

NHS Newborn Blood Spot Screening Programme News

Gateway ref: 2015216

www.gov.uk/population-screening-programmes

July 2015

Expanded test success story

Professor Kevin Fenton, Director of Health and Wellbeing, Public Health England, was among the guest speakers when we celebrated the expansion of the newborn blood spot (NBS) screening programme in England.

More than 100 people attended the event to mark the inclusion in the blood spot test of four additional rare inherited metabolic diseases (IMDs):

- maple syrup urine disease (MSUD)
- isovaleric acidaemia (IVA)

- glutaric aciduria type 1 (GA1)
- homocystinuria (pyridoxine unresponsive) (HCU)

We would like to thank everyone involved in the programme rollout of the expansion for their time and expertise, including screening laboratory staff, quality assurance teams, clinicians and dietitians.

Since January, more than 10 babies suspected of having one of these additional four conditions have been referred into clinical care. Early detection, referral and treatment may make a significant difference to the

immediate and long-term health of these babies.

The free [online learning](#) module on expanded newborn screening has been completed more than 1,100 times since it was launched. A new lab handbook is now available at www.gov.uk/government/publications/newborn-blood-spot-screening-laboratory-guide-for-imds. Parent information leaflets will be available soon.

For additional supporting documents please see www.gov.uk/government/collections/newborn-blood-spot-screening-programme-supporting-publications.

Blood spot sampling guidelines under review

We have formed a small project group to review the guidelines for newborn blood spot sampling.

The guidelines, right, which were last revised in 2012, support sample takers in obtaining informed consent for blood spot screening and good quality samples.

The project group includes midwifery, neonatal, health visiting, quality assurance and laboratory representatives and its work supports the 'improving blood spot quality' initiative.

The group will consult on a revised version of the guidelines over the summer.



Update on failsafe

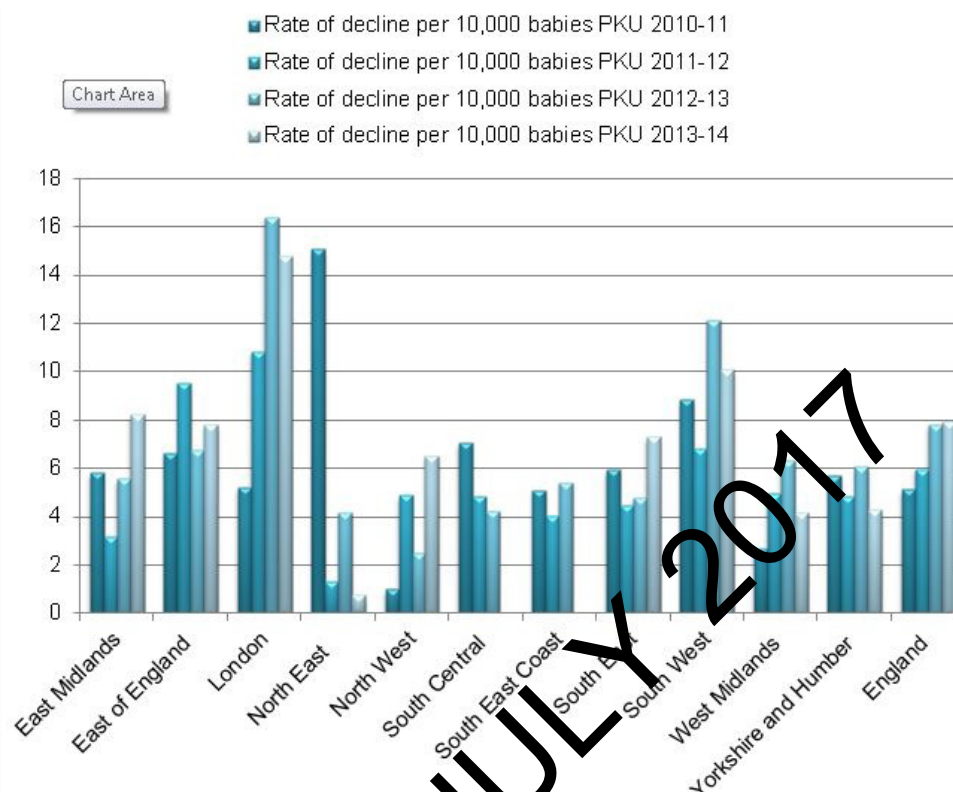
The Newborn Blood Spot Failsafe Solution (NBSFS) continues to benefit infants and families around England.

