



Public Health  
England

Protecting and improving  
the nation's health

# NHS Screening Programmes in England

2013/14



“ The screening services in England are a notable example of [Public Health England’s] ambitions already in practice and the programmes continue to show the impact high quality early interventions have in reducing the burden of disability and saving lives. ”

Professor Kevin Fenton

Director of Health and Wellbeing, Public Health England

### **This report covers the following NHS screening programmes in England:**

NHS Infectious Diseases in Pregnancy Screening Programme: [infectiousdiseases.screening.nhs.uk](https://infectiousdiseases.screening.nhs.uk)

NHS Fetal Anomaly Screening Programme: [fetalanomaly.screening.nhs.uk](https://fetalanomaly.screening.nhs.uk)

NHS Sickle Cell and Thalassaemia Screening Programme: [sct.screening.nhs.uk](https://sct.screening.nhs.uk)

NHS Newborn Blood Spot Screening Programme: [newbornbloodspot.screening.nhs.uk](https://newbornbloodspot.screening.nhs.uk)

NHS Newborn Hearing Screening Programme: [hearing.screening.nhs.uk](https://hearing.screening.nhs.uk)

NHS Newborn and Infant Physical Examination Programme: [newbornphysical.screening.nhs.uk](https://newbornphysical.screening.nhs.uk)

NHS Diabetic Eye Screening Programme: [diabeticeye.screening.nhs.uk](https://diabeticeye.screening.nhs.uk)

NHS Abdominal Aortic Aneurysm Screening Programme: [aaa.screening.nhs.uk](https://aaa.screening.nhs.uk)

Foreword	4
Introduction	5
The big picture	6
What do we screen for?	10
Reducing the burden of disease	12
Delivering innovative training	13
Getting the most out of technology	14
International collaboration	15
Preventing illness	16
Informed choice	18
World-leading research	19
Improving life chances	20
Assuring quality	21
Quality improvement	22
Finances	23

## Kevin Fenton, Director of Health and Wellbeing, Public Health England

Public Health England (PHE) recently set out its priorities for the next 5 years, at the heart of which is ensuring we provide credible, evidence-based advice, engage and support the public in making healthier choices and encourage broader action on improving the public's health. The screening services in England are a notable example of these ambitions already in practice and the programmes continue to show the impact high quality early interventions have in reducing the burden of disability and saving lives.



For example; diabetic eye disease is for the first time in over 50 years no longer the leading cause of blindness in adults of working age. This is a fantastic achievement which screening has in no small way contributed to; identifying disease early, leading to treatment to prevent permanent damage.

Screening continues to play an important role in reducing the health inequalities gap with the programmes being fundamentally equitable, offering a test to all those at risk of a particular disease. In child health, the six antenatal and newborn screening programmes are hugely important in the ambition to give children the best possible start to life, ensuring families, whatever their background, are supported from the very beginning.

We know that the first few weeks and months of a baby's life are critical to their development. Deafness, for example, can impact on a child's social, educational, language and communication development. We know that early identification of a hearing loss gives those children affected the opportunity to reach their full potential. The NHS Newborn Hearing Screening Programme was implemented across the whole of England in 2006 and has helped reduce the average age for identifying hearing loss in newborn babies. Through the programme hearing loss is identified before 2 months of age giving these children and their families access to the right support from the start.

This report is not short of examples showing why the English screening programmes are held in such high regard worldwide. I would like to thank all the screening teams for their continued efforts in achieving this.

**Dr Anne Mackie, UK NSC Director of Programmes**

2013/14 saw some big changes for us in screening as the NHS Screening Programmes successfully integrated into Public Health England. It's been business as usual for screening, however, and we have worked hard to improve our engagement with stakeholders and screening professionals, particularly with the development of our new screening helpdesk service, which provides a single point of contact for anyone wanting to contact the non-cancer screening programmes.

It will be apparent to anyone reading this report of work carried out last year that screening has delivered some important improvements for the public's health during 2013/14. HIV transmission from mother to baby is at an all-time low, a new computerised system linking every baby with their blood spot result means that no babies should now miss potentially life-saving treatment, innovative genetic technology is being trialled in the NHS which could revolutionise the screening for Down's syndrome and the efforts of our quality assurance teams are being rewarded with safer care.



These are just some examples of how through careful assessment of evidence, thorough project management and proper use of public resources, thousands of lives may be saved and disabilities avoided.

This report stands as a testament to the work of the national screening programme and quality assurance teams, screening and immunisation teams embedded in the NHS and to the thousands of front line staff who make sure that the promise of improved health is delivered. Many thanks to all of you and I look forward to

working with everyone involved in screening to take forward further improvements in the coming years.

## NHS Infectious Diseases in Pregnancy Screening Programme

Since 2004, the Health Protection Agency's National Antenatal Infection Screening Monitoring (NAISM) Programme (now part of PHE), has centrally collated IDPS surveillance data. The data is analysed and published annually: ([www.gov.uk/infectious-diseases-during-pregnancy-screening-vaccination-and-treatment](http://www.gov.uk/infectious-diseases-during-pregnancy-screening-vaccination-and-treatment))

The IDPS and NAISM programmes continue to work together to improve future data quality.

