Public Health England

NHS

NHS Screening Programmes in England

2014 to 2015

> “This report is full of examples that show why the English screening programmes are held in such high regard worldwide. We would like to thank all the screening teams for their continued efforts in achieving this and delivering improvements for the public’s health.”

Professor Kevin Fenton, National Director, Health and Wellbeing, Public Health England

Dr Anne Mackie, Director of Screening, Public Health England

This report covers the NHS screening programmes in England:

NHS Bowel Cancer Screening Programme
NHS Breast Screening Programme
NHS Cervical Screening Programme
NHS Infectious Diseases in Pregnancy Screening Programme
NHS Fetal Anomaly Screening Programme
NHS Sickle Cell and Thalassaemia Screening Programme
NHS Newborn Blood Spot Screening Programme
NHS Newborn Hearing Screening Programme
NHS Newborn and Infant Physical Examination Programme
NHS Diabetic Eye Screening Programme
NHS Abdominal Aortic Aneurysm Screening Programme

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

2014 to 2015 has been an exciting and productive year for all of us involved in screening.

When we became part of Public Health England (PHE) in April 2013, it was the first time the national cancer and non-cancer screening programmes had been part of the same organisation.

Clearly the 11 NHS Screening Programmes (both cancer and non-cancer) have much in common. They all have to find their population, enable them to make an informed choice using high quality information, carry out a test safely and accurately, provide results in a timely manner and ensure people who need a referral get it quickly.

This year, as part of PHE's internal restructuring, we were delighted to bring together the cancer and non-cancer teams for the first time in a new centre of excellence – the PHE Screening division. This will not only enable us to build on each of the 11 programmes' enviable international reputations, but also to benefit from shared learning and the ability to pool resources.

> *"This year we were delighted to bring together the cancer and non-cancer teams for the first time in a new centre of excellence – the PHE Screening division."*

The new division includes the Screening Quality Assurance Service (SQAS) which, also for the first time, brings together QA expertise from both the cancer and non-cancer teams.

On a personal note, we would like to take this opportunity to thank Professor Julietta Patnick for her enormous contribution to screening. Julietta announced her retirement during 2014 to 2015 having played a huge role in the development and oversight of the cancer screening programmes since the 1980s.

Julietta first joined the NHS in 1979 and became involved in screening with the establishment of the Breast Screening Programme in 1987. In 1990 she was appointed National Coordinator of the Breast Screening Programme and, subsequently, National Coordinator of the Cervical Screening Programme. She later took responsibility for all cancer screening with her appointment as Director of the NHS Cancer Screening Programmes. Although we will miss Julietta's expertise greatly, we are fortunate to have a hugely dedicated and expert group of colleagues delivering PHE's vision for screening.

The themes of this year's report are *turning evidence into action* and *continuous improvement*. We have a proud reputation for only implementing or changing a screening programme if supported by robust evidence. Examples of rigorous research put into action during the year include the piloting of HPV primary screening by the cervical programme (pages 14-15), the roll-out of bowel scope screening (page 17) and the expansion of the newborn blood spot programme to include four additional rare genetic disorders (pages 18-19).

It is important that we do not rest on our laurels but continuously seek to improve the quality and efficiency of our screening programmes. Again, there were many examples of continuous improvement during 2014 to 2015, including offering earlier antenatal screening for Edwards' and Patau's syndromes (page 20), improving the service provided to pregnant women who screen positive for syphilis (page 23) and using data to help screening providers tackle inequalities (page 26).

This report is full of these case studies that show why the English screening programmes are held in such high regard worldwide. We would like to thank all the screening teams for their continued efforts in achieving this and delivering important improvements for the public's health.

After a year of considerable change, we would like to pay tribute to the efforts of our many partners and stakeholders who have worked alongside us. From academics to providers, and clinicians to commissioners, screening's success is a reflection of that teamwork and a shared vision to improve health outcomes.

Dr Anne Mackie
Director of Screening
Public Health England

Professor Kevin Fenton
National Director
Health and Wellbeing
Public Health England

NHS Abdominal Aortic Aneurysm Screening Programme

The NHS Abdominal Aortic Aneurysm (AAA) Screening Programme aims to reduce 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 aims to detect 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 overs time. Polyps can easily be removed, reducing the risk of bowel cancer developing. A screening kit is offered to men and women aged 60 to 74 every two 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 now being implemented across England.

NHS Breast Screening Programme

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

NHS Cervical Screening Programme

The NHS Cervical Screening Programme aims to prevent cancer by detecting abnormalities of the cervix and referring for potential treatment. The programme uses liquid based cytology 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 three years to all women aged 25 to 49 and every five years to those aged 50 to 64.

NHS Diabetic Eye Screening Programme

The NHS Diabetic Eye Screening Programme aims to reduce 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 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 risk of their baby being born with Down's syndrome or abnormalities with the fetus. The first scan usually takes place at 10-14 weeks after conception and includes a blood test for Down's syndrome. A scan for fetal abnormalities takes place around 18-21 weeks. This allows for further diagnostic tests if required and time for women to consider the options available.

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 abnormalities of the eyes, heart, hips and testes. Screening helps ensure early detection and diagnosis of several congenital medical conditions and reduces the severity of treatment required and the likelihood of long-term disability.

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 at the very earliest stage, helping to ensure they can reach their full educational and social potential.

NHS Newborn Blood Spot Screening Programme

The NHS Newborn Blood Spot Screening Programme screens newborn babies for five rare but serious conditions: phenylketonuria, congenital hypothyroidism, sickle cell disease, cystic fibrosis and medium-chain acyl-CoA dehydrogenase deficiency. It expanded during 2014 to 2015 to screen for four additional rare genetic disorders: 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 Infectious Diseases in Pregnancy Screening Programme

The NHS Infectious Diseases in Pregnancy Screening Programme offers and recommends screening to all pregnant women for hepatitis B, HIV, syphilis and susceptibility to rubella (German measles). The programme aims to identify women with hepatitis B, HIV or syphilis so they can be offered appropriate follow-on tests and treatments, substantially reducing the risk of infection being passed on to their children. Screening also identifies women at risk of catching German measles so they can be offered a vaccination following birth in order to reduce the risks in any future pregnancies.

NHS Sickle Cell and Thalassaemia Screening Programme

The NHS Sickle Cell and Thalassaemia (SCT) Screening Programme uses questionnaires about family origin and, if necessary, blood tests to screen pregnant women for two serious inherited blood disorders – sickle cell disease and thalassaemia major. It also screens newborn babies for sickle cell disease. 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.

NHS Breast Screening Programme (BSP)	
Provisional data for 2014 to 2015	
Number of women tested (all ages)	**2,105,673**
Uptake of screening (all ages)	75.1%
Screening round length (50-70 year olds) [1]	**89.1%**

[1] Percentage of women aged 50-70 invited within 36 months of previous screening, or previous invitation if they did not attend.

