



# NHS Screening Programmes in England

1 April 2016 to 31 March 2017



November 2017

# The big picture

Between 1 April 2016 and 31 March 2017

We screened **3 million** women for cervical abnormalities.

We screened **2.6 million** people for bowel cancer.

**2.2 million** people with diabetes had eye screening.

We tested **2.2 million** women for abnormalities in breast tissue.

We screened about **660,000** pregnant women for a fetal anomaly, hepatitis B, HIV, syphilis, sickle cell disease and thalassaemia.

We screened around **670,000** babies for 15 conditions (14 for baby girls).

Around **230,000** men were screened for an abdominal aortic aneurysm.

Around **460,000** people required further testing and treatment following positive screening test results.

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# Foreword

The reach and influence of the 11 NHS screening programmes in England is of vital importance to the public's health. This year, we carried out millions of screening tests and identified around 460,000 individuals who needed further investigation or essential treatment. The vast majority of these people had not actively sought care and had no symptoms, which is why screening is such an important public health intervention. Screening enables us to provide information for people and identify conditions early in order to improve health, prevent severe disability and save thousands of lives.

Providing these world-leading screening programmes to millions of people is a remarkable achievement only made possible by many thousands of dedicated health professionals up and down the country, who turn evidence into high quality interventions to improve health on a daily basis.

This is thanks in no small part to excellent working relationships between colleagues in Public Health England (PHE), which provides professional leadership for the programmes nationally, and NHS England, which is responsible for commissioning all NHS screening services and many other public health services.

Local teams within the 4 NHS England regions plan, secure and monitor provision of screening programmes across the country. Our teams of NHS England commissioners, working collaboratively with embedded PHE staff, aim to ensure we provide high quality screening programmes that meet national performance

and quality standards. In conjunction with local providers and a range of local and national stakeholders, we continually strive to improve access to screening and reduce inequalities.

Commissioning high quality screening programmes is critical for the delivery of NHS England's [cancer strategy implementation plan](#) to prevent cancer and make sure people who do have cancer are diagnosed as early as possible. Ensuring wider coverage of screening will significantly reduce the number of people getting cancer and improve outcomes.

We will make further major improvements in cancer screening with the introduction of HPV testing in the cervical screening programme by 2020 and the implementation of faecal immunochemical testing (FIT) in bowel cancer screening. NHS England is also delivering the complete roll-out of bowel scope screening across England.

We continually work to improve existing programmes through quality assurance interventions, IT developments and data analysis. On pages 16 and 17, we explain how the collection, sharing and interpretation of the best available data between PHE, NHS England and other partners enables us to focus resources where the need is greatest to protect and improve health.

This report is full of other examples of hard work being done nationally and locally to improve the quality and consistency of screening. The Screening Quality Assurance Service (SQAS) is at the forefront of this effort. On pages 18 and

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“ *Providing these world-leading screening programmes to millions of individuals is a remarkable achievement.* ”

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19, we highlight the work of SQAS to ensure we learn from incidents.

There are also examples of quality improvement work from each of the 11 national programmes. For example, PHE Screening’s national programme team (pages 14 and 15) has worked closely with local NHS screening providers to identify barriers to women accessing sickle cell and thalassaemia screening early in pregnancy. This has resulted in national and local changes to improve early access to screening.

Fewer women have been taking up the offer of cervical screening in recent years. If every woman eligible for cervical cancer screening had a regular smear test we would save one extra life every day of the year. On page 24, we highlight an initiative involving PHE, NHS England and other stakeholders to increase access to screening and reduce health inequalities.

The proportion of all eligible men and women, aged over 55, screened for bowel cancer is considerably lower, just 59%, than the uptake in the other cancer screening programmes. Regular screening has been shown to reduce the risk of

dying from bowel cancer by 16%, which means thousands more lives could be saved if more people, particularly men, chose to follow up their invitation to get screened. The improvements to the bowel screening programme and FIT test, which requires just one sample rather than 3, will make it easier to take part and will detect bowel cancer more accurately and earlier.

In diabetic eye screening (page 28), a range of initiatives has helped improve the quality and consistency of the grading of retinal images, which is central to ensuring that people with sight-threatening disease are identified at a time when treatment is most effective.

And on page 27 we look at the newborn blood spot failsafe system, which has greatly improved the efficiency of tracking babies screened for 9 rare but serious conditions when they are 5 days old, ensuring they are not lost to screening.

These are just a few of the many examples of the fantastic work being done by our colleagues and partners up and down the country. Many thanks to all of you for your continued hard work and excellence.



**Sir Bruce Keogh**

National Medical Director  
NHS England



**Duncan Selbie**

Chief Executive  
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. 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 ultrasound scanning to all pregnant women to assess the chance of their baby being born with Down's, Edwards' or Patau's syndrome or abnormalities with the fetus. The first scan usually takes place 10 to 14 weeks after conception and includes a blood test for Down's, Edwards' or Patau's syndrome. A scan for fetal abnormalities takes place around 18 to 21 weeks. This allows for further diagnostic tests if required and time for women to consider and choose from the options available.

## 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 for problems with their eyes, heart, hips or testes. Screening helps ensure early detection and diagnosis of several congenital medical conditions and can reduce the amount of treatment required and the likelihood 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 one 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.

# 2016 to 2017 screening data

NHS Abdominal Aortic Aneurysm (AAA) Screening Programme	
Eligible for screening (2016 to 2017 cohort <sup>i</sup> )	282,357
Offered screening	281,965
Tested (2016 to 2017 cohort <sup>i</sup> )	228,563
Coverage (2016 to 2017 cohort <sup>i</sup> )	80.9%
Tested (self referrals)	17,941
AAAs detected (total)	3,009
AAAs detected (cohort)	2,471
Incidence (cohort)	1.08%
AAAs detected (self-referrals)	538
Incidence (self-referrals)	3.00%
Men on surveillance at end of year	11,601
Referrals to surgery	789
Elective AAA repairs	604
Deaths from elective repairs	6
Ruptures	15
Deaths from rupture	13

<sup>i</sup> Men registered with a GP in England and born between 1 April 1951 and 31 March 1952

**Data source:** AAA SMaRT **Data extracted:** 9 November 2017

NHS Breast Screening Programme (provisional data)	
Number of women tested (all ages)	2,199,358
Uptake of screening (all ages)	70.5%
Screening round length (50 to 70 year olds) <sup>i</sup>	89.0%

<sup>i</sup> % 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 2016 to 31 March 2017 based on in-house analysis, prior to official publication expected January 2018. 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	3,165,936
Offered screening (routine digital screening)	2,734,557
Tested (routine digital screening)	2,248,277
Uptake	82.2%
New registrations to programmes	288,688
Urgent referrals (R3A)	9,142
Routine referrals (R2M1, R2M0, R1M1)	61,142

**Data source:** programme performance reports and quarter 4 quarterly submission. **Collected:** June 2017. Data is provisional and subject to change. R1 = Background retinopathy; R2 = Pre-proliferative retinopathy; R3A = Active proliferative retinopathy; M0 = No maculopathy; M1 = Maculopathy.



# 2016 to 2017 screening data

NHS Bowel Cancer Screening Programme (gFOBt) <sup>i</sup>	
Number of people invited <sup>ii</sup>	4,420,245
Number of people adequately screened <sup>iii</sup>	2,605,674
Number of people definitively gFOBt abnormal <sup>iv</sup>	43,359
Uptake <sup>v</sup>	59.0%
Positivity <sup>vi</sup>	1.66%
Number of people diagnosed with cancer <sup>vii</sup>	3,021
Number of people diagnosed with high risk adenomas <sup>vii</sup>	3,844
Number of people diagnosed with intermediate risk adenomas <sup>vii</sup>	5,047
Number of people diagnosed with low risk adenomas <sup>vii</sup>	7,465
Number of people diagnosed with abnormal findings <sup>vii viii</sup>	10,572

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

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

<sup>ii</sup> 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-referral, later responder or opt back-in episodes.

