

Screening Programmes

Screening tests for you and your baby






Important information about the screening choices
you will have during and after your pregnancy






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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.

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.

Partners are welcome to attend screening and information sessions

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.gov.uk/private-screening-for-health-conditions-nhs-recommendations

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 details of organisations that can provide further support about any of the conditions mentioned in this booklet, please see NHS Choices.

If your routine smear test is due while you are pregnant - you'll probably need to reschedule for 12 weeks after giving birth



Infectious diseases

[nhs.uk/infections](https://www.nhs.uk/infections)

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?

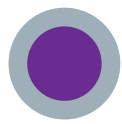
There are no risks associated with the test.

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 your child needs hepatitis B vaccination, make sure you get all four doses

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.

You can ask to be retested at any time if you think you are at risk of any of these infections



Sickle Cell and Thalassaemia

nhs.uk/sct

What is the screening test for?

To find out if you are a carrier of the sickle cell or thalassaemia gene and therefore likely to pass it on to the baby.

About these conditions

Sickle cell disease (SCD) and thalassaemia major are serious, inherited blood diseases. They affect haemoglobin, a part of the blood that carries oxygen around the body. People who have these conditions will need specialist care throughout their lives.

People with SCD can have attacks of very severe pain, get serious, life-threatening infections and are usually anaemic (their bodies have difficulty carrying oxygen). Babies with SCD can receive early treatment, including immunisations and antibiotics, which, along with support from their parents, will help prevent serious illness and allow the child to live a healthier life.

People with thalassaemia major are very anaemic and need blood transfusion every 4 to 6 weeks and injections and medicines throughout their lives.

It is best to have the test before you are 10 weeks pregnant

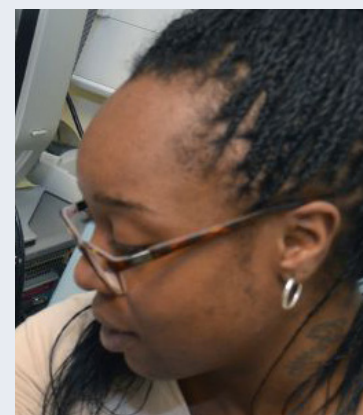
There are also other, less common, less serious haemoglobin diseases that may be found.

Sickle cell and thalassaemia are inherited diseases that are passed on from parents to children through unusual haemoglobin genes. Genes are the codes in our bodies for things such as eye colour and blood group. Genes work in pairs. For everything that we inherit we get one gene from our mother and one from our father.

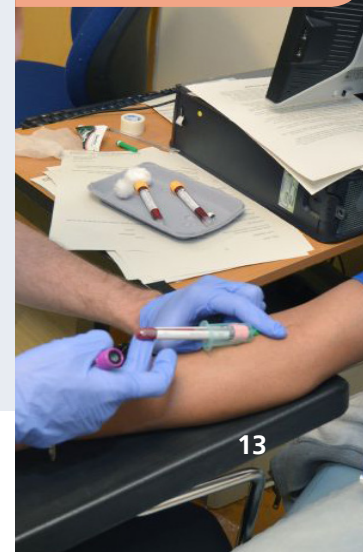
People only have sickle cell or thalassaemia if they inherit two unusual haemoglobin genes – one from their mother, and one from their father. People who inherit just one unusual gene are known as 'carriers' (some people call this having a 'trait'). Carriers are healthy and do not have the disease, although they can experience some problems in situations where their bodies might not get enough oxygen, for example, having an anaesthetic.

When **both parents** are carriers each baby has:

- a 1 in 4 (25%) chance of not being affected - the baby will not have or carry a disease
- a 1 in 4 (25%) chance of inheriting both unusual haemoglobin genes and having a haemoglobin disease



Both parents need to be a carrier for your child to be affected





Sickle Cell and Thalassaemia

- a 2 in 4 (50%) chance of inheriting one unusual haemoglobin gene and being a carrier.

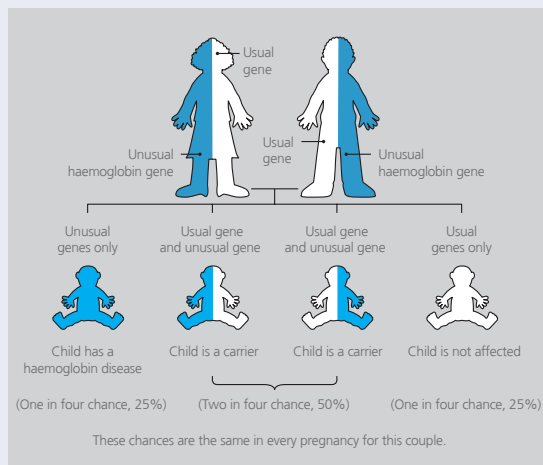
Anyone can be a carrier of a haemoglobin disease. However, it is more common among people whose ancestors come from Africa, the Caribbean, the Mediterranean, India, Pakistan, South and South-East Asia and the Middle East.

What does having the screening test involve?

Screening in pregnancy for sickle cell and thalassaemia involves having a blood test. It is best to have the test before you are 10 weeks pregnant.

