



Public Health  
England

Protecting and improving the nation's health

# Screening Quality Assurance visit report

NHS Antenatal and Newborn Screening  
Programmes University Hospitals of  
Leicester NHS Trust

Executive Summary

29 January 2019

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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 4 UK countries.

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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 (QA) visit of the NHS antenatal and newborn screening services at University Hospitals of Leicester NHS Trust (UHL) held on 29 January 2019.

### 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

University Hospitals of Leicester NHS Trust (UHL) is one of the biggest acute trusts in England, offering all 6 antenatal and newborn screening programmes across 2 sites. Leicester Royal Infirmary (LRI) and Leicester General Hospital (LGH), both located in the city provide antenatal, intrapartum and postnatal services. St. Mary's birth centre, located in Melton Mowbray offers intrapartum care only.

The East Midlands Congenital Heart Centre is based at Glenfield Hospital, and provides care for patients with congenital heart disease (CHD) from before birth to adulthood, including babies identified with CHD on the screening pathway.

In 2017 to 2018 there were 10,756 women booked for delivery and there were 10,345 babies born across UHL.

UHL has provided laboratory services for sickle cell and thalassaemia and infectious diseases in pregnancy screening since June 2018. Prior to 2018 laboratory services were provided by Nottingham University Hospitals NHS Trust (NUH). Neither of these laboratories were included in this quality assurance visit.

NUH provides regional laboratory services for Down's syndrome, Edwards' syndrome and Patau's syndrome screening. Sheffield Children's Hospital NHS Trust (SCH) provides newborn blood spot screening laboratory services. These laboratories were also not part of this quality assurance visit.

Leicestershire Partnership NHS Trust (LPT) which covers NHS Leicester City, NHS East Leicestershire and Rutland and NHS West Leicestershire Clinical Commissioning Groups (CCGs) provides the child health information services (CHIS).

NHS England (NHS E Central Midlands North) is the lead commissioner for the ANNB screening programmes. Co-commissioning arrangements are in place with NHS Leicester City, NHS East Leicestershire and Rutland and NHS West Leicestershire CCGs.

## Findings

This is the second QA visit for the antenatal and newborn screening programmes at UHL. All recommendations made in the first visit, undertaken in October 2015, were completed. Recommendations and findings from this QA visit are shown below.

### Immediate concerns

The QA visit team identified no immediate concerns.

### High priority

The QA visit team identified 3 high-priority findings:

1. Not all births at LRI were notified to LPT by the birth notification system and some NHS numbers were not produced at the time of birth. This may result in delays in identification of the cohort for newborn screening.
2. The national CHIS data validation and reconciliation exercise has not been completed. This could mean that eligible babies are not offered screening.
3. Archiving of some of the required Fetal Anomaly Screening Programme (FASP) images has failed due to the ageing IT equipment in maternity ultrasound. The workaround in place to accommodate this is time consuming and impacts on the productivity and capacity within the department.

## Shared learning

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

UHL Newborn Hearing Screening Programme (NHSP) – commended in 2018 as one of the best performing programmes in England. The programme formed part of a national audit looking at improving performance for KPI NH2 (timely assessment for referrals)

NHSP screeners have access to the live audiology appointment diary so appointments can be generated at the time of referral, which are convenient to the parents and within the required timeframes.

NHS E (Central Midlands North) has led on a number of quality improvement initiatives. Good links with relevant stakeholders has resulted in a collaborative approach to resolving issues and has made a positive impact on wider public health programmes.

# Recommendations

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

## Governance and leadership

No.	Recommendation	Reference	Timescale	Priority	Evidence required
1	Formalise trust screening programme operational meetings to make sure there is clinical oversight and governance of all antenatal and newborn screening programmes	Service specifications No. 15 to 21	6 months	Standard	Terms of reference which include membership, named clinical leads for each screening programme, governance and reporting lines, frequency of meetings, review of risks and process for escalation of issues to the commissioners and to the screening quality assurance service  Minutes of meetings