<sup>iii</sup> 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.

<sup>iv</sup> 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.

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

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

<sup>vii</sup> The episode outcomes presented here are for the invited (<sup>ii</sup>) population only (for the specified fiscal year). Specifically, those invited (<sup>ii</sup>) who were found to be definitively gFOBt abnormal (<sup>iv</sup>), 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.

<sup>viii</sup> Abnormal findings can be for any of the following results:

- 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 on 4 October 2017.

# 2016 to 2017 screening data

NHS Cervical Screening Programme	
Number of eligible women <sup>i</sup>	14,671,100
Number of women invited for screening	4,445,151
Number of women tested	3,176,648
Coverage <sup>ii</sup>	72.0%
Number of screen positive women <sup>iii</sup>	181,646

**Data source:** Cervical Screening Programme: England, Statistics for 2016-17 bulletin, published by NHS Digital on 7 November 2017. This data is now in the public domain.

<sup>i</sup> The registered female population minus any women ceased for clinical reasons (such as after a hysterectomy).

<sup>ii</sup> This is the headline figure from NHS Digital which is the percentage of eligible women who were screened adequately within the previous 3.5 years, for women aged 25 to 49, and 5.5 years for women aged 50 to 64.

<sup>iii</sup> Number of screen positive women equals number of adequate tests minus number of negative samples.

Sources:

HSCIC 2016/17 Stats Bulletin Table 11 = Eligible

HSCIC 2016/17 Stats Bulletin Table 4 = Invitations

HSCIC 2016/17 Stats Bulletin Table 5 = Tested

HSCIC 2016/17 Stats Bulletin Table 1 = Coverage

HSCIC 2016/17 Stats Bulletin Table 8 = Adequate test

NHS Fetal Anomaly Screening Programme	
Number of tests performed	504,195
Number of women at higher risk	14,738
Number of sonographers going through DQASS <sup>i</sup>	2,408
DQAS % red flags	0.2%
DQASS % red4 flags	1.9%
DQASS % amber flags	33.9%
DQASS % green flags	60.7%
DQASS % no flags	3.3%

<sup>i</sup> DQASS is the Down's syndrome Screening Quality Assurance Support Service. Flags assigned to a dataset of nuchal translucency (NT) and crown rump length (CRL) measurements. Flags indicate bias of the dataset. Green flag: NT bias  $\leq$  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.

# 2016 to 2017 screening data

NHS Infectious Diseases in Pregnancy Screening Programme	
<b>HIV</b>	
Eligible population <sup>i</sup>	634,017
Number of tests <sup>i</sup>	630,681
Coverage (%) <sup>i</sup>	99.5%
Results reported within 8 working days (%) <sup>ii</sup>	98.3%
Number of positive results <sup>ii</sup>	762
Screen positive women attending specialist assessment within 10 working days (%) <sup>ii</sup>	83.1%
<b>Syphilis</b>	
Eligible population <sup>ii</sup>	452,139
Number of tests <sup>ii</sup>	450,354
Coverage (%) <sup>ii</sup>	99.6%
Results reported within 8 working days (%) <sup>ii</sup>	98.4%
Number of positive results <sup>ii</sup>	774
Screen positive women attending specialist assessment within 10 working days (%) <sup>ii</sup>	73.8%
<b>Hepatitis B</b>	
Eligible population <sup>ii</sup>	452,139
Number of tests <sup>ii</sup>	450,276
Coverage (%) <sup>ii</sup>	99.6%
Results reported within 8 working days (%) <sup>ii</sup>	98.4%
Number of positive results <sup>ii</sup>	2,219
Women with hepatitis B (new positive/high infectivity) seen within 6 weeks (%) <sup>i</sup>	80.3%
Screen positive women attending specialist assessment within 10 working days (%) <sup>ii</sup>	73.9%
Babies born to hepatitis B positive women received first dose of vaccination <24 hours (%) <sup>ii</sup>	98.4%
Babies born to hepatitis B positive women receiving immunoglobulin (if required) <24 hours (%) <sup>ii</sup>	93.3%

<sup>i</sup> Figures based on KPI data. Exclusions made where completed data was not submitting for all 4 quarters.

<sup>ii</sup> 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.

NHS Newborn and Infant Physical Examination Programme			
Number of eligible babies	501,816	Referrals – heart	7,866
Number of eligible babies tested	495,213	% of eligible babies referred – heart	1.6%
Screening outcome set within 72 hours	481,662	Referrals – testes	3,746
% outcome set within 72 hours	96.0%	% of eligible male babies referred – testes	1.5%
Declined screen	9	Referrals – eyes	1,146
% declining	0.0%	% of eligible babies referred – eyes	0.2%
Referrals – hip	50,143		
% of eligible babies referred – hip	10.0%		

**Data source:** NIPE SMART **Data extracted:** 26 October 2017 NIPE SMART is not rolled out across the country, so this is not full cohort data. On 1 April 2016, 97 out of 139 providers were using NIPE SMART. This rose to 115 by 31 March 2017. Babies born before a site's go-live date are excluded from the data.

# 2016 to 2017 screening data

NHS Newborn Blood Spot Screening Programme	
<b>Cystic fibrosis</b>	
Babies tested	665,300
Screened positive 1st sample <sup>i</sup>	155
Screened positive 1st sample and 1st appt within 28 days <sup>ii</sup>	107
Screened positive 2nd sample <sup>iii</sup>	98
Screened positive 2nd sample and 1st appt within 35 days <sup>iv</sup>	46
<b>CHT</b>	
Babies tested	668,481
Screened positive 1st sample <sup>v</sup>	278
Screened positive 1st sample and 1st appt within 17 days <sup>vi</sup>	225
Screened positive 2nd sample <sup>vii</sup>	259
Screened positive 2nd sample and 1st appt within 24 days <sup>viii</sup>	153
<b>PKU</b>	
Babies tested	668,668
Babies screened positive <sup>ix</sup>	78
Screened positive and 1st appt within 17 days <sup>x</sup>	48
<b>MCADD</b>	
Babies tested	668,668
Babies screened positive <sup>xi</sup>	63
Screened positive and 1st appt within 17 days <sup>xii</sup>	51
<b>IVA</b>	
Babies tested	668,668
Babies screened positive <sup>xiii</sup>	9
Screened +ve and 1st appt within 17 days <sup>xiv</sup>	9
<b>GA1</b>	
Babies tested	668,668
Babies screened positive <sup>xiii</sup>	9
Screened +ve and 1st appt within 17 days <sup>xv</sup>	5
<b>HCU</b>	
Babies tested	668,668
Babies screened positive <sup>xiii</sup>	7
Screened +ve and 1st appt within 17 days <sup>xvi</sup>	1
<b>MSUD</b>	
Babies tested	668,668
Babies screened positive <sup>xvii</sup>	5
Screened +ve and 1st appt within 17 days <sup>xviii</sup>	2

<sup>i</sup> excludes 22 babies clinically diagnosed before screening

<sup>ii</sup> for babies where age at appointment data was reported. Of 119 where we have this information, 107 met standard

<sup>iii</sup> excludes 2 babies clinically diagnosed before screening

<sup>iv</sup> for babies where age at appointment data was reported. Of 62 where we have this information, 46 met standard