All pregnant women are offered a test for thalassaemia but not all women are automatically offered a test for sickle cell. The screening offered depends on where you live.

In areas where haemoglobin diseases are more common you will be offered a blood test for sickle cell. In areas where haemoglobin diseases are less common a



questionnaire is used to identify the baby's mother and father's family origins. If the questionnaire shows that either parent is at risk of being a sickle cell carrier, a screening test is offered to the woman.

You can ask to have the test even if your family origins do not suggest the baby would be at high risk of a haemoglobin disease.

Can this screening test harm me or my baby?

The screening test cannot harm you or the baby but it is important to consider carefully whether to have this test or not. The screening test can provide information that may mean you have to make further important decisions. For example, you may be offered further tests that have a risk of miscarriage.

Do I need to have this test?

You do not have to have the screening test. Some people want to find out if their baby has sickle cell disease or thalassaemia and some do not.

What if I decide not to have this test?

If you choose not to have the screening test in pregnancy, the baby can have newborn blood spot screening for sickle cell disease at five days of age.

Dads – if the mum is a carrier it's important for you to get tested too



Sickle Cell and Thalassaemia

Possible results

The test will tell you if you are a carrier or not, or whether you have the disease yourself.

Will I need any further tests?

If you are a carrier of a haemoglobin disease, the baby's father will be offered a blood test. If the baby's father is also a carrier you will be offered diagnostic tests to find out if the baby is affected.

If the baby's father is not available and you have been identified as a carrier you will be offered the diagnostic test.

About 1 in 100 (1%) of diagnostic tests result in a miscarriage. It is up to you whether or not to have the further test.

There are two types of diagnostic test.

CVS (chorionic villus sampling) is usually done from 11 to 14 weeks of pregnancy. A fine needle, usually put through the mother's abdomen, is used to take a tiny sample of tissue from the placenta. The cells from the tissue can be tested for sickle cell or thalassaemia.

Amniocentesis is usually done after 15 weeks of pregnancy. A fine needle is passed through the mother's abdomen into the uterus to collect a small sample of the fluid surrounding

the baby. The fluid contains some of the baby's cells, which can be tested for sickle cell or other thalassaemia.

If the result shows that the baby has sickle cell or thalassaemia then you will be offered an appointment with a health professional. You will be able to get information about the condition the baby has inherited and talk through your choices. Some conditions are more serious than others. Some women decide to continue with the pregnancy; others decide they do not want to continue with the pregnancy and have a termination.

If you are faced with this choice you will get support to help you make a decision.

If the test shows that you are a carrier, there is a chance that other members of your family could be carriers too. You may want to encourage them to ask for a test, especially if they are planning to have a baby.

Getting my results

The person doing the test will discuss the arrangements for providing your result.





Down's, Edwards' and Patau's syndromes

nhs.uk/downs

What is the screening test for?

To find out how likely it is that the baby has Down's syndrome (also known as Trisomy 21 or T21), Edwards' syndrome (Trisomy 18 / T18) or Patau's syndrome (Trisomy 13 / T13).

If you are expecting twins these screening tests are also offered to you.

About these conditions

Inside the cells of our bodies there are tiny structures called chromosomes. These chromosomes carry the genes that determine how we develop. There are 23 pairs of chromosomes in each cell. Problems can occur when the sperm or egg cells are produced which can lead to a baby having an extra chromosome.

Down's syndrome (T21)

In Down's syndrome there is an extra copy of chromosome 21 in each cell.

A baby born with Down's syndrome will have a learning disability. This means they will find it harder than most people to understand and to learn new things. They may have communication problems and difficulty managing some

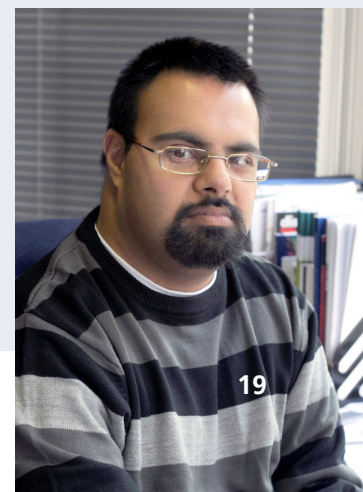
everyday tasks. It is impossible to know what level of learning disability a baby with Down's syndrome will have. It can vary from mild to severe.

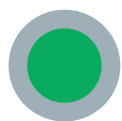
Most children with Down's syndrome attend mainstream primary school. A lot is now known about how to develop the potential of children with Down's syndrome. People with Down's syndrome can have a good quality of life. With support from their family and others, many people are able to get jobs and live fairly independently.

Some health problems are more common in people with Down's syndrome, for example, heart conditions, and problems with the digestive system, hearing and vision. Some problems can be serious but many can be treated. With good healthcare, someone with Down's syndrome is expected to live to around 60 years.

People with Down's syndrome have almond shaped eyes and distinctive facial features but they do not all look the same. Like all children, they also inherit features from their parents.

Anyone can have a baby with Down's syndrome, not just older mums





Down's, Edwards' and Patau's syndromes

Edwards' syndrome (T18) and Patau's syndrome (T13)

In T18 there is an extra copy of chromosome 18 in each cell. Similarly, in T13 there is an extra copy of chromosome 13 in each cell.