The Health & Social Care Information Centre (HSCIC) is responsible for publishing official statistics for the NHS Breast Screening Programme.

HSCIC has allowed the Screening Quality Assurance Service (SQAS) to publish this provisional data for 2014 to 2015 data based on in-house analysis, prior to official publication expected in February 2016. Please note that it is possible these SQAS figures will differ from 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 50-70 only, by definition.

NHS Cervical Screening Programme (CSP)	
Number of eligible women [1]	**26,839,844**
Number of women invited for screening in 2014 to 2015 [2]	4,538,379
Number of women tested	**3,267,260**
Coverage [3]	73.5%
Number of screen positive women [4]	**211,386**

All data is from the Cervical Screening Programme: England, Statistics for 2014-15 bulletin, published by the HSCIC on 10 November 2015.

[1] **Eligible population:** the registered female population minus any women ceased for clinical reasons – for example, after a hysterectomy.

[2] **Number invited for screening:** this is only part of the eligible population as women are screened at 3-year (aged 25-49) or 5-year (aged 50-64) intervals.

[3] **Coverage:** this is the headline figure from the HSCIC which is the percentage of eligible women who were screened adequately within the previous 3.5 years (for women aged 25-49) and 5.5 years (for women aged 50-64).

[4] **Number of screen positive women** = number of tests - (number of inadequate samples + number of negative samples)

Sources: HSCIC 2014/15 Stats Bulletin Table 7, HSCIC 2014/15 Stats Bulletin Table 8, HSCIC 2014/15 Stats Bulletin Table 2, HSCIC 2014/15 Stats Bulletin Table 4, HSCIC 2014/15 Stats Bulletin Table 1.

NHS Bowel Cancer Screening Programme (BCSP)	
Number of people invited for screening[1]	**4,117,889**
Number of people adequately screened[2]	2,395,521
Number of people definitively abnormal[3]	**42,921**
Uptake[4]	58.2%
Positivity[5]	**1.8%**
Coverage[6]	55.6%

[1] **Invited:** the number of people who received the standard invitation to participate in screening (excluding self-referrals and late responders)

[2] **Adequately screened:** the number of people reaching a definitive FOBt outcome ('Normal' or 'Abnormal')

[3] **Definitively abnormal:** the result of (possibly many) test kits sent to an individual which lead to a definitive abnormal outcome and an offer of an assessment with a specialist screening practitioner

[4] **Uptake:** percentage of people adequately screened out of those invited for FOBt screening

[5] **Positivity:** percentage of people with a definitive FOBt outcome of abnormal out of those who were adequately screened via FOBt

[6] **Coverage:** percentage of eligible people who were screened in the 30-month period (please note that population coverage will not be achieved until 2017)

NHS Abdominal Aortic Aneurysm (AAA) Screening Programme	
Offered screening	**293,779**
Tested (2014/15 cohort)	233,426
Uptake (2014/15 cohort)	**79.5**
Tested (self-referrals)	24,765
AAAs detected (total)	**3,447**
AAAs detected (cohort)	2,773
Incidence (cohort)	**1.19%**
AAAs detected (self-referrals)	674
Incidence (self-referrals)	**2.72%**
Men on surveillance at end of year	11,375
Referrals to surgery	**687**
Elective AAA repairs	515
Deaths from elective repairs	**6**
Ruptures (either during surveillance or after referral)	5
Deaths from rupture	**5**

Data source: AAA SMaRT

Data extracted: 11 August 2015

NHS Diabetic Eye Screening (DES) Programme	
Eligible people with diabetes known to programme	**2,305,176**
Offered screening (routine digital screening)	2,004,242
Tested (routine digital screening)	**1,664,890**
Uptake	83.1
New registrations to progammes	**205,688**
Urgent referrals (R3A*)	6,255
Routine referrals (R2M1*, R2M0*, R1M1*)	**43,407**

During 2014 to 2015 there were 83 local DES programmes in England. The above data is from 68 (81.9%) of those programmes that reported data purely against the new DES common pathway during the year.

It excludes the 13 programmes that were on partial common pathway data and the two programmes that were not on common pathway data.

Sources: Programme performance reports and programme screening to treatment timeline trackers

Data collected: September and October 2015

* R1 = background retinopathy; R2 = pre-proliferative retinopathy; R3A = active proliferative retinopathy; M0 = no maculopathy; M1 = maculopathy

NHS Fetal Anomaly Screening Programme (FASP)

Number of tests performed	**500,397**
Number of women at high risk	13,569
Number of sonographers supported by DQASS [1]	**2,372**
DQASS % red flags [2]	0.2%
DQASS % amber flags	**35%**
DQASS % green flags	64.8%

[1] DQASS: Down's syndrome Screening Quality Assurance Support Service (DQASS) improves the calculation of antenatal screening risk for Down's, Edwards' and Patau's syndromes by supporting local screening programmes.

[2] Red flags indicate where there may be a need to review the scan technique with supported training

21 screening laboratories in England provide first trimester screening for Down's, Edwards' and Patau's syndromes. The first trimester combined test uses two biochemical markers from maternal blood. Various factors, including maternal weight, gestational age, ethnicity and maternal smoking affect these markers. These factors require standardisation by laboratories to ensure risk calculations are as accurate as possible. The latest DQASS audit showed an improvement in this standardisation process, leading to a more effective and equitable programme and ultimately fewer women being offered unnecessary invasive tests.

NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme

Hepatitis B	
Uptake	**97.4%***
Number of tests	681,260*
Number of positive results	**2,756***
Seen by specialist within 6 weeks of identification	68.4%
Percentage newly diagnosed	**0.14*%**

HIV	
Uptake	**97.3%***
Number of tests	693,570*
Number of positive results	**1,018***
Percentage newly diagnosed	0.03%*

Rubella susceptibility	
Uptake	**97.5%***
Number of tests	704,583*
Number susceptible	**49,227***

Syphilis	
Uptake	**97.4%***
Number of tests	709,204*
Number of positive results	**971***

*Figures marked with an asterisk come from the National Antenatal Infections Screening Monitoring (NAISM) data and cover the calendar year 2014.

All other data is KPI data and covers the financial year 2014 to 2015.