<sup>v</sup> excludes 7 babies clinically diagnosed before screening

<sup>vi</sup> for babies where age at appointment data was reported. Of 230 where we have this information, 225 met standard

<sup>vii</sup> excludes 8 babies clinically diagnosed before screening; includes 25 pre-term babies

<sup>viii</sup> for babies where age at appointment data was reported. Of 172 where we have this information (full-term cohort), 153 met standard; excludes 25 pre-term babies

<sup>ix</sup> excludes 10 babies clinically diagnosed before screening

<sup>x</sup> for babies where age at appointment data was reported. Of 50 where we have this information, 48 met standard

<sup>xi</sup> excludes 10 babies clinically diagnosed before screening

<sup>xii</sup> for babies where age at appointment data was reported. Of 55 where we have this information, 51 met standard

<sup>xiii</sup> excludes 0 babies clinically diagnosed before screening

<sup>xiv</sup> for babies where age at appointment data was reported. Of 9 where we have this information, 9 met standard

<sup>xv</sup> for babies where age at appointment data was reported. Of 5 where we have this information, 5 met standard

<sup>xvi</sup> for babies where age at appointment data was reported. Of 2 where we have this information, 1 met standard

<sup>xvii</sup> excludes 1 baby clinically diagnosed before screening

<sup>xviii</sup> for babies where age at appointment data was reported. Of 3 where we have this information, 2 met standard

Data provisional as of 10 November 2017. Figures may differ from those published in the programme specific data report for 2016 to 2017 as further data is provided.

**Coverage (% of newborn babies tested and recorded on Child Health Information System at 17 days) = 96.5%**  
 (% coverage based on the annual KPI 2016-17 data for England: NB1 – Coverage (CCG responsibility at birth))

# 2016 to 2017 screening data

<b>NHS Newborn Hearing Screening Programme</b>	
Eligible babies	656,430
Eligible babies for whom the screening process is complete by 3 months corrected age	651,446
% eligible babies for whom the screening process is complete by 3 months corrected age	99.2%
% 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) <sup>i</sup> (standard 1, target $\geq 97\%$ )	98.4%
% eligible babies for whom the screen is declined	0.06%
Well baby referrals from OAE 1 hospital model (standard 2, target $\leq 30\%$ )	24.2%
Well baby referrals from OAE 1 community model (standard 2, target $\leq 15\%$ )	15.0%
Babies referred for diagnostic audiological assessment <sup>ii</sup>	17,053
% referred for diagnostic audiological assessment from hospital model (standard 3, target $\leq 3\%$ )	2.7%
% referred for diagnostic audiological assessment from community model (standard 3, target $\leq 1.6\%$ )	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. <sup>iii</sup> (standard 4, target $\geq 97\%$ )	96.4%
% 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) * (standard 5, target $\geq 90\%$ )	89.0%
Babies with a confirmed hearing impairment in both ears by 6 months of age <sup>iv</sup>	476

Figures exclude babies born or currently in Wales

<sup>i</sup> excludes babies currently less than 90 days corrected age and deceased babies

<sup>ii</sup> immediate referrals from the screen, includes incompletes who require a referral.

<sup>iii</sup> excludes babies currently less than 30 days corrected age and deceased babies

<sup>iv</sup> this figure is subject to change as further data is provided

Source for NHSP data – eSP/S4H/PMS 8 November 2017

<b>NHS Sickle Cell and Thalassaemia Screening Programme</b>			
<b>Antenatal screening</b>		Prenatal diagnostic (PND) testing	Not available <sup>iii</sup>
Antenatal samples screened <sup>i</sup>	663,088	PNDs performed	Not available <sup>iii</sup>
Coverage <sup>ii</sup>	99.3%	Affected fetal results	Not available <sup>iii</sup>
% women declining <sup>i</sup>	0.38%	<b>Newborn screening</b>	
% women tested by 10 weeks <sup>ii</sup>	53.1%	Newborn samples screened <sup>iv</sup>	667,783
Screen positive pregnant women <sup>i</sup>	12,494	Screen positive results <sup>iv</sup>	308
Rate of screen positive women <sup>i</sup>	1 in 53	Rate of screen positive babies <sup>iv</sup>	1 in 2,182
% fathers tested <sup>i</sup>	63.6%	Percentage declining <sup>iv</sup>	0.22%
At risk couples detected <sup>i</sup>	738	Carrier results <sup>iv</sup>	8,536

<sup>i</sup> Based on provisional antenatal laboratory data (130/141 expected returns). Figures may differ to those published in the programme-specific data report for 2016 to 2017.

<sup>ii</sup> Based on KPIs ST1 and ST2

<sup>iii</sup> Sickle cell and thalassaemia data on prenatal tests was not available at the time of publication

<sup>iv</sup> Based on provisional newborn laboratory data. Figures may differ to those published in the programme-specific data report for 2016 to 2017.

# We're making it easier for women to

The success of sickle cell and thalassaemia screening depends on women accessing screening early in their pregnancy. Early access to screening and the early offer of prenatal diagnosis (PND) gives women and couples time to consider their options if they're found to be at risk of having a baby with sickle cell disease or thalassaemia major.

Data from 1 April 2015 to 31 March 2016 revealed that many trusts were failing to meet acceptable national key performance indicator (KPI) standards to:

- screen women by 10 weeks' gestation
- perform PND tests by 12 weeks and 6 days

To tackle this issue, the national programme asked local screening providers for help in identifying barriers to women accessing early screening in pregnancy.

The midwifery team at Sandwell and West Birmingham Hospital (SWBH) accepted our challenge and we analysed women's journeys along the screening pathway to find out what the blockers were.

By working together and learning from each other, we have helped improve screening practice and early access to screening locally and nationally.

SWBH's local service improvements included:

- a dedicated phone line and direct access to booking appointments
- a results line operating Monday to Friday
- SCT screening samples being taken at booking appointments and at weekends



## NHS Sickle Cell and Thalassaemia Screening Programme

Information for fathers invited for a screening test for sickle cell disease and thalassaemia major



Public Health England leads the NHS Screening Programmes

## Sickle cell and thalassaemia screening

“ *Early screening allows parents time to mentally prepare themselves for the outcome of their decision.* ”

SWBH has also been working with GPs to see if haemoglobinopathy status can be added to the registration pro forma for new patients. This will speed up the screening pathway when referring women for maternity care.

We made several changes nationally to help improve early access to screening. We:

- updated the [guidelines for counselling and referral to PND](#) for at-risk women and couples to help standardise practice
- updated our 'Test for fathers' leaflet (pictured left)
- updated our information for women and couples at risk of having a baby with [thalassaemia major](#) or [sickle cell disease](#)
- added a new SCT programme standard – standard 5 'timeliness of offer of PND' – to drive improvement

These actions already appear to be improving results. When fully implemented, they should lead to sustainable improvements towards the 75% achievable standard for the 'timeliness of test' KPI.

Parent representative Lynette Adjei has 2 children with sickle cell disease and was a member of the

# access screening early in pregnancy



## The early offer of screening helps give women and couples time to consider their options

project advisory group that looked at improving early access to screening.

She said: “It is very encouraging to see the strides already made in Sandwell and West Birmingham, giving a clear indication of what is possible when and where there is a will.

“For those who have not experienced it, it is hard to describe the heartache involved in bringing up a child with sickle cell disease. Although some heartache can come through being screened, early pregnancy is a far better time to be given real choices that will make a huge difference to any family unit. I look forward very much to this being rolled out and established as the minimum standard everywhere nationally in the near future.”

Fellow parent representative and project advisory group member Adeeba Sajad said: “The importance of early screening cannot be emphasised enough. Living with a medical condition has an immense effect on the whole family unit both physically and emotionally.

