# You're pregnant!

Scans and tests

what you need to know

Pregnancy Screening Tests





### This booklet explains the screening and diagnostic tests you can have in pregnancy.

Screening in pregnancy involves simple tests that help to find out the chances of you or your baby having a health condition.

The screening tests we look at in this booklet use:

- blood tests
- ultrasound scans.

Most screening tests show that your baby is healthy. If the screening tests suggest there might be a health issue for you or your baby, you'll be offered a diagnostic test to get a definite answer. You do not have to have these tests, it's your choice.

#### The diagnostic tests we look at are:

- chorionic villus sampling (CVS)
- amniocentesis.

More information on your pregnancy can be found in the Ready Steady Baby book or online at **www.nhsinform.scot/ready-steady-baby** 

During pregnancy, you'll be offered free immunisations to protect you and your baby against whooping cough and influenza (flu). For information about immunisations offered during pregnancy, go to **www.nhsinform.scot/immunisation** 



All screening and diagnostic tests in this booklet are provided free in Scotland by the NHS. Get earlier and often more effective treatment.

> Early treatment can prevent disability and death.

# **benefits** of getting screened

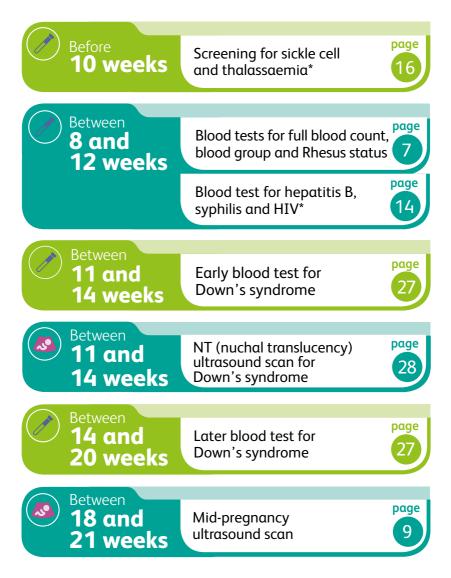
the

Helps to improve your own and your baby's overall health.

Results can help you to make decisions about your pregnancy.

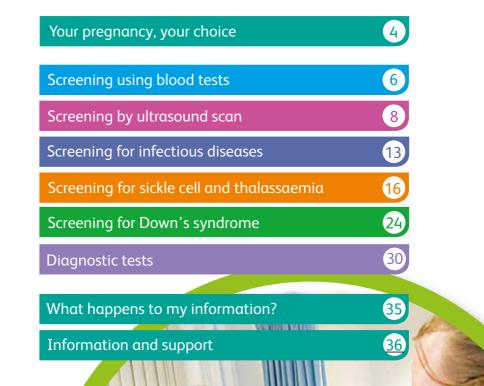
Your midwife will guide you through all the tests and scans offered during your pregnancy.

# At a glance



\* It's best if the tests are carried out in the early stages of pregnancy, but they can still be done at any point, up to and including labour.

# Contents



Remember you should discuss all screening tests with your midwife.

# Your pregnancy,

It's your choice whether to accept screening and diagnostic tests. You should have a more detailed conversation with your health professional, who will tell you more about screening and what the results can mean.

You can decide at any point that you do not want to be tested, or you only want some of the tests. No one will ever test you

without being sure you know what the test is for, how it's done, and that you're prepared to have it.

We talk about 'your health professional' throughout this booklet – this can be a midwife, your GP, a specialist doctor (obstetrician), a sonographer or any other professional involved in your care during your pregnancy.

# your choice

People make different decisions about screening and diagnostic testing. They may choose:

- **not to be screened**, because they do not want to know during pregnancy if they or their baby has a health condition
- to be screened and consider diagnostic testing, because they want to know during pregnancy if they or their baby has a health condition.

Decisions about whether to accept screening or diagnostic testing can be difficult. You may want to talk with your partner, family or friends. Your health professional and the organisations listed at the back of this booklet can help. But the final decision is yours.

Whatever decision you make, it will not affect in any way the quality of care you receive or the attitudes of professionals caring for you. If you do not speak or understand English, the NHS will provide someone who can translate what is being said into your own language. Let your health professional know if you feel you need an interpreter.

