



Public Health
England



**Screening Quality Assurance visit
report**
NHS Antenatal and Newborn Screening
Programmes
North West Anglia NHS Foundation Trust

26 and 27 September 2018

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Public Health England, Wellington House, 133-155 Waterloo Road, London SE1 8UG
Tel: 020 7654 8000 www.gov.uk/phe
Twitter: [@PHE_uk](https://twitter.com/PHE_uk) Facebook: www.facebook.com/PublicHealthEngland

About PHE Screening

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or informed decisions. National population screening programmes are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the 4 UK countries. PHE advises the government and the NHS so England has safe, high quality screening programmes that reflect the best available evidence and the UK NSC recommendations. PHE also develops standards and provides specific services that help the local NHS implement and run screening services consistently across the country.

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Executive summary

Antenatal and newborn screening quality assurance (QA) covers the identification of eligible women and babies and the relevant tests undertaken by each screening service. It includes receipt of the referral by treatment or diagnostic services as appropriate (for individuals/families with screen-positive results), or the completion of the screening pathway.

The findings in this report relate to the quality assurance visit of the North West Anglia NHS Foundation Trust screening service held on 26 and 27 September 2018.

Quality assurance purpose and approach

Quality assurance (QA) aims to maintain national standards and promote continuous improvement in antenatal and newborn (ANNB) screening. This is to ensure that all eligible people have access to a consistent high quality service wherever they live.

QA visits are carried out by the PHE screening quality assurance service (SQAS).

The evidence for this report comes from the following sources:

- routine monitoring data collected by the NHS screening programmes
- evidence submitted by the provider and commissioner
- information shared with the Midlands and East regional SQAS as part of the visit process

Local screening service

Antenatal and newborn screening programmes are provided by the North West Anglia Foundation Trust (NWAFT). NWAFT was formed on 1 April 2017 from the merger of Hinchingsbrooke Health Care NHS Trust and Peterborough and Stamford Hospitals NHS Foundation Trust.

The Screening and Immunisation Team, Midlands and East (Anglia), is the lead commissioner for the antenatal and newborn screening programmes.

Co-commissioning arrangements are in place with Cambridge and Peterborough Clinical Commissioning Groups (CCG) and South Lincolnshire CCG and NHS England specialised commissioning.

NWAFT offers all 6 NHS antenatal and newborn screening programmes at Hinchingsbrooke Hospital and Peterborough City Hospital:

- infectious diseases in pregnancy screening
- sickle cell and thalassaemia screening
- fetal anomaly screening
- newborn hearing screening
- newborn and physical infant examination
- newborn bloodspot screening

Both hospitals provide:

- antenatal clinic
- phlebotomy service
- ultrasound department
- maternity day assessment unit
- labour suite
- maternity led birth unit
- obstetric theatres
- postnatal ward
- neonatal intensive care
- community midwifery service
- audiology outpatient service

In 2017 to 2018, 8022 women were booked for maternity care at NWAFT with 7237 births being recorded by the Trust (including live births and still births).

5619 women booked at Peterborough City Hospital and the hospital recorded 4993 deliveries (including live births and still births).

2403 women booked at Hinchingsbrooke Hospital and the hospital recorded 2244 deliveries (including live births and still births).

NWAFT antenatal and newborn screening services interface with the following external providers:

- Cambridge University Hospital Foundation Trust laboratory:
 - infectious diseases screening (Hinchingsbrooke Hospital)
 - sickle cell and thalassaemia screening (Hinchingsbrooke Hospital)
 - Down's, Edwards' and Patau's syndromes for fetal anomaly screening programme
 - newborn bloodspot screening programme - regional bloodspot laboratory based in the Biochemical Genetics Unit (BGU) laboratory at Cambridge

- Provide UK are the providers for child health information services (CHIS) - a child health information service QA visit took place in July 2018
- Cambridge Community Services provide neonatal intensive care services at Hinchingsbrooke Hospital
- confirmation testing for the sickle cell and thalassaemia programme is provided by Molecular Haematology Services, Oxford
- serology reference samples and confirmatory tests:
 - Peterborough Hospital send samples to PHE Colindale
 - Hinchingsbrooke Hospital send samples to PHE specialist and reference microbiology laboratory, Sheffield

Findings

Following the creation of NWAFT in April 2017, there are clear arrangements for commissioning and a cross-site midwifery management structure was implemented in July 2018. Antenatal and newborn screening services are not aligned across the 2 hospital sites. The visit team identified the need for equal screening services across the 2 hospital sites, with further development required particularly at Hinchingsbrooke Hospital.