“Early screening will allow parents to have the necessary counselling, do the necessary research to find out about life with thalassaemia and make a fully informed decision about something that would be life changing beyond their imagination.

“It allows parents time to mentally prepare themselves for whatever the outcome of their decision.”

# Good quality data is playing a central role

Good quality data, provided at the right time to the right people, is central to running safe and effective screening programmes.

## The value of good data

Data by itself cannot change the quality of services but it does send us warning signs and point us in the right direction.

Good local knowledge and working with our partners in NHS England and service providers is fundamental to the interpretation of data so we can focus resources on areas where the need is greatest.

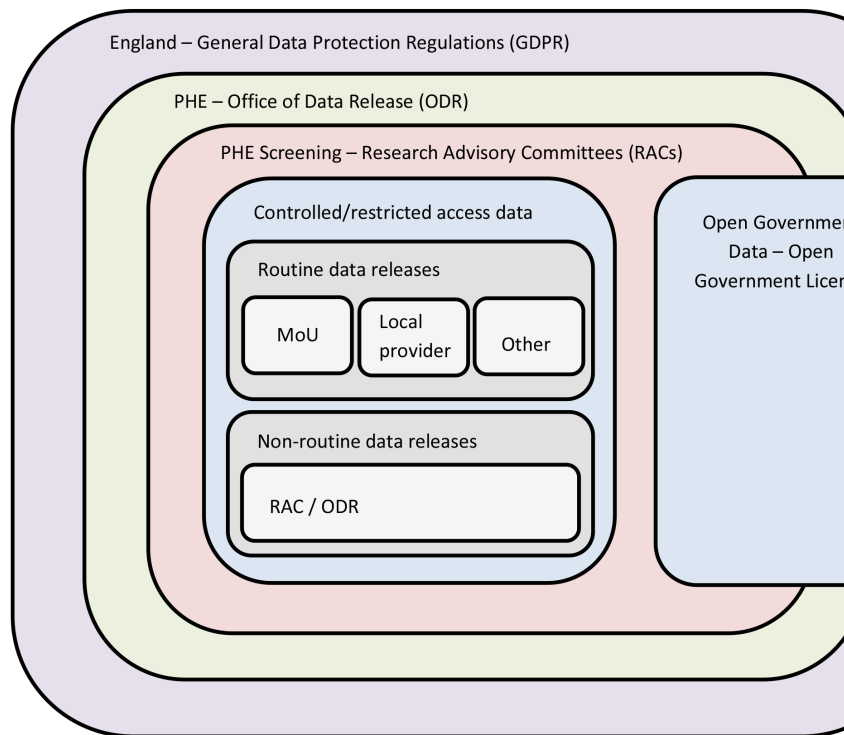
The success of what we do depends on us remembering that the numbers we look at represent babies, women and men who we are trying to help live better quality and longer lives.

## Core principles

PHE Screening’s data team bases its efforts around **trustworthiness** (trusted people, systems and process), **quality** (robust data, methods and statistics) and **value** (data that serves the public good).

We aim to collect, process and share the best available data and information about our eligible population, screening pathway and outcomes. This means we have to:

- work in a timely fashion
- quality assure data
- have good methodology
- produce consistent, comparable data reports
- have clear definitions and processes
- engage with stakeholders
- reduce possible misrepresentation of data



Graphical representation of how PHE Screening operates with regards to data release

## Highest ever KPI performances

All 6 **antenatal key performance indicators** (KPIs) saw an improvement this year compared to the previous year. Antenatal coverage for HIV and sickle cell and thalassaemia screening reached their highest ever performances at 99.5% and 99.3% respectively. Improvements were also seen in most newborn screening KPIs.

This year, we worked hard to improve all our processes, from **defining and reporting key performance indicators** (KPIs) to communicating the meaning of numbers and how data links to individuals as well as the whole population.

## What we’ve done to make data better

We always aim to collect data from the best sources. We have, for example, developed a service level agreement with the National Congenital



# Role in improving and protecting health

Anomaly and Rare Disease Registration Services (NCARDRS) for data on the number of babies born with sickle cell disease, thalassaemia and other rare diseases.

We aim to minimise the burden of data collection and have planned regional workshops to:

- better understand the issues providers face
- support providers with data collection
- show how regular monitoring of good quality data can improve safety

We follow an agreed framework for developing screening standards across all 11 national screening programmes and have a checklist to ensure a consistent approach to assessing the metrics associated with them.

We developed a range of internal guidance documents to make sure we are consistent in our processes.

Newly developed guidance includes:

- key principles on data quality
- sense checking data
- piloting, producing and publishing KPIs

We are continuously working with IT colleagues to ensure good quality data remains a priority when developing or upgrading IT systems.

We also tightened governance procedures to clarify the position of data groups in PHE Screening and started work on a central glossary with consistent terminology and definitions across all screening programmes.

## Reporting and sharing information

Collecting and reporting good quality data plays a central role in improving and protecting the nation's

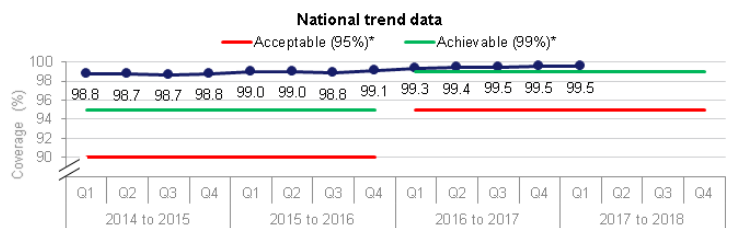
### KPI ID1: HIV coverage



National performance of ID1 in Q1 has remained at its highest ever level at 99.5%

140 out of 147 screening providers met the acceptable threshold of 95%

127 out of 147 screening providers reached the achievable threshold of 99%



\*Thresholds changed in 2016 to 2017

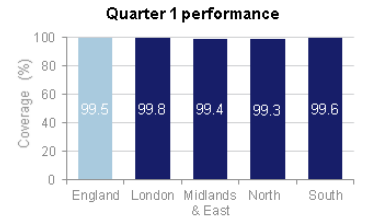
**KPI ID1**

Reporting period: **Q1 2017 to 2018**

England

- numerator = **166,430**
- denominator = **167,240**
- performance = **99.5%**

Completeness of data: **96.6%**



**KPI ID1 description**

The proportion of pregnant women eligible for HIV screening for whom a confirmed screening result is available at the day of report

Reported by: Maternity service

### An example of a factsheet we've developed to present summaries of quarterly KPIs

health. We fully support the Caldicott Principles, including the fact that 'the duty to share information can be as important as the duty to protect patient confidentiality'.

This year, we developed a memorandum of understanding with NHS England to allow free flow of population-based screening data between the 2 organisations.

We are always looking to release additional data sets into the public domain that help answer important questions and support our screening services.

# Making sure we learn from incidents to

## Screening quality assurance service

We invite millions of people for screening every year. Patient safety is our top priority but on rare occasions things don't go as planned and incidents occur. We have an extra obligation to resolve any screening incidents because they have the potential to affect large numbers of people. We also have an added responsibility because we proactively invite asymptomatic people to participate in our programmes.

Dealing with incidents is a very important part of the work of the screening quality assurance service (SQAS). If we understand why incidents occur, we can learn from them and improve the quality and safety of programmes.

This year, SQAS published updated [guidance on managing safety incidents in the NHS Screening Programmes](#). Local commissioners and providers should use this to help them manage screening safety incidents and use alongside NHS England guidance when managing serious incidents in screening programmes.

The updated guidance includes definitions of safety and serious incidents. It recommends the steps providers and commissioners need to take, from finding the problem to closing the incident and sharing learning.

