Public Health England

# Screening Quality Assurance visit report

## NHS Antenatal and Newborn Screening Programmes Kettering General Hospital NHS Foundation Trust

21 May 2019

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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 Kettering General Hospital NHS Foundation Trust (KGH) screening service held on 21 May 2019.

## 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:

- 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 collected during pre-review visits
- information shared with the Midlands and East SQAS as part of the visit process

KGH offers all 6 antenatal and newborn screening programmes. In 2018 to 2019 there were 3,924 women booked for delivery and 3,292 babies born.

Laboratory services for sickle cell and thalassaemia screening, infectious diseases screening in pregnancy and Down’s syndrome, Edwards’ syndrome and Patau’s syndrome screening are provided on site. Sheffield Children’s Hospital NHS Trust (SCH) provides newborn blood spot screening laboratory services.

Child health information services (CHIS) are provided by Northamptonshire Healthcare NHS Foundation Trust (NHFT).

NHS England and NHS Improvement - Midlands screening and immunisation team (SIT) commission the ANNB screening programmes under Section 7A of the public health functions agreement. NHS Nene and Corby clinical commissioning groups (CCGs) commission maternity services at KGH. Funding for screening is via the maternity payment pathway (MPP).

## Findings

This is the second QA visit to the KGH antenatal and newborn screening programmes. The first visit took place in September 2014 and there are no outstanding recommendations.

The QA visit team were assured overall that the ANNB screening programmes were meeting national programme standards.

### Immediate concerns

The QA visit team identified no immediate concerns.

### High priority

The QA visit team identified 4 high priority findings which were:

- women who are found to have twin pregnancies are not offered additional counselling to discuss the limitations of quadruple screening
- the audit of nuchal translucency (NT) ultrasound images showed a higher than expected level of poor images
- women who miscarry or terminate their pregnancy who have had screening tests do not receive their screening results
- the Newborn Hearing Screening Programme (NHSP) sends patient identifiable data via the use of unsecure communications to the child health records department (CHRD)

### Shared learning

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

- NHSP team participate in a pregnancy information event for the public which was held at KGH to raise the profile of hearing screening which was the subject of a PHE blog
- the SIT is involved in national screening programme workstreams which provides an opportunity to share programme developments
- KGH have a contracted service with University Hospitals of Leicester to provide women with a local service for fetal medicine

# 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 internal antenatal and newborn screening group to include;<br>• oversight of training across all screening programmes and staff groups at KGH and NHFT<br>• focus on programme standards as well as key performance indicators (KPIs) to support quality improvements in the screening service | Service specifications Nos. 15 to 21 | 6 months | Standard | Terms of reference reflect oversight of all staff training and focus on programme standards presented to programme board |
| 2. | Improve communications between maternity and ultrasound by setting up regular meetings to review risks, incidents, unexpected outcomes and performance against programme standards and KPIs | Service specification No. 16<br><br>FASP programme standards | 6 months | Standard | Confirmation that meetings have been established and agenda shared with programme board |

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|---|---|---|---|---|---|
| 3. | Include reference to managing screening incidents in accordance with 'Managing Safety Incidents in NHS Screening Programmes' in risk and incident policies across both organisations | Managing Safety Incidents in NHS Screening Programmes | 6 months | Standard | Policies for NHFT and KGH ratified and presented to the programme board |
| 4. | Update screening guidelines to reflect up to date programme guidance for;<br>• sickle cell and thalassaemia<br>• Down's syndrome, Edwards' syndrome and Patau's syndrome | Service specifications Nos. 16 and 18 | 6 months | Standard | Policies ratified and presented to the programme board |
| 5. | Seek user feedback for ultrasound services and antenatal screening pathways to support quality improvements | Service specifications Nos. 15 to18 | 12 months | Standard | Findings and actions presented to the programme board |

## Infrastructure

See recommendation 2.

## Identification of cohort – antenatal

No recommendations made.