Maternity services, including antenatal and newborn screening programmes are provided at Hinchingsbrooke Hospital and Peterborough City Hospital.

Antenatal and newborn screening programme QA visits to Peterborough and Stamford Hospitals NHS foundation Trust and Hinchingsbrooke Healthcare NHS Trust took place in March 2014 and November 2014 respectively. The action plans have been closed with no outstanding recommendations.

Immediate concerns

The QA visit team identified no immediate concerns.

High priority

The QA visit team identified 6 high priority findings as summarised below:

- the sonography department at Hinchingsbrooke Hospital has no clear framework for monitoring, escalation and reporting to support the fetal anomaly screening programme
- antenatal screening failsafe processes at Hinchingsbrooke Hospital are unreliable

- the screening service does not have mechanisms to make sure positive results are managed in accordance with NHS screening programme standards for sickle cell and thalassaemia and infectious diseases screening
- a Trust-wide gap analysis of antenatal and newborn screening services compared to services specifications, programme standards and guidance has not been performed

Shared learning

The QA visit team identified the following area of practice for sharing:

The ultrasound department use short codes on the CRIS ultrasound IT system which improves failsafe and data functions. This strengthens the fetal anomaly screening pathway by providing automated directives that reflect screening programme standards.

Themes

The QA visit identified 12 standard priority findings, summarised below:

Local guidelines and standard operating procedures need updating and ratifying. They should cover all aspects of the antenatal and newborn screening programmes and include failsafe checks.

It is not evident that NWAFT meets the requirements of the accessible information standard or the needs of women/families with protected characteristics. For example, Hinchingsbrooke Hospital screening midwives have not sought feedback from users of antenatal screening.

Ultrasound supervisory arrangements and sonographer training do not meet the requirements of the NHS Fetal Anomaly Screening Programme.

Key performance indicators are not consistently meeting the acceptable level in the following screening programmes:

- sickle cell and thalassaemia
- newborn hearing screening
- newborn and infant physical examination
- newborn blood spot

Recommendations

The following recommendations are for the provider to action unless otherwise stated.

Governance and leadership

No.	Recommendation	Reference	Timescale	Priority	Evidence required
1	Strengthen the development of antenatal and newborn screening services by carrying out Trust-wide gap analysis process	Service Specifications 16, 17, 18, 19, 20, 21	Within 3 months	High	Trust-wide action plan that is agreed and monitored by Programme Board.
2	Strengthen risk and governance processes in the sonography department to provide regular monitoring of the quality and integrity of fetal anomaly screening	NHS Screening Service Specification no.15	Within 3 months	High	Action plan that is agreed and monitored by Programme Board. Structure and processes for oversight and escalation formalised in operational policies
3	NWAFT to improve the management of screening incidents by: <ul style="list-style-type: none"> including the reference “Managing safety incidents in NHS screening programmes” in local screening guidelines and policies using governance processes to make sure action plans are implemented 	Managing Safety Incidents in NHS Screening Programmes Service Specifications	Within 12 months	Standard	Updated and published local guidelines and policies. Updated maternity risk management strategy. Evidence that processes are embedded in: <ul style="list-style-type: none"> maternity sonography audiology neonatal intensive care unit

No.	Recommendation	Reference	Timescale	Priority	Evidence required
4	Make sure that the functions of the Screening Support Sonographer (SSS) are in place within ultrasonography, particularly protected time for image audit	Service Specification No.17 FASP Programme Handbook	Within 3 months	High	Revised job description that is consistent with national guidance and details the process for the quarterly departmental review of images Evidence of ratification through local governance structure Reference to updated processes in the Trust's antenatal and newborn screening annual report
5	Make sure that sonographers complete annual e-learning training as specified by the fetal anomaly screening programme	Service Specification No.17 FASP Programme Handbook e-Learning for Health NHS screening programmes	Within 6 months	Standard	Make this training mandatory and provide evidence of percentage compliance within the annual screening report

No.	Recommendation	Reference	Timescale	Priority	Evidence required
6	<p>Update screening guidelines, operational policies and standard operating procedures (SOP) to reflect programme standards for:</p> <ul style="list-style-type: none"> • infectious diseases screening • sickle cell and thalassemia screening • fetal anomaly screening • newborn hearing screening • newborn blood spot screening • newborn and infant physical examination 	<p>Screening programme standards</p> <p>NHS screening programmes service specifications 16, 17, 18, 19, 20, 21</p>	<p>Within 12 months</p>	<p>Standard</p>	<p>Updated and published documents to:</p> <ul style="list-style-type: none"> • include the information women/parents should receive to give informed consent • include screening pathways • detail the support for non-English speaking people including interpreting services • include failsafe processes in SOPs • be recorded in the Programme Board minutes as published <p>Evidence of ratification through local governance structure</p> <p>Governance framework that includes annual update of guidelines in line with screening service specifications</p>

