

Protecting and improving the nation's health

Newborn and infant physical examination screening programmes technical guidance during the coronavirus (Covid-19) pandemic

1. Background

Antenatal and newborn screening must continue 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 and infant physical examination** screening programme

3.1 Key Messages – NIPE Programme Management

- NIPE newborn and infant screening should continue as per national pathways
- all babies should be screened in line with national guidance, but it is acknowledged that circumstances may mean screening may be delayed

- application of the NIPE pathway may need temporarily amending depending on local capacity issues (see below)
- it is acknowledged that during this period some post referral specialist appointments for babies with screen positive results may not be timely due to reduction or cessation of local services (this will be taken into account as mitigations against performance thresholds)
- the use of SMART4NIPE (S4N) NIPE national IT system to track the screening pathway for all newborn babies **should be a priority**. Under current circumstances its use will be even more important in providing reassurance of level of coverage and identification of any gaps in the screening pathway for newborn babies and the ability to follow up babies who may have missed elements of the screening pathway during this unprecedented period
 - the 3 provider Trusts not currently using S4N will need to maintain local pending lists for action and follow up

3.2 NIPE Newborn Screening Physical Examination

- Trusts should continue to undertake the newborn examination and wherever possible this should be prior to discharge from maternity unit. If this is not done within 72 hours of age, then the exam should be completed as near to that timescale as possible. For home births, or where the newborn exam has not been completed prior to discharge from hospital, the newborn examination should be undertaken in line with usual process
- if the newborn examination is not done before discharge, consideration can be given to the newborn physical examination being completed at the same time as the newborn blood spot screening or hearing screening (in either in the community or hospital outpatient setting) to prevent the need for an additional service contact
- parents should be advised that there may be a risk that infant physical examination will be delayed or omitted, so parents should be advised at the time of the newborn examination to seek professional opinion via GP or Health Visitor if they have any concerns about their baby (guidance outlined in PCHR and PHE screening publication screening tests for you and your baby)
- if the newborn examination cannot be undertaken or fully completed, the record on S4N should remain as pending to enable later follow up (see Appendix 1 for further guidance)

3.3 NIPE Infant Screening Physical Examination

- the Infant examination (usually undertaken in primary care at 6-8 weeks of age) should also be completed in line with national guidance wherever possible but where local service provision means it is not possible to complete the screen then this should be rescheduled.
- a record of the babies who have missed this screen should be maintained by GP practices and the infant physical examination done wherever possible once normal clinical practice resumes
- the numbers of missed screens should be made available to local commissioners as required

3.4 Advice for Management of Babies with Screen Positive results

- for babies with positive screening results, referrals should continue to be made and take place wherever possible at the earliest opportunity
- in all cases the screen positive result should be recorded on S4N to make sure that referral has been made and babies seen. This will support follow-up at a later stage
- standards and KPI performance targets may be breached due to capacity (allowance in data reports will be made for these mitigations)
- babies with screen positive heart or bilateral undescended testes screening results on NIPE newborn examination should be reviewed before discharge from hospital in line with national standards.
- for babies with screen positive hip results on clinical examination or screening and screen positive eye results, referrals should continue be made in line with national guidance and take place wherever possible (see below for further guidance re these pathways)
- babies with screen positive results for unilateral undescended testes should be followed up by the GP as per current practice

3.5 Outpatient Services

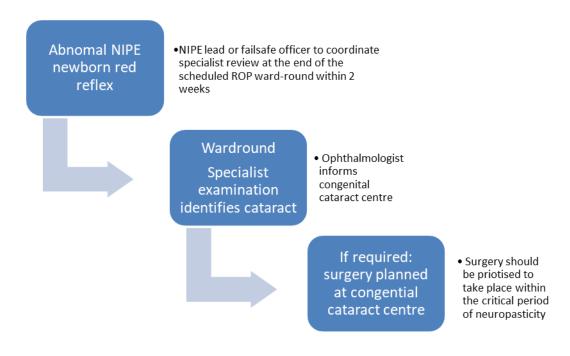
- there may be issues with capacity within ultrasound departments for hip scan and closure of outpatient services for assessment of babies
- all screen positive results should be recorded on S4N to enable follow up (at a later date) even if an appointment cannot be made
- where outpatient services are unable to meet the required timescales, (ophthalmology review or hip ultrasound and orthopaedic review) the following should occur:

3.5.1 Eye Screening – babies with screen positive results on newborn examination (abnormal red reflex)

Given the current pressures, it is likely that many babies will not have a 6-8-week examination. Therefore, the newborn NIPE eye screening examination is even more important in ensuring the early detection of congenital cataract.

