

Screening Matters

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@PHE_screening

www.screening.nhs.uk

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Successful blood spot expansion

Dr Anne Mackie

Dr Mackie is the UK National Screening Committee Director of Programmes



n excellent start to 2015 has seen the launch of the newborn blood spot extension.

From 5 January 2015 all parents of newborn babies have been offered screening for four more inherited metabolic diseases (IMD).

This extension has been based on evidence gathered through an innovative partnership between English screening programmes, the UK National Screening Committee (UK NSC) and the National Institute for Health Research (NIHR), headed by Professor Jim Bonham at Sheffield Children's Hospital.

An enthusiastic media picked up the story through interviews with screening experts and families affected by one of these diseases.

The BBC online article can be found here.

PHE is currently looking at how to take forward efficiencies in its internal structures.



In the news: Baby Hattie, screened and diagnosed with an IMD

This has provided the opportunity to explore a joint screening team combining the expertise of cancer and non-cancer programmes and QA teams, which is potentially a very exciting prospect.

This quarter, the UK NSC published its recommendations on dementia.

It has been very gratifying that the joint work we undertook with academics, the NHS, clinical and user stakeholders has meant that the debate has been well informed and focussed on improving treatments and prevention.

Further information can be found on the Alzheimer's Society website.

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Website transitions

The major overhaul of the national screening websites continues with the newborn screening public information now live on NHS Choices.

The new pages include newborn blood spot test, blood spot FAQs, blood spot cards, newborn hearing screening and the newborn physical examination.

Antenatal screening information will also move to NHS Choices soon.

All the national screening sites – the UK Screening Portal, CPD site and eight non-cancer programmes – will eventually be closed down.

Our e-learning modules will also be moving to a new home in due course.

And content for professionals is on track to be launched on *GOV.UK* by April. Examples of sickle cell and thalassaemia screening programme *outreach resources* have already been published on GOV.UK – see page 6 for more details.

We aim for minimal disruption during the website transitions. If you find anything wrong, please accept our apologies and email us at phe. screeninghelpdesk@nhs.net.



Preterm test not supported

he UK NSC has recommended against the introduction of screening for preterm labour (babies born prematurely).

Each year in the UK, more than 7% of babies are born prematurely. Preterm babies are at risk of short and long-term health issues, the severity often linked to how early the baby is born.

The UK NSC reviewed the evidence for screening to identify women at risk.

A number of concerns were raised over the potential test, including its timing, the measurement for identifying risk and the treatment.

In particular, the UK NSC found that:

- the measurement of cervical length in asymptomatic women is not reliable enough for use as a screening tool
- it is not known when the test should be offered or whether it is reliable in identifying which pregnancies are at risk or not, leading to unnecessary preventative treatment
- there is not enough evidence to be sure that vaginal progesterone (a hormone treatment) is an effective treatment for preventing preterm labour or that it

Evidence Reviews

Current

- Bladder cancer (closes 28/02/2015)
- Fragile X (closes 05/05/2015)

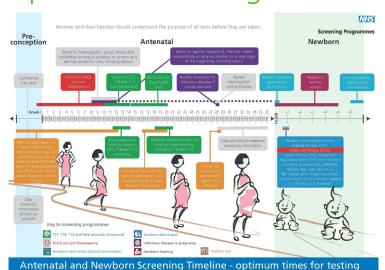
Coming up

- Psychiatric illness in pregnancy
- Hepatitis C in pregnancy
- Varicella (chicken pox) susceptibility in pregnancy
- Toxoplasmosis in pregnancy
- Hurlers in newborn
- Neuroblastoma in children
- Oral cancer in adults
- Stomach cancer in adults
- Familial Hypercholesterolaemia in adults
- Hearing loss in adults
- Prostate cancer in adults

reduces the most severe outcomes (death or disability) for the baby

The UK NSC will review the evidence for screening of preterm labour in around 3 years or sooner, if more compelling evidence is published in the meantime.

Updated screening timeline published



An updated version of the antenatal and newborn screening timeline (left) has been published.