We advise providers to:

- contact their regional SQAS team for advice if they think they have a quality or safety issue
- work closely with screening and immunisation teams that lead and commission services
- follow PHE screening incident guidance and use national resources, such as the screening incident assessment form



## Quarterly screening incident reports highlight recurring themes

During the year (1 April 2016 to 31 March 2017), services reported more than 1,000 screening incidents, of which less than 7% were classified as serious.

We produce a quarterly screening incident report that summarises and analyses all reported incidents.

We share this with commissioning and public health colleagues in PHE and NHS England and use it to make recommendations on guidance, education and training.

The quarterly reports show the number of safety and serious incidents in each of the 11 national programmes and by region.

We look at where the incidents are happening in the pathway and for common causes.

# improve screening quality and safety

This year's reports highlight recurring themes and give clear messages that local services should:

- have systems to accurately identify the people to be screened
- track screening samples and make sure each person screened gets the right result
- use failsafe (checking) systems and audit to prevent incidents
- make sure all screeners have up to date knowledge and skills, work to PHE screening guidance and appreciate the importance of accurate documentation
- ask SQAS for advice when planned changes may affect screening, such as the merging of services or introduction of new IT systems

SQAS picks up these and similar issues during routine activities, such as scheduled QA visits of local services.

## Learning from incidents helps improve the quality of screening

Reporting, managing and learning from incidents leads to national and local actions to improve services and prevent similar incidents happening elsewhere. We share messages through the PHE Screening blog and regional SQAS teams. SQAS uses case studies in screening incident training.

## What's next?

We will continue to

- provide training in dealing with screening incidents
- develop more resources to support local services
- maintain our reporting system
- align guidance with NHS arrangements for patient safety

### Case study: managing and preventing incidents in diabetic eye screening

Some patients with diabetes were not being invited for diabetic eye screening because local services did not have an up to date list of patients.

We produced national guidance to help services improve the accuracy of the lists of patients to invite.

### Case study: supporting cervical screening sample taking and screening laboratories

Incidents were commonly occurring in local cervical screening services at the time a woman had her sample taken.

This might be due to how the sample was taken, incorrect labelling of samples or how the sample is sent to the laboratory.

To try to reduce the number of these incidents PHE Screening issued new resources to support sample takers and laboratories have put in place a common acceptance criteria for samples.

### Case study: improving guidance so newborn screening tests aren't missed

There were incidents in newborn screening where it was unclear if babies who moved areas had been screened.

Midwives and health visitors weren't sure what screening tests to offer these babies.

We updated national guidance to explain which tests can be offered at different ages if a baby misses them at the usual time.

# New training boosts screening capacity

The sustainability of NHS population-based screening programmes depends on having enough suitably qualified staff to do the screening tests and any follow-up tests and interventions required safely – both now and in the future.

We are introducing bowel scope screening in the NHS Bowel Cancer Screening Programme as an additional one-off test for all 55 year olds. Bowel scope uses flexible sigmoidoscopy, which is an endoscopic investigation – putting a camera into the lower end of the bowel – to look for small polyps that might turn into cancer.

There is a shortage of staff trained to undertake endoscopy in England both for screening and diagnostic work, including all upper and lower gastrointestinal (GI) tract endoscopy. Bowel scope screening will further increase demand on the endoscopy workforce.

To help address this, the Department of Health has mandated Health Education England (HEE) to train 200 clinical endoscopists (non-medical staff) by the end of 2018. HEE, working with the Joint Advisory Committee on GI Endoscopy, is leading this work and has developed an accelerated training programme. This initiative trains suitably qualified registered health professionals to perform diagnostic procedures in either upper GI endoscopy or flexible sigmoidoscopy.

Two pilot cohorts completed this 7-month training programme in 2016. Following positive evaluation

## Bowel cancer screening

by the Office for Public Management (OPM), this is being rolled out more widely. HEE is promoting the accelerated programme with the aim of training 200 people by the end of 2018. Liverpool John Moores University and King's College London have been awarded contracts to provide the academic elements.

The training is open to certain registered health professionals, including diagnostic and therapeutic radiographers, nurses, clinical nurse specialists,

operating department practitioners, nurse practitioners, specialist screening practitioners and clinical nurse specialists in cancer.

About half the students will choose to train in flexible sigmoidoscopy and half in upper GI endoscopy. Many who have trained in flexible sigmoidoscopy will have the chance to

undertake further development and assessment to then perform bowel scope screening.

To enable professionals to train within this accelerated timeframe, employers are expected to provide considerable local support.

PHE supports HEE in the promotion of this course and recruitment of staff to the programme. We are also exploring, in discussion with HEE and the Joint Advisory Committee on GI Endoscopy, the scope for further development of clinical endoscopists in their local workplace.



**More endoscopists are needed to meet demand in bowel scope and colonoscopy**

# Developing truly accessible information

All information about screening should be clear, concise, accurate and written in plain English. It's very important we help people understand why they are being invited for screening and the potential benefits and harms of accepting or declining the offer. We therefore invest a lot of time and effort in developing and reviewing all our printed and online information.

Our information and education for public and professionals (IEPP) team has been running writing workshops for all PHE Screening staff and has developed a publications production and review process to ensure screening information is of high quality and fit for purpose. This is a collaborative process that involves clinical experts, public and patient focus groups and other stakeholders.

We need to go even further to communicate effectively with people with learning disabilities. To address this need, we have set up an expert national group to review and revise easy read information about all the population screening programmes. This group includes:

- learning disability service users (experts by experience)
- screening professionals
- learning disability clinicians
- commissioners
- public health experts
- patient organisation representatives

This year, the expert group helped update our [easy read guide to abdominal aortic aneurysm](#)

## Abdominal aortic aneurysm screening

(AAA) screening. They took part in a one-day workshop and helped draft, review and revise the leaflet. The input of service users was particularly valuable in making sure the new leaflet is clear, concise, unambiguous and easy to digest. We hope it will enable 65-year-old men with learning disabilities make choices about AAA screening that meet their needs.



### Abdominal aortic aneurysm (AAA) screening

An **easy guide** about a health test for men who are 65 or older



Lynda Pike, who manages the local South Devon and Exeter AAA Screening Programme, was part of the group.

“I really enjoyed the opportunity to meet people who shared a desire to improve information for patients with a learning disability,” she said.

“Lots of experts from different backgrounds created a good discussion, challenging us to view things from different perspectives.

“It is important to me to give our patients information in a manner which is accessible so they know what to expect from the AAA screening test while also having information to help them consider their choices.

“Some issues were difficult to resolve. We discussed terminology with a long debate about terms which might offend some even though they were common slang and easily understood compared to the correct anatomical term.

“The resulting leaflet has been really well received by staff and patients alike.”

# New measure to make sure pregnant

We developed key performance indicators (KPIs) for each of the NHS screening programmes to measure and compare how local services are performing and to drive up quality.

In April 2016, the NHS Fetal Anomaly Screening Programme (FASP) introduced KPI FA2 to measure coverage of the mid-pregnancy (18+0 to 20+6) ultrasound scan, which looks for structural anomalies in babies. We first piloted FA2 with a number of ultrasound departments to make sure it was fit for purpose.

## What we learned from the pilot

The pilot highlighted challenges and benefits of introducing this KPI.