NHS Newborn Blood Spot (NBS) Screening Programme

Cystic fibrosis	
Babies tested	**665,678**
Screened +ve 1st sample	179
+ve 1st sample and 1st appt within 28 days	**90**
Screened +ve 2nd sample	76
+ve 2nd sample and 1st appt within 35 days	**28**
CHT (congenital hypothyroidism)	
Babies tested	**666,664**
Screened +ve 1st sample	304
+ve 1st sample and 1st appt within 17 days	**260**
Screened +ve 2nd sample	245
+ve 2nd sample and 1st appt within 24 days	**177**

PKU (phenylketonuria)	
Babies tested	**666,665**
Babies screened positive	54
Screened +ve and 1st appt within 17 days	**42**
MCADD (medium-chain acyl-CoA-dehyrogenase deficiency)	
Babies tested	**666,671**
Babies screened +ve	53
Screened +ve and 1st appt within 17 days	**47**
Coverage	
% of babies tested and recorded on the Child Heatlh Information System at 17 days	**95.8%**

This is the first year that newborn blood spot screening in England met the standard for the acceptable level of completeness of coverage which is set at ≥ 95.0%.

NHS Newborn Hearing Screening Programme (NHSP)

Number of screens completed	**652,841**
Percentage of babies tested (coverage) [1]	98.0%
Percentage declining screening	**0.07%**
Number of referrals [2]	18,591
Percentage referred to hearing services (target ≤3%)	**2.85%**
Percentage referrals who attended follow-up within 4 weeks (target ≥90%) [3]	86.4%
Number of babies with confirmed hearing impairment in both ears	**547**
Rate of babies with confirmed hearing impairment in both ears per 1,000 screened (yield)	0.84

Figures exclude babies born, or currently living in, Wales

[1] Excludes babies less than 90 days corrected age and deceased babies

[2] Immediate referrals from the screen, including incompletes who require a referral

[3] Excludes babies less than 30 days corrected age and deceased babies

Data extracted: 13 August 2015

NHS Newborn and Infant Physical Examination (NIPE) Programme	
Number of eligible babies	**123,966**
Number of eligible babies tested	108,845
Screening outcome set within 72 hours	**106,479**
Percentage outcome set within 72 hours	85.9
Screen complete within 72 hours	**101,460**
Percentage screen complete within 72 hours	81.8%
Declined screen	**17**
Percentage declining	0.01%
Referrals – hip	**9,463**
Percentage of eligible babies referred – hip	7.6%
Referrals – heart	**1,895**
Percentage of eligible babies referred – heart	1.5%
Referrals – testes	**947**
Percentage of eligible male babies referred – testes	1.5%
Referrals – eyes	**264**
Percentage of eligible babies referred – eyes	0.2%

Data source: NIPE SMaRT national IT system; **Data extracted:** 5 November 2015

Please note: NIPE SMaRT was not rolled out across whole country in 2014 to 2015

NHS Sickle Cell and Thalassaemia (SCT) Screening Programme	
Antenatal screening	
Antenatal samples screened	**710,166**
Percentage of women declining	0.26
Screen positive pregnant women	**14,354**
Rate of screen positive women	2%
Percentage of fathers tested	**60.4**
High risk couples detected	822
Newborn screening	
Newborn samples screened	**661,432**
Screen positive results	278
Rate of screen positive babies	**1 in 2,400 babies screened**
Percentage declining	1.49
Carrier results	**8,942**

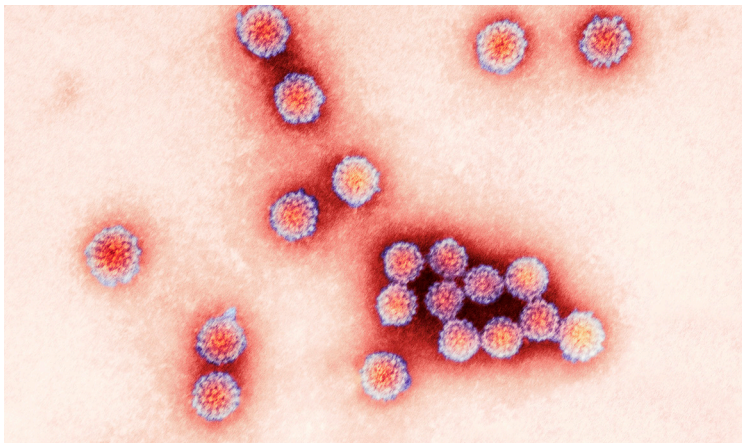
About half the antenatal samples were tested by 10 weeks gestation, but rates were lower in high prevalence areas. One in 2,400 newborn samples were identified with significant conditions and 1 in 74 were carriers. Rates for declined screening tests rose to around 1.5 per 1,000 samples screened. There were 22 F-only cases (only fetal haemoglobin present) identified by the newborn screening labs which are likely to be beta thalassaemia affected cases. SCT data reports are available on GOV.UK.

HPV primary screening offers many potential advantages following successful pilot phase

Cervical screening was formally introduced as a population screening programme in 1988. Cervical screening is still commonly known as the 'smear test', even though the technique has long since changed. Instead of the sample taker putting the cervical cells on to a slide to send off to a laboratory, the programme uses a process called liquid-based cytology (LBC). This involves putting the cells into a vial of preservative, which is then processed and analysed at a lab. LBC gives a much greater chance of an adequate sample.

Human papillomavirus (HPV) infection is a necessary but not sufficient requirement for developing cervical cancer. In 2008, the programme ran a pilot to look at introducing HPV testing in addition to the cytology testing of screening samples. After successful completion and evaluation of the pilot, the use of HPV testing was added to the screening programme to:

- determine if women with borderline changes or low grade dyskaryosis (cervical cell changes) should be referred for colposcopy (an HPV positive result indicates referral)
- look for the presence of HPV following treatment for abnormal cells (an HPV positive result indicates referral for colposcopy, while an HPV negative result indicates re-screening in three years' time)



HPV virus

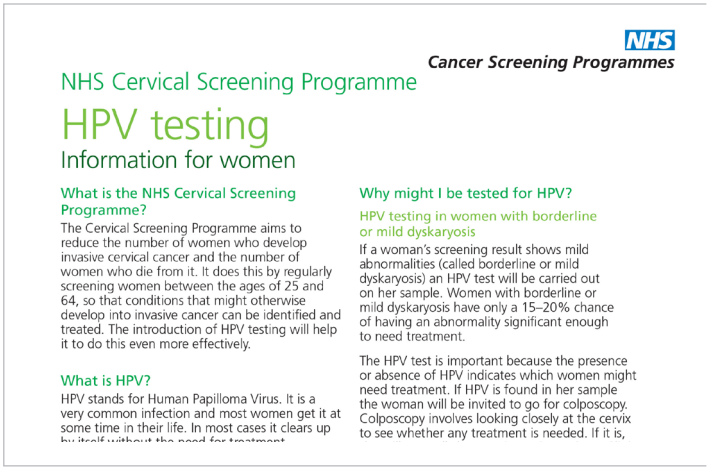
Now things look set to change. In April 2013, the programme introduced a pilot in six sites across England to look at whether HPV screening should be used as the primary test in cervical screening. Four large-scale trials on HPV primary screening have already been carried out in the Netherlands, Sweden, Italy and England. The results of these trials showed a reduction in cervical cancer incidence when HPV testing was used rather than cytology alone.