Sadly, most babies with Edwards' or Patau's syndrome will die before they are born, be stillborn or die shortly after birth. Some babies may survive to adulthood but this is rare.

All babies born with Edwards' and Patau's syndrome will have a wide range of problems, which are usually extremely serious - these may include major brain abnormalities.

Babies affected by T18 can have heart problems, unusual head and facial features, growth problems and be unable to stand or walk.

T18 affects about 3 of every 10,000 births.

Babies affected by T13 can have heart problems, a cleft lip and palate, growth problems, poorly formed eyes and ears, problems with their kidneys and be unable to stand or walk.

T13 affects about 2 of every 10,000 births.

Some hospitals might not offer earlier screening for T18 / T13 until early 2016

What does the test involve?

A screening test for these conditions is available between 10 and 14 weeks of pregnancy. This is called the 'combined test'.

If you choose to have the combined test, a blood sample is taken from you. At the dating ultrasound scan the fluid at the back of the baby's neck is measured (known as the nuchal translucency). The information from these two tests is used to work out the risk of the baby having T21 and T18 / T13.

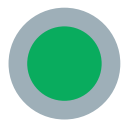
If you are too far on in your pregnancy to have the combined test for T21, you will be offered a blood test between 14 and 20 weeks of pregnancy. This test is not quite as accurate as the combined test.

If you are too far on in your pregnancy to have the combined test for T18 / T13, you will be offered a mid pregnancy scan which will look for physical abnormalities.

Can this screening test harm me or my baby?

The screening test cannot harm you or the baby but it is important to consider carefully whether to have this test or not. This test cannot tell you if the baby definitely has Down's syndrome or Edwards' and Patau's syndrome or not. The screening test can provide information that may lead to further important decisions. For example, you may be offered diagnostic tests that have a risk of miscarriage.

It is your decision whether or not to have screening



Down's, Edwards' and Patau's syndromes

Do I need to have this test?

You do not have to have the screening test. Some people want to find out if their baby has Down's syndrome or Edwards' and Patau's syndromes and some do not.

You can choose to have screening for:

- all the conditions (T21 and T18 / T13)
- T21 only
- T18 / T13 only
- none of the conditions

What if I decide not to have this test?

If you choose not to have the screening test for Down's, Edwards' and Patau's syndromes you can still choose to have other tests.

If you choose not to have the screening test for these conditions it is important to understand that if you have a scan at any point during your pregnancy it could pick up physical abnormalities. These could be related to T21 or T18 / T13 but there is a chance that other problems could be picked up on a scan. The person scanning you will always tell you if any abnormalities are found.

Possible results

You will be given two risk results: one for T21 and another for T18 / T13.

If the screening test shows that the chance of the baby having Down's or Edwards' and Patau's syndrome is lower than 1 in 150 this is called a 'lower-risk' result. Over 95 out of a 100 (95%) of screening test results will be lower risk.

A lower-risk result does not mean that there is no risk at all of the baby having T21 or T18 / T13.

If the screening test shows that the chance of the baby having Down's, Edwards' and Patau's syndrome is higher than 1 in 150, that is from 1 in 2 to 1 in 150, this is called a 'higher-risk' result. Fewer than 1 in 20 (5%) of screening test results will be higher risk.

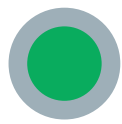
A higher risk result does not mean the baby definitely has T21 or T18 / T13.

Will I need further tests?

If you have a lower risk result you will not be offered a further test.

If you have a higher risk result you will be





Down's, Edwards' and Patau's syndromes

offered a diagnostic test to find out whether the baby has Down's or Edwards' and Patau's syndrome or not.

Diagnostic tests for Down's syndrome will also look at chromosomes 18 and 13 so will also tell you whether the baby has Edwards' and Patau's syndrome or not. Similarly, diagnostic tests for Edwards' and Patau's syndrome will also look at chromosome 21 for Down's syndrome.

About 1 in a 100 (1%) of diagnostic tests result in a miscarriage. It is up to you whether or not to have the further test.

There are two types of diagnostic test.

CVS (chorionic villus sampling) is usually done from 11 to 14 weeks of pregnancy. A fine needle, usually put through the mother's abdomen, is used to take a tiny sample of tissue from the placenta. The cells from the tissue are then tested for T21 and T18 / T13.

Screening
doesn't give
definite
answers.
That's why
you may be
offered a
diagnostic test

Amniocentesis is usually done after 15 weeks of pregnancy. A fine needle is passed through the mother's abdomen into the uterus to collect a small sample of the fluid surrounding the baby. The fluid contains cells from the baby, which are tested for T21 and T18 / T13.

A small number of women who have the diagnostic test will find out their baby has Down's or Edwards' and Patau's syndrome. They then have two options. Some women decide to continue with the pregnancy and prepare for their child with the condition; others decide they do not want to continue with the pregnancy and have a termination.

If you are faced with this choice you will get support to help you make a decision.

Getting my results

If your screening test shows a lower risk result, you should be told within two weeks of the test being taken.

