Public Health England

NHS

Screening Quality Assurance visit report

NHS Antenatal and Newborn Screening Programmes

East and North Hertfordshire NHS Trust

18 January 2018

Public Health England leads the NHS Screening Programmes

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About PHE Screening

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better 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 four UK countries. The Screening Quality Assurance Service ensures programmes are safe and effective by checking that national standards are met. PHE leads the NHS Screening Programmes and hosts the UK NSC secretariat.

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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 programme. It includes acknowledgement 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 (QA) visit of the East and North Hertfordshire NHS Trust screening service held on 18 January 2018.

Quality assurance purpose and approach

Quality assurance aims to maintain national standards and promote continuous improvement in antenatal and newborn 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 of data collected by the NHS screening programmes
- data and reports from external organisations
- evidence submitted by the provider(s), commissioner and external organisations
- information collected during pre-review visits
- information shared with the Midlands and East regional SQAS as part of the visit process

Local screening service

East and North Hertfordshire NHS Trust offer all 6 antenatal and newborn screening programmes across 3 sites. The Lister Hospital in Stevenage provides antenatal, intrapartum and postnatal services, the Queen Elizabeth II (QEII) Hospital in Welwyn Garden City and Hertford County Hospital in Hertford offer outpatient services for antenatal care as well as some ultrasound services.

In 2016 to 2017, there were 6,538 women booked for delivery and there were 5,727 births. East and North Hertfordshire NHS Trust provide laboratory services for sickle cell and thalassaemia screening. Laboratory services for infectious diseases in pregnancy are provided by Cambridge University Hospitals NHS Trust.

Regional laboratory services for Down's, Edwards' and Patau's syndromes screening are provided by Birmingham Women's and Children's NHS Foundation Trust. Great Ormond Street Hospital for Children NHS Foundation Trust provides newborn blood spot screening laboratory services. Clinical genetics services are provided by North West Thames Regional Genetics Service.

NHS England (Midlands and East - Central Midlands) is the lead commissioner for the antenatal and newborn screening programmes. Co-commissioning arrangements are in place with East and North Hertfordshire Clinical Commissioning Group.

Findings

This is the first QA visit to this service. During the visit, the visiting team commented that the service was woman and family centred and delivered by a motivated team.

Immediate concerns

The QA visit team identified no immediate concerns.

High priority

The QA visit team identified 7 high priority findings as summarised below:

- there were concerns about the accuracy of cohort matched data for coverage key performance indicators for infectious diseases in pregnancy and sickle cell and thalassaemia screening
- patient identifiable data for screen positive cases was stored in the counselling area used by the maternity screening team
- there was a delay in taking some of the newborn blood spot samples on day 5
- the turnaround time of sickle cell screening samples did not meet the national standard
- the antenatal pathology request form did not meet national programme requirements
- women who miscarry or terminate their pregnancy following screening are not informed of their results, referred to the specialist services if required or offered rescreening if their sample cannot be processed
- the newborn screening teams were not notified promptly when a baby dies, which increases the risk that deceased parents could be contacted inappropriately

Shared learning

The QA visit team identified several areas of practice for sharing, including:

- regular team meetings within the hearing screening team encourage screeners to contribute and expand knowledge
- lessons learned from screening incidents are shared monthly in the governance newsletters and via a closed Facebook page for all staff within maternity
- reasons for performing second trimester Down's syndrome screening tests are monitored and acted on
- the ultrasound team hold regular multidisciplinary meetings with fetal medicine and neonatal staff to share good practice and investigate unexpected outcomes
- audits seen within the ultrasound department were of high quality
- NIPE clinics have been extended to meet service users' needs
- women are offered a choice of venues for ultrasound examinations

