Screening tests for you and your baby

Important information about the screening choices you will have during and after your pregnancy
This booklet gives you information on the screening tests you will be offered during your pregnancy and after your baby is born. It explains the different types of test and what the tests are looking for.

We hope that reading this booklet will help prepare you for discussions with your midwife or doctor so that you can ask the questions that are important to you. It will be helpful if you have the booklet with you when you see them.

It is your decision whether or not to have any of the tests described in this booklet.
Index

What you need to know about screening

Screening tests during your pregnancy

- **Infectious diseases**
  - Page 8-11
- **Sickle Cell and Thalassaemia**
  - Page 12-17
- **Down's, Edwards' and Patau's syndromes**
  - Page 18-25
- **Physical abnormalities (mid pregnancy scan)**
  - Page 26-31
- **Eye problems in women with diabetes**
  - Page 32-35

Screening tests for your newborn baby

- **Heart, eyes, hips and testes (physical examination)**
  - Page 36-39
- **Hearing loss**
  - Page 40-43
- **Blood spot**
  - Page 44-49
Introduction
What you need to know about screening

What are screening tests?
Screening tests are used to find people at higher risk of a health problem. This means they can get earlier, potentially more effective, treatment or make informed decisions about their health. It can be helpful to imagine screening like putting people through a sieve. Most people pass straight through but a small number get caught in the sieve. The people caught in the sieve are those considered to be at higher risk of having the health problem being screened for.

Screening tests are not perfect. Some people will be told that they or their baby are at high risk of having a health problem when in fact they do not have the problem. Also a few people will be told that they or their baby are at low risk of having a health problem when in fact they do have the problem.

What is the difference between screening tests and diagnostic tests?
A screening test can find out if you, or your baby, are at high or low risk of having a health problem. But it cannot usually tell you for certain, so people found to be at high risk of a problem will often be offered a second test. This is called a diagnostic test and gives a more definite 'yes' or 'no' answer.
Screening tests during and after pregnancy
You will be offered screening tests during pregnancy to try to find any health problems that could affect you or your baby. The tests can help you to make choices about care or treatment during your pregnancy or after your baby is born.

Some screening tests are offered for your baby soon after he or she is born. We offer these so that your baby can be given appropriate treatment as quickly as possible if needed.

Some practicalities
If you know that you, the father of the baby, or a family member already has the health problem being screened for, please tell your midwife.

If you move home while you are waiting for the results of any screening test, please tell your midwife or health visitor your new address.

Do I have to have the screening tests?
Whether or not to have a screening test is always a personal choice and one which only you can make. You can discuss each of the screening tests you are offered with your health professionals and decide, based on your own circumstances, whether or not it is right for you.
Some of the screening tests described in this booklet such as blood tests for infectious diseases, eye screening if you have diabetes, and the newborn checks are recommended by the NHS. This is because results from these tests can help make sure that you or your baby gets urgent treatment for serious problems.

Screening tests in pregnancy for sickle cell disease and thalassaemia, Down’s syndrome and the mid pregnancy scan can lead to difficult decisions such as whether or not to have a diagnostic test with a possible risk of miscarriage. Diagnostic tests can lead to a decision about whether to continue or end your pregnancy. Having a further test or termination will always be your decision and health professionals will support you, whatever you decide. You may want to think carefully about whether or not you want to have these screening tests.

**Screening and the NHS**
The NHS decides which screening tests to offer based on good evidence. A group of experts called the United Kingdom National Screening Committee (UK NSC) provide advice to the NHS.
All screening tests provided by the NHS are free. Some private companies also provide screening tests that you have to pay for. The NHS cannot guarantee the quality of private screening. More advice is available at www.screening.nhs.uk/private-screening.

Confidentiality
By law, everyone working in, or on behalf of, the NHS must respect your privacy and keep all information about you safe. The NHS Constitution sets out how the NHS should handle your records to protect your privacy. In addition there are laws in place to ensure confidentiality is maintained.

Screening records are only shared with staff who need to see them. This process is strictly managed. Sometimes information is used for audit and research purposes to improve screening outcomes and services. Information will be provided to you when you are screened.

Further support
For a list of organisations that can provide further support about any of the conditions mentioned in this booklet, please see www.screening.nhs.uk/support-organisations.
Infectious diseases

What is the screening test for?
To find out if you have hepatitis B, HIV (human immunodeficiency virus), syphilis or need a vaccination for rubella (German measles) after your baby is born. Women already known to have HIV or hepatitis B need early specialist appointments to plan their care in pregnancy.

About these conditions
Hepatitis B and HIV are passed on in blood and body fluids through sexual contact or infected needles. These viruses can also be passed from mother to baby.

**Hepatitis B** virus affects the liver and can cause acute (immediate) and chronic (long-term) ill-health. Specialist care is needed for pregnant women with hepatitis B. Vaccination of the baby in the first year of life greatly reduces the risk of the baby developing hepatitis B.

**HIV** weakens the immune system making it difficult to fight off infections. It can eventually lead to AIDS (acquired immune deficiency syndrome). If untreated, it can be passed from mother to baby in pregnancy, when giving birth or by breastfeeding. Treatment in pregnancy greatly reduces the risk of passing on HIV to the baby from 1 in 4 (25%) to less than 1 in a 100 (1%).

**Syphilis** is an infection passed on through sexual contact. It can be passed from mother to baby during pregnancy. If it
is untreated, it can result in serious health problems for the baby or cause miscarriage or stillbirth.

**Rubella** is usually a mild infection in the mother. If a pregnant woman becomes infected in the first 12 weeks her baby has around a 9 in 10 chance of problems such as heart defects, cataracts and deafness. The risk is much lower if infection occurs later in the pregnancy.

**What does the test involve?**
A blood sample is taken from your arm.

**Can this test harm me or my baby?**
There are no risks associated with the test.

**Do I need to have this test?**
These tests are recommended to protect your health through early treatment and care and to greatly reduce any risk of passing an infection onto the baby, partner or other family members.

Thanks to screening, England now has its lowest ever rate of mother-to-child HIV transmission.
Infectious diseases

If you develop a rash-like illness while you are pregnant, or come in contact with someone who has, it is very important to contact your midwife or doctor straight away.

What if I decide not to have this screening test?
You will be reoffered screening later in pregnancy, at around 28 weeks. You can request retesting for hepatitis B, HIV or syphilis at any time if you change your sexual partner or think you are at risk.

Possible results
The tests will tell you if you have any of these infections and if you are immune to rubella.

If you have **hepatitis B** specialist teams will monitor your health in pregnancy and after the baby is born. Your partner and any other children may need testing and vaccination. To prevent the baby getting hepatitis they need four vaccinations:

- within 24 hours after birth
- at one month of age
- at two months of age
- a final vaccination at one year of age with a blood test to check if infection has been avoided.

It is very important that the baby has all four doses of the vaccine to protect their health.
If you have HIV you can greatly reduce the risk of passing HIV on to the baby with the specialist care and treatment, drugs, planned care for your birth, and by not breastfeeding.

If you have syphilis urgent referral to a specialist team is needed. Treatment is usually a course of antibiotics. The team will also offer to test your partner to see if they need treatment. The baby may need antibiotics after birth.

If your test shows you are not immune to rubella you will be offered two doses of the MMR vaccine (to protect against measles, mumps and rubella) after the baby is born. The first dose is given before going home from hospital. Your GP will generally offer you the second dose.

**Getting my results**
Results will usually be discussed before or at your next antenatal visit and recorded in your notes.

A health professional will contact you if you have a positive screening test result for HIV, syphilis or hepatitis B to arrange appointments to discuss results and referral to specialist services.