If your screening test shows a higher risk result, you should be told within three working days of the blood test result being available. You will be offered an appointment to discuss the test results and the further options you will have.



Physical abnormalities (mid pregnancy scan)

[nhs.uk/anomalyscan](https://www.nhs.uk/anomalyscan)

What is the scan for?

To look for physical abnormalities in the baby.

The scan only looks for certain problems in the baby and cannot find everything that might be wrong.

About the conditions that the scan will look for

The scan will look in detail at the baby's bones, heart, brain, spinal cord, face, kidneys and abdomen.

In most cases the scan will show that the baby appears to be developing as expected but sometimes a problem is found or suspected. Some problems can be seen more clearly than others. For example, some babies have a problem called open spina bifida, which affects the spinal cord. Spina bifida can usually be seen clearly on a scan and of those babies who have this problem, around 9 out of 10 (90%) will be detected. Some other problems, such as heart defects, are more difficult to see. The scan will find about half (50%) of those babies who have heart defects.

The scan looks for certain physical abnormalities but can't find everything that could be wrong

Some of the problems that can be seen on the scan will mean the baby may need treatment or surgery after it is born, for example cleft lip. In a small number of cases some very serious problems are found, for example, the baby's brain, kidneys, internal organs or bones may have not developed properly. In some very serious, rare cases where no treatment is possible, the baby will die soon after it is born or may die during the pregnancy.

For more detailed information about the main conditions that are looked for during the mid pregnancy scan please see www.nhs.uk/anomalyscan

What does having the screening test involve?

The scan for these conditions usually takes place between 18 weeks and 20 weeks and 6 days of pregnancy.

Most scans are carried out by specially trained staff called sonographers. In order for the sonographer to get good images of the baby,





Physical abnormalities (mid pregnancy scan)

the scan is carried out in a dimly lit room. You will be asked to lie on a couch. You will then be asked to raise your top to your chest and lower your skirt or trousers to your hips. Tissue paper will be tucked around your clothing to protect it from the ultrasound gel, which will then be put on your tummy. The sonographer then passes a hand-held probe over your skin to examine the baby's body. The gel makes sure there is good contact between the probe and your skin.

Having the scan does not hurt but the sonographer may need to apply slight pressure to get the best views of the baby. This might be uncomfortable. A black and white picture of the baby will then be seen on the ultrasound screen. During the examination, sonographers need to keep the screen in a position that gives them a good view of the baby. The screen may be directly facing them or at an angle.

The appointment usually takes around 30 minutes. Sometimes it is difficult to get a good picture if the baby is lying in an awkward position, is moving around a lot or if you are above average weight; this does not mean there is anything to worry about. You may need to have a full bladder when you come for the appointment. The doctor or midwife looking after you will let you know before you come. If you

You may
be offered
further tests
if a problem
is suspected

are not sure, you can contact them and ask.

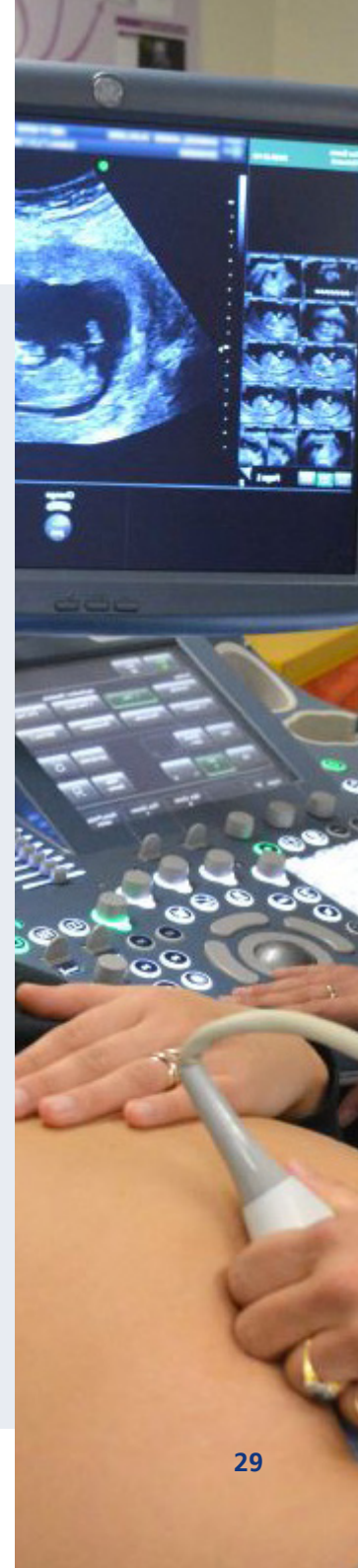
The mid pregnancy scan can sometimes find problems with the baby. You may like someone to come with you to the scan appointment. Most hospitals do not allow children to attend scans as childcare is not usually available. Please ask your hospital about this before your appointment.

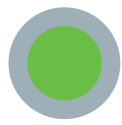
Can this scan harm me or my baby?

There are no known risks to the baby or the mother from having an ultrasound scan but it is important that you consider carefully whether to have the scan or not. The scan can provide information that may mean you have to make further important decisions. For example, you may be offered further tests that have a risk of miscarriage.

