



Screening Quality Assurance visit report NHS Antenatal and Newborn Screening Programmes West Suffolk NHS Foundation Trust

11 April 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 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 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 visit of the West Suffolk NHS Foundation Trust held on 11 April 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
- data and reports from external organisations
- evidence submitted by the provider(s), commissioner and external organisations
- information shared with the Midlands and East regional SQAS as part of the visit process

Local screening service

West Suffolk NHS Foundation Trust (WSFT) provides all 6 NHS antenatal and newborn screening programmes:

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

West Suffolk NHS Foundation Trust maternity unit provides antenatal, intrapartum and postnatal care. There is a level 2 neonatal intensive care unit.

In 2016 to 2017, 3,014 women were booked for maternity care at WSFT with 2,585 deliveries recorded by the trust (including live birth/still births).

The screening and immunisation team, Public Health England Midlands and East, (East), is the lead commissioner for the antenatal and newborn screening programmes. Co-commissioning arrangements are in place with West Suffolk Clinical Commissioning Groups (CCG) and NHS England Specialised commissioning.

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

- the North East Essex and Suffolk Pathology Services (infectious diseases screening programme, sickle cell and thalassemia screening programme)
- the Pathology Partnership (Down's, Edwards' and Patau's syndromes for fetal anomaly screening programme, newborn bloodspot screening programme)
- the Pathology Partnership regional bloodspot laboratory based in the Biochemical Genetics Unit (BGU) laboratory at Cambridge
- serology reference samples and confirmatory tests are sent to the PHE Colindale laboratory
- confirmatory testing for the sickle cell and thalassaemia programme is provided by King's College Hospital, London
- Provide UK are the providers for child health information services (CHIS).

This contract commenced on 1 April 2017, covering Essex, Cambridgeshire, Norfolk and Suffolk. There will be a child health information service QA visit in July 2018.

Findings

This was the second antenatal and newborn screening programmes QA visit to West Suffolk NHS Foundation Trust. The first QA visit took place in June 2014. The action plan has been closed with no outstanding recommendations.

Immediate concerns

The QA visit team identified no immediate concerns.

High priority

The QA visit identified 1 high priority finding.

There was no evidence of a neonatal death notification policy for the newborn hearing screening programme.

Themes

The QA visit identified 15 standard priority findings, summarised below:

- there is no clear governance framework for monitoring, escalation and reporting for antenatal and newborn screening programmes
- the evidence submitted for the newborn hearing screening service was limited. Six of the 15 standard recommendations relate to the newborn hearing screening programme - there was a lack of assurance in the following:
 - risk and governance processes
 - \circ $\,$ local guidelines and policies $\,$
 - o use of national data reports
 - o providing assurance of staff safety for home visits
 - o arrangements for training new screeners
- local guidelines and standard operating procedures are inconsistent in content and need updating: they should cover all aspects of the antenatal and newborn screening programmes, include failsafe checks and be ratified
- there is no antenatal and newborn screening audit schedule

Shared learning

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

- screening midwives send an email to women following telephone consultations that include appointment details, links to information and support groups
- focussed education and training has improved the newborn blood spot screening key performance indicator NB2 (avoidable repeats)

Recommendations

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

Governance and leadership

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|---|--|-----------------|----------|--|
| 1 | Strengthen internal risk and governance processes to make sure there is regular monitoring of the quality and integrity of antenatal and newborn screening programmes | NHS screening programmes service specifications 16,17, 18, 19, 20, 21 | Within 6 months | Standard | Terms of reference for the operational screening group with reporting arrangements demonstrating board level oversight. (Maternity department, obstetric radiography department and newborn hearing screening service) Improved governance process demonstrating appropriate level sign off of the quarterly key performance indicators, annual data returns and annual report Include the screening champion role in governance processes |

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|---|--|---------------------|----------|--|
| 2 | Update the risk management strategy and local screening guidelines to reference "Managing Safety Incidents in NHS Screening Programmes" | Managing Safety Incidents in NHS Screening Programmes NHS screening programmes service specifications 16,17, 18, 19, 20, 21 | Within 12 months | Standard | Evidence that screening guidelines and local maternity risk management strategy contain the PHE screening incident guidance and have been and ratified through the trust framework |
| 3 | Provide assurance that there are safe arrangements for newborn hearing screening staff to carry out home visits | Service specification No.20: NHS Newborn Hearing Screening Programme | Within 3 months | Standard | Lone worker risk assessment completed in line with the trust lone worker policy |

Infrastructure

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|---|---|-----------------|----------|--|
| 4 | Develop a newborn hearing screening guideline for the deceased baby pathway | NHS screening programmes service specification 20 | Within 3 months | High | Local guideline that is ratified through the organisation's governance framework Evidence of |
| | | 20 | | | Evidence of disseminati |