Women invited for cervical screening in the six HPV primary screening pilot areas in England are sent an **information leaflet** to explain that their screening sample will first be tested for HPV. Only if their result is HPV positive (high risk HPV is detected) will their screening sample then have cytology testing carried out.

Persistent high risk strains of HPV are linked to the development of abnormal cervical cells, so HPV testing is a better way of finding out if problems are present or likely to arise. Almost all cervical cancers (99.7%) contain high risk HPV DNA. This suggests that women who do not have high risk HPV are very unlikely to go on to develop cervical cancer in the short to medium term.

Advantages of HPV primary screening include:

- it picks up more abnormalities than cytology
- anyone with an HPV positive result will have a secondary screening check from the same sample using cytology
- an HPV negative result means the woman is extremely unlikely to develop cervical cancer between screening tests
- in future, women may need to be screened less often



NHS
Cancer Screening Programmes

NHS Cervical Screening Programme

HPV testing

Information for women

What is the NHS Cervical Screening Programme?

The Cervical Screening Programme aims to reduce the number of women who develop invasive cervical cancer and the number of women who die from it. It does this by regularly screening women between the ages of 25 and 64, so that conditions that might otherwise develop into invasive cancer can be identified and treated. The introduction of HPV testing will help it to do this even more effectively.

What is HPV?

HPV stands for Human Papilloma Virus. It is a very common infection and most women get it at some time in their life. In most cases it clears up

Why might I be tested for HPV?

HPV testing in women with borderline or mild dyskaryosis

If a woman's screening result shows mild abnormalities (called borderline or mild dyskaryosis) an HPV test will be carried out on her sample. Women with borderline or mild dyskaryosis have only a 15–20% chance of having an abnormality significant enough to need treatment.

The HPV test is important because the presence or absence of HPV indicates which women might need treatment. If HPV is found in her sample the woman will be invited to go for colposcopy. Colposcopy involves looking closely at the cervix to see whether any treatment is needed. If it is,

HPV testing patient information leaflet

Findings from the first 18 months of the HPV primary screening pilot were due to be presented to the UK National Screening Committee (UK NSC) in June 2015, together with an evidence summary on the cost effectiveness of HPV primary screening, and a report on HPV screening for cervical cancer by the chair of the advisory committee for cervical screening.

> *"The pilot sites have been pivotal in demonstrating how HPV primary screening can work in the programme and the results from the pilot sites are very positive."*
>
> Ruth Stubbs, Cervical Screening Programme manager

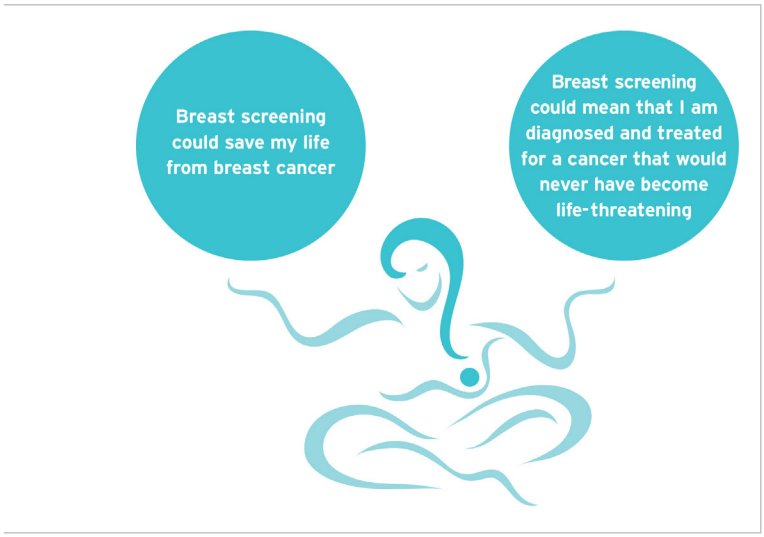
The UK NSC will then conduct a public consultation exercise on whether to change the primary cervical screening test from cytology to HPV testing. Following the closure of this consultation in October 2015, the UK NSC will decide whether or not to recommend HPV testing as the primary cervical screening test.

Ruth Stubbs, NHS Cervical Screening Programme manager, said: "The pilot sites have been pivotal in demonstrating how HPV primary screening can work in the programme and the results from the pilot sites are very positive. We look forward to hearing the UK NSC's recommendation on HPV primary screening. This year we will see women being invited into the programme who had the opportunity to have the HPV vaccination as part of the catch-up campaign in 2008. This is a further opportunity to reduce the number of women who develop invasive cancer and the number of women who die from it."

World's largest randomised trial looks into extension of breast screening age range

The NHS Breast Screening Programme was formally established in 1988 and the age range for invitations was set at 50-64, with first invitations arriving between a woman's 50th and 53rd birthdays. It extended to screen women aged 65-70 from 2003 to 2004, so we now have a lot of knowledge about the effects of routine breast screening on women aged between 50 and 70, but not for younger or older women.

In 2009, a pilot research trial was set up in six breast screening units to work out the acceptability and feasibility of extending the lower and upper age limits for inviting women for screening. A random selection of women aged 47-49 and 70-73 were invited for screening while women aged 50-70 were invited as normal. Women over 70 who were not invited under the pilot could also request three-yearly screening. The pilot ran for a year and the results were encouraging.



Breast screening's balance of potential benefits and risks

The pilot was extended into a full randomised controlled trial (RCT) which is running in 67 out of the 80 screening units and organised by a research team at Oxford University. Another nine units are inviting women aged 47-49 but not women aged 70-73, due to organisational reasons, while four units are not involved in the trial to date. All women invited for screening in trial areas receive a leaflet about the trial which explains that some younger and older women are receiving an invitation for screening.

The trial is looking at the effects of screening in slightly younger and older women, in particular:

- risks of screening – especially the chances of being diagnosed and treated for a non-life threatening cancer
- benefits of screening – in particular the chances of saving life

The screening record of each woman in the trial is linked to other NHS screening, hospital or cancer admission records. The records are anonymised, so researchers cannot identify individuals. More than two million women have been randomised into the trial, which is the largest RCT undertaken in the world to date. Results are not expected until the mid-2020s and the findings will help inform government decisions on whether to formally extend the age range for breast screening invitations across England. If introduced, women would be invited for screening nine times in their lifetime, rather than seven as at present. Women older than the invitation age range could still request screening every three years, as is currently the case.

NHS Breast Screening Programme Manager Jacquie Jenkins, said: "The trial is a good example of us using best evidence to inform screening practice. Its outcomes are eagerly awaited."

Evidence shows roll-out of bowel scope test should prevent cancers and reduce mortality

Bowel scope screening is a relatively new test that helps reduce the risk of developing bowel cancer. It finds and removes small bowel growths, called polyps, that could eventually turn into cancer.

