

NHS Newborn Blood Spot Screening Programme News

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newbornbloodspot.screening.nhs.uk

December 2014

Improving blood spot sample quality

Considerable effort has gone into reducing the avoidable repeat rate in many parts of the country.

However, variability in the criteria used by screening laboratories to decide if a repeat sample is needed remains a key issue.

Over the past few months the programme has been working with the laboratories to develop a national, evidence-based consensus for rejecting blood spot samples.

This will enable the generation of accurate and comparable data and drive improvements in blood spot quality. The implementation date is 1 April 2015.

In the lead-up to this, the laboratories will provide data to trusts to show the likely impact of the change on their avoidable repeat rates.

The message to sample takers remains the same – ensure that all the details are recorded on the blood spot card and that each circle is filled completely with a single drop of blood.

Samples where blood has been inappropriately applied or where the spots have been compressed will be rejected. These samples carry the risk of a serious condition being missed.

An information flyer for sample takers will be distributed in the Royal College of Midwives' magazine and via Heads of Midwifery.

An online learning module is also being developed – see page 2 for more information.

New e-learning module now available

Unit 1: The four additional disorders

NHS

Slide: 2. Overview

Overview

(Admin: Edit)

This video explains the four additional disorders. [Duration: 3 minutes 31 seconds]

NEW!



Key info on expanded screening

A free e-learning module for expanded newborn screening is now available.

The module provides information on the four additional disorders that will be part of the blood spot screening programme in England from early 2015. Learners can also review the five existing disorders.

The module is aimed primarily at health professionals taking

blood spot samples. A certificate is provided on successful completion of the whole module or when the section on the additional disorders is successfully completed.

The new module is available at newbornbloodspot.screening.nhs.uk/elearning.

We hope you enjoy working through the module and welcome any [feedback](#) you have.

Join in the consultation

In our July newsletter we updated you on progress on the review of policy on the retention, storage and use of 'residual' newborn blood spots.

These are the portions of the dried blood spots that remain after initial newborn screening tests have been completed.

The Health Departments in England, Wales and Northern Ireland plan to issue a joint consultation to gather the public's views on residual blood spots in early 2015.

If you would like to know more or be included on the distribution list for the consultation please contact us via the screening helpdesk.



More support for parents needed – lessons to be learnt

A recent incident involving the administration of heel prick tests and availability of lancets has highlighted the need for better support for parents of babies with PKU.

A baby with phenylketonuria (PKU) was promptly identified through screening and commenced treatment. Unfortunately the care that followed left the family feeling 'abandoned'.

The multiple heel prick samples needed every week during the initial few months

after diagnosis should be collected by an experienced healthcare professional for the first few weeks at least.

The PKU clinical team is responsible for ensuring parents are adequately trained to perform the heel prick on their baby so that a smooth transition can be made from the healthcare professional to the parent.

The specialists working within the clinical team are well educated in specific rare conditions and are therefore

well placed to empower parents with knowledge of their baby's metabolic condition.

This includes supporting parents with resources like lancets so that they are equipped to meet their baby's needs.

For more information about PKU clinical referral guidelines and standards, please visit newbornbloodspot.screening.nhs.uk/pku-supportingdocs.

First glimpse of new module

A free e-learning resource is being developed to support sample takers in obtaining good quality blood spots and reduce the need for unnecessary repeats.

The resource will enable practitioners to improve the quality of blood spot samples, understand why blood spot quality matters and the reasons why repeat samples are requested.

Development of the module is the result of a successful midwifery/laboratory study day in March which identified the importance of understanding how the samples are processed



Watch taster video on the [website](#)

by the laboratory and how poor quality samples can generate inaccurate results.

The module includes a video of samples being processed by a laboratory and an interview with a community midwife who has changed her practice.

A taster of some of the content is available to view now at newbornbloodspot.screening.nhs.uk/avoidable-repeats-elearning.

Barcoded blood spot envelopes

A reminder about a very important change to newborn blood spot envelopes.

The pre-printed envelopes have been updated to include a barcode to comply with new post office regulations (see www.b-spot.uk for further information).

All envelopes must be marked with the barcode from 26 January 2015 (this is a change to the original November deadline). Failure to use the new barcoded envelopes may result in the laboratories incurring a charge.

Accurate data so important

Midwives, nurses and other healthcare professionals are keenly aware that accurate record keeping is a key duty and responsibility.

What may be less well understood is what subsequently happens to data entered on to electronic systems, and the impact of errors made electronically.

Case study

The day 5 blood spot sample was collected from an infant and sent to the screening laboratory. Unfortunately the date of birth on the card did not match the date of birth held on the Newborn Blood Spot Failsafe Solution (NBSFS), which also indicated that the infant was only 4 days old and so ineligible for screening. The sample was rejected and a repeat requested, which the mother refused.

An investigation showed that the incorrect



Thank you

2014 has been a busy year for the blood spot programme. The full rollout of the failsafe solution and planning for implementation of expanded newborn blood spot screening are two of the highlights.

We would like to thank everyone who has contributed to projects over the past year and wish them a very merry Christmas and happy New Year.

date of birth had been entered onto NN4B by the midwife completing the birth notification.

The importance of correct data entry when the birth notification is being completed cannot be overstated.

In most maternity units, this data populates NN4B/PDS (Personal Demographics Service) as well as the local maternity IT system.