### Facts

Health care and treatment for children in Scotland born with health conditions or disabilities are provided free on the NHS.

# Screening using blood tests

## Ataglance

- Blood tests are an important part of your care during pregnancy.
- They help to protect your own and your baby's health.
- The blood needed for these tests can usually be taken at one time.

Your midwife will take blood from your arm at one of your first visits and you should get the results at your next clinic visit.

Some of the tests may be repeated routinely later in your pregnancy and this will be discussed with you.

### What will I be tested for?

### Full blood count

This test helps to find out if you have anaemia – which means your blood is not good at carrying oxygen around the body. This can be treated with iron tablets and other treatments to support your health and the health of your baby.

### Blood group and Rhesus status

People belong to one of four blood groups, called A, B, O and AB. It's important to know your blood group:

- in case you need a blood transfusion
- because substances in the blood called blood-group antibodies can sometimes affect your baby – if these antibodies are found, your health professional will discuss it with you.

The test will also show if you are Rhesus positive or Rhesus negative. About one in six women are Rhesus negative. This means they do not have a substance called the Rhesus antigen on their blood cells.

If you're Rhesus positive, you do not need treatment.

If you're Rhesus negative, there can be issues if your baby is Rhesus positive and his or her blood enters your blood stream. This is unlikely to be an issue in a first pregnancy, but can be serious in future pregnancies. Your health professional will offer you an injection in your arm – the 'anti-D' injection – that will help to protect your health and that of any future babies you might have.

Ask your midwife how and when you'll receive your results. If any health issues are found, your health professional will contact you as soon as possible and give you advice and care.

# Screening

# by ultrasound scan



## Ataglance

Your midwife will offer you two ultrasound screening scans. One between 11 and 14 weeks and a second between 18 and 21 weeks.

These scans are carried out by trained health professionals called sonographers. Some midwives are also sonographers. Scans are not 100% accurate. Sometimes there are health conditions that cannot be picked up by the scan.

Your scan will be a two-dimensional black and white image. Three-dimensional (3D) and colour scans are not routinely used in the NHS.

Ultrasound scans are safe for mother and baby.

For most people, having a scan is a happy experience, but that's not true for everybody. Screening scans look for issues and check if your baby is growing well. Read this section carefully and speak to your health professional before deciding if you want to have the scans.

### Early pregnancy screening scan

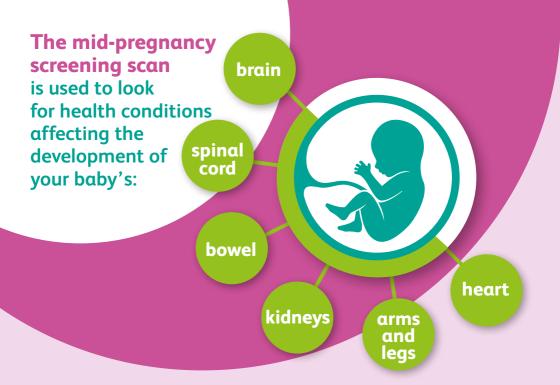
Your first screening scan is offered between 11 and 14 weeks. The scan:

- checks your baby's heartbeat, growth and development
- estimates the stage of pregnancy
- confirms whether you're having one baby or more
- gives the nuchal-translucency measurement (see page 28).

If a specific issue is found at this stage, your health professional will discuss it with you at the time.

### Mid-pregnancy screening scan

This scan is offered between 18 and 21 weeks. It is sometimes known as a fetal anomaly scan. It'll look for lots of things about your baby's health. Most women find their baby is healthy and developing well. But sometimes the sonographer finds an issue – usually these are minor, but some are serious.



Some health conditions may not be picked up by the mid-pregnancy scan. If the sonographer thinks there could be an issue, they may ask for a second opinion from another health professional. If this happens, they'll tell you what they're checking for but they may not be sure yet.

If no issues are found on the mid-pregnancy screening scan, you probably will not need another scan during your pregnancy. But you may be asked to come back on another day for a repeat scan if the sonographer has not been able to see your baby clearly.

