# Management of Maternal Antenatal Screening Tests - Full Clinical Guideline

Reference No.: UHDB/OBS/07:2023/H11

## Contents



## Terminology

Gender Inclusive Language in Maternity and Perinatal Services: It is important to note that the term ‘woman’ or mother’ as used in this document encompasses all gender identities and is intended for anyone who is pregnant. Similarly, where the term 'parents' is used, this encompasses anyone who has the main responsibility for caring for the baby.

## 1. Introduction

This document outlines the agreed guidelines for antenatal screening at University Hospitals of Derby and Burton NHS Foundation Trust (UHDB). Screening has the potential to save lives or improve quality of life through early diagnosis of serious conditions; it is not, however, a diagnostic process. In any screening programme, there is an irreducible minimum of false positive results (falsely reported as being at increased risk of having the condition or not having the condition) and false negative results (falsely reported as being at reduced risk of having the condition or not having the condition). The National Screening Committee (NSC) is increasingly presenting screening as risk reduction to emphasise this point. Antenatal screening is a public health service. Screening is different from clinical practice as it targets apparently healthy women

to identify previously undiagnosed conditions for which treatment or intervention can be offered in pregnancy and around the time of birth to improve maternal and or child health. It also offers prospective parents the opportunity to make informed reproductive choices.

## 2. Purpose and Outcomes

The NHS antenatal screening programmes aim to ensure that there is equal access to uniform and quality assured screening across England and that women are provided with high quality information so they can make an informed choice about their screening options and pregnancy choices.

Objectives

- To provide a systematic approach to antenatal screening and ensure all screening is in line with the national screening committee recommendations.
- To ensure there is a recognised designated lead for antenatal screening in the maternity service.
- To ensure that appropriate tests are undertaken within appropriate timescales.
- To ensure there is a system for ensuring that appropriate tests are taken when women book late.
- Identify the process for review of results.
- Identify the process for reporting results back to women.
- Identify the process for reporting results to other relevant healthcare professionals.
- To ensure women with screen positive test results are referred and managed within appropriate timescales.

The overall aim of this guideline is to inform and support the relevant health care professionals to:

Provide information on and discuss antenatal screening tests in accordance with the standards and recommendations outlined by the UK NSC, NHS England and the National Institute for Clinical Excellence (NICE) Clinical Guidance 62 as per links below:

https://www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc

https://www.gov.uk/topic/population-screening-programmes

Antenatal care (nice.org.uk) Overview | Antenatal care | Guidance | NICE

## 3. Key Responsibilities and Duties

There is a designated lead appointed for antenatal screening within the maternity services, who is a Consultant Obstetrician and Gynaecologist. The designated lead chairs the UHDB Hospital NHS Foundation Trust Antenatal & Newborn Screening Programme Board.
Supporting the lead is an Antenatal Screening Coordinator and Deputy Antenatal Screening midwives who are responsible for a Trust Wide uniform antenatal screening service in line with recommendations of the National Screening Committee. The antenatal screening team will inform women of high risk/screen positive results, providing access to information and support, refer as appropriate and provide a follow up appointment to a suitable professional/specialist in a timely manner.
Ongoing training for Midwives and Medical Practitioners will be provided and an ongoing monitoring system will be kept of antenatal screening activity of National Screening Committee programmes.

## 4. Abbreviations

| | | |
|---|---|---|
| AFP | - | Alpha-Fetoprotein |
| ANC | - | Antenatal Clinic |
| ANNB | - | Antenatal & Newborn |

| | | |
|---|---|---|
| CRL | - | Crown Rump Length |
| FASP | - | Fetal Anomaly Screening Programme |
| FBC | - | Full Blood Count |
| FMU | - | Fetal Medicine Unit |
| FOQ | - | Family Origin Questionnaire |
| GP | - | General Practitioner |
| HC | - | Head Circumference - |
| HIV | - | Human Immunodeficiency Virus |
| IDPS | - | Infectious Disease in Pregnancy Screening |
| GA | - | Gestational Age |
| KPI | - | Key Performance Indicator |
| MHHR | - | Maternity Hand Held Records |
| NCARDS | | National Congenital Anomaly Register |
| NIPE | - | Newborn and Infant Physical Examination |
| NSC | - | National Screening Committee |
| NT | - | Nuchal Translucency |
| NUH | - | Nottingham University Hospital |
| QHB | - | Queens Hospital Burton |
| RDH | - | Royal Derby Hospital |
| SC&T | - | Sickle Cell & Thalassaemia |
| SGA | - | Small for Gestational Age |
| UHDB | - | University Hospitals of Derby & Burton |