Challenges included:

- tracking each woman through the system
- tracking women who book and subsequently miscarry or terminate their pregnancy
- multiple IT systems that are often not linked
- women moving from one provider to another during pregnancy, sometimes several times
- following up women who do not attend appointments
- capacity issues in many ultrasound departments that make it difficult to accommodate women at short notice – for example, women who book later in the gestational window
- lag time between booking and completing the fetal anomaly scan that makes reporting more challenging

“ *This KPI highlighted a gap in our failsafe for women who do not attend their anomaly scan.* ”

## Fetal anomaly screening

KPI FA2 Completeness and performance			
Quarter	Completeness	Performance (%)	
Q1	83/145 (57.2%)	95.0%	
Q2	98/145 (67.6%)	96.3%	
Q3	103/145 (71.0%)	97.0%	
Data quality assessment			
Quarter	No. of returns	No. robust	% robust
Q2	98	79	80.6%
Q3	103	80	77.7%

**Q1:** 1 April to 30 June 2016

**Q2:** 1 July to 30 September 2016

**Q3:** 1 October to 31 December 2016

- the fetal anomaly ultrasound scan may not be uniquely identified from other pregnancy scans on IT systems

The pilot also showed that preconceived beliefs that women always attend their scans were not

correct. Sometimes it is the most vulnerable women who don't attend. One provider identified 4 women who did not have their scans in the recommended

timeframe. They were able to fix problems in their appointment booking process and provide more training for staff to address this.

Sue Ward, Antenatal and Newborn Screening Coordinator at Great Western Hospitals NHS Foundation Trust, said: “This is a useful KPI and was well received by our trust. It highlighted a gap in our failsafe for women who do not attend their anomaly scan, which has now been rectified,

# women complete screening pathway



## The new performance indicator measures coverage of the mid-pregnancy ultrasound scan

but may not have been identified as a gap without the KPI's introduction.”

### Data collection and quality

We collect KPI data 2 quarters in arrears. As FA2 is a new KPI, in its first year of collection, we are only using the data internally with healthcare professionals and quality assurance services, with the aim of improving its quality and completeness before formal publication of the data from the 2017 to 2018 (1 April 2017 to 31 March 2018) screening year onwards.

Data completeness improved over the 3 quarters of data collection. Variation across the regions ranged from 37.5% to 94.4%.

Data quality is improving and we expect this to

continue following regional data workshops by the antenatal screening programmes to support providers in understanding the data requirements and reporting processes.

FA2 will help make sure women who accept the offer of screening complete the screening pathway. It will also help us focus on reducing the number of women having scans outside recommended timeframes and addressing the rate of DNA (did not attend) appointments.

Its introduction highlights the hard work of dedicated staff, particularly local screening coordinators and ultrasound staff, and the involvement of IT and audit departments which has helped reduce time-consuming manual processes.

# Helping women access cervical test

Fewer women are going for cervical screening, despite the fact that it is free and saves lives from cervical cancer.

We invite women aged 25 to 49 for cervical screening every 3 years and women aged 50 to 64 every 5 years. But screening coverage has been falling in recent years. Coverage is the proportion of eligible women who've had an adequate screening test recorded in the preceding 3 or 5 years, dependent on their age.

We offer screening on the basis of informed choice. We recognise and respect that some women choose not to have screening. However, we also know there can be barriers to screening that make it difficult to attend. These range from not being able to get a convenient appointment to a negative experience of a previous test.

Trying to improve access to screening – and therefore increasing coverage – is an important priority for both PHE and NHS England. In April 2016, an NHS England Spotlight event on cervical screening highlighted the lack of accessible and timely data on coverage rates and barriers to screening. As a result, we set up a project group in January 2017 to:

- make more timely coverage data available to internal and external stakeholders
- develop a primary care data pack to support GP practices and clinical commissioning groups (CCGs) to improve cervical screening attendance

PHE Screening and NHS England led the group, which included representatives from:

- screening and immunisation teams
- NHS England heads of public health commissioning
- Jo's Cervical Cancer Trust
- NHS Digital

## Cervical screening

- Capita (the cervical screening call and recall system provider)
- Macmillan

Following this collaboration, we are publishing detailed cervical screening coverage data by GP practice for the first time. Data is also available at CCG level. All data is ranked so that practices and CCGs can compare their coverage rates in order to help them plan and implement uptake initiatives, evaluate them, and share good practice. We have also published information on links between screening data and factors that may affect women's ability to attend.

We publish this data quarterly on GOV.UK. We have also published a 'top tips' document providing ideas from previous initiatives to improve uptake of cervical screening, and link to the Jo's Cervical Cancer Trust website, where there are examples of successful local initiatives.

We developed a new interactive dashboard for cervical screening coverage statistics with colleagues at NHS Digital. In the first 2 weeks following its launch, the dashboard had:

- 400 hits on GP data
- 170 hits on CCG data
- 90 hits on local authority data

Our next steps are to evaluate the use of these resources and the national data after 12 months. We're looking at maintaining an annual list of local initiatives via the national network of screening and immunisation leads. We want to influence stakeholders to prioritise action in areas with the lowest coverage to support reduction in health inequalities. And we want to continue to raise awareness across PHE and its stakeholders of ways to improve access to cervical screening for women from disadvantaged groups.



# Reducing unnecessary operations

We know screening benefits the population as a whole, but it does have potential harms. Some women who have breast screening will be diagnosed and treated for a tumour that would never otherwise have been found, or caused them harm. We estimate for every woman who has her life saved from breast cancer, about 3 are diagnosed with a cancer that would never have become life-threatening.

Researchers have been trying to find better ways to tell which women have breast cancers that will be life-threatening and which have conditions that will not. In November 2016, we published new guidance in response to this evidence to help reduce unnecessary surgical interventions.

[Breast screening: clinical guidelines for screening assessment](#) explains how local providers should obtain a definitive and timely diagnosis of potential abnormalities detected during screening.

The outcome of this assessment process determines whether or not a woman is referred for further tests or therapeutic surgery.

The guidance clarifies how providers should deal with 'uncertain lesions' detected by screening. Most of these are confirmed to be benign and not cancerous.

Significant breast abnormalities are assessed by core biopsy – a sample of tissue being taken from the breast for closer examination. If the outcome remains uncertain after a biopsy, the new guidance explains that a larger vacuum-assisted biopsy should be performed.

Evidence shows that using larger vacuum-assisted biopsies should reduce the number of

## Breast screening

unnecessary surgical procedures on women who would have had a benign outcome. We are now updating the national breast screening IT system to gather evidence of the impact the new guidance is having on clinical practice and outcomes for women.

The updated national guidance also introduced the new role of a 'responsible assessor' to help ensure consistency of high quality practice across the country. This person takes clinical responsibility for the assessment of individual women. They:

- accurately monitor assessment performance
  - support governance, training and improve quality
  - provide clear leadership during clinics
  - ensure data entry in the national breast screening IT system accurately represents clinical activity
- Consultant radiologist Dr Anne Turnbull said: "The new guidance builds on best practice

“ *Researchers have been trying to find better ways to tell which women have breast cancers that will be life-threatening.* ”

that has developed in recent years, since the previous edition. It also encourages 2 responsible assessors, where it is possible, to confer over cases where further assessment appears normal or benign and where biopsy is not planned, to ensure both experts agree.”

A responsible assessor must be an accredited breast radiologist, consultant radiographer or breast clinician. An assessment is considered complete only when they're satisfied all appropriate investigations have been performed adequately. Every case requires this sign-off.

# Listening to users and working smarter

PHE provides professional leadership for the NHS population-based screening programmes. Central to this leadership role is the development of effective working relationships with NHS England commissioners and local screening providers.

One example of this is the way the NHS Newborn and Infant Physical Examination (NIPE) programme has worked with commissioners, providers and other stakeholders to improve the quality and consistency of screening nationwide.

