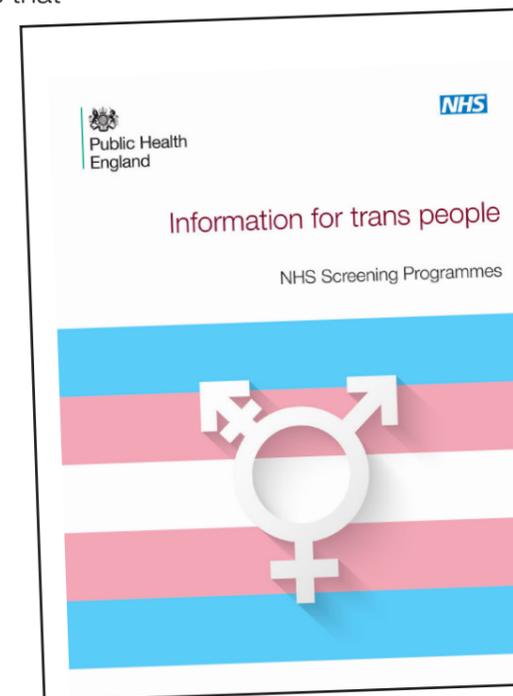
Practice team, said: "This new leaflet helps make sure that trans people can access the screening that is most appropriate for them and take charge of their own health and wellbeing – as we should all be able to do. We have distributed hundreds of copies of the resource to GP practices and trans people.

"We regularly refer to the information in training sessions, not only in primary care but when discussing the wider health needs of trans and non-binary communities.

"We hope that by making this resource widely available we can help improve access to screening among trans and non-binary people and promote the wider understanding of their experiences among providers."

The leaflet is based on original work by Public Health Wales (Screening Division) in 2014.

We developed it in consultation with [nhs.uk](https://www.nhs.uk) and are very grateful for the feedback we received from representatives of the transgender community, including Michael Toze (transgender conduit), and Harri Weeks, of the National LGB&T Partnership.



Working to improve babies' outcomes

The newborn sickle cell and thalassaemia (SCT) screening programme aims to identify babies affected by these inherited blood disorders early and promptly referring them into clinical care.

An **evaluation of the national SCT programme**, published in November 2017, showed that screening was effective in detecting affected babies but that there was scope for improvement.

The evaluation report identified a number of ongoing challenges, including delays between babies' positive screening results and referring them into care.

That was one of the main driving forces behind the development of a new IT system for referring babies with screen positive results into treatment and the collection of SCT newborn outcomes data.

We have been collecting newborn outcomes data for the **NHS SCT Screening Programme** since 2010 and the **National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)** took over the collection of this data in 2017.

We started plans to develop a new enhanced IT system by mapping out the needs of SCT health professionals and newborn screening laboratory scientists.

We also learned from their experiences of submitting data and tracking babies through the SCT pathway.

After getting our business case for the new system approved, we got to work this year on building a limited version of the system which we have been testing with small groups of users.

Our aim is to implement the full system across the country in spring 2019.

The new improved system will:

SICKLE CELL AND THALASSAEMIA SCREENING



- automate the process of referring screen-positive babies into treatment centres and record their health outcomes
- help make sure affected babies are treated as early as possible
- provide a failsafe to prevent babies getting 'lost' in the system
- improve the process of collecting and sharing data
- improve the quality and completeness of data
- remove the need for clinicians to enter the same data twice

Dr Moira Dick, a consultant paediatrician, has been helping us with the project.

She said: "I volunteered to support this project because I looked after children with sickle cell disease for many years in 2 London hospitals.

"I was always concerned about the handover from screening to treatment services and the risk that babies might get 'lost' in the system either due to families moving or some administrative or clinical glitch.

"I am therefore very excited by the new electronic system. It should not only provide a failsafe but also give laboratory staff and clinicians up to date information so babies can be started on treatment as early as possible."



People learn and take in information in different ways. To supplement our text-based information about screening we wanted to develop new approaches to getting our messages across.