Hepatitis B	
Uptake*	97.7%
<b>Number of positive results*</b>	<b>3,982</b> <b>(0.58%)</b>
Seen by specialist within 6 weeks of identification †	68.4%

HIV	
Coverage †	98.8%
<b>Uptake*</b>	<b>97.5%</b>
Number of positive results*	1,749 (0.25%)

Syphilis	
Uptake*	97.7%
<b>Number of positive results*</b>	<b>944</b> <b>(0.14%)</b>

Rubella susceptibility	
Uptake*	97.8%
<b>Number susceptible*</b>	<b>44,650</b> <b>(6.59%)</b>

\* data from NAISM † data from IDPS

## NHS Fetal Anomaly Screening Programme

In 2013/14 over 555,000 Down's syndrome screening tests were undertaken: 2.3% of women were given a result that their baby had a greater than 1 in 150 chance of being born with Down's syndrome.

The Down's screening programme relies on an accurate ultrasound measurement of part of the baby's neck. This measurement has been subject to quality assurance by the Down's syndrome Screening Quality Assurance Support Service (DQASS). DQASS highlights where there may be a need to review the scan technique with supported training (red flags). This year saw significant reductions in red flag scan measurements from 0.30% to 0.11%. This shows that the scans are getting more accurate.

<b>Number of tests performed</b>	<b>555,377</b>
Number of tests in 1st trimester (combined test)	461,074
<b>Number of integrated tests</b>	<b>3,764</b>
Number of tests in 2nd trimester (quadruple test)	90,539
<b>Number of women at high risk &gt;6 in 1,000</b>	<b>15,455</b>
Standardised screen positive rate	2.3

## NHS Sickle Cell and Thalassaemia Screening Programme

More than 730,000 pregnant women were screened for sickle cell and thalassaemia in 2013/14. More than 15,000 (2%) were identified as screen positive. Nearly 670,000 newborn babies were screened.

The programme's newborn outcomes project has reported that:

- 268 babies were suspected of having sickle cell disease and 88% of them attended clinic by 3 months
- 32 babies were suspected of having beta thalassaemia and 85% of them attended clinic by 3 months

Babies are excluded if they were suspected insignificant cases or born abroad. No deaths were attributed to sickle cell disease.

[sct.screening.nhs.uk/data-reports](http://sct.screening.nhs.uk/data-reports)

[sct.screening.nhs.uk/evaluation-annb-outcome-project](http://sct.screening.nhs.uk/evaluation-annb-outcome-project)

### Antenatal screening

<b>Antenatal samples screened</b>	<b>730,779</b>
Screen positive pregnant women	15,281
<b>Proportion of fathers tested</b>	<b>64%</b>
High risk couples detected	944

### Prenatal diagnostic (PND) testing\*

<b>PNDs performed</b>	<b>353</b>
Affected fetal results	89

\* This is a process where a sample of amniotic fluid or piece of the placenta is taken for further tests and diagnosis

### Newborn screening

<b>Newborn samples screened</b>	<b>668,117</b>
Screen positive results	319
<b>Carrier results</b>	<b>8,850</b>

## NHS Newborn Blood Spot Screening Programme

### Cystic fibrosis

<b>Babies tested</b>	<b>671,120</b>
Screened positive 1st sample	171
<b>Screened positive 1st sample and 1st appt within 28 days</b>	<b>114</b>
Screened positive 2nd sample	72
<b>Screened positive 2nd sample and 1st appt within 35 days</b>	<b>27</b>

### CHT (congenital hypothyroidism)

<b>Babies tested</b>	<b>673,233</b>
Screened positive 1st sample	298*
<b>Screened positive 1st sample and 1st appt within 17 days</b>	<b>248</b>
Screened positive 2nd sample	219
<b>Screened positive 2nd sample and 1st appt within 24 days</b>	<b>138</b>

### PKU (phenylketonuria)

<b>Babies tested</b>	<b>673,328</b>
Babies screened positive	54
<b>Screened positive and 1st appt within 17 days of birth</b>	<b>45</b>

### MCADD (medium-chain acyl-CoA dehydrogenase deficiency)

<b>Babies tested</b>	<b>672,107</b>
Screened positive	71
<b>Screened positive and 1st appt within 17 days</b>	<b>64</b>

### Coverage

<b>% of babies* tested and recorded on the Child Health Information System at 17 days</b>	<b>94%</b>
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\*One baby died before screening could be completed

## NHS Newborn Hearing Screening Programme

The coverage of newborn hearing screening is defined as the percentage of babies with a completed screen. Coverage has continued to improve year on year and in 2013/14 it exceeded targets.

The proportion of babies being referred to hearing services is rising. The programme is investigating this increase, which mostly relates to hospital based screening services.

The number of babies attending their first follow-up within the target time of 4 weeks of age continued to improve in 2013/14 but did not meet the target of 90%.

There are indications of a decline in the percentage of babies with confirmed permanent hearing impairment, although

the complete picture may take some time to emerge.