A randomised controlled trial between 1994 and 1999 looked at whether a one-off bowel scope test using flexible sigmoidoscopy would be cost-effective and acceptable in helping to reduce mortality from bowel cancer. Evidence from the trial and the follow-up of its participants showed bowel scope screening could reduce mortality from bowel cancer among men and women aged 55-64 by 43% and reduce their incidence of bowel cancer by 33% [1]. After the publication of trial results in 2010 the UK NSC concluded that screening for bowel cancer using flexible sigmoidoscopy met the criteria for a population screening test.

> *"The main aim [of bowel scope screening] is to find and remove polyps, which can prevent bowel cancers developing."*
>
> John Davy, Bowel Cancer Screening Programme manager

Bowel scope screening looks at the inside of the large bowel. It is carried out at bowel cancer screening centres that already offer colonoscopy investigations for individuals with abnormal faecal occult blood (FOB) test results. It is offered to men and women at the age of 55 and they can have the test any time between then and their first invitation for screening using the FOB test at 60. During the bowel scope procedure, any polyps that are found can usually be removed straight away.

John Davy, NHS Bowel Cancer Screening Programme manager, said: "In rare cases, bowel scope screening will find a cancer that has already developed. However the main aim is to find and remove polyps, which can reduce the risk of bowel cancers developing."

The government made a commitment to incorporate bowel scope screening into the bowel cancer screening programme in 2011 and pathfinder sites were then established to look at how bowel scope screening could be implemented. The experience of these sites helped inform the introduction of the pilot for bowel scope screening in March 2013.

The pilot in turn helped inform the strategy for national roll-out and, at the start of 2014 to 2015, 39% of bowel cancer screening centres were offering bowel scope screening. By the end of March 2015 that had risen to 63% after 17 more screening centres had started to offer bowel scope screening. These centres are spread across England and are supported by the five regional programme hubs. Before going live, each centre must meet strict criteria, including having a highly skilled workforce and the support of NHS trusts and other stakeholders. The implementation of bowel scope screening should be completed by the end of 2016 and it is anticipated that the addition of bowel scope screening to the existing FOB test will save up to 3,000 lives per year.

[1] The Lancet, Volume 375, Issue 9726, p. 1624-1633, 8 May 2010

Expansion of newborn blood spot screening will prevent disability and save lives

The UK has a proud reputation of implementing or changing an NHS screening programme only if supported by robust evidence.

In January 2015, we expanded the newborn blood spot (NBS) programme to screen babies for four additional rare genetic disorders: **maple syrup urine disease (MSUD)**, **isovaleric acidaemia (IVA)**, **glutaric aciduria type 1 (GA1)** and **homocystinuria (HCU)**. These inherited metabolic diseases (IMDs) affect only 1 in every 100,000 to 1 in every 150,000 babies. If they are not picked up early, they almost always cause severe developmental problems, including serious mental disability, or even death. Affected babies can live healthy and active lives with well managed treatment after early detection.

Blood spot screening was expanded because the evidence showed that testing for these four conditions should prevent around 30 babies each year from dying or being severely disabled for the rest of their lives. Before implementing this change, we first needed to pilot it to show it would work in practice and the national programme team had to plan the associated screening, care and treatment pathways.

The piloting started in 2012 to 2013 when Sheffield Children's NHS Foundation Trust expanded the blood spot test for five additional conditions using tandem mass spectrometry (MS/MS) technology at an additional cost of 59p per baby. During the pilot, run in six centres, the Sheffield researchers screened more than 430,000 babies and identified 30 screen positive cases, which was in line with expectations. One of the identified babies was 16-month-old Phoenix Thompson from Lincolnshire, who was diagnosed with GA1. Phoenix's mother, Michelle Thompson, said: "It is unexplainable how important the screening was for us. It means Phoenix can receive the care and treatment he needs. It doesn't bear thinking about what would have happened if the condition wasn't picked up early."

After reviewing the pilot data and other evidence, the UK NSC recommended screening for four of the five conditions. The only exception was long-chain 3-hydroxyacyl-CoA dehydrogenase deficiency (LCHADD) because there was no evidence that the test was effective at diagnosing that condition in babies who had no previous symptoms.

Professor Jim Bonham, who headed the pilot at Sheffield, said: "The pilot study provided the evidence to be confident that in four of the new conditions trialled, children would benefit significantly from the early detection offered by newborn screening. We were therefore delighted when an announcement was made in May 2014 that this would become part of screening policy in England from 2015. More than 40 children and their families have already benefitted directly from this life changing test. In some cases this has averted significant developmental delay and consequent handicap while, for others, lives have been saved."

> *"The pilot study provided the evidence to be confident that in four of the new conditions trialled, children would benefit significantly from the early detection offered by newborn screening."*
>
> Professor Jim Bonham

After the announcement that the four conditions would become part of screening policy, the national NBS programme team got to work putting together all the necessary protocols, pathways and professional resources to ensure screening would be safe and effective.

The national programme set up working parties to develop protocols for the screening, diagnosis and treatment pathways for each of the four conditions. It also put together an overarching working group to ensure the protocols were consistent across all the IMDs and to publish a joint IMD laboratory handbook.

Other important preliminary work included:

- development of new online resources, leaflets and videos
- separate e-learning module on expanded NBS screening
- addition of information on the four conditions to the **Screening Tests for You and Your Baby** booklet that is given to all pregnant women and covers every antenatal and newborn screening test

The NBS programme launched the new e-learning resources at the Royal College of Midwives conference in November 2014 and the updated Screening Tests for You and Your Baby booklet was ready in time for the expansion of the newborn blood spot screening test in January 2015.

Work started in 2014 to 2015 on amending the laboratory information management systems (LIMS) and child health information services (CHIS). These changes will ensure the systems can cope with the recording of the additional four conditions and that the NBS programme can collect data on outcomes for babies born with one of these IMDs.

Earlier screening for rare conditions gives parents more time to make decisions

NHS screening programmes offer world-leading screening services by continually improving processes and pathways. To do this they need a robust evidence base to demonstrate the benefits of change. Not only should change lead to better clinical outcomes, it should be feasible, timely and cost-effective.

The fetal anomaly screening programme (FASP) offers antenatal screening to all pregnant women to check for Down's syndrome (T21) and fetal anomalies. Two of the fetal anomalies checked for are Edwards' syndrome (T18) and Patau's syndrome (T13). The 'T' refers to trisomy, which is an extra copy of the chromosome. Edwards' and Patau's syndromes are serious but rare conditions that affect approximately 3 in 10,000 and 2 in 10,000 births respectively. Most babies with either syndrome die before or shortly after birth due to complex physical abnormalities.