Changes to the previous version include:

- additional blood spot information to include the new conditions covered by screening
- revised fetal anomaly text to include first trimester screening for T18 and T13 syndromes
- reoffer of infectious diseases screening at 28 weeks

February 2015

Helpdesk supporting YPA programmes

The screening helpdesk will start supporting the young person and adult (YPA) screening programmes from 1 April, in addition to the support it already provides for the six antenatal and newborn programmes.

From 1 April, enquiries to the abdominal aortic aneurysm and diabetic eye screening national programme teams should be directed to the helpdesk. More details will be sent directly to local AAA and diabetic eye screening programmes beforehand.

We are developing the helpdesk reporting processes and hope to start publishing stats in forthcoming issues of Screening Matters.

Contact us!

phe.screeninghelpdesk@nhs.net
Telephone: 020 3682 0890

We are pleased to announce that Linda Harrison is now back on board after being away for a short while. We would also like to welcome Marcia Jackson who has been appointed on a half-time basis to provide additional helpdesk support.

The helpdesk moved location in November 2014. Please note the new contact number details above.

QA highlights image storage

he national quality assurance team continues to carry out quarterly analysis of all screening safety incidents reported.

There were 170 screening incidents reported in non-cancer screening between July and September 2014 and 5% of these incidents were classed as serious.

The following summary highlights learning points from four separate incidents that were reported in the abdominal aortic aneurysm (AAA) screening programme.

Background

The national AAA IT system (SMaRT) was enhanced recently with the implementation of a national image storage solution for QA purposes.

This now enables the ultrasound images that are captured in screening clinics to be uploaded from the ultrasound machines to SMaRT so that a permanent record exists for quality assurance purposes. The solution also includes failsafe processes to identify screening tests with no associated images.

The successful upload of ultrasound images in SMaRT requires the screener to have the correct patient record open at the time of scanning.

If an image is recorded on an ultrasound machine against the wrong man then NAAASP's IT supplier can assist in reassigning the image to the correct person in SMaRT.

However, if the local screening provider is unsure of the identity of an image recorded on a machine then they should recall the man for screening. This is both inconvenient and reduces confidence in the screening service.

What happened?

Automatic failsafe processes within SMaRT identified screened men with missing images. This occurred in cases where both single and multiple staff were involved in the process.

It is important to note that the implementation of the national image storage solution has made it much easier to pick up this sort of incident.

Learning points

Programmes should make sure that protocols for checking the identity of men being screened are used at every stage. Open records should be closed promptly when men leave the screening clinic.

If in doubt about whether or not to report an incident in any of the non-cancer screening programmes, please discuss with your regional QA team who will be able to advise you appropriately.

Changes to e-learning

Our e-learning modules will start moving to the new Health Education England (HEE) platform this year.

This platform will replace the e-Learning for Healthcare site, be easier to use and quicker to register on.

The transition will provide an opportunity to introduce new interactive elements to make learning more enjoyable and memorable.

In the meantime we have moved all our e-learning modules to the screening *CPD website* so they are easier to find while the national programme sites are closed down over the next few months.

The HEE platform will require users to register with an NHS email address, so we have also updated our modules to require new registrants to have an ac.uk, nhs.net or nhs.uk address.

NN4B closure

The NN4B service for issuing NHS numbers to newborn babies has now shut down and users must have migrated to the Birth Notification Application (BNA).

Any queries should be emailed to nn4bmigration@hscic. gov.uk.



Publication is proud moment after nearly five years' work

PHOF includes screening data

or the first time national data on access to non-cancer screening programmes has been included in the public health outcomes framework (PHOF) publication.

It is a proud moment for all of us as it represents the culmination of almost five years' work.

Much work has been done by national programmes, regional teams, QA teams, external partners and consultants in defining, implementing and improving data quality of screening key performance indicators (KPIs) and, more importantly, improving the quality of screening services.

KPIs are now embedded into screening service specifications.

The February update of the PHOF included data on three indicators reported by local authority: newborn hearing screening coverage, newborn

blood spot screening coverage and abdominal aortic aneurysm completeness of offer.

It also included two indicators reported by sub-region: antenatal sickle cell and thalassaemia screening and antenatal HIV screening coverage.

First quarter KPI data for 2014-15 on UK Screening Portal

KPI data for the NHS Screening Programmes covering the first quarter of 2014/15 has been published.