Proportion of babies getting a test by 4/5 weeks (coverage) (target $\geq 95\%$ )	97.82%
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<b>Coverage by 3 months (target <math>\geq 95\%</math>)</b>	<b>99.08%</b>
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Proportion declining screening	0.06%
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<b>Percentage referred to hearing services (target <math>\leq 3\%</math>)</b>	<b>2.81%</b>
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Percentage referrals who attended follow-up within 4 weeks (target $\geq 90\%$ )	85.88%
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<b>Number of babies with confirmed hearing impairment in both ears</b>	<b>591</b>
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Number of babies with confirmed hearing impairment in both ears per 1,000 screened (yield)	0.89
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## NHS Newborn and Infant Physical Examination Programme

The implementation of consistent new national standards for the programme, supported by the NIPE SMaRT IT system, began in 2013/14.

By April 2014, 17 of the 145 trusts had 'gone live' on NIPE SMaRT and implemented the new standards while a further 9 were in the process of implementation. It is anticipated that full rollout of the new NIPE standards will be completed by May 2016.

A new e-learning module was launched on 25 November 2013 for health professionals who deliver the routine head to toe neonatal assessment. More than 850 health professionals registered on the resource between its launch and April 2014.

NIPE implementation by trusts April 2014		
	Implementing	Live
London	0	3
<b>Midlands &amp; East</b>	<b>2</b>	<b>3</b>
North	7	10
<b>South</b>	<b>0</b>	<b>1</b>
Total	9	17

NIPE e-learning registrations April 2014	
<b>Midwives</b>	<b>377</b>
Junior doctors	158
<b>GPs</b>	<b>124</b>
Consultants	50
<b>Hospital registrars</b>	<b>35</b>
Nurses	31
<b>Other</b>	<b>86</b>
Total	861



## NHS Diabetic Eye Screening Programme

There were 84 local services providing diabetic eye screening (DES) during 2013/14. We know that different services test people with diabetes at different time intervals so work is under way to make sure everyone is offered the same core service.

This is known as the common pathway and is supported by an agreed set of data implemented by 3 software suppliers. By the end of the year 47 (57%) of services had started to use the pathway for screening.

A new process to use and report the data from the common pathway was piloted in four programmes. This pilot successfully identified a range of problems which were then fixed.

The 2013/14 data showed that: 93%

(1,962,319 out of 2,111,309\*) of those attending for screening had results issued within 3 weeks of the screening test.

During 2013/14 the regional QA teams undertook a total of 13 external quality assurance visits divided by regions as follows:

- North - 5
- Midlands - 2
- London - 3
- South - 3

The Midlands and East region also undertook a QA visit of the Wales DES programme.

\*Programmes migrating from Orion software were exempt from submitting KPI data for the quarter in which they migrated.

## NHS Abdominal Aortic Aneurysm Screening Programme

The NHS AAA Screening Programme (NAAASP) screened more than 260,000 men during 2013/14 and detected nearly 3,700 aneurysms. The prevalence of aneurysms among men invited for screening was just 1.3% – down from 1.4% in 2012/13. This was the first year of full national coverage – all men in England who turned 65 between 1 April 2013 and 31 March 2014 were invited for a scan.

A total of 491 screened men underwent planned surgery to repair large aneurysms detected by screening. Sadly 4 men died following these elective repairs. In addition, 10 screen-detected aneurysms ruptured (burst) and sadly 7 of these men died.

[aaa.screening.nhs.uk/2013-14datareports](http://aaa.screening.nhs.uk/2013-14datareports)

<b>Offered screening</b>	<b>300,889</b>
Tested (2013/14 cohort)	235,409
<b>Uptake (2013/14 cohort)</b>	<b>78.2%</b>
Tested (self-referrals)	27,679
<b>AAAs detected (total)</b>	<b>3,694</b>
AAAs detected (cohort)	2,941
<b>Prevalence (cohort)</b>	<b>1.3%</b>
AAAs detected (self-referrals)	753
<b>Prevalence (self-referrals)</b>	<b>2.7%</b>
Men on surveillance end of year	9,031
<b>Referrals to surgeons</b>	<b>614</b>
Elective AAA repairs	491
<b>Elective deaths</b>	<b>4</b>
Ruptures	10
<b>Rupture deaths</b>	<b>7</b>



### **NHS Fetal Anomaly Screening Programme (FASP)**

FASP uses ultrasound scanning to screen all pregnant women in England to assess the risk of their baby being born with Down's syndrome or abnormalities with the development of the fetus.

The first scan usually takes place between 10 and 14 weeks after conception and includes a blood test for Down's syndrome. A second scan for fetal abnormalities takes place at around 18 to 21 weeks. The timing of the scans allows for further diagnostic tests if required and allows as much time as possible for pregnant women to think through the options available.



### **NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme**

The IDPS programme offers and recommends screening to all pregnant women for hepatitis B, HIV, syphilis and currently 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 so the risk of the infection being passed on to the child can be substantially reduced. 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 (SCT) Screening Programme**

The SCT 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 think through the options available. It also means that babies who have either condition can be given the best support and treatment from the very start.



### **NHS Newborn and Infant Physical Examination (NIPE) Programme**

The NIPE 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 (NHSP)**

NHSP 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 (NBS) Screening Programme**

The NBS 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.

The programme uses a heel prick test to collect spots of blood which are tested to find babies who have one of the five conditions. Babies who test positive can then be treated early, improving their health and, in some cases, preventing severe disability or even death.



