NHS Fetal Anomaly Screening Programme News

Gateway number 2014085

fetalanomaly.screening.nhs.uk

May 2014

Consultation on T18 and T13

The UK National Screening Committee (UK NSC) is currently consulting on whether the fetal anomaly programme should offer screening earlier for Trisomy 18 (Edward's syndrome) and Trisomy 13 (Patau's syndrome).

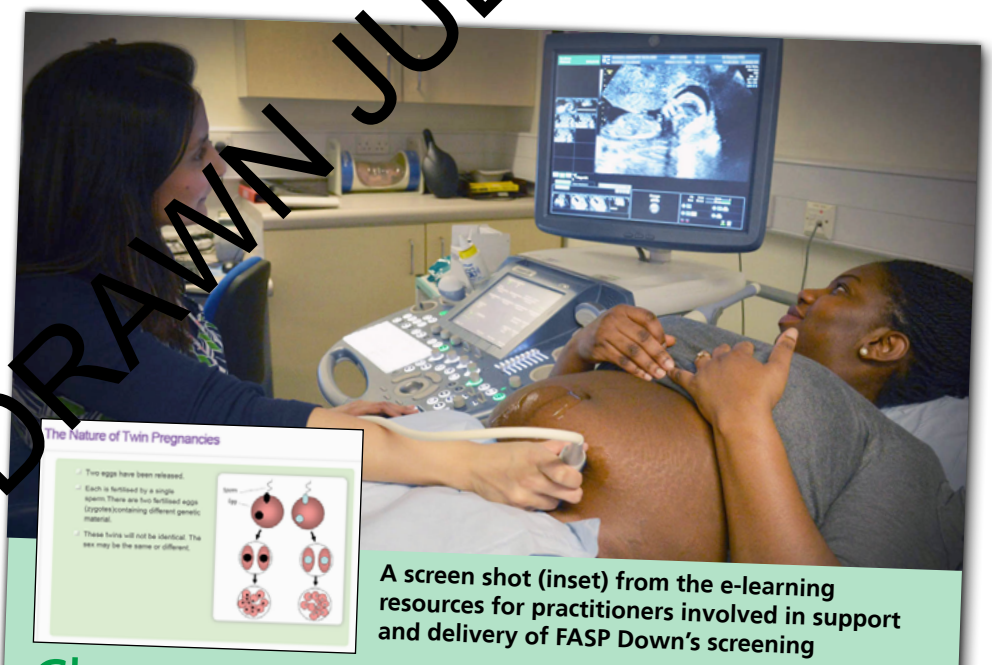
The UK NSC has not previously reviewed the evidence for Edward's Syndrome and Patau's Syndrome but there is now enough evidence for a formal review.

The current policy is to offer screening for Edward's Syndrome and Patau's Syndrome as part of the 18^{+0} to 20^{+6} week fetal anomaly scan in the second trimester of pregnancy.

The review is considering screening for T18 and T13 through a blood test and an ultrasound scan as part of the current 'combined' test for Down's syndrome in the first trimester.

First trimester screening would facilitate earlier diagnosis, enabling affected women to make decisions about their pregnancies at an earlier stage.

The **consultation** runs until 16 June and submissions are welcomed from all interested parties. The UK NSC will make a policy recommendation following the consultation.



A screen shot (inset) from the e-learning resources for practitioners involved in support and delivery of FASP Down's screening

Changes to e-learning resources

The Condensed Education Module for T21 screening (CEMT21) and the Nuchal Translucency (NT) e-learning modules have been updated on the **FASP website**.

This is the first stage in a project to redevelop all the e-learning resources for screening professionals.

On completion of the CEMT21 and NT modules, users can generate a certificate as evidence of their learning. Staff managing training locally can access a report of numbers completed in their organisation.

To support these enhancements registration is now required:

- Go to the **training page** of the FASP website
- Click on the REGISTER button
- Enter your details and the characters from the security image that appears
- You will be sent a confirmation email with a link to access the resources. If you don't receive it, contact the **screening helpdesk**

Feedback on DQASS

A multi-disciplinary workshop was held to review the outputs from the Down's Syndrome Screening Quality Assurance Support Service (DQASS) following the transition into Public Health England.

DQASS is the statistical support service for Down's syndrome screening laboratories.

Workshop participants included biochemists, sonographers, fetal medicine specialists and regional quality assurance teams.

Participants were asked for their ideas to ensure the laboratory and sonography reports produced by DQASS are fit for purpose in the new commissioning landscape.

The outputs from the workshop have been collated and we have identified a number of areas where changes are warranted.

We will share a report of the workshop with participants in the near future.