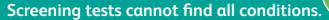
### Before, during and after your scan

• You'll be asked to drink some water (about a pint/500 ml) an hour before the early pregnancy screening scan. Having water in your bladder will help the sonographer to see your baby more clearly.

- You do not need a full bladder before the mid-pregnancy screening scan, but drinking a glass or two of water will help the sonographer.
- Most hospitals are happy for you to have someone with you during the scan. Young children may not be allowed in with you because they can distract the sonographer. It's a good idea to check beforehand.
- The sonographer will ask you to lie on a couch, raise your top to your chest and lower your skirt or trousers to your hips. He or she will squeeze some gel onto your abdomen (tummy) then gently pass a hand-held device across it the device sends and picks up ultrasound waves that allow a computer to build an image of your baby.
- The scan does not hurt at all, but the gel might be a little cold at first. Sometimes the sonographer needs to press your tummy if some parts of your baby are difficult to see.

**Finding out** about a health issue before birth can help parents to plan and prepare. For example, if your baby may need an operation, health professionals can help you plan to give birth in a hospital where vou and your baby can have the care you'll need

### Facts



- The sonographer might not be able to get a clear view of your baby.
- Some conditions develop after 21 weeks.
- Some conditions cannot be seen on a scan because they do not affect your baby's appearance.



- The scan will take up to 30 minutes.
- You should be able to recognise parts of your baby's body on the screen as the sonographer does the scan – he or she will point them out to you.
- Finding out the sex of your baby is not the purpose of the scan unless there is a medical reason for doing so. Often it's impossible to tell because of the position of your baby. It's not completely reliable and can sometimes be wrong.
- The vast majority of scans show that babies are healthy and no issues are found.

# Screening

# for infectious diseases

## Ataglance

Simple treatments can reduce the chances of you and your baby being affected by infectious diseases. You'll be offered blood tests for hepatitis B, syphilis and HIV.

You'll usually get the results at your next clinic visit, but you'll be contacted sooner if an infection is found. You can find more information about how infectious diseases are caused, diagnosed, treated and prevented at www.nhsinform. scot/healthy-living/ screening/pregnancy/ screening-forinfectious-diseases

Ask your midwife about your free whooping cough and flu vaccines.



### What will I be tested for?

### Hepatitis **B**

Hepatitis B is caused by a virus which can be passed from mother to baby during birth. The virus can cause serious liver disease, but women carrying hepatitis B may have no signs of infection. Without a test, they would not know they're infected.

Without immunisation, many babies born to mothers who are infected with hepatitis B will become infected themselves.

If the test shows you're infected with hepatitis B, you'll be offered specialist treatment.

Your baby will be immunised against hepatitis B at birth. This will usually stop them getting hepatitis B and protect them from serious liver disease.

### Syphilis

Syphilis can damage your own and your baby's health if it is not found and treated. It can be treated quickly and simply with antibiotics. People can have syphilis without realising it.

### HIV

HIV is the virus that causes AIDS. Over time, HIV damages the body's defences against infection and disease. People with HIV cannot be cured, but with treatment they can usually expect to live a full and healthy life. A woman who has HIV can pass the infection to her baby during pregnancy, birth and through breastfeeding. Like hepatitis B and syphilis, women with HIV may not know they're infected until they have a test – it can take years for HIV to make someone ill.

If your pregnancy screening test shows you may have HIV, you'll be offered another test to check for sure. You'll be offered antiviral medicines to keep you healthy and greatly reduce the chance of you passing HIV to your baby. Your health professional will give you advice about the safest way to deliver your baby and feed your baby. They'll also tell you about medicines your baby can have after he or she is born to help protect against HIV.

### Support and advice

Organisations listed at the end of the booklet can provide information and support on infectious diseases.

### Facts

Having a blood test for HIV does not affect your current or future life insurance policies, but if a health condition is found, it could affect your insurance. You might wish to check any policies you have for further details.

It is still recommended that you take the test.

### Screening

# for sickle cell and thalassaemia



# Ataglance

Sickle cell and thalassaemia are serious blood disorders that affect haemoglobin.

Haemoglobin carries oxygen around the body.

People who have these conditions need specialist care throughout their lives.

Your baby's father might also be offered a test. This will make the results more accurate.