### **NHS Diabetic Eye Screening Programme (NDESP)**

NDESP aims to reduce the risk of sight loss for people with diabetes through the early detection, appropriate monitoring and treatment of diabetic retinopathy, which is one of the biggest causes of blindness among people of working age.

NDESP offers screening using digital photography every 12 months to all people identified with diabetes who are aged 12 and over.



### **NHS Abdominal Aortic Aneurysm Screening Programme (NAAASP)**

NAAASP aims to reduce premature deaths from ruptured abdominal aortic aneurysms (AAAs) among men aged 65 and over by up to 50% through early detection, appropriate follow-on tests and treatment.

NAAASP offers all men an ultrasound scan test of the abdomen during the year they turn 65 while men over 65 who have not previously been tested can self-refer for screening.

## Reducing the burden of disease

**The national offer and recommendation of screening for HIV in pregnancy, introduced in 2000, to protect both the health of the mother and her unborn baby, has dramatically reduced the number of babies catching the virus from their mothers. The NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme aims to ensure every pregnant woman is offered the test and those who test positive get the right support and treatment at the correct time.**

In February 2014, the journal AIDS reported that the proportion of HIV-positive diagnosed women passing the infection to their babies in the UK was now at its lowest ever level, having dropped from 2.1% in 2000/01 to just 0.46% by 2010-2011.

Screening is at the heart of this success story. If a woman is unaware of her HIV infection, her baby has about a one in four chance of being infected. But this risk can be all but eliminated if she knows she is HIV positive. Transmission of HIV from mother to baby is almost entirely preventable through careful management in pregnancy including antiretroviral therapy, appropriate mode of delivery and avoidance of breastfeeding.

HIV specialist midwife Lynne Barnes works at Homerton University Hospital, London, where, despite high levels of HIV in the local population, no baby has been born with HIV if their mother was diagnosed in pregnancy in recent years. "We have greatly reduced the risk of transmission," said Lynne. "That is not only due to the success of the medication but also having the right support systems in place to care for the women properly. We really enjoy our job and have seen improvements year on year in the service we provide. It is a huge success story in terms of the health of babies. It is really rewarding when I see perfectly healthy children who were born to HIV-positive mothers I supported five or seven years earlier."

Twenty years ago most HIV positive pregnant women in the UK did not even know they had the infection when they gave birth. The availability of comprehensive antenatal screening has changed all that.

Pat Tookey, the epidemiologist who manages the National Study of HIV in Pregnancy and Childhood (NSHPC), said: "The screening programme has had the most amazing impact. It means almost all women are diagnosed before delivery so that mother to baby transmission is now incredibly unlikely.

"Before 2000, HIV testing was only offered to those thought to be at risk. Midwives were understandably unhappy with that system because they were being asked to pick and choose. The offer and recommendation of screening to all pregnant women has helped normalise the whole process of HIV testing in pregnancy and has also got the message across to the whole of society that an HIV test is a normal thing to have.

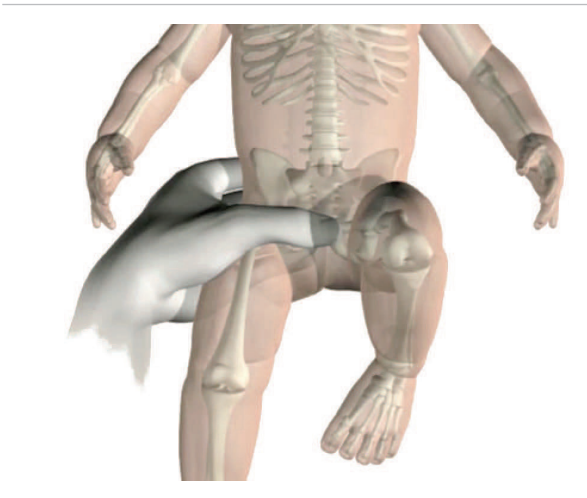
"Uptake will never be 100% because it is a voluntary programme. But the undiagnosed population is getting smaller due to the impact and success of the screening programme."

## Delivering innovative training

### **The newborn and infant physical examination (NIPE) programme helps hundreds of babies born with life-threatening heart disease, sight problems and other abnormalities, reducing the risk of lengthy treatment or long-term disability.**

Thousands of midwives and GPs deliver the routine head to toe neonatal assessment. In November 2013, NIPE launched an e-learning audio-visual package that aims to help ensure every examination is carried out safely and effectively to consistent national standards.

The module, developed with the help of leading neonatologists, midwives, GPs and representatives of the Royal College of GPs, Royal College of Paediatrics and Child Health and the Royal College of Midwives, is available in condensed (20-minute) or full (35-minute) versions. It covers the four screening elements of the physical examination – heart, hips, eyes and testes – using film and animation to illustrate best practice. More than 700 users completed the module between its launch and the end of 2013/14 and they have been overwhelmingly positive about its impact.



Exeter GP Dr Guy Bradley-Smith said: “It was excellent. In fact it was so good that I emailed the link straight away to our GP trainee and to the other partners in the practice to encourage them to use it.

“The demonstration of examining one hip at a time was new to me and really useful, as was refreshing my knowledge of hand positions during the examination. The videos were very professional and the convenience of being able to do the learning in my own time at home is the real benefit of modern technology.