## 5. Provision of Patient Information

Information should be given to women when the blood tests are offered, in a form that is easy to understand to pregnant women with additional needs and to pregnant women who do not speak or read English (NICE 2021). Refer to UHDB handheld records.

Patient information about antenatal screening must be given to all pregnant women in early pregnancy. This can be done by signposting women to nationally accredited digital information, online or paper versions. It covers the risks and benefits of the screening tests on offer Screening tests for you and your baby (STFYAYB) - GOV.UK (www.gov.uk).

All women who accept antenatal screening blood test should be given clear information about how they will receive their results at the time the test is taken.

The Community Midwife will document in the appropriate “explained” tick box within the MHHR denoting that she has explained each of the individual blood tests and ultrasound scans, if the woman has accepted/declined and the date the test is taken.

Women should be advised on the availability of sexual health testing at any stage of pregnancy especially if the woman deems herself to be at risk; changes her sexual partner or identifies risk factors.

The screening information includes NHS screening for:

**Antenatal screening:**

- Sickle Cell and Thalassaemia (SC&T)
- Fetal Anomaly Screening Programmes (FASP) - Down’s syndrome, Edwards’ syndrome & Patau’s syndrome & Fetal Anomaly 20-week ultrasound scan
- Infectious Diseases in Pregnancy Screening (IDPS) - Hepatitis B, HIV, Syphilis.

The following newborn screening tests are also offered; these are covered in separate guidelines, see KOHA:

**Newborn screening:**

- Newborn Blood Spot Screening (NBSS)

- Phenylketonuria
- Cystic Fibrosis
- Congenital Hypothyroidism
- Sickle Cell
- Inherited metabolic diseases:
  - Medium Chain Acyl CoA Dehydrogenase Deficiency (MCADD)
  - Maple Syrup Urine Disease (MSUD)
  - Isovaleric Acidaemia (IVA)
  - Glutaric Aciduria type 1 (GA1)
  - Homocystinuria (pyridoxine unresponsive) (HCU)
  - Severe Combined Immunodeficiency (SCID)
- Newborn and Infant Physical Examination (NIPE)
- Newborn Hearing (NHSP)

## 6.0 Antenatal Screening tests

The antenatal screening tests offered at UHDB follows guidance from the National Screening Committee and includes:

- Sickle Cell and Thalassaemia (SC&T)
- Fetal Anomaly Screening Programmes (FASP) - Down's syndrome, Edwards' syndrome & Patau's syndrome & Fetal Anomaly 20-week ultrasound scan
- Infectious Diseases in Pregnancy Screening (IDPS) - Hepatitis B, HIV, Syphilis.

Screening tests are offered at appropriate times, following discussion with the woman; this is documented in the MHHR. At the initial booking visit with the Community Midwife, the women will be offered booking blood tests and samples will be obtained, if accepted at the initial booking visit:

| | |
|---|---|
| Haemoglobinopathy including sickle cell and thalassaemia | 8-9+6 weeks or as early as possible, aiming for a reported result by 10+0/40 |
| HIV | 8-9+6 weeks or as soon as attends |
| Syphillis | 8-9+6 weeks or as soon as attends |
| Hepatitis B | 8-9+6 weeks or as soon as attends |
| Down's syndrome (T21) 11+2 – 20+0. | Down's syndrome 11+2 – 20+0. This is the upper gestation screening window for T21. |
| Edward's syndrome (T18) and Patau's syndrome (T13) 11+2 - 14+1 | The screening window for Edward's syndrome and Patau's syndrome is 11+2 -14+1 weeks gestation.<br>Note screening for T18/13 after 14+1 weeks gestation is via the FASP 20-week scan. |
| Fetal Anomaly USS 18+0 – 20+6 weeks | The first attempt at the 20-week Fetal Anomaly USS should be between 18+0 – 20+6 weeks gestation. If the first attempt is incomplete, a second attempt should be undertaken by 23+0 weeks gestation. |