### People with sickle cell:

- can have attacks of very severe pain
- may have serious life-threatening infections
- are usually anaemic (which means their blood is not good at carrying oxygen)
- may need medicines and injections throughout their lives to stop them getting infections.

### People with thalassaemia:

• may be very anaemic

What

- may need blood transfusions every four to six weeks
- may need injections and medicines throughout their lives.

You'll be offered screening tests for sickle cell and thalassaemia at or shortly after your first midwife visit. You should decide early whether you want to have the tests, as they should be done as soon as possible in the pregnancy – ideally by 10 weeks, although it can still be helpful to have them later.

### What causes the conditions?

Sickle cell and thalassaemia are passed from parents to children through **altered haemoglobin genes**.

### Genes

Genes determine your characteristics, from the colour of your hair to your blood group. For all our characteristics, we inherit one gene from each parent. People only have these disorders if they inherit **two** altered haemoglobin genes – one from their mother and one from their father. People who inherit just one altered gene and do not have either condition are known as **carriers**.

### Carriers

Carriers do not have either sickle cell or thalassaemia. But if a carrier has a baby with someone who is also a carrier, or who has sickle cell or thalassaemia, there is a higher chance that the baby could have one of the disorders, or be a carrier.

Anyone can be a carrier. But you are more likely to carry the altered genes if your ancestors (parents, grandparents and those further back in your family line) came from places where malaria was common, such as:

- an African country
- South Asia (India, Pakistan or neighbouring countries)
- the Caribbean
- the Middle East

- South America
- Southern Europe
- East and South-East Asia (China, Hong Kong, Malaysia or their neighbours).

People from Poland may also be affected because some Polish people moved many generations ago from areas where malaria was common.

### **Facts**

Although sickle cell carriers are healthy, they can have issues when their bodies do not get enough oxygen (when having an anaesthetic, for example). Knowing you're a carrier can help you manage these situations.

People who are thalassaemia carriers do not experience these issues.

### The Family Origin Questionnaire

To help find out if you or your baby's father have a chance of carrying genes for these conditions, your health professional will ask you questions from the **Family Origin Questionnaire**.

The aim is to find out where your immediate family and your ancestors came from and if you have a higher chance of carrying the genes.

### What will I be tested for?

You will be screened for **sickle cell** and **thalassaemia** by:

- a blood test
- answering questions from the Family Origin Questionnaire.

Your baby's father may be invited for a blood test too, as testing both parents gives more accurate results. If this is not possible, you may be offered diagnostic testing to confirm whether or not your baby has or carries one of the conditions.

### Tell your health professional if ...

you and your partner are related by blood. If you each have inherited genes from a shared relative, it may be more likely that you are both carriers.

### What will the results tell me?

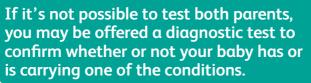
The most likely result is that you and your baby's father are not carriers for sickle cell or thalassaemia. If one of you is, your health professional will talk to you about what this could mean for you, your baby and your family.

Very rarely, the test may show that one or both of you has a blood disorder without knowing it. A health professional will discuss this with you and give you more information.

The test is usually very reliable, but if the result is unclear you'll be offered another test to be sure.

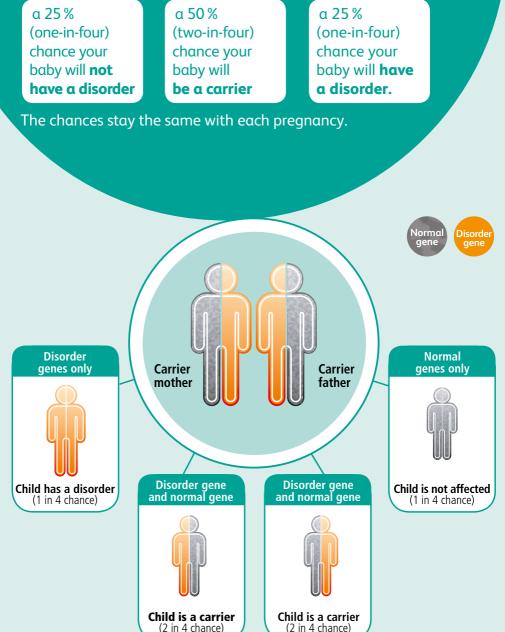
Results from your own and your baby's father's tests will then be used to see if your baby has a higher chance of developing one of the conditions.