No.	Recommendation	Reference	Timescale	Priority	Evidence required
7	Improve the user feedback survey by including users of antenatal and newborn screening services from both hospital sites	NHS screening programmes service specifications 16, 17, 18, 19, 20, 21	Within 12 months	Standard	Findings of user satisfaction surveys presented at the Programme Board

Identification of cohort – antenatal

No.	Recommendation	Reference	Timescale	Priority	Evidence required
8	<p>Improve the antenatal screening failsafe processes at Hinchingsbrooke Hospital to make sure:</p> <ul style="list-style-type: none"> all missing information is identified and followed up there is IT support for the antenatal failsafe database 	<p>NHS screening programmes service specifications 16, 17, 18, 19, 20, 21</p> <p>NHS population screening: failsafe procedures</p>	Within 3 months	High	<p>Hinchingsbrooke Hospital site-Standard operating procedure details:</p> <ul style="list-style-type: none"> the data reports to be generated and how they will be used to identify any gaps in each woman's screening pathway and follow up action how IT support is provided to maintain and develop the failsafe database <p>Evidence of ratification through local governance structures</p> <p>Reference to updated processes in the Trust's antenatal and newborn screening annual report</p>

Identification of cohort – newborn

No recommendations were identified in this section.

Invitation, access and uptake

No.	Recommendation	Reference	Timescale	Priority	Evidence required
09	The commissioners and Trust should develop an action plan to identify and reduce screening inequalities in underserved and protected population groups	NHS screening programmes service specifications 16,17, 18, 19, 20, 21 Guidance for NHS commissioners on equality and health inequality duties 2015 NHS Accessible Information standard and specification	Within 12 months	Standard	Public Health profile of the maternity population Action plan addressing needs identified presented at local governance group and Programme Board

Sickle cell and thalassaemia screening

No.	Recommendation	Reference	Timescale	Priority	Evidence required
10	<p>Implement and monitor a plan to consistently meet the acceptable level for key performance indicators:</p> <ul style="list-style-type: none"> • ST1: sickle cell and thalassaemia screening – coverage • ST2: sickle cell and thalassaemia screening – timeliness of test 	<p>NHS screening programmes service specification 18</p> <p>NHS Sickle Cell and Thalassaemia Screening Programme Standards</p>	Within 9 months	Standard	<p>Action plan that is agreed and monitored by Programme Board.</p> <p>Submission of data that shows consistent achievement of the acceptable standard</p>
11	<p>Improve the screening pathway to make sure women are offered pre-natal diagnosis by 12+6 weeks by:</p> <ul style="list-style-type: none"> • the consistent use of the antenatal screening integrated request form • improving the timeliness of communication of screen positive results to the screening team • improving the access to blood taking clinics • identifying and fast tracking of known at risk couples • making sure midwives who manage positive results are trained in accordance with NHS screening programme standards 	<p>NHS screening programmes service specification 18</p> <p>NHS Sickle Cell and Thalassaemia Screening Programme Standards</p> <p>Guidance Counselling and referral for prenatal diagnosis</p>	Within 3 months	High	<p>Updated and published sickle cell and thalassaemia screening guidelines that detail failsafe/checking processes so that screen positive results are prioritised and followed up eg telephone contact when there is a confirmed screen positive result</p> <p>Evidence of ratification through local governance structure</p> <p>Genetic counselling training included in the training schedule</p> <p>Reference to updated processes in the Trust's antenatal and newborn screening annual report</p>

