# NHS Sickle Cell and Thalassaemia Antenatal Screening Programme: checks and audits to improve quality and reduce risks

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| **Identify the eligible population**; have systems in place to:* record all pregnant women take the screening test by 10 weeks + 0 days gestation
* record the screening offer, test or decline in the eligible population in every pregnancy
* collect data for KPIs ST1 coverage and ST2 timeliness of antenatal screening test
 | To ensure the eligible population are offered screening. Timing is crucial to informed choice; we have evidence that early offer of screening affects the choices people make We have evidence from KPIs and screening safety incidents of:* women who are not offered screening
* unnecessary delays between presenting for maternity care and booking/screening
* quarterly KPIs do not allow checking in good time
 | Maintain an accurate list of eligible population which includes gestation at booking, screening test and decline | Weekly | Submit data on KPIs ST1 (standard 1: antenatal coverage) and ST2 (standard 2: timeliness of antenatal test) to the NHS screening programmes **quarterly**  |
| Trust response: this row is for you to enter results or summarise whether you have these checks in place. If not, you can use this space to identify gaps and develop an action plan |

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| **Provide information and offer screening**; have systems in place to:* record that each woman is given ‘Screening tests for you and your baby’
 | To ensure informed choice; we have anecdotal evidence that the limitations of screening are not always communicated and/or understood e.g. screening is not 100%, is not diagnostic | Record ‘Screening tests for you and your baby’ given in the maternity notes/system | Date ‘Screening tests for you and your baby’ is given to woman | Audit that the booklet was given evidenced by records in the maternity notes/system**annually** |
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| **Take sample and send to laboratory with completed family origin questionnaire (FOQ);** have systems in place to:* identify sample as antenatal in the laboratory
* access hard copy or electronic FOQ
* record information on ancestry of biological mother and father or not known
* collect data for KPIs ST3 completion of FOQ
 | To ensure a fit for purpose sample and completed FOQ arrive at the laboratoryWe have evidence from KPIs and screening safety incidents that screening is inaccurate, incomplete or delayed because:* samples are not identified as antenatal in the laboratory
* samples arrive without an FOQ
* samples are taken but do not arrive in the laboratory
* checks are in place but these are not timely
* we have evidence of an unexpected affected birth following failure to elicit correct partner/baby’s biological father when completing FOQ
* avoidable expense and anxiety from partner recall
 | Record samples taken/declined and match against the eligible population  | Weekly | Audit of repeat requests and rejected samples **annually**Submit data on ST3 (standard 3 completion of family origin questionnaire (FOQ))**quarterly** |
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| **Laboratory tests****samples as per national****guidelines and reports results as per national format**; have systems in place to comply with the programme laboratory handbook | To accurately identify women and couples with genotypes specified as requiring further investigationWe have evidence of:* false negative and false positive cases when the national screening algorithm is not followed
* misinterpretation of screening results when national reporting format is not used
 | Investigate incidents identified by newborn screening programme e.g. unexpected affected babyParticipate in UK national external quality assessment service haematology schemes (all that apply) | Contemporaneously | Submit data on standard 4: antenatal test turnaround times to NHS SCT national programme **annually** |
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| **Nothing abnormal detected**have systems in place to ensure:* results are documented in the maternity records
* communicated to women
* communicated to the GP