FASP previously offered screening for these two syndromes as part of the 18-21 week mid-pregnancy ultrasound scan. In 2014, the UK National Screening Committee (UK NSC) recommended offering earlier screening for Edwards' and Patau's syndromes as an expansion of the previously established 'combined test' for Down's syndrome during the first trimester (first three months) of pregnancy. This test combines the results of a blood sample with the measurement of fluid at the back of the neck (nuchal translucency) from the baby's first ultrasound scan. During 2014 to 2015, the FASP team laid the groundwork for putting the UK NSC's recommendation into action from April 2015 onwards. This preparatory work included publishing a new implementation resource with detailed guidance on the processes, pathways and standards for screening women for Edwards' and Patau's syndromes during the first trimester.

This earlier screening improves informed choice for pregnant women. Jane Fisher, director of Antenatal Results and Choices (ARC), said: "Most women who decide to have screening for these two rare but devastating chromosomal syndromes will be reassured their baby is very unlikely to be affected. At ARC we know first-hand that expectant parents who are given the shattering news that their baby has one of these conditions, prefer to have the diagnosis earlier in pregnancy. This gives them time and space to make individual decisions on how to proceed."

During 2014 to 2015, FASP also introduced an additional fifth view of the fetal heart during the mid-pregnancy scan. This three vessel and trachea view (3VT) will increase the diagnosis of serious fetal heart defects – one of 11 physical abnormalities that the ultrasound scan can detect. Fetal medical consultant Pranav Pandya welcomed this change, saying: "The three vessel and trachea view screens for congenital heart defects (CHDs). We know that prenatal diagnosis can improve the outcome for some CHDs and yet the detection rate for major CHDs is around 50% in England. Our focus is to improve this detection rate nationally by including the 3VT view and providing training via a new online resource and hands-on training."

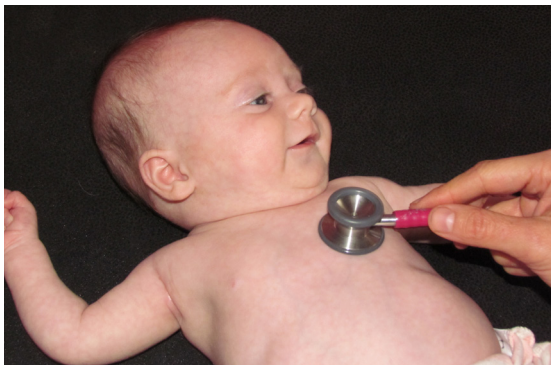
Bespoke national IT system improves quality and safety of newborn physical examination

A good quality IT system combined with effective local and national collaboration have underpinned the formal implementation of the NHS Newborn and Infant Physical Examination (NIPE) Programme.

During 2014 to 2015, national NIPE implementation leads worked closely with NHS trusts and local leads to roll out England's newest national screening programme. The NIPE Screening Management and Reporting Tool (NIPE SMART) IT system has been fundamental to this implementation. NIPE SMART went live in 17 trusts as part of a pilot in 2011 to 2012. Since then, its roll-out has gathered pace with 2014 to 2015 seeing a significant rise in the number of trusts going live.

The NIPE SMART IT system, which is commissioned nationally and provided free to trusts:

- provides a failsafe system that helps ensure no babies are missed
- supports clinical practice and accurate data collection
- collates and manages the newborn NIPE data sets
- tracks all newborn babies through the screening pathway
- manages and reports on programme activity, clinical referrals, and outcomes
- helps healthcare professionals identify the eligible cohort
- improves the quality, timeliness and consistency of the newborn and infant examinations
- tracks the screening pathway (including referrals) and thus helps reduce the number of babies diagnosed late with congenital medical conditions



Clinicians have praised the role of NIPE SMART in improving the quality and safety of the newborn physical examination. Consultant neonatologist Rahul Kachroo, from Portsmouth Hospitals NHS Trust, said: "I think NIPE SMART is an incredible tool. It has structured and standardised the NIPE programme right across the country. It has provided us with a database and audit tools that we can use to continually improve this service."

Paediatric consultant Chris Anderson said: "We (Salisbury NHS Foundation Trust) started using the NIPE SMART system for hospital NIPE screening in March 2015. It is quite a different way of working and making the change has enabled us to focus on the quality and safety of a number of aspects of our screening programme. It has improved data collection and documentation. I have been impressed with how supportive the NIPE SMART roll-out team were, putting a huge amount of effort into individualising the way our database looks and functions so that it is easy to use and saves us lots of time."

Data drives improvements in timeliness of offer of screening to at-risk mothers

Feedback of accurate data is essential in monitoring whether screening programmes are meeting national standards. National teams, the screening quality assurance service (SQAS) and commissioners use key performance indicator (KPI) data to scrutinise programmes at national, regional and local level. This level of scrutiny helps improve programmes so they can offer a more effective and efficient service to users.

Testing at-risk mothers early in pregnancy is one of the NHS Sickle Cell and Thalassaemia (SCT) Screening Programme's key objectives. The programme aims to offer screening to every pregnant mother by 10 weeks gestation. This target is enforced by a national programme standard which sets 50% as the minimum acceptable proportion of pregnant women to be offered screening by 10 weeks gestation. This helps ensure there is enough time for further tests to be carried out, if required, by 12 weeks and six days gestation – the target for completion of all SCT prenatal diagnostic tests. There are religious and cultural reasons why this is particularly important for some ethnic groups at increased risk of sickle cell disease and thalassaemia.

One of the SCT programme's three KPIs monitors whether this timely offer is being met and the 2014 to 2015 data showed an improvement in the number of services meeting the target. This was particularly true in the Midlands and East region, which saw a 10% improvement against the national standard. Southend University NHS Foundation Trust, in the East of England sub-region, proved how targeted action could improve performance. The proportion of women being screened by 10 weeks gestation increased from 50.7% in quarter 1 to 66.4% in quarter 4 following the launch of a pregnancy booking line in May 2014. Women who contact the booking line now receive a follow-up phonecall from a midwife, are provided with information about screening and receive a home visit from a community midwife before 10 weeks gestation.

Midwife Jane Hann, who helps man the Southend trust booking line, explained that women who contact the line receive their follow-up call from a midwife within five working days. She added: "During this call the women are encouraged to arrange their blood tests as soon as possible and the forms are dispatched the same day, with information regarding our local phlebotomy clinics. Many women are now receiving their forms at five to six weeks gestation, which has seen a significant rise in our KPI standards."

Progress is still required to meet SCT KPI targets, especially in high prevalence areas in London and the West Midlands. In 2014 to 2015, the programme built on its proud history of outreach work to these at-risk communities with the publication of an **online outreach resource tool and good practice guidance**. National programme manager Cathy Coppinger said: "Working with the voluntary sector, we have been highly effective in reaching out to communities at risk. We wanted to create a record of what we did and to provide advice for other people undertaking outreach – whether in sickle cell and thalassaemia or other health issues."