In February 2018, we launched a new animation about the screening tests offered during pregnancy and after birth. Visual content of this sort can be particularly helpful for people with lower literacy levels or who have English as a second language.

The 2½ minute video, which you can find on YouTube and the [nhs.uk](https://www.nhs.uk) website, is the culmination of 2 years of hard work by PHE's screening information and education team and colleagues at NHS Digital.

During the animation the viewer is introduced to Katie, who is expecting a baby. Over the course of her pregnancy Katie is offered a number of screening tests. Later, she gives birth to baby Thomas and is offered further tests for him too.

Nick Johnstone-Waddell, PHE Screening public and professional information lead, was in charge of the project and is delighted with how it turned out. He explained the process for developing the animation.

“ *We ran focus groups with pregnant women and a few dads-to-be, which were incredibly helpful.* ”

“We ran focus groups with pregnant women and a few dads-to-be, which were incredibly helpful,” he said.

“They told us they really did not like the original character designs and as a result we went back and designed a much better character they could all relate to.

“We’re now hoping to develop a few more animations in the series, for instance to explain screening offered to men and women throughout their lives.”

Thousands of people have watched the animation online and many NHS trusts have requested the video file to show on local screens. So the animation seems to be making quite an impact.

Watch it by searching for 'screening tests in pregnancy' at www.nhs.uk.

Shared learning drives up standards

The success of newborn hearing screening depends on very early detection of permanent hearing loss.

This is important because children with hearing loss often fall behind their peers in speech and language development, cognitive and social skills.

PHE Screening uses key performance indicators (KPIs) to measure how the NHS screening programmes are performing. KPIs help drive improvements and reduce inequalities by identifying variation and under-performance.

One of the newborn hearing screening KPIs looks at the time between screening outcome and attending an audiological assessment for babies referred to a hearing specialist.

This year, we set about seeing what we could learn from local providers that were consistently meeting and in some cases exceeding the target for this KPI of $\geq 95.0\%$. We did this by:

- identifying the best improvers from KPI data
- designing a survey for best performers to complete, inviting them to share best practice



NEWBORN HEARING SCREENING

- analysing what the sites told us and putting their feedback into themes
- publishing a **report of what we learned from those sites**

The report highlighted the importance of:

- communication between screeners and audiology
- information for parents and communication with parents
- the appointments booking process, flexibility and reminders

We also developed a checklist to help providers look at ways to improve their processes based on learning from these best performing sites.

During the year, we published a series of **blog article examples** of how services had improved their performance by changing the way they work.

One such example was **Lancashire Teaching Hospitals Trust**, which made a big effort to improve the efficiency of its service and reduce parental anxiety by introducing a 3-stage screening process and reviewing its outpatient service.

This has resulted in a much more efficient service, with the referral rate from screening to audiology falling from 4% to 1%, reduced anxiety for parents and the trust often achieving a perfect performance of 100% for this KPI.

Making good use of data and sharing learning between providers will continue to drive improvements in performance and quality and reduce inequalities, leading to better outcomes for children who have permanent hearing loss.

“ *Sharing learning will reduce inequalities, leading to better outcomes for children with permanent hearing loss.* ”



Listening to stakeholders to improve hip screening pathway

NEWBORN AND INFANT PHYSICAL EXAMINATION

The NHS Newborn and Infant Physical Examination (NIPE) programme screens babies for conditions relating to their eyes, heart, hips and testes.

It is important to involve all stakeholders in any change to the programme to make sure the change benefits the population.

The NIPE hip screening expert working group has been considering proposed changes to the hip screening pathway, including optimum timescales for screening, referral and the best age to start treatment. These proposals have also gone out to consultation.

NIPE Programme Manager Jill Walker said: “The hip screening expert group is a great example of how PHE engages with its stakeholders. We have worked closely with royal colleges, orthopaedic surgeons, sonographers, radiologists, midwives, lecturers, charities and other health professionals to make sure we had lots of different perspectives.

“We have reviewed all the comments and suggestions. Timescales will then be set for the release of new guidance and standards, which will replace what we currently have in the programme standards and handbook.”

Emma Morley is a research and information officer for the charity STEPS, which works for those affected by childhood lower limb conditions.