Do I need this scan?

You do not have to have the scan. Some people want to find out if their baby has problems and some do not.





Physical abnormalities (mid pregnancy scan)

What if I decide not to have this scan?

If you choose not to have the scan your antenatal care will continue as normal.

Possible results

Most scans show that the baby seems to be developing as expected, and no problems are found.

If any problem is found or suspected, the sonographer may ask for a second opinion from another member of staff.

Scans cannot find all problems. There is always a chance that a baby may be born with a health problem that scans could not have identified.

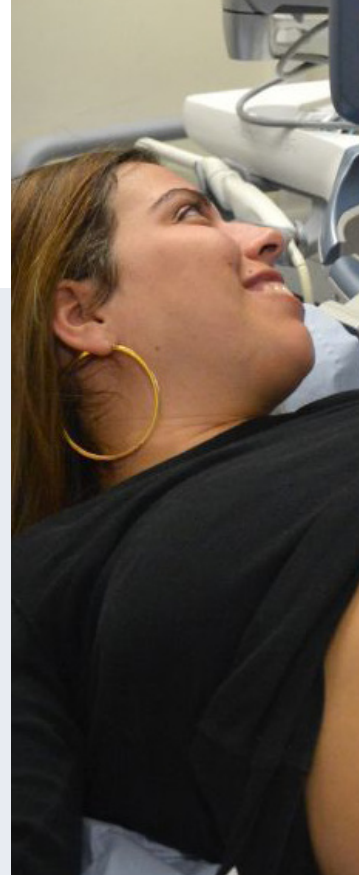
Will I need further tests?

You might be offered another test to find out for certain if there is a problem.

If you are offered further tests you will be given more information about them so that you can decide whether or not you want to have them. You will be able to discuss this with your midwife or consultant. If necessary, you will be referred to a specialist, possibly in another hospital.

Getting my results

The sonographer will be able to tell you the results of the scan at the time.





Eye problems in women with diabetes

nhs.uk/diabeticeye

What is the test for?

To check for signs of diabetic retinopathy and other eye problems caused by diabetes and monitor the health of your eyes if you are pregnant and have type 1 or type 2 diabetes. You will not need diabetic eye screening if you did not have diabetes before pregnancy.

About this condition

Diabetic retinopathy is caused when diabetes affects the small blood vessels in the retina at the back of the eye.

Everyone with diabetes is offered eye screening but screening is very important when you are pregnant because the risk of serious eye problems is greater.

What does having the test involve?

You will be offered screening at, or soon after, your first antenatal clinic visit and also after 28 weeks of pregnancy. If early stages of retinopathy are found at the first screening, you will be offered another test between 16 and 20 weeks of pregnancy. If serious retinopathy is found at any screening, you will be referred to an eye specialist.

Screening will only be offered if you already had diabetes before you were pregnant

Retinal screening in pregnancy is the same as routine eye screening when you have diabetes.

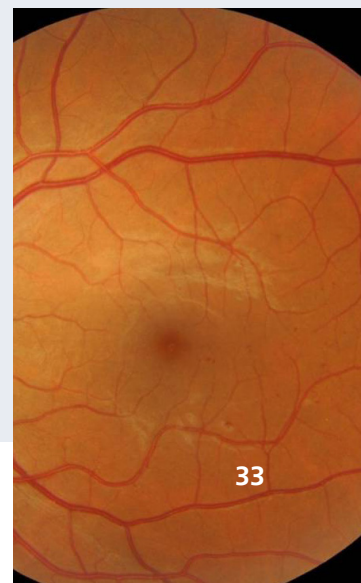
Screening staff will record your details and level of sight. They will put drops in your eyes to make your pupils larger so the retinas can be seen more clearly and take digital photographs of your retinas.

If the images are not clear enough you will be referred to an eye specialist for a different test.

Can this screening test harm me or my baby?

The photograph is painless and the camera does not come into contact with the eye. The eye drops may sting for a few seconds and cause blurred vision for 2-6 hours after the test. Take all your usual spectacles with you. Take sunglasses with you to wear home, as everything may look very bright after the screening test.

Diabetic retinopathy is treatable, especially if caught early





Eye problems in women with diabetes

Arrange to use public transport or get a lift for the journey home. **You should not drive after screening as the eye drops can blur vision.**

Very rarely, the drops can cause a sudden, dramatic rise in pressure within the eye. Symptoms of pressure rise include:

- pain or severe discomfort in the eye
- redness of the white of the eye
- constantly blurred sight.

If you experience any of these symptoms after screening, you should return to the eye unit or go to an Accident and Emergency department.

Do I need this test?

This test is strongly recommended if you already had diabetes before getting pregnant.

Eye screening is a part of managing your diabetes and diabetic retinopathy is treatable, especially if it is caught early.

What if I decide not to have this test?

People with diabetes can decide not to attend eye screening appointments.

If you decide not to have the test you should notify the clinician looking after your diabetes care during pregnancy.

Possible results

If you have the screening test, possible results are:

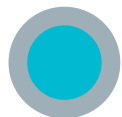
- no retinopathy
- early signs of retinopathy
- more serious retinopathy that requires referral to a specialist.

