

Blood spot tests

An **easy guide** to screening tests for your new baby



Contents: what is in this booklet

Page



Your choice

3



About these tests

5



Sickle cell disease

7



Cystic fibrosis

8



Congenital hypothyroidism

9



Inherited metabolic
diseases

10



Test results

11

Your choice



This booklet has information about the tests that your baby can have.

The tests can find out if your baby may have a serious health problem. The tests can show if your baby might need extra care.

These tests can find problems before you even notice them. They may not find every problem.

If we find a problem early we can help your baby.



You can choose if you want your baby to have these tests.



We recommend that your baby has all of these tests because we may find a problem early.

If we find a problem early we can help your baby to be healthy.



If you say no to the tests then you can change your mind and choose for your baby to have the tests later if you want to.

Your baby can have most of the tests up to 1 year old.



But the test for a condition called cystic fibrosis has to be done before your baby is 8 weeks old.



If you are worried, you can talk to your midwife or doctor.

They can help you decide if you want your baby to have these tests.

PRIVATE

We will keep your test results private.

We only show the results of the test to health staff who need to see them.



It is important to tell your midwife or health visitor about any health problems you and the baby's father have, as your baby may have them too.



The blood spot tests look for rare and serious illnesses.

Finding these illnesses early means we can help babies stay healthy.



When your baby is 5 days old we will prick his or her heel.

We will collect some drops of blood on a card.



Before the test make sure your baby is warm and comfy.

Feed your baby and cuddle them.

Your baby may feel a little pain when the heel prick is done.



Sometimes we need to do another blood spot test later on.

This does not mean there is anything wrong with your baby.

Sickle cell disease

7



Sickle cell disease is a very serious blood illness.

Very few babies in England have sickle cell disease.

You can get it from your parents. If you get it from your parents you then have it for life.



Sickle cell disease can cause problems in your blood that make you pale, very tired and weak.

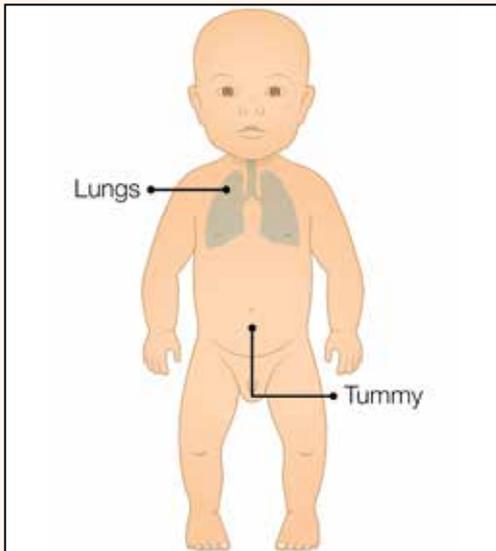
Sickle cell disease can give you very bad pain and very serious illnesses.



Babies with sickle cell disease can have medicines soon after they are born.

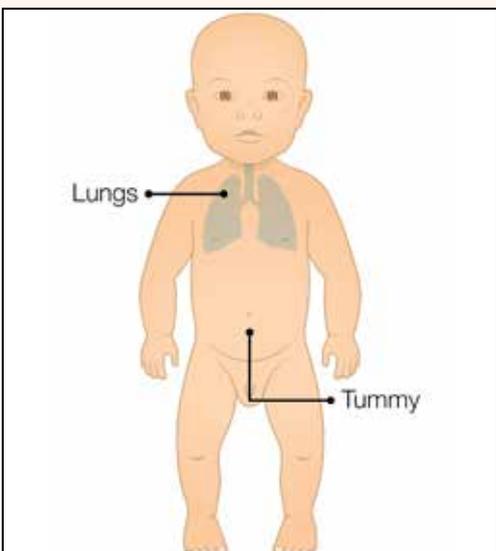
Medicines will help them to stay healthy.

Cystic fibrosis



Cystic fibrosis is a condition that affects the baby's lungs and tummy.

Very few babies in England have cystic fibrosis.



Cystic fibrosis fills up the lungs and tummy with sticky fluid.



Babies with cystic fibrosis can be given special food, medicines and physiotherapy.

Physiotherapy is a type of treatment that helps to clear the lungs of sticky fluid.

The medicines and physiotherapy help babies to be healthy and live longer.

Congenital hypothyroidism

9



Congenital hypothyroidism is a condition that affects how a person grows.

Very few babies in England have this condition. Congenital hypothyroidism is also called CHT.



Babies with this condition do not grow well.

If they are not treated they may become disabled and have learning disabilities.



Babies with congenital hypothyroidism can be given medicine.

This medicine can help them stay healthy.



Inherited metabolic diseases are conditions that cause problems with eating some foods.

Very few babies in England have an inherited metabolic disease.

We test for 6 of these diseases.



If the disease is not dealt with properly the baby may become very ill or die.

We can tell you what food your baby can and cannot eat to stay healthy.

Test results



You should get the results by the time your baby is 8 weeks old.

If we think there is a problem we will contact you before then.



If your baby has one of these diseases, we will send them to see an expert.

Sometimes other diseases are found and babies may need more tests.



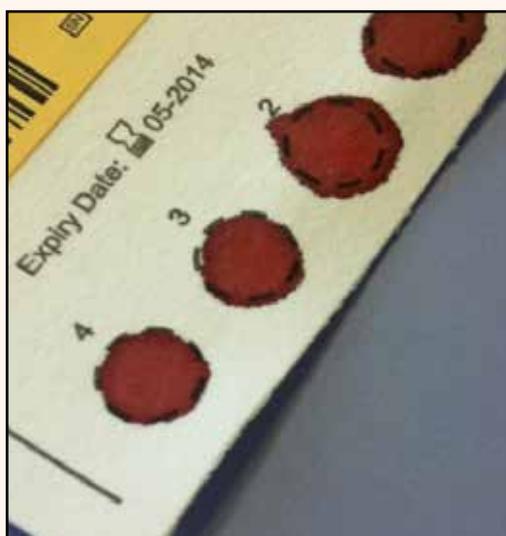
You will be given a red book to keep a record of your baby's health checks in. Keep the red book safe.

Take it with you when you see anyone about your baby's health.



New home

It is important to tell your midwife or health visitor if you move home.



We keep the blood spot test cards for at least 5 years.

We may use them to help us find out how to improve care for babies. This is called research.



Research helps make the tests better.

There is a small chance that the people doing the research will ask to meet you.

If you do not want to be asked, please tell your midwife.

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Photosymbols - calendar (pages 4 and 11), house move (page 11)

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Find out how Public Health England and the NHS use and protect your screening information at www.gov.uk/phe/screening-data.

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