Research improves service for pregnant women who screen positive for syphilis

Screening programmes have a responsibility to provide services based on the best available, current evidence. Programmes often commission universities to undertake high quality research to fill in the gaps where current evidence is missing.

The NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme commissioned **the Surveillance of Antenatal Syphilis Screening (SASS) study**, based at University College London's (UCL's) Institute of Child Health, to highlight potential areas of service improvement. The study assessed the proportion of women identified as having syphilis through antenatal screening (in 2010 and 2011) who needed treatment to reduce the risk of transmitting syphilis to their babies. It also assessed how they were managed and their baby's outcome.

> *"Important national studies like this are only possible with the support and contribution of screening coordinators and clinicians in trusts."*
>
> Sharon Webb, Infectious Diseases in Pregnancy Screening Programme manager

Syphilis can be transmitted to the fetus during pregnancy and may lead to stillbirth, neonatal death, or disorders such as deafness and neurological impairment. Timely diagnosis and treatment is essential to prevent congenital syphilis. Antenatal screening has been offered to all pregnant UK women for over 50 years and uptake is consistently above 95%. After a positive screening result, confirmation of maternal syphilis and decisions about management depend on both laboratory results and clinical judgment. All women with a positive screening result need prompt referral to genitourinary medicine. Paediatric follow-up is necessary for all babies born to women who require treatment in pregnancy.

SASS researchers were notified of all pregnant women in the UK who had a positive antenatal syphilis screening result or were known to have active syphilis in pregnancy during the study period. More than 1,900 screen positive pregnancies were reported and over 1,400 were confirmed positive. Only 25% of these had newly diagnosed infections but about 40% needed treatment in pregnancy (mainly penicillin). Six children born to women needing treatment had confirmed congenital syphilis – generally these were pre-term infants or babies born to women who were diagnosed very close to delivery.

During 2014 to 2015, the SASS results:

- informed the current review of the IDPS programme standards, service specifications and programme operational handbooks
- contributed to new patient information, professional e-learning, and counselling resources
- were shared with clinical leads in the **British Association for Sexual Health and HIV** (BASHH) to support the current review of clinical care guidelines

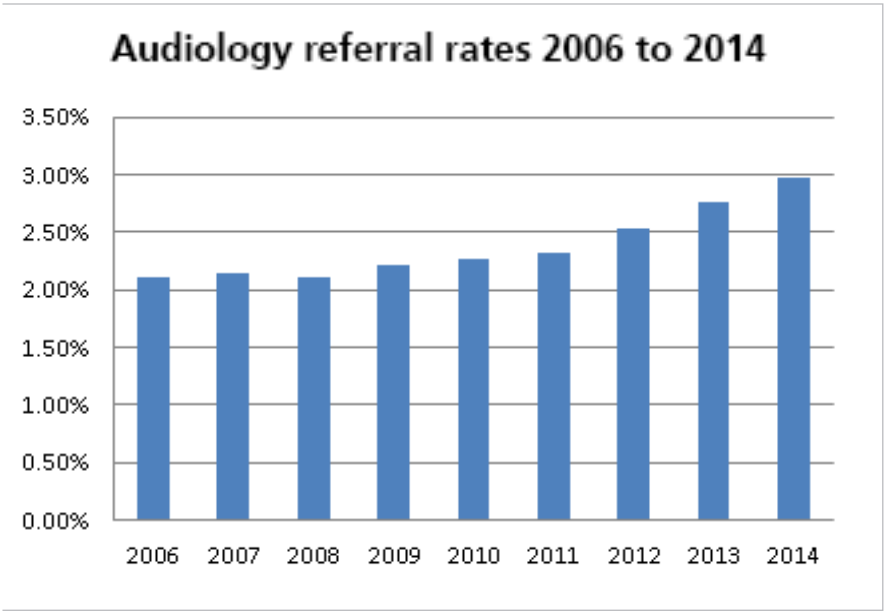
IDPS programme manager Sharon Webb said: "Important national studies like this are only possible with the support and contribution of screening coordinators and clinicians in trusts."

Tackling variation in audiology referral rates will reduce anxiety among parents

National screening programmes are fundamentally equitable, offering a test to everyone in a given population. Screening should therefore help reduce the health inequalities gap. This can only happen if national programmes successfully identify and reduce variations in the way screening is provided. This in turn improves both the efficiency and overall quality of screening and ultimately improves patient outcomes.

The NHS Newborn Hearing Screening Programme (NHSP) aims to minimise the number of babies who are referred to a hearing specialist. This not only reduces the workload in busy audiology departments, but also reduces anxiety among parents whose babies do not have a hearing impairment.

One of the programme's national standards is that no more than 3% of the 'well-baby' population should be referred to a hearing specialist in audiology. The 'well-baby' population is all babies except those who spend more than 48 hours in a neonatal intensive care unit. Across England, the average referral rate is well within this standard at 2.6% but there is considerable variation between local programmes – from 0.6% to 5.8%. Since 2010, this referral rate has been increasing, generally in the 'well-baby' population screened in hospitals.



Audiology referral rates from newborn hearing screening

The national NHSP team set up a project group to investigate why referral rates vary so much. The group is analysing more than 10 years of NHSP data to identify the causes. It will then develop a set of tools to share with local screening providers. These tools will enable local services to review any practices that may be distorting the chances of a referable result.

Jane Hibbert, NHSP Programme Manager and project group member, said: "We are using the wealth of screening data available to us with the help of statistician Professor David Wright from Exeter University. We hope to be able to identify and thus eliminate those factors which introduce variability in referral rates, so that babies are not referred for further tests in audiology unnecessarily. This quality improvement initiative should help reduce the number of parents who experience the anxiety of their baby's referral to audiology."

NHSP clinical advisor Sally Wood said: "The objective of this project is to reduce the variability of referral rates across and within programmes and in this way address the increasing referral rate over time. This will improve the efficiency of the screening programme, reduce the workload for audiology departments and, importantly, reduce the need for some families to attend outpatient appointments with their new baby."

Research supports extended diabetic eye screening intervals for lowest risk patients

The NHS Diabetic Eye Screening (DES) Programme aims to reduce the risk of sight loss for people with diabetes. It invites all people with diabetes (types 1 and 2) for screening every 12 months, regardless of their risk of developing sight-threatening disease. Should new proposals be approved, that may be about to change. This is because evidence, reported in 2014 to 2015, suggests the programme should introduce variable screening intervals according to patient risk.