The data is available on the screening portal. Highlights include:

- first quarter in which child health record departments provided NB1 and NB3 data by clinical commissioning groups (CCGs)
- HIV coverage completeness (ID1) increased by nearly 3% nationally
- all trusts in England submitted data for the timeliness of referral for Hepatitis B positive women (ID2)
- performance for the ID2 indicator

increased by 1.5 percentage points, and was reported to be 69.2%, just below the acceptable level of 70%

 this is the first quarter in which the abdominal aortic aneurysm

 completeness of offer indicator
 (AA1) data has been published.

 This is an annual KPI and quarterly figures will be aggregated from Q1 to Q4.

Thank you Rebecca

KPI data analyst Rebecca Halliwell has left screening and PHE.

We would like to thank Rebecca very much for her contribution to the KPI work. She has been a great help from the very beginning of the KPI development.

Her public health experience, knowledge and dedication was valued by everyone in the team. We wish her all the best in her new role.

The email for KPI submissions is: phe.screeningdata@nhs.net

Events, meetings and conferences

5 March:

NHS AAA Screening Programme Clinical Skills Information Day, National Motorcycle Museum, Birmingham; NHS SCT Screening Programme Advisory Group, London

11-13 March:

Diabetes UK Professional Conference, Excel, London. NHS Diabetic Eye Screening Programme exhibiting as part of 4 nations stand and presenting in diabetic eye screening session on 11 March

12 March:

NHS Newborn Hearing Screening Annual

Conference, The Kia Oval, Surrey County Cricket Club, Kennington, London; Newborn Blood Spot CF Screening Advisory Board, London

9 April:

NHS AAA Screening Programme best practice event, National Motorcycle Museum, Birmingham

24 April:

National Diabetic Eye Screening Conference, Royal Society of Medicine (RSM), London

28-30 April:

Royal College of Paediatrics & Child Health (RCPCH) Conference, Birmingham

NHS Fetal Anomaly Screening Programme

FASP National Conference

The FASP National Conference takes place at the KIA Oval in London on Friday 20 March and is an opportunity for all health professionals involved in the FASP pathway to gain an insight into the programme's current priorities.

Expert speakers will provide the latest information, data and reports on policy, standards and screening pathway changes.

There will be opportunities to discuss the use of non-invasive prenatal testing (NIPT) in screening for Down's, Edwards' and Patau's syndromes.

Professor Lyn Chitty will present on the progress of the current NIPT research trial and Dr Anne Mackie will be discussing the start of the UK NSC policy review.

Full programme and booking details are available at www.phe-events.org.uk/fasp2015

Implementing changes

The publication of the 2015-16 FASP service specifications included the implementation of:

- screening for Edwards' and Patau's syndromes (T18/13) in the first trimester as part of the first trimester combined screening strategy
- the use of the quadruple test for women with twin pregnancies

Screening pathways, public information and educational resources are currently under development.

A laboratory handbook is being produced and the current manual for sonographers will be updated and re-issued as the Ultrasound Practitioner's Handbook.

The national programme, Down's syndrome quality assurance support service (DQASS) and software suppliers continue to work to ensure that risk calculation software supports additional reporting requirments. All

documentation will be released by the end of March 2015.

Cardiac protocol of the mid-pregnancy scan

The service specification for the 18+0 - 20+6 week scan includes the requirement to view and report the 3 vessel and trachea view.

FASP has not introduced a requirement to archive images of any of the fetal heart views as part of this current review.

Work is ongoing nationally to update the FASP/FMF echocardiography resource and to develop a new interactive resource to support the rollout of this protocol change. FASP will also be coordinating training for sonographers using a cascade approach to support implementation.

The timeframe for implementation is April 2015 to December 2016.

NHS Infectious Diseases in Pregnancy Screening Programme

Revised service specification

The IDPS service specification for 2015/16 has been published for use by commissioners and service providers.

Some of the changes include:

- screen positive women should be seen by an appropriate specialist midwife within 10 working days of the result
- non-attendance at the specialist appointment should be reviewed within a multidisciplinary framework and an action plan developed
- coordinated care for women who undertake screening and subsequently miscarry

Positive screening standards

The IDPS Programme is convening a series of regional workshops across England to provide an opportunity for healthcare professionals involved with the screening and subsequent management of screen positive

women and their babies to review and input into the current revision of the national screening standards.