Dr Morley said: “We were delighted to be asked to join the hip working group.

“Our role is to give a parent’s perspective on the impact of hip problems and to ensure discussions take parental concerns into account.

“It is critical that information is presented so parents and carers from all social backgrounds find it easy to understand.”

Some newborns have hip joints that are not formed properly. This is known as developmental dysplasia of the hip (DDH). Left untreated, this can cause a limp or joint problems. The aim of the screening programme is to spot problems early so that treatment can start as soon as possible.

Professor Robin Paton, a consultant orthopaedic surgeon, is a member of the working group and has been able to share his many years of experience.

He said: “The screening programme picks up potentially disabling conditions. There are always new developments which mean we must regularly tweak the screening programme.

“It’s important this group has a mixture of clinical experts as well as representatives from the likes of STEPS. We have been working to give practical and sensible evidence-based advice which will be fed into future screening policy.”

You can find out more about the changes to the hip pathway by **subscribing to our screening blog** and by viewing the **consultation and responses**.

Hepatitis B: we're working together to improve care

An estimated 257 million people in the world are living with hepatitis B virus infection. An estimated one third of the world's population are infected at one point in their lives.

The World Health Organisation's vision is a world where everyone living with viral hepatitis can access safe, affordable and effective care and viral hepatitis is eliminated as a public health threat by 2030.

Achieving these targets requires:

- increased public awareness
- advances in medicines and technologies
- an increased commitment to health equality

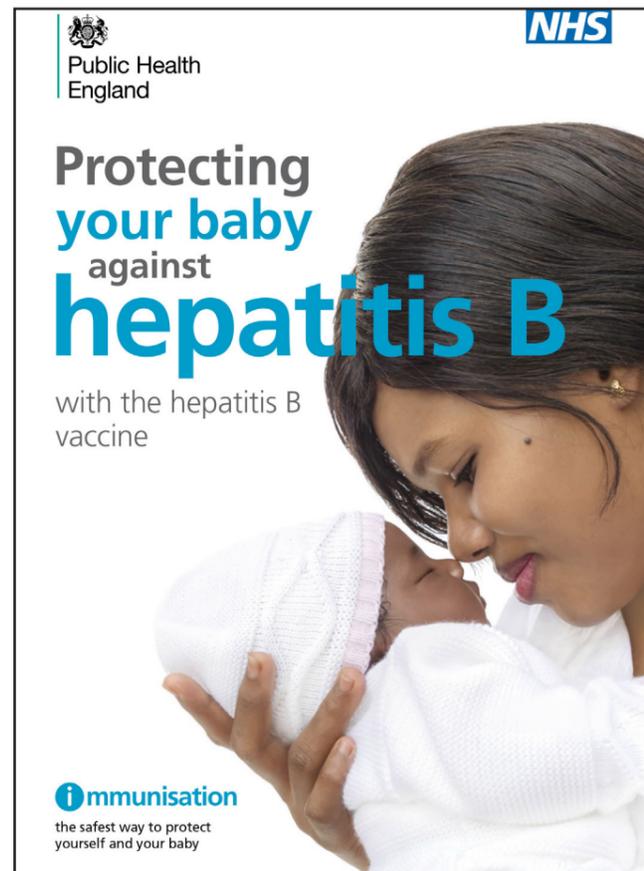
Since 1982, a vaccine against hepatitis B has been available that is 95% effective in preventing infection and the development of chronic disease and liver cancer due to hepatitis B.

In England, about 3,000 babies each year are born to women with hepatitis B. The PHE Infectious Diseases in Pregnancy Screening Programme and national immunisation team have joined forces to address prevention of mother-to-child transmission of hepatitis B.

Our National Hepatitis B in Pregnancy Audit identified important areas we can improve. We found that most chronic infections occur in migrants acquiring the infection overseas. Newly screened positive women are:

- often younger
- likely to have booked for antenatal care late
- less likely to have basic English
- more likely to have arrived in the UK in the past 2 years

We have been consulting with stakeholders and



INFECTIOUS DISEASES IN PREGNANCY SCREENING

working on an enhanced hepatitis B screening and immunisation pathway which we will implement from April 2019.