Recommendations

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

Governance and leadership

No.	Recommendation	Reference	Timescale	Priority	Evidence
1.	The commissioner should work with the commissioners of the infectious diseases in pregnancy screening laboratory service providers to provide feedback and identify issues and risks	Service specification No. 15 IDPS Laboratory Handbook	6 months	Standard	Documentation of communication with commissioners Action plan for any issues or risks identified monitored through programme board
2.	The commissioner and stakeholders should work together to undertake a health equity audit	Service specification Nos. 15 to 21 Guidance for NHS Commissioners on equality and health inequality duties 2015 NHS Accessible Information standard and specification	12 months	Standard	Summary of the audit and findings Action plan monitored at programme board
3.	Make sure the newborn infant physical examination screening programme has a	Service specification No. 21	6 months	Standard	Nominated lead for NIPE screening programme

No.	Recommendation	Reference	Timescale	Priority	Evidence
	clinical lead to oversee and manage the programme				reporting to programme board
4.	Establish an internal screening group to make sure there is clinical oversight and governance of the antenatal and newborn screening services	Service specifications Nos. 15 to 21	6 months	Standard	Terms of reference include membership, named clinical leads for each screening programme, governance and reporting lines to the trust board, frequency of meetings, review of risks and escalation of issues to the commissioners and to the screening quality assurance service There is a Trust director who is responsible for the antenatal and newborn screening programmes
5.	Update/amend relevant local policies to include reference to managing antenatal and newborn screening incidents in accordance with 'Managing Safety Incidents in NHS Screening Programmes'	Managing Safety Incidents in NHS Screening Programmes	6 months	Standard	Relevant local policies include reference to managing screening incidents in accordance with 'Managing Safety Incidents in NHS Screening Programmes'
6.	Make sure all screening guidelines meet national programme service specifications and guidance	Service specifications Nos. 15 to 21	12 months	Standard	Ratified guidelines in place and presented to programme board

No.	Recommendation	Reference	Timescale	Priority	Evidence
7.	Audit the antenatal and newborn screening records to demonstrate compliance with antenatal and newborn screening guidelines	Service specifications Nos. 15 to 21	12 months	Standard	Summary of the audit and findings and action plan monitored at programme board Audit added to annual schedule
8.	Complete a user survey to gather views about the antenatal and newborn screening pathways to improve standards	Service specifications Nos. 15 to 21	12 months	Standard	User feedback survey, evidence of actions taken discussed at programme board

Infrastructure

No.	Recommendation	Reference	Timescale	Priority *	Evidence
9.	Staff within the sickle cell and thalassaemia screening laboratory should complete the e-learning module	Service specification No. 18	6 months	Standard	Completed training logs presented to programme board for all involved staff
10.	Make sure the delay in replacing the laboratory analysers is placed on the risk register and replacement is accelerated to enable standards for turnaround times to be met	SC and T standard 4	3 months	High	Risk register score and resolution of business case is reported to programme board Action plan that is agreed and monitored by programme board

No.	Recommendation	Reference	Timescale	Priority *	Evidence
11.	Make sure that no patient identifiable information is accessible in rooms used for counselling women and families	Service specifications Nos. 15 to 18	3 months	High	Assurance that no patient identifiable information is accessible in counselling rooms reported to programme board

Identification of cohort – antenatal

No.	Recommendation	Reference	Timescale	Priority *	Evidence required
12.	Make sure that matched cohort data is used for KPI coverage submissions to confirm that all eligible women are offered screening and have an outcome reported	IDPS standards 1, 2 and 3 SC and T standard 1	3 months	High	KPI coverage data for ST1, ID1, ID3, ID4 is cohort matched

Identification of cohort – newborn

No.	Recommendation	Reference	Timescale	Priority *	Evidence required
13.	Implement a process for notifying stakeholders about deceased babies (including updating the baby's status as deceased on the screening IT systems)	Newborn screening programmes service specifications Nos. 19, 20, 21	6 months	High	Standard operating procedure for the notification of deceased babies with roles and responsibilities clearly outlined