Women who have a miscarriage or terminate their pregnancy following screening test will need to receive their results via a letter if results are within normal parameters (see separate UHDB AN screening results *No Longer Pregnant* letter template in appendix and/or on Koha).

At QHB site it is the responsibility of the midwife who offered the test to send the letter to the woman and ensure a copy is in her medical records and copy to GP.

At RDH the screening team send result letters to women who are no longer pregnant and copy to GP.

If results are positive for infectious diseases, the woman will require a follow-up appointment. Carriers of sickle cell and thalassaemia will be given a follow up appointment via the screening team and RDH site and Haemoglobinopathy team.

Please note that the only antenatal screening programme considered NOT to be recommended as opt-out screening should be presented as an optional 'opt-in' choice, is Trisomy screening for Down's (T21), Edwards' (18) and Patau's (T13) syndromes.

Infectious Diseases in Pregnancy Screening (IDPS) for HIV, hepatitis B, syphilis; Sickle Cell and Thalassaemia (SC&T) screening and blood tests for Full Blood Count (FBC), blood grouping and red cell antibody screening are all nationally recommended opt-out screening / blood tests.

Women who decline a recommended screening test should be made aware that they can request the test at a later date if they choose and will be referred for discussion with one of the ANNB screening midwives. The tests, if accepted, will be undertaken at the earliest opportunity either within the community or in the hospital setting. It is a national standard that these tests routinely offered again before they are 20 weeks and opportunistically as appropriate (e.g. on admission in labour or the early PN period), which should be clearly documented

Woman DECLINES one or all recommended antenatal screening / blood tests at any gestation.

### 6.1 Late booking (20 weeks gestation and over) / un-booked and presenting in labour

Any woman who books late will be offered IDPS for hepatitis B, HIV, and syphilis, Sickle cell and Thalassaemia screening, Blood group and red cell antibodies at the venue that they first present. Samples marked urgent on the request form.

It is essential that women presenting un-booked in labour should be offered screening for the above tests if stage of labour allows, priority should be given to obtaining hepatitis B, HIV and Syphilis. These samples should be marked urgent, and the laboratory contacted to request urgent processing. If inappropriate due to advanced stage of labour the above screening should be offered in the immediate postnatal period and arrangements made to relay the results to the woman. An accurate history should be obtained from the woman to assess the risk of the woman of having one of the above and the assessment relayed to the obstetrician responsible for the woman. Arrangements by instigator of test must be made to review/action result. Preferably the woman should not be discharged home until the results have been reviewed because of the potential implications for baby.

### 6.2 Ultrasound Scans

Ultrasound scans in pregnancy are currently performed in the hospital. All women are routinely offered an ultrasound scan at around 12 weeks to establish single or multiple pregnancies, exact gestation, identify gross fetal abnormalities such as anencephaly and measure the nuchal translucency (NT) if a woman has decided to have screening or Down's syndrome, Edward's syndrome and Patau's syndrome.

All pregnant women should be offered a FASP ultrasound scan to screen for fetal anomalies, including the 11 auditable conditions, between 18+0 and 20+6 (NHS 2022) 11 physical conditions.

Screening for fetal anomalies via the 20-week scan should be discussed with a woman at first contact with a midwife to explain the purpose and implications of the anomaly scan. Specific information should include:

- The FASP anomaly scan is optional.
- The possibility that the scan may identify a fetal abnormality.

- Women should understand the limitations of routine ultrasound screening and that detection rates vary by the type of fetal anomaly.
- The woman's decision to accept or decline screening should be documented in the MHHR.