The focus will be on:

- promoting a multidisciplinary approach
- improved communication with primary care
- national surveillance and reporting processes
- increasing professional knowledge of hepatitis

We will publish new resources including:

- hepatitis B antenatal screening and infant immunisation guidelines
- updated screen positive information leaflet
- vaccination leaflet
- safety checklist for trusts
- delivery suite vaccination box for trusts that will include immunoglobulin and all documents required for the baby at birth
- updated screening and laboratory handbooks
- new e-learning package

Importance of clear and balanced info

Writing information leaflets about screening can be a challenge as we need to explain very complex tests and processes in a simple and straightforward way.

In 2016, the government announced its decision to include non-invasive prenatal testing (NIPT) in the screening programme during pregnancy for Down's syndrome, Edwards' syndrome and Patau's syndrome. PHE started preparations, including setting up an information and education group.

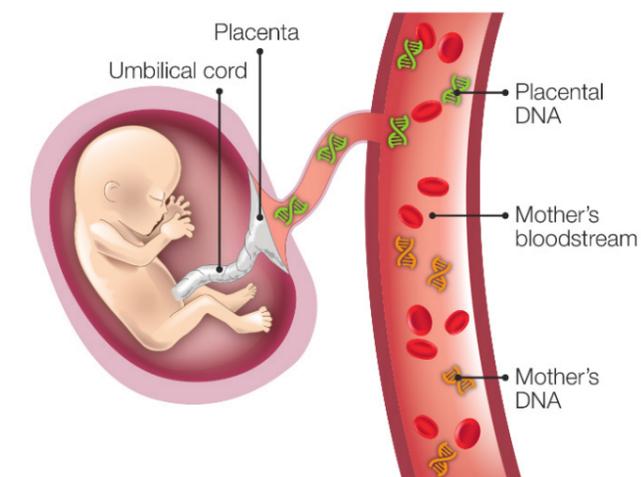
One task for this group was to develop a new version of our antenatal and newborn screening information leaflet – Screening tests for you and your baby.

We understand there are a range of views and experiences of antenatal screening. Concerns have been raised about NIPT and its potential impact on the number of women deciding to end a pregnancy because of one of these conditions. So getting the information right was very important.

We wanted to be completely open about how we produce our leaflets. So the first thing we did was to develop a standard process and publish this on GOV.UK (find it by searching for 'PHE Screening publications production and review'). This explains the principles, as well as the process, of developing new information. For example, it commits us to understanding the requirements of people reading our leaflets (the 'user needs'), of writing in plain English for a reading age of around 11 and – perhaps most importantly of all – of involving stakeholders.

We could not consult every single person who'll read the leaflet but we were fortunate to have fantastic representation on the NIPT information group from:

- the Down's Syndrome Association



Non-invasive prenatal testing works by measuring the amount of placental DNA in the mother's bloodstream

FETAL ANOMALY SCREENING

- the Down's Syndrome Research Foundation
- SOFT-UK, which supports parents of children with Edwards' syndrome and Patau's syndrome
- Antenatal Results and Choices, which provides non-directive support to women around antenatal screening

Through them we were able to talk to parents of children with Down's syndrome, Edwards' syndrome and Patau's syndrome. We also spoke to pregnant women and fathers to be, women who had decided to end a pregnancy because of an antenatal screening result and health professionals who have years of experience of talking to women about screening results.

Everyone supported the need for clear, accurate and balanced information about screening. We used all the feedback to produce a new version of the leaflet. As well as detailing NIPT, it better explains the conditions and the choices and support women have throughout the screening pathway. The updated leaflet will be available when NIPT is launched, some time in 2019.



Making sure ‘movers in’ don’t miss out

All babies under a year of age are eligible for newborn blood spot (NBS) screening for 9 rare but serious conditions. Babies who test positive can be treated early, improving their health and, in some cases, preventing severe disability or even death.