“The baby examination takes me about five minutes and the e-learning was suitably timed to reflect that. It was a really helpful little refresher, not just in terms of how to do the examination but also as a reminder of why we do it.”

Becky Adcock, midwifery team manager at Bedford Hospital, was similarly impressed. “It is fantastic – I could have done with it years ago,” she said. “I feel it will really enhance practice.

“Everything is described and explained so well and the short videos are great. Watching a video of the examination is especially helpful because you pick up little things and maybe become aware of any bad habits you have got into. The ability to download and print out fact sheets is also really useful. I now have little crib sheets saved on my hard drive that I will refer back to. I would definitely recommend it.”

Access the module at [cpd.screening.nhs.uk/nipe-elearning](http://cpd.screening.nhs.uk/nipe-elearning)

## Getting the most out of technology

### **Getting the most out of new technology plays a pivotal role in ensuring continuous improvements in the quality and safety of the NHS Screening Programmes.**

In 2013/14, the NHS Newborn Blood Spot (NBS) Programme piloted a computer programme (web-based failsafe solution) to reduce the number of babies who miss or are delayed in receiving newborn blood spot screening to detect rare but serious conditions.

In September 2013, the Newborn Screening Failsafe Solution (NBSFS) project won top prize for Efficiency in Clinical Support Services in the prestigious Health Service Journal awards. The judges described the failsafe solution as 'a fantastic example of innovation which safeguards the future of the NHS, ensures that its resources are used to their full potential and helps to make savings in a way which enhances, rather than damages, patient care'.

Although in its early stages, the benefits of the NBSFS are already being reported. Examples include cases where a sample had been taken but not sent to the lab, and where the lab had not received samples which had been sent.

Sheila Reed, antenatal and newborn screening coordinator, County Durham and Darlington NHS Foundation Trust, said: "The NBSFS is easy to use and only takes a few minutes a day to monitor. It is an invaluable tool which has improved communication between my team, the laboratory and child health. Checking the system daily reminds me of the importance of the newborn blood spot programme and getting it right first time. The system has picked up a few babies who had not been screened by 12 days and enabled us to ensure screening took place before 17 days. These babies could have previously slipped through the net."

Alison Fiddler, quality assurance manager in London, was also enthusiastic. "Thanks to NBSFS there is now a heightened level of awareness, scrutiny and responsibility within each organisation which helps regional quality assurance managers to provide ongoing support to local organisations and commissioners."

The IT solution, which is in line with data protection standards, matched babies born in England with blood spot cards received by the screening laboratories. Babies for whom a blood spot card has not been received are identified. Each maternity unit has designated users who access the system daily. Babies who have no blood spot card received in the laboratory by 12 days of age are automatically flagged up and action can be taken to ensure that screening takes place with minimal delay. Child health record departments and neonatal units can also be set up to use the system.

By the end of March 2014, implementation was well under way with most of the English newborn screening laboratories providing screening data to the NBSFS database. 30% of maternity units in England were using NBSFS, a further 23% had started the implementation process and plans for full national coverage were well established.

**International collaboration**

**NHS Screening Programmes are internationally renowned for quality, rigour and effectiveness. In recent years, expert advice and support from the NHS Sickle Cell and Thalassaemia (SCT) Programme has been integral to efforts to start newborn screening for sickle cell disease in Nigeria.**

In England, about 300-350 babies per year are born with sickle cell disease, a hereditary blood disorder that can cause life-threatening health complications. The SCT programme supports people to make informed choices during pregnancy and identifies affected babies early so they can get the best support and treatment.

In Nigeria, the impact of the disease is much greater. A quarter of the nation's 175 million people carry the gene and at least 150,000 babies are born with the disease every year – but only 50% may live past the age of 10. Efforts to introduce newborn sickle cell screening in Nigeria began in 2009 following the award of a European Community; United Nations Development Programme Joint Migration Development Initiative (JMDI) grant under lead investigator Dr Baba Inusa, consultant in blood disorders and children's medicine at Guy's and St Thomas' NHS Foundation Trust. Since then, screening has started in several parts of the country, underpinned by expert support and advice from the English screening programme.

Dr Inusa said: "The introduction of the screening programme in Nigeria was four years in the making and finally came about thanks to the hard work and dedication of a collaboration of people. The time and advice given by colleagues from the UK National Screening Committee and SCT programme has been invaluable. Counsellors in Nigeria now use the SCT handbook for parents to talk about sickle cell carrier status and diagnosis. They also use the SCT video because it is set in a Nigerian context. The literature has been a major benefit of working with the English programme. It is so relevant that we have not had to change it. We are now looking to develop and translate many of the excellent UK resources into Hausa – the main language in the north of the country."

Biomedical scientist Dr Yvonne Daniel is Dr Inusa's laboratory adviser at Guy's Hospital and a scientific adviser to the SCT programme. She has travelled to Nigeria several times to train staff in the use of the high performance liquid chromatography (HPLC) machines that provide the most reliable screening results. She has also adapted protocols to fit with local practices.