### Facts





If you and your baby's father both carry the gene for sickle cell, thalassaemia or another blood disorder, there is usually:



# Please give staff as much information as you can if ...

you have an assisted pregnancy (for example IVF – in vitro fertilisation). This could affect your screening result. Your health professional will explain your results.

### Can my unborn baby be tested?

As with all screening tests, screening for sickle cell and thalassaemia is not 100% accurate. Diagnostic testing is the only way to know for sure if your baby has or carries one of the conditions. See pages 30–34.

Your health professional will help you to understand what it will mean if the results show your baby has a blood disorder. He or she will talk with you about the care that is available and whether you wish to continue with your pregnancy.

A genetic counsellor is a professional who is specially trained to give you information and support if you have worries about a genetic disorder. Your midwife or GP will be able to refer you.

### Testing new babies for sickle cell

All newborn babies are offered a 'blood spot' screening test, ideally when they are 5 days old. Your midwife will prick your baby's heel and put a few spots of blood onto a card. The card is sent to a laboratory where tests are done for nine conditions, including sickle cell. You'll get the results on or before your baby's check-up at 6–8 weeks.

Your baby!

### For more information about blood spot test and other newborn screening tests

Look out for the booklet 'Your baby! Tests offered' which you'll receive later in your pregnancy.

Or you can visit the NHS inform website at **www. nhsinform.scot/ newbornscreening** 

# Screening

# for Down's syndrome

## Ataglance

- A baby with Down's syndrome is born with more of chromosome 21 in all or some of their cells.
  - With the right help and support, people with Down's syndrome can lead active, healthy and fairly independent lives into their 60s, 70s and beyond.
- Most people with Down's syndrome will have mild to moderate disabilities and some may have more complex needs. This cannot be known before birth.
- Some health issues can be more common in people with Down's syndrome.

### What is Down's syndrome?

Nhai

Down's syndrome is a genetic condition caused by a full or part of a third copy of chromosome 21 in the body's cells. This usually happens by chance and is not caused by anything parents do before or during pregnancy.

### Chromosomes

Chromosomes carry genes that determine how we develop. People usually have 46 chromosomes, 23 from the mother and 23 from the father.

Older mothers are more likely to have a baby with Down's syndrome and the chance increases with the mother's age at pregnancy.

- For pregnant women **aged 20 years or younger**, the chance is **1 in 1,500**.
- For pregnant women aged 30, the chance is 1 in 900.
- For pregnant women aged 40, the chance is 1 in 100.

But Down's syndrome can occur in women of any age. All pregnant women, no matter what age, can have the test.

### People with Down's syndrome

There are increasing opportunities and support within education, work and housing for people with Down's syndrome. People with the condition can live healthy and fulfilling lives as part of their families and communities. Some may live independently, have jobs, be in relationships and socialise with minimal support.

Children with Down's syndrome can attend a mainstream school and receive any additional support they need.

Most people with Down's syndrome will have mild to moderate learning disabilities. Some can have more complex needs. The amount of help and support they'll need cannot be known before they're born.

Many children with Down's syndrome just have similar health issues to other children. Some health issues can be more common in people with Down's syndrome.

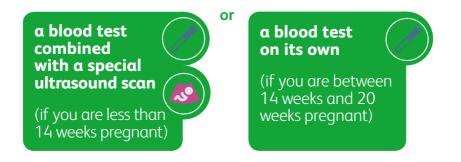
People with Down's syndrome receive regular health checks throughout their life to ensure that any associated health issues can be picked up early and they can receive the care they need.

### Why will I be offered this screening?

You'll be offered this screening to find out how likely it is that your baby has Down's syndrome. Some people want to find out if their baby is likely to have Down's syndrome and some do not. It's your choice.

### What type of screening test will I be offered?

You'll be offered either:



Some tests can only be done at certain times during pregnancy. If your early pregnancy scan shows you're at a different stage of pregnancy than you thought, your midwife will explain which tests you can have.

### Blood tests

The blood test measures substances that have passed between you and your baby. If you decide to have the test, a sample of your blood will be taken between 11 and 20 weeks.