One of the most important quality improvement initiatives is the ongoing roll-out of the NIPE Screening Management and Reporting Tool (NIPE SMART) IT system, which is provided free to trusts. NIPE SMART tracks newborn babies throughout the screening pathway and provides a failsafe system to ensure no babies miss out on the detailed physical examination of eyes, heart, hips and testes.

Clinicians have praised NIPE SMART for improving the quality and safety of the newborn physical examination and 86% of trusts in England now use the system.

This year, the national programme focused efforts on listening to users and helping them get the best out of the system. This included support and training for trust 'superusers'. Superusers help ensure the smooth running of the system locally on a day-to-day basis, managing failsafe processes and reporting.

National support for superusers included regional events, teleconferences, webinars and site visits, all of which helped improve understanding of

## Newborn and infant physical examination

roles and responsibilities within the screening pathway and increased awareness of NIPE SMART functionality.

We also published a NIPE SMART user guide that includes detailed information about all aspects of the system. Users can access the guide from within NIPE SMART. In March 2017, we set up the NIPE SMART User Group to provide a forum for discussion and look at future developments.

Public health midwife Claire Parr took over as NIPE lead at Western Sussex Hospitals NHS Foundation Trust shortly after NIPE SMART was introduced in the trust's 2 hospital sites in March 2016. She is a member of the new user group.

“ *The support from the NIPE national team was essential to implement failsafes for our newborn babies.* ”

“The support I received from the national team was essential for me to implement failsafes for our newborn babies,” said Claire. “None of this would have been possible

without the national team being on the end of the phone or email to iron out queries and concerns raised by clinicians in our trust. When concerns were raised, the team has set about proactively determining what the best evidence is to support trust providers/leads with the information they need to implement service improvements locally.

“Being invited to be part of the NIPE SMART user group was a great honour. Coming together with NIPE leads and other experts meant we can collate feedback locally and share ideas in order to continuously improve the system.”

# Making sure no baby is overlooked

All babies should be offered newborn blood spot (NBS) screening for 9 rare but serious conditions when they are 5 days old. Timely screening is important so we can start treatment quickly for affected babies. But it's easy for the test to be delayed, or even for babies to miss out on it altogether. This can happen, for example, if mother and baby move to a different address or if a blood spot sample gets lost in transit to the laboratory.

We therefore introduced a national failsafe IT system, the [newborn blood spot failsafe solution](#) (NBSFS), to make sure all babies get offered the test on time. It identifies every baby born in England by their NHS number. Any baby who was not tested is flagged up to the local maternity service. Their record remains flagged until the test is carried out or declined.

Nearly all respondents to a user survey in June 2016 said the NBSFS had identified babies whose screening test would otherwise have been missed or delayed. They told us babies in special care baby units were at higher risk of missing screening and that samples can get lost on the way to the laboratory.

They also told us there is sometimes a lack of communication between services when mother and baby are discharged from hospital. This can mean mother and baby not receiving any postnatal care, so the NBSFS has helped to highlight this additional, very important, quality care issue. By identifying weaknesses in the screening pathway, the NBSFS has helped local

## Newborn blood spot screening

services make improvements, such as changing the way the NBS sample is transported to the laboratory or how discharges are managed.

Introducing the NBSFS was an ambitious project. In 2016 it was fully implemented by all maternity sites and NBS laboratories in England. In January 2017, we held a conference to celebrate this achievement. Speakers explained how the NBSFS had improved the efficiency of tracking babies in their care and had flagged babies who

could have missed screening, including a baby who was found to have one of the screened conditions.

All families deserve the offer of NBS screening for their babies and we're proud to have the

NBSFS in place so no baby is overlooked.

Midwife Sheila Reed, an antenatal and newborn screening coordinator in County Durham, is an enthusiastic supporter of the system. She said: "I love the NBSFS, having been involved in a serious incident before the failsafe was in place where several babies missed screening. It has been a fantastic addition to the screening programme to the benefit of many babies who could otherwise have missed screening.

"It makes such a difference having the results available on the failsafe as we can check that babies who have had a repeat test have now got a result recorded quickly and easily, without having to contact the laboratory."

The image shows a 'NEWBORN SCREENING BLOOD SPOT TEST' card. It includes fields for:
 

- Baby's NHS No.
- DATE OF SPECIMEN
- Is this a repeat (-/+) YES NO
- Has baby had a blood transfusion (-/+) YES NO
- If yes, date of transfusion
- Is the baby in hospital (-/+) YES NO
- If yes, current hospital and ward
- Comments (Family history e.g. Mother's carrier status (Autosomal NBS) code; NBS Outcome code; temporary address)
- Barcode with number 1520139416
- Expiry Date: 01-2018
- Four numbered circles (1-4) for marking
- Surname

**A newborn blood spot card**

# Driving up image grading consistency

Diabetic eye screening looks for signs of disease in the back of the eye using digital photography. A large specialist national workforce grades these images. Depending on the grade, people are:

- re-invited for screening the following year
- placed on surveillance
- referred to hospital eye services

This year, we worked to improve both the quality and consistency of grading, which are essential for screening to be effective.

## Standards and quality measures

All national graders have to undertake the same grading qualification and monthly grading test (TAT), which means people should expect to get the same results wherever they are screened.

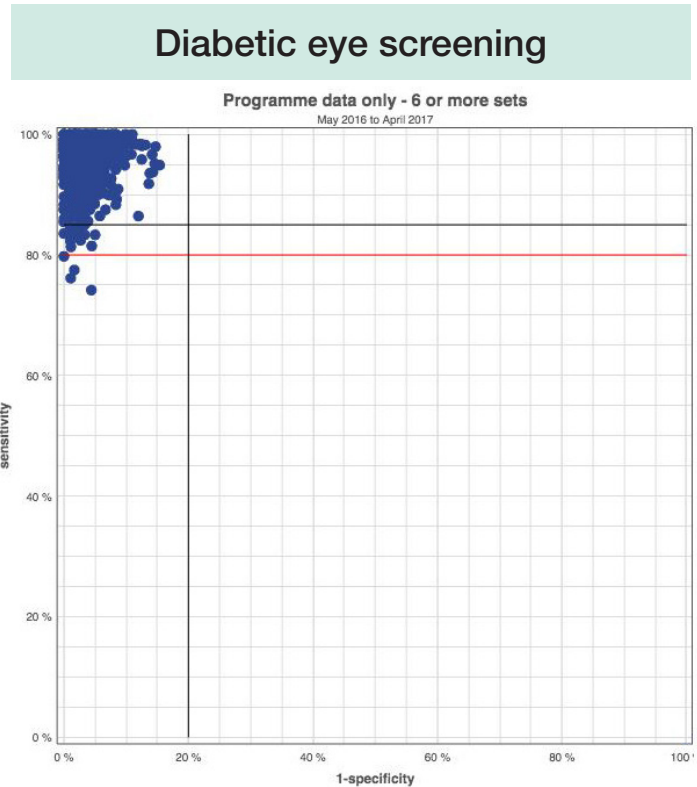
We upgraded TAT to include a performance monitoring tool, so providers can monitor the performance of individual graders and the Screening Quality Assurance Service (SQAS) can monitor providers. This year, we saw an overall improvement in national grading quality in TAT.

Providers use QA tools in the screening software to check the accuracy of grading and report this to commissioners and SQAS.

## Variation

The UK National Screening Committee has recommended extending screening intervals for low-risk patients from 1 to 2 years – but only if we can prove accurate and consistent grading is taking place across all local providers.

National data has highlighted variation between providers. This variation is much lower than 2 years ago, which we think is due to improved reporting functions of the screening software. But some unaccounted variation remains.