- although face-to-face ophthalmology clinic appointments have been severely
 restricted by the Covid-19 arrangements, continuing to comply with the NIPE 2 week
 pathway for specialist review after abnormal newborn red reflex assessment remains
 essential to ensure timely surgical management.
- trusts may find it difficult to organise these examinations in an outpatient's clinic, particularly if the paediatric service has reduced capacity, in these circumstances, an alternative route is illustrated below which has been suggested by the Royal College of Ophthalmologists (Paediatric Sub Committee). In this model, these examinations can be scheduled to coincide with Retinopathy of Prematurity (ROP) ward rounds (or by the colleague covering your ROP screening services). It is advised that these babies are seen after the ROP ward round in a different venue to the neonatal unit such as the maternity ward or other suitable area to reduce the risk of cross-infection.

Alternative NIPE abnormal red reflex pathway (newborn screening examination)



- as they have oversight of the programme and to avoid missing parts of the pathway
 for babies with screen positive results, the NIPE Lead / failsafe officer should be
 responsible for these follow up appointments. This will be particularly important where
 there is no NICU on site and liaison is required between local services and will rely
 heavily upon good communication and collaboration between NIPE screeners and
 ROP screeners (some of whom may be cross covering from outside hospitals on days
 not normally set aside for ROP screening for that unit)
- where baby / parents are known to be infected or in self-isolation it is suggested they should be examined in the designated area for that Trust's paediatric clinic or eye clinic) and in line with the Trust's Covid-19 policy, ensuring that appropriate personal protective equipment is provided to the ophthalmologist. The equipment used by Ophthalmologists is transportable, so these babies can be seen in any suitable location
- babies under 32 weeks gestational age and/or 1500g birthweight should continue to be identified for the ROP screening programme in addition to newborn red reflex screening (in line with current national guidance)
- in all cases, screen positive results should be recorded on S4N to enable follow up

The above guidance has been produced in consultation with Royal College of Ophthalmologists Paediatric Sub-Committee

3.5.2 Hip Screening

It is accepted that during this crisis routine non-urgent ultrasound scanning may not take place resulting in a delay for the scanning of unstable or at-risk hips. It may well not be possible to keep to the present NIPE standards. Medical and ultrasound personnel may not be available.

Screen Positive after clinical examination (suspected dislocated or dislocatable hip)

- considering the current pressure on all services, **only babies with screen positive results on the newborn physical examination** should be referred for hip ultrasound. As far as possible the recommended target times should be kept to, but we recognise that this may not be possible and so the scan should be done as soon as is reasonably possible.
- One possible approach to manage these babies is that if a maternity hospital has the capacity and experience, babies could receive the hip ultrasound prior to discharge from the hospital, where possible. If the ultrasound is normal (centered hip and Graf >55 degrees) the child can be discharged. If the child has any abnormality, the child should be rescanned at 6 weeks of age. Treatment need not automatically begin at this stage, and parents should be reassured that many hips will resolve spontaneously. Parents should be advised not to swaddle their child. Commencing treatment early will increase unnecessary face to face follow-ups for many with its incumbent risks during the period of physical distancing.
- if a maternity hospital does not have the capacity and/or experience to undertake hip scan prior to discharge, the child should be scanned at 6 weeks of age. If hip ultrasound is not possible 6 weeks of age the scan should arranged as soon as possible after this when services resume.
- for those scanned at 6 weeks of age (for either of the above reasons), if the hip in not normal (a normal hip is a centred hip <u>and</u> Graf >55 degrees), orthopaedic review will be required and a harness may be commenced. Once in a harness, treatment follows the standard harness protocol.

Screen positive (for hip risk factors - i.e. breech or family history)

- babies with presence of hip risk factors who would usually have hip scan at 6 weeks of age, should **NOT** be referred for hip ultrasound during this period. This should be delayed until normal services resume when these children will be then followed up through clinical examination and/or ultrasound/ radiographic follow-up.
- accurate records should be kept on S4N so that any babies who have missed out on a scan or orthopaedic opinion can be traced and followed up as appropriate, when resources permit. The screen positive result should be recorded on S4N to enable follow up at a later stage. In all cases where screening or follow up cannot be completed, outcome records will remain as pending on S4N for later follow up
- Trust who do not use S4N should keep accurate local records regarding these babies, to make sure they are followed up when normal services resume
- referring babies with clicky hips is not national policy so in line with current national guidance, babies with screening finding of 'clicky hips' should **NOT** receive hip ultrasound

The above guidance has been produced in consultation with Orthopaedic Surgeon Clinical Advisors to the NIPE programme and member of British Society for Children's Orthopaedic Surgery (BSCOS)