"It is important to build a network of expertise among the lab staff to ensure that protocols are followed and reliable results are produced," she said. "It's not just about the knowhow in the lab though; it's also awareness of the bigger picture and the whole screening pathway. You need to be pragmatic about what you can achieve in Nigeria but we try to mirror the English screening programme as much as possible."

Find out more at [www.score-international.org](http://www.score-international.org)

**For many years, the leading cause of blindness in people of working age was diabetic retinopathy, a disease that only affects people with diabetes. Now, for the first time in more than half a century, inherited retinal disorders have overtaken diabetes as the main cause of sight loss in the working age population.**

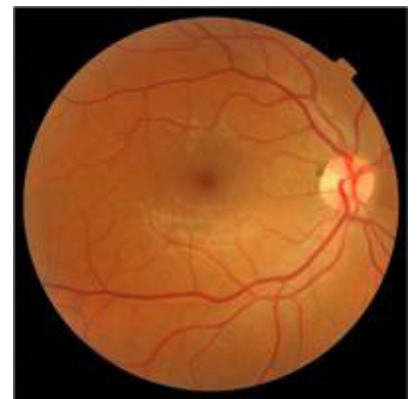
“ for the first time in more than half a century, inherited retinal disorders have overtaken diabetes as the main cause of sight loss in the working age population ”

This change, documented in research carried out by Moorfields Eye Hospital and UCL Institute of Ophthalmology and published in March 2014, is significant given the sharp rise over the past decade in the number of people with diabetes. Routine screening has contributed to this achievement by identifying disease at an early stage when treatment can prevent permanent damage.

Before the national implementation of the NHS Diabetic Eye Screening Programme (NDESP), less than half of all people with diabetes had regular eye screening. The uptake of annual screening is now around 80% but the consistent delivery of a high quality public health intervention to well over 2.5 million people is an enormous challenge.

In 2013/14, NDESP began a major project to implement a core set of activities for every person to be screened (new national common screening pathway) in order to build on its success and further reduce the number of people suffering sight loss due to diabetes. Consistent delivery of the new pathway will reduce variation in the way screening is delivered and provide reliable data that will help to drive up quality.

Simon O’Neill, Diabetes UK director of health intelligence, said: “Diabetes UK is incredibly supportive of the NHS Diabetic Eye Screening Programme. It has played an important role in ensuring diabetes-related eye problems are being picked up before they become sight threatening and enables us to look at what is happening with diabetic retinopathy at a population level.



“We had, however, been aware of issues and problems with the consistent delivery of screening related to the different software configurations that were out there. These issues have been identified and now addressed with the rollout of the new common pathway. This will ensure that local programmes all work to the same standards throughout the country and this in turn will improve the quality and consistency of screening to the benefit of all people with diabetes.”



## Preventing illness

Consultant ophthalmologist Timothy Dabbs, chairman of NDESP's programme advisory group, says the new pathway will also benefit clinicians.

He said: "Everyone agrees that more consistency has to be a good thing. What ophthalmologists want is for patients to be identified and referred at an appropriate stage – not too late but also not too early.

"The ability to put patients into digital surveillance in the new pathway is very useful from a clinician's point of view because we only want people to attend ophthalmology clinics when they need to be seen for treatment.

"The pathway will also enable better consistency and comparability between units for failsafe and quality assurance purposes. Its implementation has been hard work, but delivering and changing a national screening programme is complex. The fact that there is a diabetic eye screening programme at all is a phenomenal achievement we should be proud of, even it has brought enormous challenges."



**It is vital we clearly communicate all the potential harms and benefits of screening programmes so people can make better informed choices about their health based on accurate, unbiased and easily accessible information.**

This principle is particularly important for those programmes that carry the most serious potential risks. Evidence shows abdominal aortic aneurysm (AAA) screening should reduce preventable deaths from ruptured aneurysms among men aged 65 and over by around 50%. However, there is the small but real risk that an individual man will die or suffer serious complications following planned surgery to repair a screen-detected AAA that may never have burst if left alone.

To help men weigh up this decision, the NHS AAA Screening Programme (NAAASP) developed an interactive online patient decision aid, which launched officially in January 2014. Developed as part of the National Shared Decision Making Programme, it includes diagrams, video clips and animations and asks men to consider their screening options based not only on the evidence but also their own values. It launched after extensive collaboration with experts, clinicians and patient representatives as well as thorough piloting and evaluation.

Dr Steven Laitner, shared decision making lead commissioner at the Department of Health, said: "It is essential that everyone invited to have AAA screening understands the pros and cons of screening and, as much as possible, what they mean for them. They also need to be supported to think about how they value different screening and treatment options. They need to know they have a choice and there is no right answer. The AAA screening patient decision aid, developed by clinical, patient and shared decision making experts, guides and supports men through the process to help them make a decision that is right for them."

Around 4,000 men used the decision aid between its launch and the end of 2013/14 and Dr Margaret McCartney, a Glasgow GP who writes about evidence-based medicine, also welcomed its launch. "It is very important to ensure that citizens make properly informed choices about screening tests," she said. "Although the risk/benefit for the whole group of older men of aortic aneurysm screening is favourable, individuals must be respected and given fair information which includes comparable data on risks and harms. I'd like to see even more being done to promote informed choice, for although many people have access to the internet and are literate enough to make sense of the information, many people benefit from personal conversations around screening."