## Identification of cohort – newborn

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|---|---|---|---|---|---|
| 6. | Make sure standard operating procedures (SOPs) in CHRD for newborn screening include all stakeholders | Service specification No. 19, 20 and 21 | 12 months | Standard | SOPs presented to programme board cover all newborn screening pathways and communication with stakeholders |

## Invitation, access and uptake

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|---|---|---|---|---|---|
| 7. | Update trust website to include access to maternity care and a link to NHS.UK for information about antenatal and newborn screening | Service specifications Nos. 15 to 21 | 6 months | Standard | Updated website with link to NHS.UK and information on access to maternity care and screening |
| 8. | The commissioner and providers should work together to develop a screening inequalities action plan to include women who do not access early maternity care to reduce inequalities in screening | Service specifications 15 to 21<br><br>Guidance for NHS Commissioners on equality and health inequality duties 2015 | 12 months | Standard | Action plan monitored at programme board |

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|---|---|---|---|---|---|
| 9. | Make sure all women who miscarry or terminate their pregnancy who have had screening tests receive their results | Service specifications 15 to 18 | 3 months | High | Template letters presented to the programme board and confirmation they are being sent |

## Sickle cell and thalassaemia screening

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|---|---|---|---|---|---|
| 10. | Revise laboratory reports to meet recommended formats | Service specification No 18<br>Lab handbook SCT | 6 months | Standard | Revised reports meet programme recommended formats |

## Infectious diseases in pregnancy screening

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|---|---|---|---|---|---|
| 11. | Put a pathway in place for babies born to women who screen positive for hepatitis B to provide a failsafe for the scheduling of infant vaccinations | Service specification No.15 | 12 months | Standard | Pathway presented to programme board |

## Fetal anomaly screening

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|---|---|---|---|---|---|
| 12. | Make sure the laboratory is part of a managed network for quadruple testing by April 2020 | Service specification No. 16<br><br>FASP screening handbook for laboratories | 8 months | Standard | Evidence of contracts in place with laboratories in the network with clear governance and reporting structures presented to the programme board |
| 13. | Revise laboratory reports to meet FASP recommended formats to report as chance rather than risk | FASP screening handbook for laboratories | 6 months | Standard | Revised reports meet programme recommended wording |
| 14. | Implement and monitor a plan to meet KPI FA1 (completion of laboratory request forms) | FASP standard 6<br><br>Service specification No. 16 | 12 months | Standard | Action plan monitored at the programme board |
| 15. | Make sure the NT image audit demonstrates that actions are being taken to improve quality and that all practitioners are included in the audit process | FASP handbook for ultrasound practitioners | 6 months | High | Audit presented to the programme board demonstrates that poor images are being followed up |
| 16. | Make sure women who have twin pregnancies are counselled appropriately when having quadruple testing | FASP screening handbook for laboratories | 3 months | High | Confirmation at programme board that all women who have a twin pregnancy have appropriate counselling |

## Newborn hearing screening

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|---|---|---|---|---|---|
| 17. | Make sure all patient identifiable data is sent to other stakeholders by secure methods | Service specification No. 20 | 3 months | High | Confirmation that secure communications are being used for patient identifiable data |

## Newborn and infant physical examination

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|---|---|---|---|---|---|
| 18. | Make sure the outcome for referrals for standard 2 (abnormalities of the eye) and standard 5 (bilateral undescended testes) are recorded on S4N | NIPE programme standards | 6 months | Standard | Outcomes for all referrals added to the NIPE record and confirmed at the programme board |
| 19. | Make sure there is enough capacity to meet standard 3 – timeliness of intervention of developmental dysplasia of the hip (DDH) and standard 4 – timeliness of intervention (DDH risk factors) | NIPE programme standards | 12 months | Standard | Assurance about plans to increase capacity reported to the programme board and risk managed appropriately |

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|---|---|---|---|---|---|
| 20. | Record the completion of NIPE in the child health record | Child Health Information Services (CHIS) Provider service specification<br><br>Service specification No. 21 | 12 months | Standard | Recording of NIPE as part of the child health information system confirmed at programme board |

## Newborn blood spot screening

| No. | Recommendation | Reference | Timescale | Priority | Evidence required |
|---|---|---|---|---|---|
| 21. | Implement and monitor a plan to meet:<br>• standard 4 (taking sample on day 5)<br>• standard 5 (timely receipt of sample into laboratory) | NBS standards 4 and 5<br><br>Service specification No. 19 | 12 months | Standard | Action plan monitored at programme board |
| 22. | Make sure result letters are sent to all parents/carers where there is a suspected positive result, or the baby is too old for cystic fibrosis screening | Service specification No. 19 | 6 months | Standard | Updated SOP including template letter, presented to programme board |

## Next steps

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

SQAS will work with commissioners for 12 months to monitor activity and progress in response to the recommendations following the final report. SQAS will then send a letter to the provider and the commissioners summarising the progress and will outline any further action needed.