NBSFS picks up cases where infants would have been missed, or delayed, in blood spot screening.

Phase 1 of the NBSFS implementation is now complete. All newborn screening laboratories provide 'card received' data and all maternity units in England and the Isle of Man (including the Portland hospital) are established as live sites. A link to the Welsh failsafe solution is facilitating cross-border tracking of babies, and work continues to add selected paediatric hospitals to the system.

An important but challenging next step is to ensure that all laboratories can provide full screening results data with status codes/subcodes to NBSFS. This will enable the generation of some key performance indicator data.

The programme is also exploring options for potential future developments of NBSFS, including recording outcome data for babies with screen-positive referrals.



Data for the number of people declining newborn blood spot screening from 2010 to 2014

Declined tests are on the rise

The number of people declining newborn blood spot screening has been increasing since 2010, both among the 'mover in' and 'born and registered' populations.

Other European countries have identified a similar trend. The NBS programme does not know if this is due to avoidable repeat samples being requested or the way in which information about blood spot screening is communicated to parents. Less than 0.1% of parents decline newborn screening but a higher decline rate does increase the risk of a baby with a condition being missed.

Blood spot screening is recommended but not compulsory. It is important that high quality information is available to support parents in making an informed choice and that they can discuss any concerns with their health professional. If parents give a reason for declining screening, this should be recorded in the baby's and mother's notes.

The NBS programme will follow up in areas that have reported a decline rate of over 5 per 10,000 and more than five declines in total.

We will also develop some key messages for health professionals to ensure that information given to parents is consistent and of high quality.

Data report out soon

Keep an eye out for the NBS programme's latest data report covering 2013/14, which we will publish very soon.

The report will feature data on the 2013 standards for the first time.

In the meantime an interim report is available on GOV.UK.

Previous reports are available on request by contacting the [screening helpdesk](#).

Join us at RCM conference

All six antenatal and newborn screening programmes will be represented at the Royal College of Midwives annual conference this year.



If you are going to Telford International Centre on 10 to 11 November, please make sure you visit the NHS Screening Programmes stand (76-77).

You can meet the programme teams, pick up some information resources and there will

Spot of improvement

A short film to support midwives is available on the [CPD screening website](#).

In it, a community midwife discusses how she improved her practice in blood spot quality.

be a Screening Master Class at lunchtime on 11 November.

Attendees will receive a certificate of attendance for their CPD portfolio. Programme managers for the antenatal and newborn screening programmes will also be available to answer any queries.

Never warm the foot

We have been made aware of a new incident in which the heel of a baby was scalded by hot water by a community midwife taking a newborn blood spot sample.

This follows a small number of similar previous incidents when babies were scalded/burned during the warming of their heels in preparation for blood spot sampling.

The *Guidelines for Newborn Blood Spot Sampling* state: 'Ensure the baby is warm and comfortable. Additional warming of the foot is not required. There is no evidence that warming aids blood flow.'

It is important to take good quality samples but the foot should never be warmed, especially using hot water, in an attempt to achieve this.

Welcome Miguel

Miguel Heinonen has joined the NBS programme to provide maternity leave cover for data manager Tessa Morgan.

Miguel, who is from the USA, says he is looking forward to trying to understand the British sense of humour.



Laboratory data shows units can achieve national standards

Guidelines drive avoidable repeat improvements

Recent data shows that maternity units can achieve the acceptable standard for blood spot quality.

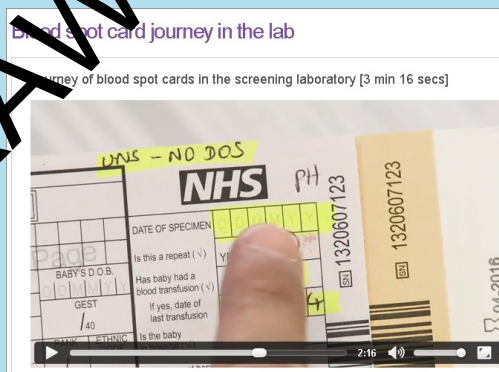
The new laboratory consensus guidelines, which were introduced in April, aim to:

- standardise acceptance and rejection criteria for blood spot samples
- drive improvements in quality
- gather accurate and comparable avoidable repeat data

At the end of April, one laboratory reported that over 40% of its maternity units had an avoidable repeat rate of 2% while the overall repeat rate was 3.3%.