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|---|--|---------------------|----------|---|
| 5 | Update screening guidelines, operational policies and standard operating procedures (SOP) to reflect programme standards for: • infectious diseases screening • sickle cell and thalassemia screening • fetal anomaly screening • newborn hearing screening • newborn blood spot screening • newborn and infant physical examination | Screening programme standards NHS screening programmes service specifications 16, 17, 18, 19, 20, 21 | Within 12 months | Standard | Updated and published documents to: 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 Evidence of approval through local governance structure Governance framework that includes annual update of guidelines in line with screening service specifications |

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|--|--|---------------------|----------|--|
| 6 | Include antenatal and newborn screening in the programme of audits and develop a process for feeding back findings and actions. | NHS screening programmes service specifications 16,17, 18, 19, 20, 21 | Within 12 months | Standard | Audit report and related action plan Copies of minutes of local operational meetings to evidence monitoring |
| | | | | | Programme board minutes demonstrating escalation |

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|---|---|-----------------|----------|--|
| 7 | Improve processes to make sure audiology and national newborn hearing screening data reports are: followed up in line with the screening programme operational guidance used to improve the newborn hearing screening service | Newborn hearing screening operational guidance NHS screening programmes service specification 20 | Within 6 months | Standard | Standard operating procedure describing the required actions in response to audiology and NHSP data reports with evidence of monitoring through local governance structure Audit reports to evidence quality of screening service and improvements plans Evidence of monitoring through local governance structure Actions recorded in: • minutes of local hearing screening meeting • minutes of WSFT screening steering group • programme board minutes |

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|---|--|-----------------|----------|--|
| 8 | Formalise the deputy screening coordinator role | NHS screening programmes service specifications 16,17, 18, 19, 20, 21 | Within 3 months | Standard | Deputy screening midwife job description Documented in minutes of local governance meetings and programme board |
| 9 | Strengthen the functions of the Screening Support Sonographer (SSS) | NHS screening programmes service specification. No.17 FASP Programme Handbook | Within 6 months | High | Revised job description that is consistent with national guidance Evidence of approval through local governance structure |
| 10 | Update the job description for the hearing screening manager to reflect current processes | NHS screening programmes service specification 20 | Within 6 months | Standard | Revised job description that is consistent with national guidance Evidence of approval through local governance structure |
| 11 | Improve the quality of screening updates and training by: using resources provided by the screening programmes making sure midwives who perform NIPE screening receive updates and training to give assurance of competency | NHS screening programmes service specifications 16,17, 18, 19, 20, 21 | Within 3 months | Standard | Training slides and resources NIPE midwives included in the training needs analysis Evidence of approval through local governance structure |

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|---|--|---------------------|----------|--|
| 12 | Strengthen the newborn hearing screening service to make sure training for new hearing screeners is facilitated. | Newborn hearing screening operational guidance | Within 12 months | Standard | Evidence that the local manager or deputy is completing the Certificate in Assessing Vocational Achievement (CAVA) course or evidence of formalised arrangements for assessment support Information recorded in minutes from local screening steering group and programme board |

Identification of cohort – antenatal:

See recommendation: 5.

Identification of cohort – newborn:

See recommendation: 4.

Invitation, access and uptake:

No recommendations were identified in this section.

Sickle cell and thalassaemia screening

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|---|---|-----------------|----------|---|
| 13 | Improve the screen positive pathway to make sure women are offered pre- natal diagnosis by 12+6 weeks | Standards for sickle cell and thalassaemia screening | Within 6 months | Standard | Updated and ratified screening guidelines Evidence of approval through local governance structure |

Infectious diseases in pregnancy screening

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|---|--|-----------------|----------|--|
| 14 | Make sure women who miscarry or terminate their pregnancy following antenatal screening are informed of the outcome of their screening tests | Screening service specification no.15 | Within 6 months | Standard | Updated and published infectious diseases screening guidelines |
| | | | | | Evidence of approval through local governance structure |

Fetal anomaly screening:

See recommendation: 5.

Newborn hearing screening:

See recommendations: 01, 02, 03, 05, 07, 12.

Newborn and infant physical examination:

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|---|--|-----------------|----------|--|
| 15 | Implement a process to record outcomes for all screened conditions. This should be is recorded electronically on the NIPE Smart IT system | NHS screening programmes service specifications 21 | Within 6 months | Standard | Updated standard operating procedure Evidence of change via local governance structure |

Newborn blood spot screening:

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|-----|---|---|-----------------|----------|--|
| 16 | Produce and implement an action plan to meet programme standards 3, 5 and 6 | Screening service specification no. 19 Newborn Bloodspot Programme standards | Within 6 months | Standard | Action plan and minutes from screening steering group meeting. Quarterly newborn bloodspot laboratory report monitoring: standard 3: use of NHS number standard 5: timely sample receipt standard 6: bloodspot quality; avoidable repeat rate Evidence of monitoring through local governance structure |

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 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.