Sir David Spiegelhalter, Winton Professor of the public understanding of risk, advised on the presentation of statistics in the decision aid. He said: "The AAA screening patient decision aid is based on the principles of informed choice and does not make a specific recommendation for screening. It presents the pros and cons in a balanced way, highlighting both the 'lives saved', and the unnecessary treatments following from detecting disease that would not have caused a problem. It is quite appropriate that people should be helped to make up their own minds in this way, if they wish to do so."

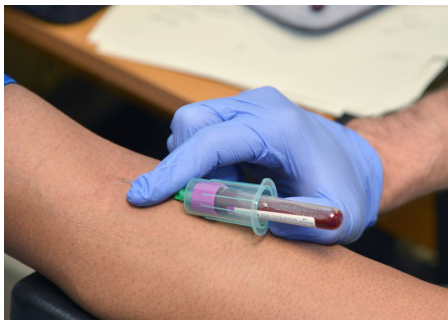
Access the decision aid at [aaa.screening.nhs.uk/decisionaid](http://aaa.screening.nhs.uk/decisionaid)

## World-leading research

**We only alter the way screening is delivered if there is robust evidence. Research must show that any change would be feasible, cost effective and deliver tangible benefits under real world conditions.**

The national programmes and UK National Screening Committee (UK NSC) evidence team collaborate closely with leading researchers when considering any innovation.

In November 2013, Great Ormond Street Hospital for Children (GOSH) initiated a major new study to investigate the possibility of offering an improved prenatal test for Down's syndrome. The RAPID (Reliable Accurate Prenatal non-Invasive Diagnosis) team, funded by the National Institute for Health Research (NIHR), in close collaboration with the UK NSC, developed a study to explore the costs and feasibility of offering non-invasive prenatal testing (NIPT) to pregnant women as part of the fetal anomaly screening programme (FASP).



NIPT detects a baby's genetic material in a sample of the mother's blood and could improve the early detection of Down's syndrome, potentially leading to 90% fewer women needing invasive tests and therefore fewer associated miscarriages. If the RAPID project's findings are favourable, it could lead to a UK NSC review and a change in screening policy.

Lead investigator Lyn Chitty, Professor of Genetics and Fetal Medicine at GOSH, said: "The study is looking at whether NIPT can improve the safety and accuracy of screening for Down's syndrome. At present, pregnant women who are shown to be at a higher risk of having a baby with Down's syndrome are offered invasive follow-up tests which carry a small risk of miscarriage. It is hoped that the introduction of NIPT will reduce the number of these invasive tests, while detecting more cases of Down's syndrome than we currently do.

"We will also develop educational materials for women and health professionals, and evaluate their views, opinions and experiences. One of the very important aspects of our study is looking at ways to ensure women understand the test and the implications of the results so that they can make an informed choice whether or not to have it."

**The early weeks and months are critical in the development of babies' communication skills. Babies born with a hearing loss have much better life chances if their condition is detected and appropriate support provided as early as possible.**



Before the introduction of the NHS Newborn Hearing Screening Programme (NHSP) in 2001, babies born with permanent moderate to profound hearing loss in both ears were typically 18 months old before diagnosis was confirmed. It would usually be another 8 months before they had hearing aids fitted. For babies born in 2012/13 NHSP had helped reduce the average age for confirmation of hearing loss to under 2 months and for hearing aid fitting to under 3 months, meaning children and their families can be offered the right support, treatments and information from the start.

Some babies born with mild hearing loss or hearing loss in only one ear may not need a hearing aid but all babies born with moderate, severe or profound hearing loss will benefit from hearing aids to help them to hear. Evidence shows that the development of speech, language and social skills are much better if such intervention is provided at a very early age. Many deaf children now acquire age appropriate language skills and have the opportunity to attend mainstream schools and reach their full potential.

Georgie Hill, a clinical scientist in audiology at the South Tees NHS Trust, sees babies who are referred for hearing assessment following their newborn hearing screening test showing possible hearing loss in one or both ears. Georgie, who has worked in audiology for nine years, said: "When I first started working in audiology, the newborn hearing screening programme had only recently started, so we were still seeing babies/children who had not been screened and had been identified late.

"The speech clarity, listening and attending skills are all much better in children identified early compared to those picked up late. Children whose hearing loss is detected early and have the appropriate interventions put in place have better speech and language and their social and emotional outcomes are also significantly better. It is also much easier for children to get used to wearing a hearing aid if it has been fitted at a very early age."

About two babies per 1,000 are born with a permanent hearing loss in one or both ears. Georgie sees about 20 such babies every year and follows them up, from initial hearing assessment, throughout their childhood. "I get a huge amount of job satisfaction because having confirmed a hearing loss there is something we can do to help," she said. "It is then quite a privilege to see a child's speech and language develop."

**Quality assurance is important to make sure that screening programmes deliver the potential benefits and also to support improvement.**

The Down's syndrome Quality Assurance Support Service (DQASS) is funded by Public Health England. DQASS works closely with the Fetal Anomaly Screening Programme (FASP) and Screening Quality Assurance (QA) to support the improvement of quality and effectiveness of screening for Down's syndrome in England. DQASS provides feedback to Down's syndrome screening laboratories on performance and also to ultrasonography units on measurements for combined screening.