Babies who are born abroad and move into the UK during their first year can be at risk of missing out on these screening tests. We updated our guidance on these ‘movers in’ to help make sure they do not miss out on screening.

The guidance includes information on finding documented results, offering screening and taking the blood spot sample. There is also a section on providing advice to parents.

We offer NBS screening for 9 conditions recommended by the UK National Screening Committee (UK NSC). These are:

- sickle cell disease
- cystic fibrosis (test only offered up to 8 weeks)
- congenital hypothyroidism
- phenylketonuria
- medium-chain acyl-CoA dehydrogenase deficiency
- maple syrup urine disease
- isovaleric acidaemia
- glutaric aciduria type 1
- homocystinuria (pyridoxine unresponsive)

NEWBORN BLOOD SPOT SCREENING

The new guidance explains that:

- all babies under a year of age should have documented NBS results (or declines) for all 9 conditions
- only results documented in English are accepted (this includes translations)
- if a baby under a year does not have all the results, screening should be offered for the untested conditions before they reach a year
- if a sample is taken before the baby’s first birthday, the laboratory will complete all screening processes
- all 9 conclusive blood spot results should be recorded on the child health information system within 21 days of a health care professional finding out the child has moved into England

Christine Cavanagh, national NHS NBS programme manager, said: “Babies who are new to the country or are yet to have a heel prick test are eligible for testing up to a year old for all 9 conditions except cystic fibrosis, the test for which is not reliable after 8 weeks of age.

“In publishing the updated guidance we aim to make sure babies who move in from abroad will be offered screening and are not disadvantaged.”

Developing expert screening workforce

High quality information and training is essential for assuring and sustaining population screening programmes.

PHE Screening works with Health Education England (HEE), local providers, commissioners and professional and public stakeholders to develop and support an expert screening workforce with access to high quality training.

Level 3 diploma

The Level 3 Diploma for Health Screeners is a national requirement for new (non-professionally registered) screeners working in the abdominal aortic aneurysm, diabetic eye and newborn hearing screening programmes.

Level 3 Diploma learners as of 31 March 2018			
Programme	Complete	In progress	Total
AAA	9	53	62
DES	12	291	303
NHSP	9	72	81
All	30	416	446

The diploma is delivered in the workplace and assessed by local qualified assessors.

This year, we continued to support the embedding of the diploma across the country and our multi-stakeholder qualification oversight group supports the ongoing governance of the qualification.

e-Learning

e-Learning is an increasingly important part of PHE Screening’s accessible education and training strategy.

In March 2017, we transitioned our e-learning resources to Health Education England’s **e-Learning for Healthcare** website.

This year, we updated and improved existing

EDUCATION AND TRAINING

modules and created innovative new content to support the screening workforce.

In collaboration with HEE, we launched the interactive cervical e-learning module on e-Learning for Healthcare on 12 October 2017.

In the first 3 months, 1,947 people completed the course and numbers continue to rise, demonstrating the need for this nationally endorsed flexible training.

As of 31 March 2018, more than 40,000 individual learners had signed up to use PHE Screening’s e-learning courses. The newborn blood spot and newborn hearing screening modules were the most popular.

e-Learning users as of 31 March 2018	
AAA screening	385
Antenatal and newborn cross-programme	5,627
Cervical screening	3,853
Fetal anomaly screening	6,980
Newborn blood spot screening	10,546
Newborn hearing screening	9,231
Newborn infant physical examination	2,888
Sickle cell and thalassaemia screening	952
Quality assurance in NHS screening	212
Total	40,674

We continue to develop our suite of e-learning resources, based on user need, with new modules to support:

- infectious diseases in pregnancy screening
- the introduction of faecal immunochemical testing in bowel cancer screening
- the introduction of non-invasive prenatal testing in the fetal anomaly programme
- the rollout of human papillomavirus as the primary cervical screening test

Collecting, reporting and sharing data

We collect data to drive quality improvement in screening. Screening programmes rarely stand still. New technologies, published evidence and data highlight what is working well and what we can improve.

The amount of data available varies considerably between programmes. For example, we have comprehensive data sets for abdominal aortic aneurysm (AAA), newborn hearing and bowel cancer screening but very limited data by maternity unit for some antenatal programmes.