This evidence emerged from the Four Nations Diabetic Retinopathy Screening Study Group which carried out the largest study of its kind[1]. The group studied screening results from more than 350,000 patients from the whole nation programmes in Wales, Scotland and Northern Ireland, plus four English programmes: Brighton, Derbyshire, Leeds and Staffordshire. Researchers reviewed patient follow-up data (up to four years) looking at the natural progression of retinal changes. Their analysis showed it would be both clinically and cost effective to screen the lowest risk patients – those who have had no signs of retinopathy at their two most recent screening appointments – every two years rather than every 12 months. Introducing this change would reduce the total demand for diabetic eye screening by 35% – or more than 650,000 appointments a year – compared to the current system of inviting everyone on an annual basis.

> *"We could use the slots freed up by the introduction of risk-based intervals to accommodate the additional demand from the growth in the number of people with diabetes."*
>
> Professor Peter Scanlon

DES clinical lead Professor Peter Scanlon said: "Reducing the number of screening episodes for these low risk patients would release capacity. The number of people with diabetes has increased steadily by around 5% per annum in recent years because more people are living longer, are obese, have low levels of physical activity or come from ethnic groups at higher risk. If this worrying trend continues, we could use the appointment slots freed up by the introduction of risk-based screening intervals to accommodate the additional demand resulting from this growth in the number of people with diabetes."

Introducing risk-based intervals could also release resources to implement local projects to improve uptake among patients who are not engaged with screening and are at the highest risk of developing sight-threatening disease. On the basis of the Four Nations Diabetic Retinopathy Screening Study Group evidence, the UK NSC has proposed extending screening intervals from one year to two years in low risk patients, provided:

- accurate and consistent grading of screening results is in place nationwide
- data and IT processes are robust
- stakeholders and patients receive clear information about risk in a way that is accessible to all

[1] Progression of diabetes retinal status within community screening programs and potential implications for screening intervals. Leese GP, Stratton IM, Land M, Bachmann MO, Jones C, Scanlon P, Looker HC, Ferguson B; Four Nations Diabetic Retinopathy Screening Study Group. Diabetes Care. 2015 Mar;38(3):488-94. doi: 10.2337/dc14-1778. Epub 2014 Dec 18.

Audit of national AAA screening data will help providers tackle health inequalities

Although screening programmes are fundamentally equitable, inequalities can still exist, both in the incidence of a condition and the uptake of screening.

National uptake of abdominal aortic aneurysm (AAA) screening is just under 80%. Until recently, it was not known if this varied according to factors such as deprivation and ethnicity. The national programme team therefore carried out an audit of national data to identify:

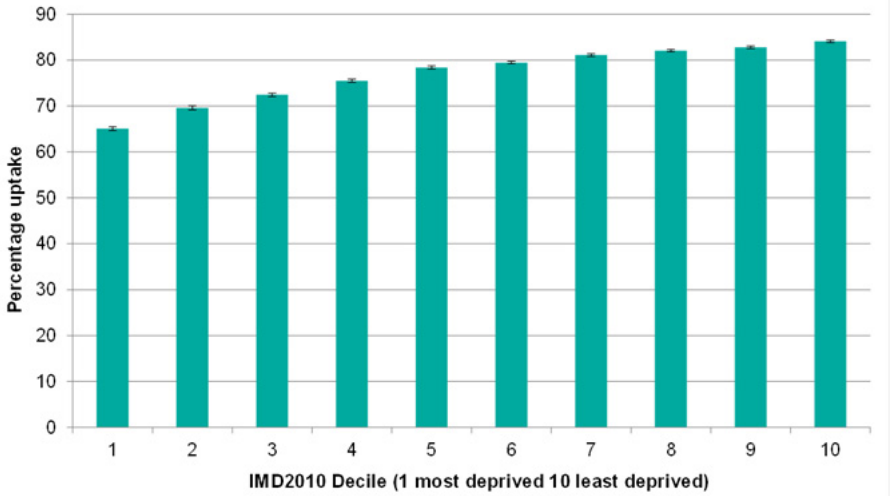
- any groups that are more at risk of AAA
- any groups less likely to take up the offer of screening

The research looked at:

- uptake of screening across England in 65-year-old men between 2013 and 2015
- deprivation using Index of Multiple Deprivation (IMD) 2010 data
- estimates of the ethnic mix of areas using 2011 census data

The data showed that:

- more deprived areas tend to have lower uptake but a higher incidence of aneurysms
- uptake of screening in the most deprived tenth of the country was 65.1% compared to 84.1% in the least deprived
- white men, particularly white Irish men, have a higher incidence of aneurysms compared to other ethnic groups
- white men in the most deprived 10% from IMD data had highest incidence of aneurysms



Uptake of AAA screening 2013 to 2015 according to levels of deprivation

The data suggests many aneurysms may be going undetected in men who are most at risk but least likely to attend. The national team is developing a routine report on inequalities and encouraging local providers and commissioners to use this data to develop targeted interventions.

Mark Gannon, clinical director of the Central England programme, said: "We know men subject to socioeconomic deprivation and some ethnic groups use our services poorly and we have to put particular effort and initiative into these groups to ensure they do not become systemically disadvantaged."

Karen Bentley-Hollins, co-ordinator of the Somerset and North Devon programme, said: "Knowing that there is a direct correlation between deprivation and uptake has really helped us focus our promotion of the programme with these men. We are currently working with the most deprived ward in Taunton, taking screening to the men thanks to this knowledge."

NHS Bowel Cancer Screening Programme

Pay costs: £378,560
Non-pay costs: £16,978,100
Total costs: £17,356,660

NHS Breast Screening Programme

Pay costs: £271,620
Non-pay costs: £9,868,730
Total costs: £10,140,350

NHS Cervical Screening Programme

Pay costs: £293,300
Non-pay costs: £913,930
Total costs: £1,207,230

NHS Abdominal Aortic Aneurysm and Diabetic Eye Screening Programmes

Pay costs: £1,287,328.04
Non-pay costs: £1,773,257.60
Total costs: £3,060,586.44

NHS Infectious Diseases in Pregnancy Screening Programme

Pay costs:£132,706
Non-pay costs:£59,498
Programme costs: £18,703
Total costs: £210,907

NHS Newborn Blood Spot Screening Programme

Pay costs: £546,558
Non-pay costs: £297,758
Programme costs: £1,067,361
Total costs: £1,911,677

NHS Sickle Cell and Thalassaemia Screening Programme

Pay costs: £440,352
Non-pay costs: £204,648
Programme costs: £140,700
Total costs: £785,700

NHS Fetal Anomaly Screening Programme

Pay costs: £170,350
Non-pay costs: £976,900
Total costs: £1,147,250

NHS Newborn and Infant Physical Examination Programme

Pay costs: £879,309
Non-pay costs: £1,750,300
Total costs: £2,629,609

NHS Newborn Hearing Screening Programme

Pay costs: £729,616
Non-pay costs: £1,687,600
Total costs: £2,617,216

About Public Health England

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

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Published: December 2015
PHE publications gateway number: 2015494