The screening pathway must be completed by $23^{+0}$ weeks. A National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) form should be completed and submitted at the time the anomaly is identified and following the baby's birth.
Antenatal Form (publishing.service.gov.uk) Delivery Data Collection Form (publishing.service.gov.uk) Post natal collection form (publishing.service.gov.uk)

**6.3 Women who decline screening**

If any woman declines HIV, Hepatitis B, Syphilis screening earlier in pregnancy the Screening team should be informed (as soon as possible ) via emailing: (QHB) bhft.antenatalscreening@nhs.net and RDH at dhft.antentalandnewbornscreening RDH@nhs.net

For further information please phone to discuss any queries screening tests on:
QHB Screening team 01283 511511 ext:4297 / ext:3100 or 07788 388473 or 07385 411592 or Antenatal Clinic 01283 511511 ext:4993 Monday - Friday 08:30 – 16:30

RDH Screening team 01332 789924 / 785435 / 07585966169 / 07385493357 or Antenatal Clinic 01332 785435 / 785142

**Midwife (community or acute) to:**

1. Discuss woman's reason for declining – offer appropriate support if needle phobic (refer to needle phobic guideline Division of Specialist Services (koha-ptfs.co.uk) or difficult venous access.

2. Refer to national information — Screening Tests for You and Your Baby booklet digital in different languages / easy read, screening animation and online ANNB resource tools. Screening tests for you and your baby (STFYAYB) - GOV.UK (www.gov.uk)

3. Advise all screening is nationally recommended in every pregnancy (except Trisomy screening for Down's, Edwards' and Patau's syndromes), which is optional.

4. Advise optimum screening window for bloods is 8 - 9+6 weeks gestation or at 1st contact with maternity services. National standard is result authorised in laboratory by 10+0 weeks for Sickle cell and Thalassemia.

5. Discuss recommendation for early screening to facilitate timely intervention for any issues identified and identify where an offer of prenatal diagnosis is appropriate for any genetically inherited conditions.

6. Advise on benefits of screening and risks of not being screened, as per individual screening programmes and blood tests.

7. Complete request form, ticking the test has been Declined and send form to Pathology.

8. Document woman's details proforma with action plan in right-hand column and follow up any screening test or blood results the woman may have selectively consented to within 10 working days.

9. Document in MHHR and on the EPR / IT system AN Review.

10. Advise she will be contacted by a specialist midwife for further appointment by 20 weeks; it is a national requirement to formally re-offer IDPS testing by 20 weeks gestation at a face-to-face meeting to:

    - Discuss her decision to decline and ensure that she is fully apprised of the benefits of screening for IDPS for her and the baby (to facilitate an informed choice)

- Reoffer the screening test and if accepted arrange testing and follow up of result

11. Reoffer of screening to take place by 20 weeks, at 28 weeks and on admission in labour if the woman has previously declined

12. Documented all offers of screening in the MHHR /or Maternity IT system .

14. Advise the woman that she can opt in / request a screening test at any gestation for screening blood tests if the tests were not time specific

15. Advise that if remains unscreened when baby is born, a referral to a paediatrician may take place to undertake a risk assessment to consider baby testing and/or prophylactic treatment of the newborn.

## 7.0 Obtaining consent

As a registered midwife, you must obtain consent before you give any treatment or care. Information should be accurate, truthful, and presented in such a way to make it easily understood (NMC 2020).

### 7.1 Individuals with Diagnosed Learning Disabilities

It should be recognised that individuals with a diagnosed learning disability may require additional specialist support for the discussion on antenatal screening.
The learning disability team should be contacted, and the named allocated worker should be involved. Where there is an identified advocate working with the individual, they would also be involved, providing consent has been given for this.

In cases where there has been a referral by, or the involvement of, the Children's Social Care Team or the Leaving Care Team then the named social worker will be informed of events. Additional discussions with the hospital Safeguarding Team should also take place as appropriate.

