

NHS Sickle Cell and Thalassaemia Programme News

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Reaching out to communities

For more than 10 years, the Sickle Cell and Thalassaemia Programme has led on innovative public outreach and educational activities.

A suite of resources has now been published online based on the findings of this work. This is a resource for those involved in outreach work both in the NHS and the voluntary sector.

Cathy Coppinger, Sickle Cell and Thalassaemia Programme Manager, said: "Working with the voluntary sector, we have been highly effective in reaching out to communities at risk."

"We wanted to create a record of what we did, and to provide advice for other people undertaking outreach – whether in sickle cell and thalassaemia or other health issues."

The online resources include:

- [good practice](#) tips and advice including video clips and photographs from outreach sessions
- a [case study](#) explaining what the programme did, the research to inform the work and how the projects were managed
- [examples](#) of materials to support the work including presentations and training resources
- copies of the [research](#) used to develop the project

New Programme Advisory Group Chair



Welcome to Glenda Augustine

The programme welcomes Glenda Augustine as chair of the advisory group. She is a Consultant in Public Health with a long-standing interest in haemoglobinopathies.

Glenda initially worked in the field of haemoglobinopathies as a clinical nurse specialist then as a lead nurse, managing the first day care centre in England for patients with sickle cell and thalassaemia.

She has vast experience in

screening including working as the National Lead for Child Health Screening Coordinators. She also supported the implementation of the screening programme in the West Midlands and developed a training resource used across England and Wales.

Glenda appreciates the opportunity to chair the advisory group and support the continued delivery of a robust screening programme.

Newborn Outcomes

The **newborn outcomes project** uses named data to assess outcomes for babies and children under five with sickle cell disorders or beta thalassaemia.

The newborn screening policy aims to reduce mortality and morbidity by starting penicillin prophylaxis for babies with sickle cell disease by 3 months of age.

In 2013/14:

268 babies were suspected of having sickle cell disease and of these 88% attended clinic by three months.

32 babies were suspected of having beta thalassaemia and of these 85% attended clinic by three months.

Three babies were excluded, one was a suspected insignificant case and two babies were born abroad. No deaths were attributed to sickle cell disease but further work is ongoing.

The screening programme appears to be detecting all babies known to the care system.

The primary measures of morbidity (entry to care and age seen in clinic) indicate that the system is capable of meeting the 3-month standard. However, further work is needed to prevent delays in the interphase between screening and care for some babies.

Excellent feedback on GCSE resources

Teachers have responded enthusiastically to the resources developed by the programme for GCSE science.

There are two lesson plans: one for **sickle cell** and the other for **thalassaemia**.

The resources use the conditions as models to explain genetic inheritance. They also encourage students to consider wider ethical and

practical issues for individuals and society.

In each lesson, the student is given a dilemma and source material to explore the issues. This includes film and audio clips, fact sheets and web links.

Some of the feedback included:

"I thought the resources

were well thought out and displayed in an engaging fashion on PowerPoint."

"This resource engaged a class of Year 8 boys – it was well presented, easy to navigate around and some of the slides were useful as worksheets."

Please share and encourage your local schools to access the resources.

Performance data 13/14

The Sickle Cell and Thalassaemia Programme's annual data report for 2013/14 is being published this month.

The report includes data from screening laboratories across England, as well as Key Performance Indicator (KPI) data.

The full report can be accessed on the [programme website](#). The following summarises the findings and figures of the 2013/14 report.

The key findings include:

Antenatal screening – early testing is important to allow time for all tests to be completed by 12 weeks and six days gestation. The data suggests that there has been an increase in the proportion of tests performed by 10 weeks gestation, although this is still lower in high prevalence areas than in low prevalence areas.

Prenatal diagnostic (PND) testing – PND testing is offered to 'high risk' couples identified through antenatal screening. Laboratory data shows that approximately half of PND tests are being performed by 12 weeks and 6 days gestation.

Newborn screening – in 2013/14 there were 668,117 babies screened, which represents a reduction compared to previous years. There were 319 babies identified with a significant condition (1 in 2,094 babies screened), and 8,850 babies were identified as carriers (1 in 76 babies screened).

The key figures outlined in the report include:

Antenatal screening

Antenatal samples screened	730,779
Pregnant women identified as 'screen positive'	15,281 (1 in 48 samples received)
Proportion of babies' fathers tested	9,687 (64% of screen positive women)
'High risk' couples detected	944 (1 in 16 screen positive women)

Prenatal diagnostic (PND) testing

PND tests performed	353 (approx. 40% of 'high risk' couples)
Number of 'affected' fetal results	89 (25% of PNDs performed)

Newborn screening

Number of newborn samples tested	668,117
Screen positive results	319 (1 in 2,094 babies screened)
Carrier results	8,850 (1 in 76 babies screened)

Content live on NHS Choices

Public information for sickle cell and thalassaemia screening is now available on NHS Choices: nhs.uk/sct

How to achieve 10-week standard

The standard to offer screening by 10 weeks (AP1) has always been an important goal for the programme – it is fundamental to providing parents with informed choices about the pregnancy.

Those choices include the option of prenatal diagnosis (PND) and if the baby is affected, an early termination. This means that all screening tests for mother and father and PND need to be offered by 12+6 weeks.

Research in the UK shows that timely screening is important to parents. When screening is offered early in pregnancy, more parents choose to have PND. The timing is particularly important for some ethnic groups at high risk for sickle cell and thalassaemia for religious and cultural reasons.

The standard is supported by the NICE Antenatal Screening Guidelines (2008) and Quality Standards. It is monitored by the screening key performance indicator (KPI) ST2 – this has shown that many trusts struggle to achieve the standard. However, the following case studies provide examples of good practice from trusts that have been successful:

Ealing

In July 2012, the maternity unit at Ealing Hospital, working with the local Primary Care Trust and GPs, launched the **As Soon As You're Pregnant (ASAP)** campaign, to improve the uptake of early antenatal booking.