Another laboratory reported a similar overall rate during April.

However, in some areas, the rate has stabilised at around 5% after an initial but significant rise. Screening and immunisation and quality assurance teams are working with maternity units to drive further



Screen shot of blood spot elearning module



improvement, and the NBS programme will continue to monitor data from the laboratories.

The next phase of the project is to review and update the Guidelines for newborn blood spot sampling to reflect the consensus guidelines and [elearning module](#) (which has been completed nearly 1,700 times).

GOV.UK screening content now live

Online screening information for health professionals is now live on GOV.UK.

The launch of population screening content on the government's digital platform was the culmination of a huge amount of work to transition our national screening websites.

Our aim is to make it easier for screening professionals, providers, commissioners and other stakeholders to find the information they need.

We have concentrated on what our users have told us they need. As a result, the GOV.UK content is much more concise and focused on those user needs than the old websites were.

We have got rid of anything that was no longer useful, updated all the information and rewritten unclear content in plain English. New cancer screening content will soon be integrated alongside the non-cancer information.

If you're not sure where to start on GOV.UK then take a couple of minutes to watch our [short video guide](#) to the new screening content.

The old non-cancer screening

Where to find what

GOV.UK: information for professionals

Screening blog: news and updates for providers, commissioners and other stakeholders

NHS Choices: information for the public

CPD site: education and training resources

Screening legacy site: evidence base and extranets

National archives: copies of the old national screening websites

websites and UK Screening Portal now redirect to the new GOV.UK content.

We have moved the UK National Screening Committee's list of screening recommendations to a [screening legacy site](#) along with the password-protected extranet sites.

And you can still access all the content we decided not to transition via copies of our old websites saved on the [national archives](#).

We are still looking at options

for the long-term home for our e-learning modules and other training information. For now they can still be found on the [CPD site](#).

We have launched a new [screening blog](#) that will replace the newsletters as the main way we keep providers and commissioners updated with screening news and developments.

Please sign up to receive all new posts from the blog which covers:

- new or updated publications
- events, conferences and consultations
- lessons learnt from incidents
- team changes, programme milestones and achievements
- anything else that does not fit on the main part of GOV.UK

The transition of our website information is a major change for everyone involved in screening but we hope you quickly find the new content to be a significant improvement.

If you cannot find the information you are looking for or find an error in any of the new sites, please let us know by contacting the [screening helpdesk](#).

Academic report praises world-leading UK NSC

A newly published academic report praises the UK National Screening Committee (UK NSC).

International comparisons of screening policy making: a systematic review shows how the UK NSC is seen worldwide as a best practice model for national population based screening programmes.

The report, by the University of Warwick, praises the UK NSC for implementing 'the most integrated and evidence-based screening programmes in the world'.

The report supported and informed an in-depth review of the UK NSC,



UK National Screening Committee

which aims to ensure all aspects of its work are based on best practice. Dr Anne Mackie, director of programmes for the UK NSC, said: "The findings reassure us that the work we do bears favourably in comparison with other screening bodies across the world."

Current consultations:

- [congenital adrenal hyperplasia](#) (closes 1 Oct)
- [glaucoma](#) (11 Sept)
- [hearing Loss \(adult\)](#) (11 Sept)

- [MPS1](#) (1 Oct)
- [neuroblastoma](#) (5 Oct)
- [oral cancer](#) (4 Sept)
- [prostate cancer](#) (4 Sept)

Upcoming consultations:

- [stomach cancer](#)
- [non invasive prenatal testing \(NIPT\) \(antenatal\)](#)
- [toxoplasmosis \(antenatal\)](#)
- [cystic fibrosis \(antenatal\)](#)
- [chicken pox \(antenatal\)](#)
- [familial hypercholesterolaemia \(children\)](#)
- [methylmalonic acidaemia and propionic acidaemia](#)
- [familial hypercholesterolaemia \(adults\)](#)