By taking a QA approach to FASP, we have reduced the number of miscarriages of healthy pregnancies associated with prenatal diagnosis for Down's syndrome. DQASS has worked with FASP to review the quality of tests in the screening programme in order to improve quality and consistency in the screening programme. This has meant that we are able to give parents a more accurate risk level and reduce the number of invasive tests.

Professor Dave Wright, statistician at DQASS, said: "We estimate that the improved accuracy of the test has reduced the number of prenatal diagnosis (PND) associated miscarriages, following a high risk screening result, from 245 per year to 98 per year\*.

"The model we have developed for FASP is being adapted to other screening programmes within the NHS and has been adopted by other countries across the world including the USA, Canada, Australia, New Zealand and China."

Through the process of audit and standardisation, as well as training and feedback from professionals, DQASS has greatly impacted the understanding and engagement of health professionals working in Down's syndrome screening services and driven quality improvement.

Teresa Lardner, superintendent sonographer, explained how taking a QA approach has improved quality in her unit. She said: "In my experience, the image quality for NT [nuchal translucency] and CRL [crown rump length] (measurements needed for accurate screening in Down's syndrome screening) have greatly improved and we have also seen improvements across the board including the anomaly scan.

"The feedback from DQASS is invaluable and has been extremely helpful in improving and sustaining good performance for the sonographers in our unit."

\* This estimate is based on 70% of pregnant women opting for screening and 70% of screen positive women opting for PND, with a 1% miscarriage rate following PND.

**The success of the NHS AAA Screening Programme (NAAASP) depends crucially upon timely and effective treatment of men who have large aneurysms (5.5cm or bigger) detected by screening. NAAASP has two quality standards for timely treatment:**

- **men should be seen by a vascular specialist within 2 weeks of referral**
- **men deemed fit for intervention should be operated on within 8 weeks of referral**

These standards minimise the potential harms from screening by reducing the risk of the aneurysm bursting between diagnosis and treatment. A national audit in spring 2013 found that several local AAA screening providers were struggling to meet one or both of the timeliness standards. This was often due to delays in the local referral pathway, including waiting for CT scans and CT reports which help to determine patients' suitability for different surgery methods.

In June 2013, NAAASP and the quality assurance (QA) team therefore developed a timeliness tracker to monitor compliance with the standards. Providers not meeting the standards were asked to develop action plans to address any issues. This collaborative approach between providers, NAAASP and QA has already led to significant progress in streamlining referral processes and improving waiting times.

The Leicestershire AAA screening programme was among those highlighted as struggling to meet the referral to treatment target. The programme, together with the referral unit's anaesthetics and imaging departments, has put together an improvement plan which includes:

- employing a second vascular nurse to help monitor the standards
- establishing a weekly AAA clinic
- developing an AAA pathway for CT prioritisation and establishing a protocol to ensure men receive a CT scan within 10 days of referral
- additional training for screening nurses

Leicestershire programme manager Lucy Spence said: "Throughout 2014-2015 we will monitor and evaluate the processes we have put in place to ensure that we are meeting the timeliness standard and make any necessary changes to ensure this occurs. At the end of the year we will undertake a patient satisfaction survey to get the opinion of our patients with regards to this service. Their input into how we approach and adhere to the standards is of the utmost importance when running any service."

The Somerset and North Devon AAA programme responded to the challenge by expanding the national tracker to include predictive dates for all the events involved in hitting the treatment targets. Local programme administrator Hannah Baker said: "These dates are then shared with the whole team so everyone knows the targets from day one. This is particularly helpful when you refer to more than one centre. Even if we have to postpone a man, no-one gets lost in the system if we are all aware. This process has helped us hit our targets and, when we do not, we have a real understanding as to why they are not being achieved. Linking all points in the pathway – diagnostics, outpatients, consultants, surgeons and admin/secretarial – has led to a leaner pathway, better communication and a better experience and service for our men."

**NHS Newborn and Infant Physical Examination Programme**

Pay costs: £879,309  
Non-pay costs: £3,175,500  
Total costs: £4,054,809

**NHS Newborn Hearing Screening Programme**

Pay costs: £729,616  
Non-pay costs: £3,533,813  
Total costs: £4,263,429

**NHS Fetal Anomaly Screening Programme**

Pay costs: £528,185  
Non-pay costs: £516,851  
Total costs: £1,045,036

**NHS Abdominal Aortic Aneurysm and Diabetic Eye Screening Programmes**

Pay costs: £1,123,018  
Non-pay costs: £1,076,880  
Total costs: £2,199,898

**NHS Infectious Diseases in Pregnancy Screening Programme**

Pay costs: £104,381  
Non-pay costs: £48,061  
Programme costs: £101,000  
Total costs: £253,442

**NHS Newborn Blood Spot Screening Programme**

Pay costs: £473,458  
Non-pay costs: £138,796  
Programme costs: £481,495  
Total costs: £1,093,749

**NHS Sickle Cell and Thalassaemia Screening Programme**

Pay costs: £365,545  
Non-pay costs: £148,711  
Programme costs: £486,187  
Total costs: £1,000,443

# 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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