The strategy included a new online antenatal booking referral system, a telephone referral line and a central e-mail address for women and GPs. Leaflets and posters promoting the new quick access system of booking were distributed in health and community settings and were available in a range of languages.

It was agreed with the local PCT that the maternity service would record all late referrals and report back on a quarterly basis, the number and reasons for late referral and which GP surgeries they came from.

Following the initial campaign launch, the number of women attending their first appointment by 12+6 weeks increased from 75% to 85%. Since 2012 the service has consistently met the acceptable level of the KPI ST2 with the 2013/14 year end position achieving 59.2% of women having a screening result by 10+0 weeks of pregnancy.

East Cheshire

At East Cheshire NHS Trust, first point of contact

(FPC) for pregnant women has been well established for several years.

The initial campaign was aimed at encouraging women to access antenatal care in a timely manner. This involved working with local GP's and promoting FPC with leaflets and posters.

At FPC, the midwives discuss all the antenatal screening programmes and provide the 'Screening tests for you and your baby' booklet. A booking appointment is arranged by the midwife with the aim of booking women before 10 weeks of pregnancy where ever possible.

Sickle cell and thalassaemia screening is offered at the booking appointment where the offer, consent for screening and blood sample are all recorded electronically. The FOQ form is completed at the time and blood is usually taken by the midwife.

There is on-going education of the midwives regarding the target to screen for sickle cell and thalassaemia before 10 weeks of pregnancy, which helps to maintain the practice. This has resulted in the trust meeting the acceptable level target for KPI ST2 each year since the 2011/12 collection period.

Southend

At Southend University NHS Foundation Trust, the ST2 KPI was consistently red until they launched their pregnancy booking line in May 2014.

Women contact the booking line by telephone or email and an online booking form is currently being developed. Women then receive a phone call from a midwife. The midwife takes consent for first antenatal blood tests and explains the importance of having blood taken before 10 weeks of pregnancy.

The blood form which is dedicated to first antenatal blood and incorporates a copy of the family origin questionnaire and 'Screening test for you and your baby' booklet, are sent by post. The woman is seen at home by her community midwife ideally before 10 weeks gestation.

This has seen the KPI steadily rise from 50.7% in Q1 2014, 64.2% in Q2 2014 and currently reporting at 67.4%.

Thank you to all contributors of this article.

Newborn low haemoglobin A project

Beta thalassaemia major can be a very severe condition requiring lifelong blood transfusion and other therapies.

Currently, detection in the newborn bloodspot screening programme is a by-product of screening for sickle cell disease.

Beta thalassaemia major is suspected when laboratory results show low levels of the normal adult haemoglobin.

A three year project aimed at determining the best value to identify those babies needing further investigation for beta thalassaemia major was started summer 2013.

Anonymised data is being requested from all newborn screening laboratories.

At the end of the three years, this will be reviewed by the programmes' scientific advisors.



UK National Screening Committee News

Response to parliamentary committee report published

Following the [House of Commons Science and Technology Committee's Report on National Health Screening](#), the UK Health Departments and the UK National Screening Committee (UK NSC) have developed a response to the key recommendations.

This response has now been published.

The independent review of the role, terms of reference and membership of the UK NSC is also due to be reported on shortly.

These independent reviews will help inform future UK NSC developments with the aim of improving health screening in the UK.

We will share these publications when available.

Preterm labour test not recommended

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

Each year in the UK, over 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 raised a number of concerns over the evidence for screening to identify women at risk, including its timing, the measurement for identifying risk and the treatment

Recommendations in consultation.

- [Fragile X syndrome in pregnancy](#) (closes 9 May)



Evidence news

Due for consultation soon:

- [Toxoplasmosis in pregnancy](#)
- [Neuroblastoma in children](#)
- [Oral cancer in adults](#)
- [Stomach cancer in adults](#)
- [Glaucoma in adults](#)
- [Familial Hypercholesterolaemia in adults](#)
- [Mucopolysaccharidosis \(Hurler's syndrome\) in newborns](#)

[Congenital adrenal hyperplasia in newborns](#)

- [Psychiatric illness in pregnancy](#)
- [Hepatitis C in pregnancy](#)
- [Varicella \(chicken pox\) susceptibility in pregnancy](#)
- [Hearing loss in adults](#)
- [Prostate cancer in adults](#)

Follow us on Twitter



The Twitter account, [@PHE_Screening](#), is a great source of information on health screening in England. Please note that our Twitter activity will be limited during the pre-election period.

Other news in brief

Data guidance published

New guidance for the submission of key performance indicator (KPI) and quality assurance standards data for the diabetic eye and abdominal aortic aneurysm screening programmes has been published and can be uploaded from the [NAAASP](#) or [NDESP](#) websites.

Information in other languages

Translations of the 'Screening tests for you and your baby' booklet are now available to [download](#).

The languages include Bengali,

Punjabi, Portuguese, Polish, Urdu, Arabic, Chinese (Mandarin), French, Somali and Romanian.

New e-learning module

The NHS Newborn Blood Spot Screening Programme's new e-learning module is now live on the [CPD website](#).

PHOF includes screening data

Screening indicators have been published in the Public Health Outcomes Framework (PHOF) for the first time. The PHOF interactive tool is at www.phoutcomes.info.

Updated timeline available

The [antenatal and newborn screening timeline](#) has been updated.

It offers a visual reference to optimum times for NHS antenatal and newborn screening tests to take place.

New online search function

The screening services near you function is now live on NHS Choices. You can use it to search for local abdominal aortic aneurysm, diabetic eye and newborn hearing services by postcode or town.