The next stage will be to make changes to the reporting process and letters produced.

These changes will be trialled with a small group before being implemented later this year.

Thank you to everyone who has taken part in this valuable exercise.

Updating info for key audiences

The national fetal anomaly screening programme (FASP) team has been reviewing the public and professional information provided by the programme.

You may already have noticed some streamlining of the FASP website content. This process will continue as we aim to make it much easier for public and professionals to find the information they need.

In addition, a project group was set up specifically to review the information provided for women and professionals about the first trimester scan and, in preparation for policy changes, to look at information on T18 and T13 and quadruple screening for twins in the second trimester.

Chaired by Professor Jenny Hewison, the group is updating the tear-off pad for mid-pregnancy scan (new copies will be available soon). It has also prepared updated information for the Screening Tests For Your and Your Baby about T18 and T13 and professional information on quadruple screening for twins in the second trimester.

More details about these resources will be made available in the coming months.

Standards are up for review

The NHS non-cancer screening programmes are aiming to develop a uniform process for the production of consistent and measurable standards for screening.

FASP is currently reviewing both the 2007 Antenatal Working Standards for Down's syndrome screening and the 2010 National Guidance and Standards for the 12^{+0}-20^{+6} week mid pregnancy scan.

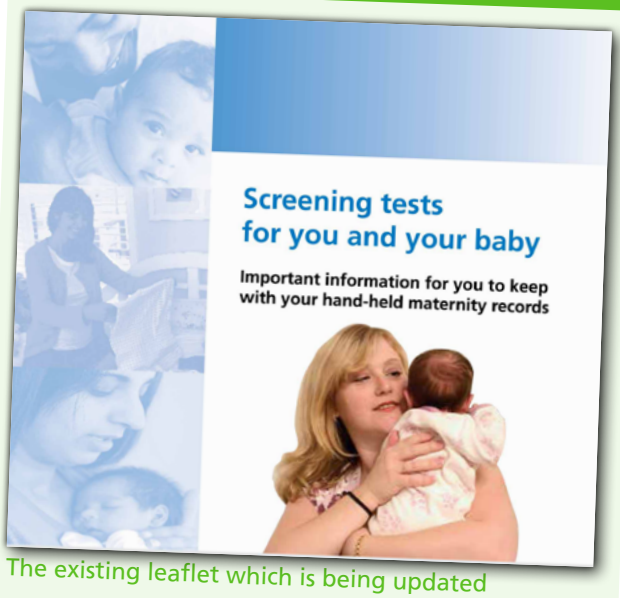
All work undertaken by expert groups prior to the transition of the programme into Public Health England in April 2013 will inform these reviews.

The current standards will continue to apply while the review process is being agreed.

The current standards should be used in conjunction with the revised Fetal Anomaly and Down's syndrome screening **service specifications** (2014/15) to inform local service provision.

The national team will notify stakeholders when revised standards are ready for consultation, publication and implementation.

Revised booklet for mums is on its way



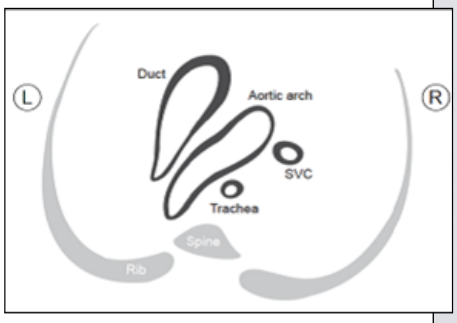
The existing leaflet which is being updated

The review of the Screening Tests for You and Your Baby booklet for pregnant women is nearly complete.

Public focus groups provided valuable insight into how the existing booklet could be improved and draft new designs were well received.

The revised text, explaining all the antenatal and newborn screening tests, is being checked for consistency and the new and improved booklet should be ready for printing this summer.

Training needs in the spotlight



Above: The 3VT view, showing the aortic arch, ductal arch and trachea, taken from Fi Maddocks' Fetal Cardiac Screening Protocol 2013 presentation at FASP's 2013 SSS conference event

All screening support sonographers (SSSs) have been asked to complete an online survey to help ensure that proposed changes to the fetal cardiac protocol are implemented effectively.

The deadline for completion of the survey is 30 May.

The proposed revised standards will involve the three vessels trachea (3VT) view being examined and four cardiac images archived with the overall aim of improving fetal cardiac anomaly detection.

The online training needs analysis survey will help identify the education and training requirements of key staff who are directly involved in the delivery of this element of the fetal anomaly programme and the current image storage practices and facilities.