If the individual does not have a named, allocated worker then general information and guidance on an appropriate approach can be requested and is advised that the Trust Safeguarding team for vulnerable adults is contacted. Uhdb.safeguarding@nhs.uk

### 7.2 Consent for Use of Confidential Data

The woman must be informed of information sharing – results stored on IT system and shared if essential for care provision.

### 7.3 Consent for Infectious Diseases, Sickle Cell and Thalassaemia screening, taken at the initial community booking visit

The woman will be seen by the Community midwife where these antenatal tests will be offered. Verbal consent for the test/s will be supported by information in the appropriate language to reinforce that consent has been given. The midwife should respect the right of the woman to decline testing; however, the woman should be informed that she will be re-offered infectious disease screening by 20 weeks gestation by the screening team.

The CMW should aim to book women by 8-9 weeks gestation to ensure that the booking bloods are obtained as early as possible Early screening is recommend to expediate the clinical pathway and reproductive choice options in the event of a positive result. The Key Performance Indicator (KPI) for Sickle Cell and Thalassaemia is that all women are offered and screened with a result available by 10+0 weeks gestation.

The "Agreed to by mother" "yes" or "no" boxes for each individual test will be annotated as appropriate by the Midwife in the MHHR. The date of the sample taken along with the signature of the midwife responsible for ordering the test is recorded.

Women having blood tests should be informed at the time of the test how they will receive the result and they will be recorded in the MHHR at the next community appointment. Any positive

results the woman will be informed by the screening team within 3 working days.

**7.4 Consent for Screening Scans – Dating, Nuchal translucency and 18 – 20+6 week scan**

For 1st trimester screening please see operational guideline for Down's syndrome, Edwards' syndrome and Patau's syndrome screening. Offer and discuss and consent for first trimester screening (T21, T18, T13) and second trimester screening (T21 only) and complete section in MHHR reflecting that discussion and consent for both screening tests has been discussed by the community midwife.

The "Agreed to by mother" "yes" or "no" boxes for the early scan will be annotated and signed as appropriate by the professional performing the early scan in the MHHR.

Women who decline the screening scans should be notified to the Antenatal Screening Team through using the following process: E-mail QHB bhft.antenatalscreening@nhs.net and RDH dhft.antenatalandnewbornscreeningRDH@nhs.net

It is essential that the NUH Trisomy blood form is completed completely otherwise it will be rejected. Ensure that the pregnant woman is aware that she must bring her MHHR and the Trisomy blood form with her for the booking scan so that the screening bloods can be taken. This is the responsibility of the community midwife who undertakes the initial booking.

## 8.0 Ensuring Bloods Sample have been Taken and Tested for all Screening above

It is the responsibility of the practitioner who requested and consented the woman to perform the test, whether that be a Community Midwife or staff within the hospital. Note- this means even if the women is given a blood form to take to a phlebotomy or given to the women to attend an appointment at a hospital, it remains the responsibility of the practitioner who requested and consented the woman to confirm the sample has been obtained/processed/result actioned.

**8.1 Blood tests taken by Community Midwives**

When the community midwife has consent and obtains a blood test it must be logged on the blood test log form held within the clinic base. If the community midwife has given the woman a blood request form to be taken via phlebotomy/antenatal clinic it remains the responsibility of the community midwife to review the result. Any actions taken for results that deviate from normal/require repeating will be logged on blood test log form.

**8.2 Ensuring Ultrasound Scans are completed (where consented to)**

Where a woman fails to attend an outpatient ultrasound scan for the initial dating/screening scan, the antenatal clinic coordinator will be informed by the receptionist who will give the coordinator the patient's hospital records. The ANC midwives will review the hospital notes and make enquiries where appropriate (i.e. miscarriage) and inform the community midwife to confirm pregnancy is on-going.

For the 18 - 20+6 weeks scan a second appointment is sent. The midwife will attempt to notify the woman/Community midwife is informed by telephone to ensure a pregnancy is ongoing prior to issuing a further appointment.