If your test shows early signs of retinopathy, your health professional will give you advice about looking after your diabetes during pregnancy and you will be invited for additional screening tests during your pregnancy. If you are a smoker, seek help to stop or at least cut down.

If the test shows you have referable retinopathy you will receive an appointment with an eye specialist.

Getting my results

A letter will be sent to you and your GP within 6 weeks following your screening appointment.



Heart, eyes, hips and testes (physical examination)

nhs.uk/newborninfantexam

What is the screening test for?

Within 72 hours of giving birth, you will be offered an all over physical examination for your baby. This will include four specific screening tests to find out whether your baby has a problem with their eyes, heart, hips or, in boys, their testes that would benefit from early investigation and possible treatment.

The screening tests are carried out again between 6-8 weeks of age as some conditions do not develop or appear until then.

About the conditions

Each of the parts of the physical examination is looking for different conditions.

Eyes – the examination checks the appearance and movement of the eyes and investigates whether your baby has cataracts and other problems. About 2 or 3 in 10,000 babies are born with cataracts. The examination cannot tell how well your baby can see.

Screening is part of a top-to-toe physical examination of your baby

Heart – there is a general examination of your baby's heart and sometimes murmurs are picked up.

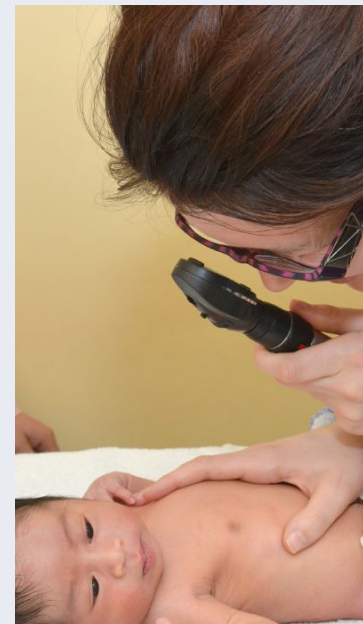
A murmur is a noise made by the blood as it passes through the heart. In almost all cases when a murmur is heard, the heart is normal. Murmurs are common in babies and this does not always mean there is a problem. However, around 1 in 200 babies have a heart problem that needs treatment.

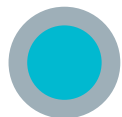
Hips – babies can be born with hip joints that are not formed properly and if untreated this can lead to a limp and to joint problems. About 1 or 2 in 1,000 babies have hip problems that need treatment.

Testes – baby boys are checked to make sure their testes are in the right place, for example, that they have descended. It can take several months for testicles to drop down into the scrotum. About 1 in 100 baby boys have problems with undescended testes that need treatment to reduce the risk of problems later in life, such as reduced fertility.

What does the examination involve?

The health professional will carry out a physical examination of your baby and ask





Heart, eyes, hips and testes (physical examination)

you questions about your baby's feeding, how alert they are and their general wellbeing. Your baby will need to be undressed for part of the examination.

During the examination, the health professional will:

- look into your baby's eyes focusing on how their eyes look and move
- listen to their heart using a stethoscope to detect heart sounds
- examine their hips to ensure the joints are in the correct place
- examine baby boys to check if their testes are in the right place.

These screening tests are carried out within 72 hours of birth and again when your baby is between 6 to 8 weeks of age.

Can this examination harm my baby?

There are no risks associated with having this test.

Does my baby need to have this examination?

The examination is intended to identify any of the problems

early so that treatment can be started as soon as possible. The general physical examination including this screening is therefore recommended for your baby.

What if I decide that my baby doesn't have this examination?

You can decide to have your baby examined and screened for any or all of the conditions. If you have any concerns you should discuss them with your midwife and the health professional who offers the examination.

Possible results

Usually there will be nothing of concern found. If the health professional finds a possible problem, your baby will be referred for further assessment and tests if appropriate.

Getting my results

The health professional carrying out the examination will give you the results straight away. If a referral for further assessment is needed, this will also be discussed with you at the time of the examination.

The results will be recorded in your baby's case notes and personal child health record ('red book'). You will need to keep this record safe and make sure it is available whenever your baby sees a health professional.

Early detection of problems means quicker treatment and better health outcomes

Screening is offered within 72 hours of birth and again at 6-8 weeks



Hearing loss

[nhs.uk/newbornhearing](https://www.nhs.uk/newbornhearing)

What is the screening test for?

To find babies who have a hearing loss so that support and advice can be offered right from the start.

About this condition

1 to 2 babies in every 1,000 are born with a permanent hearing loss in one or both ears. Most of these babies are born into families with no history of hearing loss. Permanent hearing loss can significantly affect a baby's development. Finding out early can give these babies a better chance of developing speech and language skills. It will help babies make the most of relationships with their family and carers from an early age.

What does the test involve?

In many hospitals you will be offered a hearing screening test for your baby before discharge or invited to attend a clinic appointment; in some areas it will be done by the health visitor within the first few weeks. The test can be done up to 3 months of age.