 (also applies to all screening and diagnostic results and baby’s biological father results) | Women are entitled to their test results We have evidence that women accept screening tests but:* screening is not completed
* women and fathers are not informed of their results
* results are not recorded on the GP and primary care systems
 | Check that all women who want the test are tested; record results and match against the eligible population  | Weekly  | Audit that results are given to women recorded in the maternity notes/system**annually**Audit that results are given to baby’s father recorded in the maternity notes/system**annually**Audit that all screening results are sent to GPs**annually** |
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| **Inconclusive and carrier results and affected mother SCD**; have systems in place to ensure:* results are documented in the maternity records
* communicated to women and their healthcare professional
* provide written information
* offer of screening to baby's biological father
* counselling and prenatal diagnosis to women if:
	+ baby’s father is not available
	+ risk assessment of inconclusive results indicates potential at risk couple
* match baby’s fathers result with antenatal sample
 | To ensure timely intervention for women/couples ‘at high risk’ of an affected pregnancy * we have evidence from screening safety incidents of:
* biological father not offered screening
* delayed diagnosis and/or treatment
* maternal morbidity and mortality in affected mothers
* unexpected affected births because baby’s biological father was not tested/result not followed up
 | Check that all women and babies’ biological fathers who want the test are tested;record inconclusive, carrier and affected results and match against the eligible population  | Weekly | Audit that the ‘tests for dads’ and ‘information for couple at risk of a baby with thalassaemia major or sickle cell disease’ were given and recorded in the maternity notes/system**annually** |
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| **Confirmed carrier or****affected result in both****parents** – ‘at risk couple’; have systems in place to: offer pre-natal diagnostic testing* by a trained HCP
* supported by NHS SCT programmes resources and;
* rapid referral for those that elect PND
* collect timeliness data (gestation at offer and PND) on all at risk women/couples
* alert newborn screening laboratory
 | To ensure timely intervention for women/couples ‘at high risk’ of an affected pregnancy Timing is crucial to informed choice; we have evidence that early offer of screening affects the choices people make about accepting PND and TOP and in some circumstances limits the options for method of TOPWe have evidence from annual data collection that PND outcome data is incomplete; about 60% of women are offered screening and receive PND tests later than the national standardsWe have anecdotal evidence from the public and voluntary sector that counselling is not always done well | Record PND decline/result and referral for termination of pregnancy and match against all at risk women/couplesCheck NBS result for all high risk babies whether PND accepted or not | WeeklyQuarterly | Audit of at risk couples counselled by a trained HCP evidenced by documentation in the maternity notes and comparison with local register of trained practitioners**annually**Submit data on standard 5: timely offer of PND to women at risk of having an affected infant**annually (KPI pilot)**Standard 6: timeliness of prenatal diagnosis (PND)Standard 7: timely reporting of prenatal diagnosis resultsto NHS SCT national programme **annually** |
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| **Baby affected by a major haemoglobin disorder**; have systems in place to:* provide information and choice
	+ by a trained HCP
	+ supported by NHS SCT programmes resources and
* refer for TOP if requested
* provide counselling and follow up support
* record timeliness of offer and tests and results and outcomes on women that have had PND
* report anonymised pregnancy outcome data on women that have had PND
* alert newborn screening laboratory
* record antenatal and PND results on the blood spot card
 | To ensure timely intervention for women/couples ‘at high risk’ of an affected pregnancy We have anecdotal and evidence from screening safety incidents of:* delays between decision to accept TOP and accessing TOP which also impacts on choice of method of TOP
* counselling is not always done well
* to help interpret the newborn blood spot screening result
 | Check that choices of continuing or terminating the pregnancy have been followed up | Weekly | Audit of completion of short and long-term pregnancy outcome forms (link) gestation at offer**annually**Audit of alert forms to NBS laboratory**annually** |
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| **Carrier or normal PND result**; have systems in place to:* provide counselling and follow up support
* record timeliness of offer and tests and results and outcomes on women that have had PND
* report pregnancy outcome data on women that have had PND to the PND laboratory
* alert newborn screening laboratory
* record antenatal and PND results on the blood spot card
 | The mother’s antenatal screening test and PND results help interpret the newborn blood spot results Outcome data is essential to evaluate the screening programme, PND laboratories send data to the National Congenital Anomolies & Rare Disorders Registration Service  | Check that all women and babies’ fathers who want the test are testedRecord inconclusive, carrier and affected results and match against the eligible population  | Weekly |  |
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