Infectious diseases in pregnancy screening

No.	Recommendation	Reference	Timescale	Priority	Evidence required
12	<p>Strengthen the infectious diseases screening pathway to make sure screen positive results are communicated to women within 10 days by:</p> <ul style="list-style-type: none"> improving the timeliness of communication of screen positive results to the screening team improving antenatal clinic capacity making sure that positive results are identified and followed up urgently 	<p>Standards for infectious diseases in pregnancy</p> <p>NHS Screening service specification no.15</p>	Within 3 months	High	<p>Updated and published infectious diseases screening guidelines that detail failsafe/checking processes so that screen positive results are prioritised and followed up eg telephone contact when there is a confirmed screen positive result</p> <p>Evidence of ratification through local governance structure</p> <p>Reference to updated processes in the Trust's antenatal and newborn screening annual report</p>
13	<p>Make sure women who miscarry or terminate their pregnancy following antenatal screening are informed of the outcome of their screening tests</p>	<p>NHS Screening service specification no.15</p> <p>IDPS programme handbook</p>	Within 6 months	Standard	<p>Updated and published infectious diseases screening guidelines that detail how women who miscarry or terminate their pregnancy are given their screening results.</p> <p>Evidence of ratification through local governance structure</p> <p>Reference to updated processes in the Trust's antenatal and newborn screening annual report</p>

No.	Recommendation	Reference	Timescale	Priority	Evidence required
14	Make sure each woman who declines the initial offer of IDPS screening (HIV, hepatitis B and/or syphilis) is identified, tracked and re-offered screening by 20 weeks of pregnancy	NHS Screening service specification no.15	Within 6 months	Standard	<p>Updated and published guideline or standard operational procedure</p> <p>Evidence of ratification through local governance structure</p> <p>Database to demonstrate tracking Evidence required for recommendation 8 also applies.</p> <p>Submission of coverage key performance data ID1, ID3 and ID4</p> <p>Reference to updated processes in the Trust's antenatal and newborn screening annual report</p>

Fetal anomaly screening

See recommendations:

Recommendation 02

Recommendation 03

Recommendation 05

Recommendation 06

No.	Recommendation	Reference	Timescale	Priority	Evidence required
15	Strengthen the fetal anomaly screening pathway to make sure screen positive results are communicated to women within 3 days	NHS Screening service specification no.15	Within 6 months	Standard	<p>Improved arrangements for managing and communicating results to women and to follow up missing results.</p> <p>Documented in updated guideline or standard operational procedure</p> <p>Evidence of ratification through local governance structure</p> <p>Reference to updated processes in the Trust's antenatal and newborn screening annual report</p>

Newborn hearing screening

No.	Recommendation	Reference	Timescale	Priority	Evidence required
16	<p>Implement and monitor a plan to consistently meet the acceptable level for key performance indicators:</p> <ul style="list-style-type: none"> NH1: newborn hearing screening test – coverage NH2: newborn hearing screening test - timeliness of audiology assessment 	<p>NHS Screening service specification no. 20</p> <p>Newborn hearing screening standards</p>	Within 9 months	Standard	<p>Action plan that is agreed and monitored by Programme Board.</p> <p>Submission of data that shows consistent achievement of the acceptable standard</p>

Newborn and infant physical examination

No.	Recommendation	Reference	Timescale	Priority	Evidence required
17	<p>Implement and monitor a plan to consistently meet the acceptable level for key performance indicators:</p> <ul style="list-style-type: none"> NP1: newborn and infant physical examination screening test - coverage NP2: newborn and infant physical examination screening test - timely assessment of developmental dysplasia of the hips 	<p>NHS Screening service specification no. 21</p> <p>Newborn and infant physical examination screening standards</p>	Within 9 months	Standard	<p>Action plan that is agreed and monitored by Programme Board.</p> <p>Submission of data that shows consistent achievement of the acceptable standard</p>

Newborn blood spot screening

No.	Recommendation	Reference	Timescale	Priority	Evidence required
18	<p>Implement and monitor a plan to consistently meet the acceptable level for key performance indicators and standards:</p> <ul style="list-style-type: none"> • NB2: newborn blood spot screening - avoidable repeat tests • Standard 3: barcoded NHS number label is included on the blood spot card • Standard 4: the blood spot sample should be taken on day 5 • Standard 5: timely receipt of a sample in the newborn screening laboratory all samples received less than or equal to 3 working days of sample collection 	NHS screening service specification No. 19	Within 9 months	Standard	<p>Action plan that is agreed and monitored by Programme Board</p> <p>Submission of KPI data that shows consistent achievement of the acceptable standard</p> <p>Submission of quarterly newborn blood spot laboratory data that shows consistent achievement of the acceptable standard</p>

Next steps

The screening service provider is responsible for developing an action plan in collaboration with the commissioners to complete the recommendations contained within this report.

SQAS will work with commissioners to monitor activity and progress in response to the recommendations made for a period of 12 months after the report is published. After this point, SQAS will send a letter to the provider and the commissioners summarising the progress made and will outline any further action(s) needed.