We are keen to put as much meaningful data as possible into the public domain under the **Open Government Licence** (OGL) if it is associated with a high public health benefit. But we are careful not to publish any information that could be used to identify individuals or be misleading.

Data shared between public health professionals working in different organisations sometimes includes small numbers and needs to be considered confidential. Special provisions are put in place to underpin the way we share this data, and how we use it.

Data becomes more powerful and useful if linked. For example, linking cancer registration, vaccination or mortality data with screening histories provides richer data that can help us understand the state of the public's health and how well our screening programmes are doing.

Data can also help us plan changes in our screening programmes based on population changes or new medical and scientific knowledge.

We treat all data with respect. This involves continuous risk assessment to establish if we can release data under OGL. We can also release data back to local providers to support provision of direct care to individuals.

DOWN'S SYNDROME SCREENING QUALITY ASSURANCE SUPPORT SERVICE

Flagging up variation helps improve quality

PHE commissions the Down's syndrome screening Quality Assurance Support Service (DQASS) to support fetal anomaly screening.

DQASS monitors and supports the quality and effectiveness of screening for Down's syndrome, Edwards' syndrome and Patau's syndrome. It helps improve the calculation of the screening result, monitoring the practice of biochemistry laboratories and sonographers and advising them, where necessary, on improvements.

In particular, DQASS supports continual improvement in the quality of ultrasound measurements of the unborn baby's nuchal translucency (NT) and crown rump length (CRL).

It assigns green, amber or red flag status to the NT and CRL data sets of sonographers depending on how much they deviate from expected. This is also known as bias which has a direct impact on the screen positive rate (SPR). A positive bias of just 0.40mm more than doubles the SPR from 2.6% to 5.7%.

DQASS data flag categories

Green flag	Bias \leq 0.10mm
Amber flag	Bias 0.11mm to 0.40mm
Red flag	Bias $>$ 0.40mm

Since DQASS started providing feedback to sonographers in 2010, the SPR has fallen from 6% to just over 2% and the proportion of data sets given a green flag status has doubled.

This year, we tightened the threshold for red flag bias from \pm 0.40mm to \pm 0.30mm. We hope this will lead to further improvements.

nationally to benefit all stakeholders



One of the national antenatal screening data workshops to support local NHS providers

How we support local NHS providers

The national antenatal screening team ran 7 data workshops in England this year ranging from Leeds in the north to Taunton in the south.

The interactive events gave local providers support and clarity in how to submit complete and accurate data on screening standards and key performance indicators (KPIs), remembering all the time that each individual number represents a woman going through the screening pathway.

Staff from more than 110 maternity providers attended the workshops. They included local screening coordinators, sonographers, IT analysts, failsafe officers and biomedical scientists, supported by regional screening quality assurance service teams and screening and immunisation leads.

Delegates told us that the collection and reporting of standards and KPI data had led to many improvements in local screening services, including:

- raising the profile of screening

“ It was really nice to be appreciated for the work we do and I felt the team were talking with us, not to us. So many of us have been in this role for many years and truly value the data collection. It is so nice to know the national leads appreciate how difficult it can be. ”

– workshop delegate

- highlighting the need for failsafe offices and audit clerks to support data collection
- identifying and procuring maternity IT systems with the right functionality
- highlighting and identifying improvements that would not have otherwise been realised

Most delegates rated the workshops as very good and found all the sessions useful.

Research vital for evidence-based tests

The NHS screening programmes provide a unique opportunity for researchers to explore new tests, treatments and specific theories relating to screening from a population perspective.

Data collection and analysis is central to the safety, effectiveness and continuous improvement of NHS screening programmes and we collect a wealth of programme data.

Ultimately we aim to make sure any research will benefit individuals in the screening programme. One example of this is the research that led to the upcoming implementation of the faecal immunochemical test in the bowel cancer screening programme.

It is essential that any research, evaluation and audit involving screening data is feasible, of high quality and protects the safety of patients.