The recent workshops were very successful and a synopsis report will be produced.

For further information visit infectious diseases. screening.nhs.uk/regional consultation workshops 2015

New leaflets for screen positive women

We are developing new patient leaflets to support the counselling of women who screen positive with syphilis or hepatitis B in pregnancy.

They are currently being reviewed by user focus groups and will then be distributed to all screening coordinators for final comments before being finalised and uploaded online.

Hep B in pregnancy national audit update

The notification system is still open for submission of data on women booking in 2014 – please notify the team of any outstanding cases ASAP, and by the end of February 2015.

When your trust's notifications are complete for 2014, or if you did not have any eligible cases at your trust last year, please send an email to phe. hepbaudit@nhs.net

The audit team will soon request brief information on referral status of women notified and outcome information for high and low risk pregnancies.

If you have any problems contact Heather Bailey **phe.hepbaudit@nhs.net** or call 020 7905 2396.

For further information visit infectious diseases. screening.nhs.uk/hepbaudit

IDPS Newsletter

The January edition of the IDPS newsletter is available at infectious diseases. screening.nhs. uk/newsletters



NHS Sickle Cell and Thalassaemia Screening Programme

Raising public awareness

The SCT programme has published new resources as part of the strategy to improve public understanding of sickle cell disease, thalassaemia and genetic screening.

Education and outreach have been important for the SCT programme because it was the first national genetic screening programme in the NHS. There has been widespread ignorance and stigma around the conditions, which mainly affect people from black and minority populations.

Outreach resources on GOV.UK

Examples of SCT programme resources used in outreach have been published on GOV.UK along with a good practice guide for people who commission, fund, deliver and evaluate outreach programmes, an overview of the work delivered since 2005 and the research underpinning it.

These resources capture the learning from 10 years of outreach work. And there is a detailed guide that explains the learning and includes



Case study

Sickle cell and thalassaemia screening: overview of community outreach

video clips from public events and interviews with service users and people who delivered the outreach.

GCSE science resources

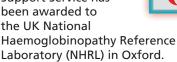
Lesson resources supporting the GCSE curriculum have been published on the **Engaging science website**.

They use sickle cell and thalassaemia as models to explain genetic inheritance to students and highlight wider ethical and practical issues for individuals and society.

There are two lessons: one for sickle cell, the other for thalassaemia. In each, the student is given a dilemma and source materials to explore the issues. The materials include film and audience clips, factsheets and web links.

SCT lab service

The contract for the SCT Laboratory Support Service has been awarded to the UK National



NHRL will provide a dedicated support service for antenatal and newborn haemoglobinopathy screening laboratories in England.

Objectives include:

- telephone and email support
- liasion with programme centre, including two meetings per year
- participation in twice yearly workshops
- supporting newborn and antenatal enquiries in line with national programme policy and standards

Tel: 01865 572 767

Secure fax: 01865 572 775

Secure email: lab.support@nhs.net

NHS Newborn Blood Spot Screening Programme

Failsafe solution a success

The Newborn Blood Spot Failsafe Solution (NBSFS) is now fully implemented across all English providers of maternity services.

Every baby born in England now benefits from the NBSFS and there is also a link with the Welsh NBS failsafe system.

All screening laboratories in England are providing 'card received' data with some also sending screening results to the NBSFS.

Maternity units are also receiving weekly reports which capture site activity.

The NBSFS continues to identify infants who would have been missed or delayed in screening. For example, there were three cases recently where discharge summaries had not been received by the maternity unit.

Blood spot quality e-learning

The NBS 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.

A free e-learning module to support sample takers in improving blood spot quality is now available. The module will enable sample takers to understand:

- why blood spot quality matters
- the principal reasons why repeat samples are requested
- how to take good quality blood spot samples

The module is intended to support local initiatives to reduce avoidable repeat rates and screening laboratories to standardise sample rejection.

A printable certificate is provided on successful completion of the whole module. The new module is available at: newbornbloodspot.screening.nhs. uk/training.