The test called the AOA (automated otoacoustic emission) takes a few minutes. A small soft tipped earpiece is placed in the

outer part of your baby's ear and soft clicking sounds are played. When an ear receives sound, the inner part (called the cochlea) responds and this can be picked up by the screening equipment.

It is not always possible to get clear responses from the first test. This does not necessarily mean your baby has a hearing loss. It can mean:

- your baby was unsettled when the test was done
- there was background noise
- your baby has fluid or a temporary blockage in their ear. This is very common and passes with time
- your baby has a hearing loss

In these cases your baby will be offered another test. This may be the same as the first test, or another type called the AABR (automated auditory brainstem response) test. This involves three small sensors being placed on your baby's head and neck. Soft headphones are placed over your baby's ears and soft clicking sounds are played. This test takes between five and fifteen minutes.

Most babies with hearing loss are born into families with no previous history



The hearing test is straightforward and most babies sleep right through it





Hearing loss

Can this test harm my baby?

There are no risks associated with having these tests.

Does my baby need to have this test?

This screening test is recommended for your baby. Finding hearing loss early is important for your baby's development.

What if I decide that my baby doesn't have the test?

If you decide not to have the newborn hearing screening test you will be given checklists to help you check on your baby's hearing as they grow older and if you have any concerns you should speak to your health visitor or GP.

Possible results

If your baby has a clear response in both ears then they are unlikely to have a hearing loss. However, newborn hearing screening does not pick up all types of hearing loss and children can develop hearing loss later on. It is important to check your child's hearing as they grow up. The checklist in your baby's personal child health record ('red book') tells you how to do this. If you have any concerns about your child's hearing tell your health visitor or family doctor.

The hearing test is straight forward and most babies sleep right through it

If the screening test results do not show a clear response from one or both of your baby's ears an appointment will be made with audiology to see a hearing specialist. About 2-3 babies in every 100 do not show a clear response on the screening tests. Being sent for further tests does not necessarily mean your baby has a hearing loss.

A hearing specialist should see you within four weeks of having your baby's hearing screen. It is very important that you attend the appointment in case your baby has a hearing loss.

Getting my results

You will be given your baby's results as soon as the hearing test is done.





Blood spot



nhs.uk/bloodspot

What is the test for?

To find out if your baby has any of nine rare but serious health conditions. Early treatment can improve your baby's health and prevent severe disability or even death. If you, the baby's father, or a family member already have one of these conditions please tell your health professional straight away.

Blood spot screening is recommended as it can save your baby's life

About these conditions

Sickle cell disease

About 1 in 2,000 babies born in the UK has a sickle cell disease (SCD). These are serious, inherited blood diseases. They affect haemoglobin, a part of the blood that carries oxygen around the body. Babies who have these conditions will need specialist care throughout their lives.

People with SCD can have attacks of severe pain, get serious, life-threatening infections and are usually anaemic (their bodies have difficulty carrying oxygen). Babies with SCD can receive early treatment, including immunisations and antibiotics, which, along with support from their parents, will help prevent serious illness and allow the child to live a healthier life.

Cystic fibrosis

About 1 in 2,500 babies born in the UK has cystic fibrosis (CF). This inherited condition affects the digestion and lungs. Babies with CF may not gain weight well, and frequently have chest infections.

Babies with CF can be treated early with a high-energy diet, medicines and physiotherapy. Although children with CF may still become very ill, early treatment is thought to help them live longer, healthier lives.

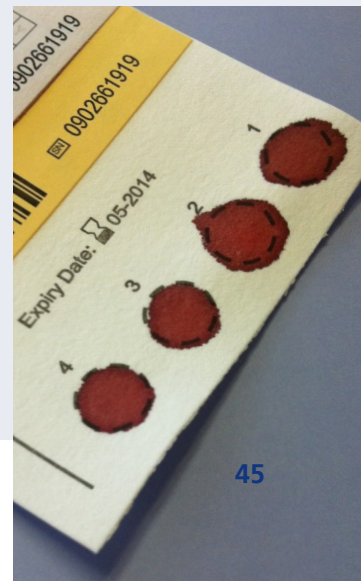
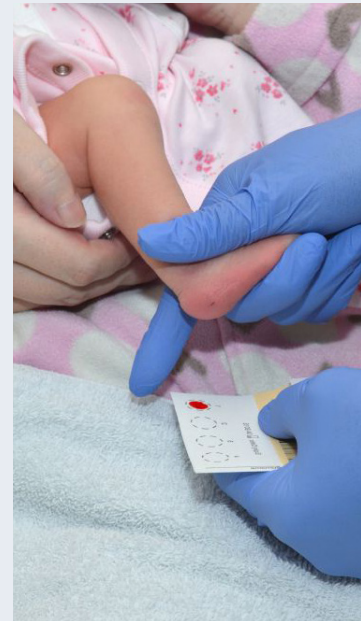
Congenital hypothyroidism

About 1 in 3,000 babies born in the UK has congenital hypothyroidism (CHT). Babies with CHT do not have enough of the hormone thyroxine. Without thyroxine babies do not grow properly and they can develop permanent serious physical problems and learning disabilities.

Babies with CHT can be treated early with thyroxine tablets and this will allow them to develop normally.

Inherited metabolic diseases

It is important to let your health professional know if you have a family history of a metabolic condition.