Before 2017, each programme dealt with research and data requests slightly differently. So we set about streamlining and standardising processes across all programmes.

We first established 6 research advisory committees (RACs), covering abdominal aortic aneurysm (AAA) screening, bowel cancer screening, breast screening, cervical screening, diabetic eye screening and antenatal and newborn (ANNB) screening.

The RACs now work to a single term of reference, meet on a quarterly basis and have project submission and decision deadlines. Each RAC reviews applications to make sure proposals are workable, of high quality and protect patients' interests.

RESEARCH

We have set up a central database to track and log all project enquires appropriately. This year we received a total of 138 enquires.

Enquiries received 2017 to 2018

Programme	Number of enquiries
Bowel	48
Breast	44
Cervical	23
Diabetic eye	2
AAA	3
ANNB	18

We also set up a generic screening research inbox, screening.research@phe.gov.uk, so that we log, manage and respond to all enquiries consistently and in a timely manner.

We work closely with the PHE Office of Data Release (ODR) which publishes the data release register, documenting who PHE has disclosed data to and for what reason.

This year, the screening programmes released 25 sets of data, some

covering more than one programme, including 5 data releases from the cervical programme, 16 from the bowel cancer programme, 6 from the breast programme and 3 from the ANNB programmes.

There is still work to do, including improving the RAC information on GOV.UK and setting research priorities for each programme. Once these have been finalised they will enable us to continue to prioritise research proposals that are most beneficial to our screening programmes.



National teams

Divisional office

The PHE Screening Director, Prof Anne Mackie, heads up the divisional office, which supports the rest of the division and the secretariat function for the UK National Screening Committee (UK NSC).

Data and information team

The data and information team is responsible for the provision of high quality and timely information on screening programmes.

Information and technology team

The information and technology (IT) team provides technical advice to the national screening programmes, supports the development of complex IT solutions and oversees the management and procurement of national screening systems.

Evidence team

The evidence team is responsible for managing the process of reviewing the UK NSC's current screening recommendations every 3 years. It also runs the annual call for topics and provides a specialist knowledge and evidence service for the UK NSC and screening programmes.

Information and education for public and professionals (IEPP) team

The IEPP team ensures a joined-up approach to the development of information and professional development resources across the English screening programmes. The team manages PHE Screening digital content on GOV.UK, the PHE Screening blog and Twitter feed.

Screening quality assurance service

The PHE screening quality assurance service (SQAS) undertakes quality assurance to check that services are meeting national standards and to encourage continuous improvement. There are 4 regional SQAS teams working alongside NHS screening programme teams.

Finances

NHS Sickle Cell and Thalassaemia Screening Programme

Pay costs: £395,338
Non-pay costs: £280,000
Total costs: £675,338

NHS Infectious Diseases in Pregnancy Screening Programme

Pay costs: £309,859
Non-pay costs: £237,875
Total costs: £547,734

NHS Newborn Blood Spot Screening Programme

Pay costs: £482,003
Non-pay costs: £757,709
Total costs: £1,239,712

NHS Newborn Hearing Screening Programme

Pay costs: £282,122
Non-pay costs: £1,307,900
Total costs: £1,590,022

NHS Fetal Anomaly Screening Programme

Pay costs: £421,791
Non-pay costs: £413,500
Total costs: £835,291

NHS Newborn and Infant Physical Examination Screening Programme

Pay costs: £495,323
Non-pay costs: £1,290,800
Total costs: £1,786,123

Young Person and Adult (YPA) Programmes

Pay costs: £1,763,600
Non-pay costs: £25,783,400
Total costs: £27,547,000

The YPA screening programmes include the NHS Abdominal Aortic Aneurysm Screening Programme, NHS Bowel Cancer Screening Programme, NHS Breast Screening Programme, NHS Cervical Screening Programme and NHS Diabetic Eye Screening Programme.

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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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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www.gov.uk/topic/population-screening-programmes

Twitter: [@PHE_Screening](https://twitter.com/PHE_Screening) Blog: phescreening.blog.gov.uk

For queries relating to this document, please contact: phe.screeninghelpdesk@nhs.net

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