### Speak to your health professional if ...

- you smoke

### NT ultrasound scan

The NT (standing for 'nuchal translucency') ultrasound scan is carried out between 11 and 14 weeks of pregnancy, usually as part of your early pregnancy screening scan. You might hear it called the 'combined' test, because it combines the results from the scan with your blood test.

The ultrasound measures the amount of fluid lying under the skin at the back of your baby's neck. The results of your NT ultrasound scan and blood test, along with your age, weight, stage of pregnancy and some other information (like whether you smoke or not), are put into a computer to work out the chance of your baby having Down's syndrome. If you're having twins, you'll be offered the same tests as people only having one baby. Your midwife will help you make decisions that feel right for you.

# What happens when I get the results of the Down's syndrome test?

If the screening test shows the chance of your baby having Down's syndrome is low, you will not be offered diagnostic testing.

### Facts

More than 95% of screening test results show the chance of the baby having Down's syndrome is low. It does not mean there's no chance at all that the baby has Down's syndrome, just that it's unlikely.

If the screening test shows a higher chance that your baby has Down's syndrome, you'll be contacted by a health professional who'll discuss the results with you and answer any questions you may have. The higher chance result usually means that there is a greater chance than one in 150 that your baby has Down's syndrome. You'll be offered diagnostic tests to confirm whether your baby has the condition.

As with all tests, you can choose whether or not to have the diagnostic tests.

# **Diagnostic tests**



## Ataglance

- These tests are offered to women whose screening tests show they have a higher chance of being a carrier for (or having) sickle cell or thalassaemia. Or whose baby has a higher chance of having Down's syndrome.
- There are two types of diagnostic tests: chorionic villus sampling (CVS) and amniocentesis.
  - Diagnostic tests can tell you for sure if your baby has one of these health conditions.
- Diagnostic tests increase chance of miscarriage.

It's very important you know that **the choice of whether to** have the diagnostic tests is yours.

Your health professional will talk it through with you and answer any questions you have. He or she will support you to make decisions that feel right for you. Other sources of information and support are listed at the back of this booklet.

### CVS (chorionic villus sampling)

CVS can be done from 11 weeks of pregnancy. It's usually only offered in a specialist centre.

With the help of an ultrasound scan, a specialist doctor (obstetrician) will guide a fine needle through your abdomen (tummy) and will take a small sample of tissue from the placenta.

Chromosomes from the placenta can be counted from the sample. CVS does not give a clear result in around two in every 100 samples. If this happens you may be offered a repeat test.



### Placenta

The placenta is inside your womb. It links your blood to your baby and provides nourishment.

### Amniocentesis

Amniocentesis (you might hear it shortened to 'amnio') can be carried out after 15 weeks of pregnancy. It usually takes about 10 minutes.

An ultrasound scan will check your baby's position in the womb. The specialist doctor (obstetrician) will guide a fine

needle through your abdomen (tummy) into your womb. The doctor can then take a sample of the fluid surrounding your baby (called amniotic fluid).

Your baby's chromosomes can be counted from the sample. Amniocentesis does not produce a clear result in around one in every 100 samples. If this happens, you may be offered a repeat test.

### **Referral to the fetal medicine team**

Your health professional may refer you to the fetal medicine team.

The team includes a specialist doctor, midwife and other health professionals. The team, which could be based in another hospital, may offer you further tests and will give information and advice about any health issues or disabilities you or your baby might have. You'll usually have an appointment within a few days.

# How safe are the diagnostic tests?

CVS and amniocentesis are not completely safe but they are the only way to know for sure if your baby has a health condition. It's your choice and health professionals will support you whatever you decide.

### Support

Organisations listed at the back of this booklet can also provide further information and support.



### Are the diagnostic tests painful?

Many women find the tests uncomfortable.

Some discomfort in your lower abdomen for a couple of days is usual, and you can take paracetamol for this. You should take things easy and avoid hard exercise for a day or two afterwards. If the discomfort carries on beyond this, or if you have any other worries, please contact your midwife.



# What happens if the diagnostic test finds a health condition?

If your baby has a health condition your midwife or health professional will talk to you about your result and give you time to understand what it means.