Blood spot

Babies are screened for six inherited metabolic diseases (IMDs). These are:

- phenylketonuria (PKU)
- medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
- maple syrup urine disease (MSUD)
- isovaleric acidaemia (IVA)
- glutaric aciduria type 1 (GA1)
- homocystinuria (pyridoxine unresponsive) (HCU).

About 1 in 10,000 babies born in the UK has PKU or MCADD. The other conditions are rarer, occurring in 1 in 100,000 babies to 1 in 150,000 babies.

Babies with these inherited conditions cannot process certain substances in their food. Without treatment babies with some of these conditions can become suddenly and seriously ill. The symptoms of the conditions are different; some may be life threatening or lead to severe developmental problems. They can all be treated by a carefully managed diet, which is different for each condition and may include additional medicines.

The information collected on your baby's blood spot card is important - make sure all the details are correct

What does the test involve for my baby?

When your baby is five days old the health professional will prick your baby's heel using a special device to collect some drops of blood onto a card. Occasionally this may be later than five days. The heel prick may be uncomfortable and your baby may cry. You can help by making sure your baby is warm and comfortable, and by cuddling and feeding them.

Sometimes, a second blood spot sample is required later on, if so the reason will be explained. It does not necessarily mean there is something wrong with your baby.

Can this test harm my baby?

There are no known risks to your baby associated with having the test.

Does my baby need to have this test?

Screening your baby for all these conditions is recommended but it is not compulsory. You can choose to have screening for SCD, CF or CHT individually but you can only choose to have screening for all six IMDs or none at all. If you do not want your baby screened for any of these conditions, please discuss it with your midwife.

What if I decide that my baby doesn't have the test?

If you change your mind, babies can be screened up to 12 months of age for all the conditions except for CF (only up to eight weeks of age). If you have any concerns about the tests please discuss them with your health professional.



Blood spot

Possible results

Most babies will have normal results indicating that it is unlikely that they have any of the conditions. A small number of babies will be found to have one of the conditions and they will be referred for specialist treatment. Some babies will need some further tests.

Screening for cystic fibrosis finds some babies who may be genetic carriers of the condition. These babies may need further testing. Screening does not detect all carriers.

Occasionally, other medical conditions might be identified through these screening tests. For example, babies with beta thalassaemia major (a serious blood disease) will usually be detected. These children also need to be referred for lifelong treatment and care.

Screening for sickle cell disease also finds babies who are genetic carriers of these or other red blood cell diseases. Carriers are healthy although they can experience some problems in situations where their bodies might not get enough oxygen, for example if they are having an anaesthetic.

Getting my results

You should receive the results from a health professional by the time your baby is six to eight weeks old. The results should be recorded in your baby's personal child health record ('red book'). Please keep this safe and bring it with you to any further appointments.

You will be contacted sooner if there is thought to be any problem with your baby.

What happens to my baby's blood spot card and data after screening?

After screening blood spot cards are stored for at least five years and may be used:

- to check the result or for other tests recommended by your doctor
- to improve the screening programme
- for research to help improve the health of babies and their families in the UK.

This research will not identify your baby, and you will not be contacted. The use of these blood spots is governed by the code of practice available from your midwife, or on the website.

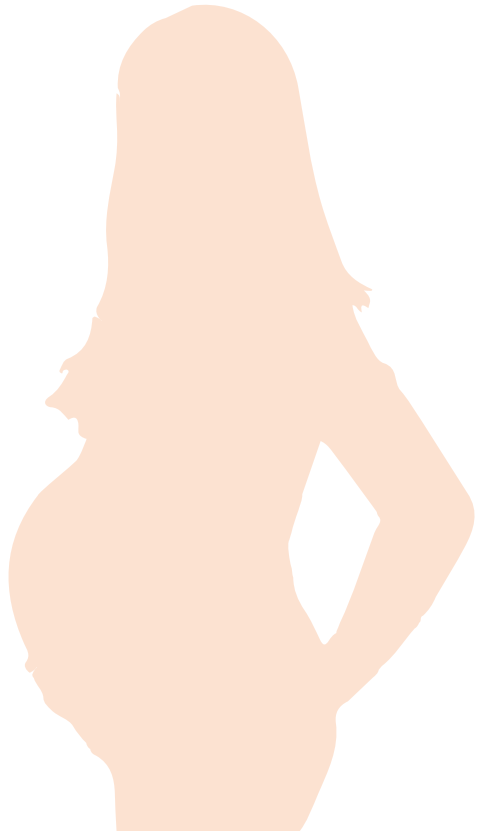
There is a small chance researchers may want to invite you or your child to take part in research linked to this screening programme. If you do not want to be invited to take part in research, please let your midwife know.

It is also important to know that identifiable data on babies affected with sickle cell disease or thalassaemia may be used to evaluate and improve screening. If you do not wish your baby's screening data to be used in this way, call 0207 848 6627 or find out more at www.gov.uk/newborn-outcomes-project-definition-and-implementation

Notes

You can write down any notes here from discussions with your health professionals

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First published October 2014

Updated February 2015

Review due October 2016

Reference 1014ANPL

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