**Each dot on the scatter plot is a national grader – most now have a grading sensitivity above 85% and specificity over 80%**

## Next steps

We are looking for a reliable method to show day-to-day grading outcomes are accurate and early disease is not being missed. We are starting to investigate the use of automated grading to look back at large numbers of images to assess this accuracy.

We have helped several providers audit specific cases involving unexpected outcomes by giving them a tool to extract data and check grading accuracy. These audits will form part of our overall review of national grading accuracy.

In addition, a project will look at specific characteristics in the population to see if there is any correlation between these characteristics and the rate of detection of diabetic retinopathy.

# Continuing to reduce HIV transmission

National screening for HIV in pregnancy has contributed to the reduction in the transmission of the virus from mothers to babies.

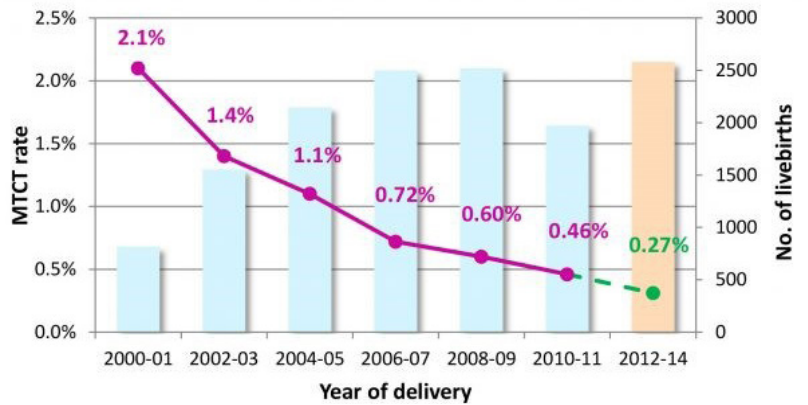
The mother-to-child transmission rate in the UK has continued to decline to record low levels – just 0.27% between 2012 and 2014 – demonstrating the impact of sustained efforts to provide optimal treatment and care to women and babies before, during and after pregnancy.

Small numbers of babies do still acquire HIV from their mothers. Over half of these are born to women not diagnosed with HIV before delivery. These infants are only diagnosed when they present with clinical indicators of HIV infection, or as a result of their mother or other family member being diagnosed with HIV.

The NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme commissioned an audit of perinatal HIV infection in babies born in the UK between 1 January 2006 and 31 December 2013, and reported by March 2014. These 108 cases were identified in the National Study of HIV in Pregnancy and Childhood (NSHPC) database. An expert panel reviewed these cases and made a number of recommendations.

Cases were often complex with psycho-social issues and other contributing factors including:

- women declining antenatal HIV screening
- women acquiring HIV after testing negative
- women having problems engaging with specialist care
- pre-term delivery
- problems with the HIV testing pathway



**Falling rates of mother to child HIV transmission**

## Infectious diseases in pregnancy screening

- women booking late in pregnancy, impacting on duration of treatment
- postnatal mother-to-baby transmission, likely through breastfeeding

We have focused on addressing the panel’s recommendations to improve the screening pathway for HIV, which include:

- a formal reoffer before 20 weeks’ gestation and management of women who initially decline screening in pregnancy
- face-to-face appointments for women who screen positive or are known positive, within 10 days of their result or notification of positivity
- information resources for screen-positive women
- a new multimedia e-Learning resource for health care professionals
- plans for a single integrated system to submit and collate data on the 3 conditions IDPS screens for – HIV, syphilis and hepatitis B.

Since 2014, there have been 22 newly reported HIV transmissions, mostly involving children born to undiagnosed women.

# Smooth birth of our new IT system

Thursday 1 December 2016 was a big day for the NHS Newborn Hearing Screening Programme (NHSP) with the arrival of its new national IT system.

We switched on SMaRT4Hearing (or S4H for short) at midnight. A baby in Birmingham was the first to have screening test results in S4H early that morning.

The system manages babies throughout the screening pathway to audiological assessment. It has thousands of users in NHS screening, audiology and aetiology departments who have been very positive about its style and features.

Launching S4H was NHSP's biggest challenge, nationally and locally, since the programme's full implementation across England in 2006. S4H will eventually replace the original IT system, eSP. Until then, the 2 systems will be used in tandem.

We worked with IT provider Northgate Public Services (NPS) to develop and implement S4H, supported by the NHSP user group who made a significant contribution to the system testing and developing training resources. We are very grateful for their help and support. S4H provides a more modern software platform than its predecessor, although care was taken to make sure it looks and feels like eSP where possible.

S4H:

- links with the birth registration system to create a record for every baby born in England
- identifies babies eligible for screening and

## Newborn hearing screening

provides failsafes to minimise the risk of babies being missed, which in turn improves screening coverage

- allows the smooth transfer and sharing of records between NHSP providers
- stores audiological follow-up assessment data where appropriate
- ensures consistency of data across England
- helps the sharing of information with other services such as audiology and aetiology
- supports local and national reporting and audit

Sarah Whittaker, NHSP manager at County Durham, Tees Valley, Hambleton and Richmond, said: "The days leading up to the launch of S4H were some of the most stressful I have

worked through. I had been involved in the development and testing of the new system but there were uncertainties and unanswered questions, not least would it work on a national scale?

“ *It looks so much more stylish and modern than its predecessor and is a lot easier to work with.* ”

"In fact, launch day was a huge anti-climax because it behaved as it was supposed to, and everything ran smoothly. Since then, my screeners and I have become rather fond of S4H. It looks so much more stylish and modern than its predecessor and is a lot easier to work with.

"It makes managing all our births very straightforward. We are able to run reports and interrogate the system easily, meaning we can track each baby's progress smoothly through the hearing screening process."

# Finances

## NHS Fetal Anomaly Screening Programme

Pay costs: £277,172

Non-pay costs: £296,764

Total costs: £573,936

## NHS Infectious Diseases in Pregnancy Screening Programme

Pay costs: £235,843

Non-pay costs: £330,962

Total costs: £566,805

## NHS Newborn Blood Spot Screening Programme

Pay costs: £500,146

Non-pay costs: £650,996

Total costs: £1,151,143

## NHS Newborn Hearing Screening Programme

Pay costs: £264,979

Non-pay costs: £1,484,300

Total costs: £1,749,279

## NHS Newborn and Infant Physical Examination Screening Programme (including pulse oximetry pilot study)

Pay costs: £435,259

Non-pay costs: £1,050,700

Total costs: £1,485,959

## NHS Sickle Cell and Thalassaemia Screening Programme

Pay costs: £365,670

Non-pay costs: £301,507

Total costs: £667,177

## Young Person and Adult (YPA) Screening Programmes \*

Pay costs: £1,957,500

Non-pay costs: £22,691,300

Total costs: £24,648,800

\* The YPA programmes include:

- NHS Abdominal Aortic Aneurysm Screening Programme
- NHS Bowel Cancer Screening Programme
- NHS Breast Screening Programme
- NHS Cervical Screening Programme
- 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.

Public Health England, Wellington House, 133-155 Waterloo Road, London SE1 8UG

Tel: 020 7654 8000 [www.gov.uk/phe](http://www.gov.uk/phe)

Twitter: [@PHE\\_uk](https://twitter.com/PHE_uk) Facebook: [www.facebook.com/PublicHealthEngland](https://www.facebook.com/PublicHealthEngland)

## About PHE Screening

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

PHE Screening, Floor 2, Zone B, Skipton House, 80 London Road, London SE1 6LH

[www.gov.uk/topic/population-screening-programmes](http://www.gov.uk/topic/population-screening-programmes)

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For queries relating to this document, please contact: [phe.screeninghelpdesk@nhs.net](mailto:phe.screeninghelpdesk@nhs.net)

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