Some parents may decide to continue with the pregnancy, while others will feel that ending the pregnancy is right for them. Only you can decide what is best for you and your family.

Your midwife will help you get the information you need and will support your decision.

# What happens to my information?

Your personal health information will be kept private, which means it is only shared with other staff involved in your care. Processes are reviewed regularly to make sure you are offered the best service possible.

After being looked at, any of your leftover blood samples will be stored in the laboratory for at least 12 months. This is so they can be used in future if any test results need to be checked.

Your leftover blood samples may be used anonymously for other monitoring, laboratory, education and training purposes to improve the quality of patient care. This could be comparing different screening methods and developing new tests.

If this happens your personal details will be removed. Samples which are identifiable to you will never be used without your consent.

If you do not want your stored blood samples to be used for research, please ask the midwife to write 'no research' in the comments box on the request form.

You have rights in relation to the access and the use of your personal health information. Contact the NHS inform helpline free on **0800 22 44 88** (textphone **18001 0800 22 44 88**) or visit **www.nhsinform.scot/confidentiality** and **www.nhsinform.scot/data-protection** 

# **Information and support**

The information about screening tests in pregnancy can be a lot to take in. Please talk to your health professional if you have any questions or worries.

You can ask them which organisations may be able to give you support that's right for you and your family. The following contact details may be useful.

#### **NHS inform**

The helpline is open every day. Please check the website for opening hours. It also provides an interpreting service. Phone: 0800 22 44 88 Textphone: 18001 0800 22 44 88 www.nhsinform.scot/ pregnancyscreening

## Antenatal results and choices (ARC)

Provides support and information to parents throughout the pregnancy screening and diagnostic testing process. And to parents who are affected by a diagnosis of fetal abnormality. Phone: 0845 077 2290 or 0207 713 7486 from a mobile phone http://arc-uk.org

#### **Contact a Family Scotland**

Provides information and support to parents and carers of children with any additional need or disability.

#### http://contact.org.uk/adviceand-support/resource-library

Phone: 0808 808 3555 (voice and text)

http://contact.org.uk

#### Down's Syndrome Scotland

Provides information to parents during screening and ongoing support throughout life to people with Down's syndrome, and their parents, carers and professionals. Phone: 0131 442 8840 www.dsscotland.org.uk

#### **Positively UK**

Offers a range of peer support, advice, information and advocacy services for HIV-positive women and men.

Phone: 0207 713 0444 http://positivelyuk.org

#### **Sickle Cell Society**

Phone: 0208 961 7795 www.sicklecellsociety.org

#### **SOFT UK**

Supports families affected by Patau's syndrome, Edwards' syndrome, partial trisomy, mosaicism, rings, translocation, deletion and related disorders.

http://soft.org.uk

#### Spina Bifida Hydrocephalus Scotland

A family support service for those affected by spina bifida, hydrocephalus and allied conditions. Helpline: 0345 521 1300 www.sbhscotland.org.uk

#### **UK Thalassaemia Society**

Phone: 0208 882 0011 http://ukts.org

#### Waverley Care

Provides care and support to people living with HIV and hepatitis C and their partners, families and carers. Phone: 0131 558 1425 www.waverleycare.org

#### Healthtalkonline

Provides short recorded interviews and written descriptions of people's experiences of health procedures, tests and conditions. This includes experiences of pregnancy screening and diagnostic testing, including those for sickle cell and thalassaemia, and termination of pregnancy following diagnosis of a fetal abnormality.

http://healthtalk.org

#### British Pregnancy Advisory Service (BPAS)

BPAS provides help to women with an unplanned pregnancy or a pregnancy they choose not to continue with. Phone: 03457 30 40 30 Email: info@bpas.org www.bpas.org This booklet explains the screening and diagnostic tests you can have in pregnancy.

Screening in pregnancy involves simple tests that help to find out the chances of you or your baby having a health condition and what choices are available.

# This resource may also be made available on request in the following formats:



### 🕻 0131 314 5300

#### 🖾 nhs.healthscotland-alternativeformats@nhs.net

Published by NHS Health Scotland

1 South Gyle Crescent

Edinburgh EH12 9EB © NHS Health Scotland 2020

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