Amendments subsequently made on the local maternity IT system will not be updated on NN4B/PDS. Data from NN4B/PDS is used by other systems such as NBSFS, eSP (hearing screening), NIPE SMART (newborn and infant physical examination) and CHIS (child health). Therefore errors made on the initial birth notification can have a wide impact.

Amendments should be notified to the service desk of your local system supplier (NN4B/PDS) and NBSFS.helpdesk@nhs.net (NBSFS).

Blood spot failsafe rollout update

We are pleased to report that the Newborn Blood Spot Failsafe Solution (NBSFS) is very close to complete rollout across England.

All English laboratories are now providing all or some of their blood spot data to the NBSFS and nearly all maternity units are live.

Thank you to everyone who has helped ensure the success of this project.

The NBSFS recently identified several babies who had missed newborn screening before this was picked up by the child health records department.

These included a fostered infant who had

moved between two addresses, two infants admitted to paediatric hospitals on day 4, five babies whose blood samples were in a batch that did not reach the laboratory and two infants discharged from inpatient care where the mother informed the community midwife that screening had been completed in hospital but no sample reached the laboratory.

An NBSFS User Group has been formed to represent users, monitor the quality of the service and contribute to its development.

Details can be found at newbornbloodspot.screening.nhs.uk/failsafe. Any queries can be sent to julie.wilcox2@nhs.net.

Annual data collection

We are pleased to announce that our latest data report covering 2012/13 has been published.

This is the ninth such report published by the programme. The data report is available at newbornbloodspot.screening.nhs.uk/reports (previous reports are available upon request – please contact phe.screeninghelpdesk@nhs.net).

2013/2014 data recently submitted to the programme highlights the importance of taking good quality blood spot samples.

A total of eight babies with suspected congenital hypothyroidism had delayed entry into clinical care due to insufficient or unsuitable first samples. Reasons for the requested repeats included contamination, insufficient blood and no NHS number on the card.

It is imperative that babies with suspected positive results are referred into care as soon as possible and poor quality blood spots may lead to a delay in treatment.



Final UK NSC meeting of the year

The UK National Screening Committee (UK NSC) met for the final time in 2014 on 25 November and reviewed the recommendations on screening for Gaucher disease, dementia, preterm labour and bacterial vaginosis.

Its recommendations will be published in January 2015.

Current policy consultations:

- **Depression** (closes 26 December)
- **Sudden cardiac death** (closes 1 February)
- **Galactosaemia** (closes 19 February)
- **Fatty-acid oxidation disorders**



UK National Screening Committee

(closes 23 February)

- **Amino acid metabolism disorders** (closes 23 February)
- **Bladder cancer** (closes 28 February)

Consultations due to start soon:

- **Hearing loss in adults**
- **Psychiatric illness in pregnancy**

New Screening Tests For You and Your Baby launched

Booklet revamped

The UK NSC has launched a new version of the national **Screening Tests For You and Your Baby** booklet for parents.

The updated booklet contains detailed information on all the screening tests offered during pregnancy and after the birth of a child.

This includes the four new screening tests for rare conditions that will be rolled out across England early in 2015 as part of the newborn bloodspot

screening programme.

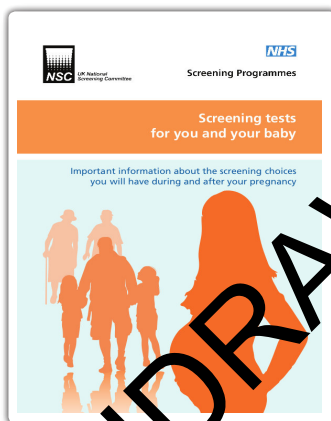
A key element of the booklet is to promote the concept of screening as an informed choice.

For the first time, the booklet includes explicit recognition that some screening choices are easier than others. Some tests are recommended because the information gained may enable important treatment to be given promptly for mother and baby.

Others require people to think more deeply about whether they want to know the information that a screening test may give them.

There will be some small changes made to the current booklet in the next print run from January. The possible options available for blood spot screening will be explained more clearly should parents only want to choose screening for certain conditions. The photographs of the hearing screening test will also be updated.

Leaflets can be ordered by emailing RebeccaO@harlowprinting.co.uk or phoning 0191 4969735. Trusts should stop using the old booklet (version with blue and white cover) and recycle any remaining copies.



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Other news in brief

Website transition

The transition of the content of the NHS Screening websites to NHS Choices (public information) and GOV.UK (professional information) has continued with diabetic eye screening information for the public now live on NHS Choices at www.nhs.uk/diabeticseye.

The transition of screening online content is due to be completed early in 2015. If you experience any problems during this time, please email the helpdesk at phe.screeninghelpdesk@nhs.net.

Commons committee

In October, the **Science and Technology Committee's report on health screening** was published which the UK NSC contributed to earlier this year. A number of recommendations were made which the UK NSC is discussing with the Department of Health before contributing to a formal response to the committee in due course.

New helpdesk number

The UK NSC Screening Helpdesk contact number has changed to 020 3682 0890.

National teams have moved

The national antenatal and newborn screening programme teams have moved to a new office in London. The new address is: Public Health England, Zone B Floor 2, Skipton House, 80 London Road, London, SE1 6LH.

Christmas leaflet ordering

Harlow Printing will be closed from Tuesday 23 December until Monday 5 January. If screening services have any queries regarding leaflet orders or stock of current leaflets, please contact Harlow on 0191 4969735 before this time.