Expanded screening launch success



In January the NBS programme celebrated the rollout of expanded newborn blood spot screening with a launch event to commend all those involved in the pilot and implementation process.

UK NSC Director of Programmes Dr Anne Mackie thanked Professor Jim Bonham of Sheffield Children's Hospital for driving the pilot.

Professor Kevin Fenton, Director of Health and Wellbeing at PHE, thanked everyone for making this a very proud moment for Public Health England.

The programme's work on expanded screening will continue as parent information leaflets are reviewed and updated.

Supporting documents for all inherited metabolic conditions are available on the NBS website.

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NHS Newborn and Infant Physical Examination Programme

2008 standards reviewed

Newborn and Infant Physical Examination Programme (NIPE) 2008 standards are currently being reviewed.

The aim is to review and produce standards in line with the new UKNSC processes, ensuring that standards are measurable. They will be accompanied by clinical guidance so will be in a slightly different format to the current standards.

The NIPE team will be taking the view of the NIPE Advisory Board in the development of the standards and it is hoped that they will be ready for wider consultation later in the year.

Rollout update

More than 50% of trusts across the country are now live or working closely with NIPE implementation leads to implement the nationally commissioned NIPE SMART (Screening Management and Reporting Tool) IT system.

NIPE SMART provides a route for accurate data capture of the screening

pathway, provides key performance indicator (KPI) data and, importantly, ensures maternity trusts have robust screening failsafe processes in place.

The programme is in the early stages of discussions with maternity system suppliers to look at the feasibility of data-sharing technology.

If an interface solution is developed it will still require NIPE SMART to be in place, so providers are encouraged to contact NIPE Programme Manager Jill Walker jillwalker1@nhs.net to discuss interoperability issues or express interest in implementing NIPE SMART by emailing the screening helpdesk at PHE.screeninghelpdesk@nhs.net

Pulse oximetry

The pulse oximetry pilot is progressing well and Phase 1 data collection is due to start soon.

The aim of the newborn pulse oximetry screening pilot is to evaluate the impact of implementing newborn pulse oximetry screening on NHS services and to establish feasibility for future national rollout as an addition

to the existing suite of screening tests undertaken as part of the newborn NIPE examination (<72 hrs).



Considerable work has been undertaken over the past few months in the development of the pilot methodology and a suite of documents to support the project.

Newborn pulse oximetry screening pilot project lead, Claire Evans has been working closely with NIPE programme manager Jill Walker, clinical experts and the wider pilot project board.

The programme has now recruited 15 trusts as part of the pilot and Claire and Jill have recently been meeting clinicians who will be leading the pilot at local level.

The pilot project board (chaired by Dr Anne Mackie) continues to meet regularly to oversee the project.

Further details will be posted on the pulse oximetry pilot webpage.

NHS Newborn Hearing Screening Programme

National conference

The NHSP national conference will take place on 12 March 2015 at the Kia Oval, London.

It will bring together NHSP local managers and team leaders, audiologists, screening managers/ coordinators, hearing screeners, practitioners, commissioners, clinicians and quality assurance teams for an update on practice and research developments in relation to the hearing screening care pathway.

Planned topics and updates will include the screen referral rates audit project, performance data and the new NHSP IT system platform

To book your place visit www.phe-events.org.uk/nhsp15

NHSP site restructures

The NHSP programme has recently produced a guidance document to support providers and commissioners considering or planning a change to NHSP service provision.

Further guidance can be found at hearing.screening.nhs.uk/operationalguidance.

This was in direct response to an increasing number of queries from sites affected by change.

It is essential, where a service reconfiguration is being planned, that Appendix 2 of the document is completed and submitted to allow the changes to be made to the national NHSP IT system. These changes take at least 9 weeks to make which is why it is so important to complete.

Some sites are looking to train maternity support workers to undertake the hearing screen.

It is essential that anybody who performs the hearing screen completes all training as specified by the national programme.

Update from Northgate

Northgate is working with the national screening programme team to develop a new IT application to support newborn hearing screening to

replace the existing eSP application.

The new application is being developed in a modular way that will give the programme a platform that will more readily support future flexibility and allow us to introduce new changes more quickly.

Development is already well under way and the programme team has been fully involved in the design process.

