Newborn blood spot screening programmes technical guidance during the coronavirus (Covid-19) pandemic

1. Background

It is paramount that that antenatal and newborn screening continues during the covid-19 pandemic as specified in the NHS England Service Specification for each programme. Antenatal and newborn screening programmes are time critical and early detection and intervention for some of these medical conditions screened for is important and can have significant mortality and morbidity.

It is important the women and babies with screen positive/higher chance results are given the information they need to make the right choices for them and are safely referred onto the correct care pathway. This can be a highly anxious time for women/parents and they must be adequately supported by health professional advice and information.

2. Purpose

This document provides additional technical guidance on how best to deliver these screening programmes as the Covid-19 pandemic evolves and staff and capacity become more challenging.

This guidance provides recommendations on screening continuity in response to Covid-19. It is acknowledged that maintaining the current service during these unprecedented times will be challenging.

3. Scope

This technical guidance is specific to **Newborn Blood Spot screening programme**

- It is believed that it is safe to take samples from a baby in a family in isolation provided that protective clothing and good practice are used but maternity units would make that determination based on staffing levels, availability of protective clothing and risk. If a mum is affected then it may be sensible for someone else to hold the baby during bleeding.
- 2. Once a sample is obtained and dried it is believed that it is safe to post or transport by courier.
- 3. If the post or courier services are disrupted the samples/babies will be tracked via the Newborn Blood Spot Failsafe Solution (NBSFS). Royal Mail have been contacted to check if

- contingency plans are in place to safeguard these samples. Labs monitor the number of samples arriving daily and in addition, during this period, have been asked to provide a weekly status report to the Programme.
- 4. Day 4 samples will be accepted.
- 5. If midwifery visits need to be re-scheduled samples should be taken as soon as possible after day 5. As children with some of these conditions can become acutely ill during the first few weeks of life, testing should be performed as soon as reasonably possible and every effort should be made to obtain a sample before one month of age.
- 6. 'Mover in' babies should still be screened up to one year of age. It is accepted that there may be difficulty in tracking, locating and testing an individual child. This should be assessed against other health care priorities by the health care worker involved and their manager. It may not be possible in all cases and, if reasonable efforts have failed, this should be documented.
- 7. Any unsuitable/insufficient samples, or samples collected on to expired cards that are no more than 5 years old, can be accepted although labs are expected to exercise reasonable judgement and, if it would be clearly unreliable to analyse and report the sample, then a repeat will be requested.
- 8. Labs should still ensure that the NHS number is present on the card.
- 9. Permitted transit time for samples will be extended from 14 days to one month
- 10. In the event that Lab staffing is very limited, testing may need to be prioritised. IMDs and CHT should be tested and reported within the current turnaround times. Testing and reporting for CF and Sickle may be delayed, but samples should be tested and reported as soon as it is practical.
- 11. Reporting screen positive results can be prioritised over labs daily reporting of "normals" to CHIS, but upload to NBSFS is **imperative** and should be maintained so that babies can be tracked. If labs are forced to delay or suspend sending results to CHIS, labs will notify CHIS.
- 12. Referral of positive cases should be attempted by the current routes and, if these are modified, new guidance from the providers should be followed. Confirmatory testing may be delayed, but clinicians may elect to begin to treat the child based upon the information that they have and this will remain their responsibility.
- 13. The requirement to check and report IVA, MCADD and MSUD results on Saturday mornings will be operated at the discretion of the Laboratory, dependent on staffing.
- 14. Two new subcodes are to be used when reporting and recording screening results affected by COVID-19.

Code 09 - not screened/ screening incomplete:

Subcode 0911 – affected by COVID-19 - not screened

Subcode 0912 – affected by COVID-19 - screening delayed

15. If a laboratory's services cannot be maintained, if possible, a backup laboratory would be used. Initially the back-up laboratory as defined in the lab's own contingency plan should be approached and if they are unable to provide support, the Blood Spot Programme should be notified and other laboratories may be approached via UKNSLN. The QA team will be alerted.

3 Additional things to consider

3.1 Information for parents

It is important that parents understand which appointments they should attend and especially in situations where appointments need to be rescheduled. Usual information will be given to screen positives including contact numbers for audiology for any parental concerns.

4.2 Screening safety incidents

As far as possible, the principles in the <u>national guidance</u> should be followed. Incidents or potential incidents should be reported to the screening quality assurance service (SQAS) and commissioners so that they know about problems occurring. SQAS will continue to give advice whilst recognising the intense pressure that many providers staff will be under.

4.3 QA visits and network meetings

All screening QA visits and network meetings are postponed from 23 March until further notice.

This will support our NHS colleagues who are focusing their efforts on frontline activity. We will regularly review this situation and keep staff and stakeholders informed. Communication to both providers due a QA visit and network meeting attendees will be via regional quality assurance teams.

5 Data requests/submissions for key performance indicators and standards Our aim is not to put any additional pressure on screening providers or the wider NHS.

Performance against thresholds – we appreciate meeting some thresholds is challenging and will caveat any reporting of data during this time.

6 PHE Screening publishing and social media activity

We have stopped all social media activity, including blogging and tweeting, and will not be publishing any new guidance on GOV.UK at present; including quality assurance executive summary reports.

7 Documenting changes as they happen

We anticipate that there will be a need to evaluate the impact of the pandemic had sometime in the future, so we advise providers document dates and changes made to the delivery of screening for audit purposes.

8 For further queries

PHE.screeninghelpdesk@nhs.net

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