All actions and decisions will be documented on the antenatal clinic summary sheet in the patient's health records by the screening team or on the IT system V6/Lorenzo. Ensure the non-engagement guideline is followed for support in these cases.

## 9.0 Monitoring Compliance and Effectiveness

As per agreed business unit audit forward programme

## 10.0 References


Fetal anomaly screening programme handbook - GOV.UK (www.gov.uk)

Diabetic eye screening: programme overview - GOV.UK (www.gov.uk)

Infectious diseases in pregnancy screening: standards - GOV.UK (www.gov.uk)

Infectious diseases in pregnancy screening programme: laboratory handbook - GOV.UK (www.gov.uk)

Newborn blood spot screening: standards - GOV.UK (www.gov.uk)

Cystic fibrosis: screening laboratory handbook - GOV.UK (www.gov.uk)

Laboratory guide to screening for CHT in the UK - GOV.UK (www.gov.uk)

Newborn blood spot screening: laboratory guide for IMDs - GOV.UK (www.gov.uk)

Newborn hearing screening programme: standards - GOV.UK (www.gov.uk)

Newborn and infant physical examination screening: standards - GOV.UK (www.gov.uk)

Sickle cell and thalassaemia screening programme: standards - GOV.UK (www.gov.uk)

**Screening results letter template for women who are No Longer Pregnant**

NHS
University Hospitals of Derby and Burton
NHS Foundation Trust

Patient Hospital N° – *[insert]*
NHS N° – *[insert]*
Date of letter: *[insert]*

**Private and Confidential**
*Address [insert address]*
*Address*
*Address*
*Address*

Dear [*insert name*]

**Re: Screening and Blood Results**
We have been informed that you had some blood tests taken by the community midwife on *[insert date]* and apologies for contacting you at this time. We have a duty of care to give results to all women who undertake any screening or testing. It is also important for your future health that you are aware of your results. A copy of this letter has been sent to your GP practice to update your health records.

We wish to inform you that the results of the blood tests were all within normal ranges:

- Sickle Cell and Thalassaemia – (*add result and commentary as needed)*
- Full Blood Count – (*add result and commentary as needed)*
- Blood Group – (*add result and commentary as needed)*
- HIV – (*add result and commentary as needed)*
- Syphilis – (*add result and commentary as needed)*
- Hepatitis B – (*add result and commentary as needed)*

We recommend that you check with your GP practice to ensure you have had **2 doses of the MMR** (measles, mumps, and rubella) vaccine at some point in your life (which includes childhood). You need this vaccine for your own protection but also to protect any future pregnancies against infection with rubella. If you would like to discuss anything further, please contact:

Derby on 01332 785435 / 789924.
Burton on 01283 511511 ext 4297 / 3100

For further support, contact:

- The Miscarriage Association info@miscarriageassociation.org.uk; Pregnancy Loss Helpline 01924 200799 (Monday to Friday 9am to 4pm)
- Antenatal Results and Choices (ARC) info@arc-uk.org; Helpline 0845 077 2290 or 0207 713 7486 (Monday to Friday 10.00am to 5.30pm)

Yours sincerely,
UHDB Screening Team

CC GP:

**Private and Confidential**

MISCARRIAGE ASSOCIATION
The knowledge to help

ARC
Antenatal Results & Choices

**Documentation Control**

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|---|---|---|---|---|
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| Version / Amendment | Version | Date | Author | Reason |
| | 6 | March 2016 | E. MacGregor Specialist Midwife Antenatal Screening Co-ordinator | Amended in light of PHE recommendations re Rubella screening |
| **WC/OG/12** | **Burton Trust prior to merged document:** | | | |
| | 9 | May 2018 | Annette Haynes, MW Lead for AN Screening | Inclusion of section 8.6 Managing Screening Safety Incidents in response to ANNP recommendations |
| **Version control for UHDB merged document:** | | | | |
| | 1 | August 2022 | Jo Wallace – Deputy HOM<br>Rachel McLean - Antenatal and Newborn Screening Lead Midwife | Review / merge |
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| Key Contact: | Joanna Harrison-Engwell | | | |