Invitation, access and uptake

No.	Recommendation	Reference	Timescale	Priority *	Evidence required
14.	Make sure pathways are in place to enable all women to have equitable and early access to screening services	Service specifications Nos.15 to 18	6 months	Standard	Pathway demonstrating equitable and early access Action plans from any audits such as late bookings and use of early bird referrals
15.	Revise request forms (paper or electronic) to meet minimum data fields specified by the national programme	Service specifications Nos. 15 and 18 SC and T laboratory handbook IDPS laboratory handbook	3 months	High	Revised request form in use that does not include rubella Revised form uses latest version of FOQ Revised form records consent or decline of each of the IDPS conditions
16.	Establish a failsafe to make sure all women who are asked to book a dating or nuchal scan have received an appointment	FASP standard 1 Service specification No. 16	6 months	Standard	FASP annual data report Failsafe and action plan presented to programme board
17.	Make sure all women who miscarry or terminate their pregnancy after screening receive their results and those who screen positive are referred directly to specialist services	Service specification No. 15	3 months	High	Ratified guideline includes information about women who miscarry or terminate pregnancy after screening

Sickle cell and thalassaemia screening

No.	Recommendation	Reference	Timescale	Priority *	Evidence required
18.	Implement and monitor a plan to meet the acceptable standard for KPI ST2 (timeliness of test)	Service specification No. 18 SC and T standard 2	6 months	Standard	Action plan that is agreed and monitored by programme board Submission of KPI data for ST2
19.	Update the pathology handbook to include sickle cell and thalassaemia screening samples Make sure it includes tracking of samples sent away for confirmatory testing and a complete failsafe from receipt of sample to issuing of results	Service specification No. 18 SC and T antenatal laboratory handbook	6 months	Standard	Laboratory handbook updated and reported to programme board Updated SOP presented to programme board Audit of tracking of samples sent away presented to programme board Failsafe process in place to evidence receipt of sample in the lab and result issued/received

Infectious diseases in pregnancy screening

No.	Recommendation	Reference	Timescale	Priority *	Evidence required
20.	Make sure all samples sent to the infectious disease screening laboratory are tracked to confirm receipt of sample and issue of result	Service specification No. 15	6 months	Standard	Action plan that is monitored by programme board
21.	Make sure that women who screen positive for syphilis meet the acceptable standard for referral and management	IDPS standard 5c Service specification No. 15	6 months	Standard	Submission of annual data report for IDPS that meets programme standard

Fetal anomaly screening

No.	Recommendation	Reference	Timescale	Priority *	Evidence required
22.	Implement and monitor a plan to meet the acceptable level for referral for all women with a suspected/confirmed abnormality at the anomaly screening scan	FASP standard 8a and 8b	6 months	Standard	Submission of annual data report for FASP that meets acceptable standards

Newborn hearing screening

No.	Recommendation	Reference	Time	Priority *	Evidence required
23.	Implement and monitor a plan to meet the acceptable rate for standard 2 AOAE1 (referral rate for well babies)	NHSP standard 2	6 months	Standard	Action plan that is agreed and monitored at programme board Submission of data for standard 2
24.	Implement an audit to investigate the low yield to make sure the report is accurate	NHSP operational guidance	12 months	Standard	Audit presented to programme board that demonstrates the accuracy of the yield report All cases where PCHI is missed at screening are investigated

Newborn and infant physical examination

No.	Recommendation	Reference	Tim	Priority *	Evidence required
25.	Implement and monitor a plan to meet NIPE standards 2, 4 and 5 (outcomes of referrals)	NIPE standard 2, 4 and 5 Service specification No. 21	6 months	Standard	Action plan that is agreed and monitored at programme board Submission of annual data for standards 2, 4 and 5

Newborn blood spot screening

No.	Recommendation	Reference	Timescale	Priority *	Evidence required
26.	Implement and monitor a plan to meet KPI NB 2 (avoidable repeats)	Service specification No. 19 NBS standard 6	6 months	Standard	Action plan that is agreed and monitored by programme board Submission of KPI data – NB2
27.	Implement and monitor a plan to meet standard 4 (sample taken on day 5)	NBS standard 4	6 months	High	Action plan that is agreed and monitored by programme board NBS laboratory report demonstrates standard 4 met

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/progress in response to the recommendations made for a period of 12 months following the issuing of the final report. 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.