Analysis of data from the survey will help determine the final content of the revised standards which are due to be agreed in the autumn. The analysis will build on the valuable feedback received from the 2012 SMART survey.

Register will provide outcome data

Public Health England's (PHE's) Disease Registration division has begun work on implementing an England-wide Congenital Anomaly Register.

To achieve this, it will expand current registration and surveillance across London, the North West, South of England and East of England and build a national data system to draw in more data sets and improve quality assurance of data across regions.

The national register will include a patient portal, with access controls, to enable patients to self-register and access peer support.

The register will aim to provide screening programmes in England with the outcome data they need for monitoring purposes. PHE is working with FASP to achieve this for the fetal anomaly programme.

At present, less than half of all births are monitored for congenital anomalies by regional congenital anomaly registers. The national register is expected to be operational by April 2015, with the patient portal ready for use in April 2016.

Sub-group expanded

The laboratory sub-group has been expanded to include ultrasound representation and is now called the FASP Laboratory and Ultrasound sub-group.

The sub-group, chaired by Elizabeth Normandy of the national QA team, reports to the FASP Advisory Group.

The sub-group's workstreams, which follow from the programme objectives, include:

- **producing a laboratory handbook**
- **working with Clinical Pathology Accreditation (CPA), United Kingdom Accreditation Service (UKAS) and UK National External Quality Assessment Scheme (UK NEQAS) to ensure there are no gaps or duplications between quality assurance processes across the screening pathway**
- **working on implementation details to support the policy consultations on screening twins in the second trimester and T13/T18 screening**

Updates on these workstreams will be included in future editions of this newsletter.

Go-ahead for pulse oximetry pilot

The UK NSC has recommended piloting the pulse oximetry test to screen newborn babies for congenital heart defects in England.

Pulse oximetry is a simple test where a clip placed on a baby's fingers and toes measures the amount of oxygen in their blood.

Its use can help find babies with serious heart disease so they can be treated to prevent deaths and long term disability. Piloting the test will help the UK NSC understand better the implications of using pulse oximetry in the Newborn and Infant Physical Examination (NIPE) programme.

Congenital heart defects affect about six in 1,000 newborn babies. The new test will help ensure early detection for more babies with these conditions.

The recommendation was made at the UK NSC's March committee meeting, the minutes of which have been **published online**. Also at the meeting, the UK NSC recommended against screening for dental disease and coeliac disease.

Rare disorders added to newborn screening

The UK NSC has announced its recommendation to screen every newborn baby in the UK for four genetic disorders.

This will see the NHS Newborn Blood Spot Screening programme expanded to screen for:

- homocystinuria (HCU)
- maple syrup urine disease (MSUD)
- glutaric aciduria type 1 (GA1)
- isovaleric acidaemia (IVA)

Testing for these conditions, leading to early detection and treatment, will help prevent deaths or severe disabilities in affected babies.

Dr Anne Mackie, UK NSC Director of Programmes, said: "We are delighted to announce our recommendation to expand the programme.

"We supported a pilot to look into the impacts of screening for these conditions. Since the start of the pilot in July 2012 more than 700,000 children in England have been tested for these disorders and 47 possible cases identified with 20 confirmed."

Babies currently have a heel prick blood test at 5-8 days old to test for five conditions: phenylketonuria (PKU), congenital hypothyroidism (CHT), sickle cell disease (SCD), cystic fibrosis (CF) and medium-chain acyl-CoA dehydrogenase deficiency (MCADD).

Other news in brief

DATA: The NHS Sickle Cell and Thalassaemia Screening Programme has published its latest **data report** covering 2012/13, entitled Data Report 2012/13: Trends and performance analysis. This is the sixth systematic data report of data for the linked sickle cell and thalassaemia antenatal and newborn screening programme in England.

EVENTS AND CONFERENCES: More than 200 delegates attended a hugely successful first joint national conference on diabetic eye screening held by the NHS Diabetic Eye Screening Programme (NDESP) and the Royal Society of Medicine (RSM).

QA: The regional antenatal and newborn (ANNB) quality assurance (QA) teams have undertaken their first visits. Visits have been planned throughout the year in each region. Findings from these visits will determine if changes are needed.

NHS NUMBERS FOR BABIES: the way the NHS Number is issued for newborn babies is changing. For more information, visit the **Health & Social Care Information Centre** website.

UK NSC review: The role, terms of reference and membership of the UK National Screening Committee is currently being reviewed. Visit the **About Us** page of the **UK NSC Portal** for more information on this independent review.

SOCIAL MEDIA: Hundreds of people have signed up to follow the new national Twitter account for all things screening, **@PHE_Screening**.