3.6 Decline or Request for Delay in Screening or Onward Referral

Where there is a clear decline and the implications of not screening or completing the pathway have been discussed with parents, then the screening outcome can be set on S4N as outlined below (please see appendix 1)

In cases where parents express a wish to delay screening due to Covid-19 or where babies have been too ill to screen, screening should be offered at an appropriate time

Reasons that NIPE screening or onward referral for babies (with screen positive results) is not completed may include:

- lack of capacity in midwifery or medical staffing to complete the newborn examination
- mothers/babies symptomatic or self-isolating and therefore not attending screen or onward referral
- babies not being brought for screening or onward referral appointment because of infection control concerns in relation to the virus
- capacity in clinical services for managing the screen positive pathway

In order not to lose track of babies with screen positive results, an ongoing failsafe list must be maintained via use of S4N (or locally collated failsafe list for Trusts without S4N) to follow up babies who need or may have missed appointments but who still require follow up

 screening for 'movers in' is dependent on community-based services and should not be prioritised

3.7 Implementation of S4N

Implementation of S4N for the 3 remaining Trusts will likely be rescheduled and trusts are being contacted directly via the NIPE programme to discuss

3.8 Suggested Actions Once Normal Services Resume

Use of S4N (or locally collated failsafe lists in trust without S4N) to identify babies who have missed screening or any part of the screening pathway

There should be prioritisation of babies that:

- have screen positive results that require hip ultrasound or specialist review
- have missed NIPE screening
 - babies should have the newborn examination or infant physical examination undertaken in primary care as soon as practicable up to one year of age.
 - \circ $\$ babies who have not had the newborn examination should be prioritised
- have 'moved-in' and have not had NIPE screening (screening should be offered as soon practicable up to one year of age)

4 Additional things to consider

4.1 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

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<u>Appendix 1</u>

Suggested Management of S4N Records - NIPE Newborn Screening

- 1. Unable to offer screen due to non-availability of screening staff
 - a. Further attempts when staff available leave on active worklist
 - b. No further attempts will be made: Overall outcome Not done Missed Newborn Screen; reason Covid19 – staff. User to create a case note – Covid19 – Staff
- 2. Unable to offer due to early discharge and trust's decision to suspend all community appointments
 - a. Overall outcome Not done Missed Newborn Screen; reason Covid19 community. User to create a case note Covid19 community
- 3. Parents decision to discharge before screen is started/completed
 - a. Consent set to Decline; reason Covid19 parent decision (Creates a system generated case note)
 - Screen partially completed, parents decline appointment to complete. Change consent from full to partial, reason Covid19 – parent decision (Creates a system generated case note).
- 4. Suspected/confirmed baby having Covid19
 - a. Follow trust's access policy
 - b. If unable to screen, overall outcome Not done Missed Newborn Screen, reason Covid19 affected; User to create a case note – Covid19 affected. (Baby should be screened when well enough if possible)
- 5. Screen positive referrals follow up as normal where possible.

Screen positive-Eyes /Hips (abnormality suspected)

- a. Parents decline referral appointment: to record outcome select;
 - Attendance status 'Not Seen'
 - Reason not seen- record covid19- declined follow up [Creates a system generated case note]
- Referral appointments delayed or not available due to outpatient service suspended / capacity issues;
 - record outcome when service resumed (in comments box record- covid19 appt delay)
- c. Babies not being brought for onward referral because of infection control concerns about the virus- to record outcome select
 - Attendance status- cancelled or DNA
 - Attendance outcome cancelled and rebooked or DNA (this allows further appts to be recorded)
 - comments box -record covid19-parent concerns

Screen positive for hip risk factors (i.e. Breech or Family History)

This should be delayed until normal services resume;

- Records will remain on S4N for outcomes to be added when services resumed
- When outcomes added remember to record covid19 appt delay in the comments box

Screen positive -Heart /bilateral undescended testes

a. Parents take baby home prior to review by senior clinician and no arrangements in place for the baby to be seen (extreme circumstances- we would strongly advise these babies are prioritised and seen before they go home) to record outcome select 'Not Seen' reason not seen- record covid19- declined follow up [Creates a system generated case note]

(GP should be informed)

Screen positive -unilateral undescended testis

In line with current guidance, record on S4N that GP has been informed of screening finding

Possible Searches for Records on S4N

- Able to search by Overall Outcome Not done Missed Newborn Screen for babies born during a given period
- Able to search for partial consent
- Able to search case notes for user created case notes = Covid19 (User would need to do this locally as not possible on national NIPE programme reporting system)
- Able to search patient notes for system generated case notes Covid19 (User would need to do this locally as not possible on national NIPE programme reporting system)