We have included rigorous testing in our plans to minimise potential risk to the screening programme with phased testing of the application planned to run from March 2015.

Together with the NHSP programme team, current members of the NHSP User Group have indicated their willingness to participate in the testing of the new system and a schedule of dates has been arranged.

Northgate plans to demonstrate some of the features of the new system at the NHSP Conference in March.



NHS Diabetic Eye Screening Programme

Common pathway implementation

More than 150 delegates attended a post-implementation common pathway event at Kingsholm, in January.

Local programme staff, software suppliers, regional QA staff and the national team shared good practice and discussed what went well and not so well during implementation.

Feedback from the workshop was positive with 71% of respondents rating the event good or very good. NDESP will use the detailed feedback to inform future national projects and meetings.

National programme manager Lynne Lacey said: "The national implementation of the new common pathway has been a challenging and complex task and I would like to thank all national and local programme colleagues for their hard work and support.

"The new pathway will lead to better consistency and comparability between services, more reliable and accurate data and improved patient safety."

National Diabetic Eye Screening Conference

The second joint national diabetic eye screening conference will be held at the Royal Society of Medicine (RSM), London, on Friday 24 April.

The joint meeting between NDESP and RSM's ophthalmology section will be of interest to all those involved in diabetic eye screening, including local programme managers and clinical leads, screeners, graders, GPs, diabetologists, paediatricians, ophthalmologists, public health professionals and commissioners.

For more details or to book your place, please visit the RSM website or email ophthalmology@rsm.ac.uk

Diabetes UK Professional Conference 2015

NDESP will share an exhibition stand with the national retinal screening programmes from the other UK nations and the Republic of Ireland at this year's Diabetes UK Professional Conference, which is being held at the Excel in London on 11-13 March.

The programme on the first day

of the conference includes a slot entitled *UK retinopathy* screening: the state of the nations, hosted by Simon O'Neill, Diabetes UK's director of health intelligence.



This will include contributions from the four UK nations and conclude with a panel discussion.

New patient leaflet

Local diabetic eye screening programmes can now order free supplies of two new national patient leaflets and an information sheet for primary care professionals.

The new leaflets, Your guide to diabetic retinopathy and Closer monitoring and treatment for diabetic retinopathy, are for patients who have positive screening results.

The information sheet gives GPs and other primary care professionals a summary of how the screening programme works and the importance of their role in raising awareness of the screening programme among their patients.

NHS Abdominal Aortic Aneurysm Screening Programme

Inspirational research

Around 120 delegates attended a highly successful AAA research and audit event hosted by NAAASP in Manchester on 9 February. The meeting included several examples of local programme audit that highlighted the link between social deprivation, higher incidence of disease and lower uptake of screening.

The event culminated in a presentation from Swedish professors of surgery Anders Wanhainen and Martin Björck. They explained how Sweden's AAA screening programme had been inspired by the English experience. As in the UK, the prevalence of aneurysms in older men has been declining in Sweden in recent years while smoking, high blood pressure and family history are consistent risk factors for the disease in both countries.

Presentations from the meeting can be downloaded from the **event web page**.

Clinical skills day

NAAASP will be holding its first national clinical skills Information day on 5 March 2015 at the National Motorcycle Museum, Birmingham. The day is open to AAA screening technicians and clinical skills trainers (CSTs) only and will be an opportunity to update knowledge as well as to network with clinical colleagues.

Places are available for one CST and two screening technicians per programme. Anyone wishing to attend should speak to their local programme co-ordinator who has details of how to register.

British Heart Foundation endorsement

The British Heart Foundation (BHF) has created a **new web page** to help raise awareness of abdominal aortic aneurysms and the national screening programme. Future print runs of NAAASP's patient information leaflets

will signpost to the BHF as well as the Circulation Foundation.

ion.

Image storage

NAAASP's national image storage IT solution has been rolled out in 40 of the 41 local AAA screening programmes in England. The remaining programme is currently testing the system, which stores the images captured during screening for quality assurance purposes.

Networking and sharing best practice event

NAAASP is holding a networking and sharing best practice event at the National Motorcycle Museum, Birmingham, on 14 May for local programmes, QA teams and commissioners. Details of how to register for the event will be circulated to teams in due course.