No.	Recommendation	Reference	Timescale	Priority	Evidence required
2	<p>Update screening guidelines, and standard operating procedures (SOPs) to reflect up to date programme standards for:</p> <ul style="list-style-type: none"> <li>• fetal anomaly screening for Down’s syndrome, Edwards’ syndrome and Patau’s syndrome</li> <li>• fetal anomaly ultrasound</li> <li>• infectious diseases in pregnancy screening</li> <li>• newborn blood spot screening</li> <li>• newborn infant physical examination</li> </ul>	<p>Service specification No. 15,16,17,19,21</p> <p>FASP, IDPS, NBS, NIPE screening programme standards</p>	12 months	Standard	Guidelines updated and ratified are confirmed at the programme board
3	<p>Make sure the screening team have appropriate administrative support to maintain timely failsafes, checks and audit procedures</p>	<p>Service specifications No. 15,16,17,18,19, 21</p> <p>SCT, FASP, IDPS, NBS, NIPE checks and audits to improve quality and reduce risks</p>	6 months	Standard	Administrative support confirmed at the programme board

## Infrastructure

No.	Recommendation	Reference	Timescale	Priority	Evidence required
4	Improve the process for archiving ultrasound images, for example replace aged IT equipment	FASP handbook for ultrasound practitioners	3 months	High	Improved process for archiving images reported to programme board

## Identification of cohort – antenatal

No recommendations made

## Identification of cohort – newborn

No.	Recommendation	Reference	Timescale	Priority	Evidence required
5	Investigate the process of birth notification to make sure the eligible cohort is identified	Service specification No. 19,20,21 and 28	3 months	High	Outcome of investigation and agreed action plan reported to programme board
6	Complete the national CHRD data validation and reconciliation exercise to make sure the eligible cohort is identified	Service specification No. 28	3 months	High	Confirmation of completed exercise reported to the programme board
7	Investigate performance of NB4 (movers in) for Leicester City and implement a plan to reach the acceptable level	Service specification No. 19 NBS standard 1b	12 months	Standard	Findings presented to the programme board Submission of KPI data – NB4



### Invitation, access and uptake

No.	Recommendation	Reference	Timescale	Priority	Evidence required
8	Update the maternity website to include up to date information on antenatal and newborn screening tests	Service specifications No. 15 to 21	6 months	Standard	Updated website with current antenatal and newborn screening information and link to NHS.UK
9	The commissioner and providers should work together to develop a screening inequalities action plan to include women who do not access early maternity care	Service specifications Nos 15 to 21  Guidance for NHS Commissioners on equality and health inequality duties 2015	12 months	Standard	Action plan that is agreed and monitored by programme board

### Sickle cell and thalassaemia screening

No recommendations made.

### Infectious diseases in pregnancy screening

No recommendations made.

## Fetal anomaly screening

No.	Recommendation	Reference	Timescale	Priority	Evidence required
10	Implement and monitor a plan to meet KPI FA1 (completion of laboratory request forms)	Service specification No. 16	6 months	Standard	Action plan that is agreed and monitored by programme board  Submission of KPI data – FA1
11	Implement a system to record, report and monitor data for KPI FA3 (coverage for Down’s syndrome, Edwards’ syndrome and Patau’s syndromes)	Service specification No. 17	6 months	Standard	Submission of KPI data – FA3, monitored by programme board

## Newborn hearing screening

No recommendations made.

## Newborn and infant physical examination

No.	Recommendation	Reference	Timescale	Priority	Evidence required
12	Implement the recording of outcome data onto NIPE SMaRT	Service specification No. 21	6 months	Standard	Recording of outcomes demonstrated and confirmed at programme board

No.	Recommendation	Reference	Timescale	Priority	Evidence required
13	Record the completion of NIPE in the child's health record, in line with CHIS provider service specification, national programme standards and outcome codes	Child Health Information Services (CHIS) Provider service specification  Service specification No. 21	12 months	Standard	Recording of NIPE demonstrated and confirmed at programme board

### Newborn blood spot screening

No.	Recommendation	Reference	Timescale	Priority	Evidence required
14	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
15	Implement and monitor a plan to make sure standards are met for: <ul style="list-style-type: none"> <li>• standard 3 (use of barcoded labels)</li> <li>• standard 4 (taking sample on day 5)</li> <li>• standard 5 (timely receipt of sample into laboratory)</li> </ul>	NBS standards 3, 4 and 5	12 months	Standard	Action plan monitored at programme board

No.	Recommendation	Reference	Timescale	Priority	Evidence required
16	Make sure result letters are sent by CHRD to parents/carers including where there is a suspected positive result	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 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.