Public Health England

NHS

Babies in special care units: screening tests for your baby

Information for parents of babies who are in a special care baby unit, neonatal intensive care unit or paediatric intensive care unit.

This leaflet is for parents of babies who are in a special care baby unit, neonatal intensive care unit or paediatric intensive care unit.

It explains some important differences in the way that the newborn screening tests are carried out for babies in special care baby units. It is important you also read the 'Screening tests for you and your baby' booklet that you received during your pregnancy. This explains all the screening tests offered for newborn babies.

The screening tests in this booklet should ideally be completed before you take your baby home.

Your baby's health care team will be able to answer any questions you might have.

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

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

Heart, eyes, hips and testes (physical examination)

nhs.uk/newborninfantexam

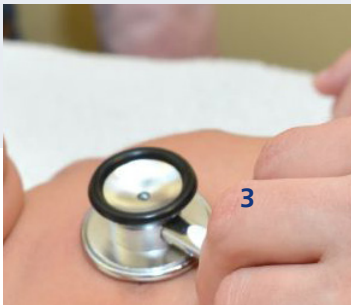
What is the screening test for?

All babies should be offered a newborn physical examination after birth. This includes examination of the heart, eyes, hips and testes (in boys).

How is the test different?

The newborn physical examination screening tests will not be done until your baby is well enough. If you choose to have this screening test, the examination should take place before your baby goes home.

You will be offered a further examination when your baby is 6-8 weeks of age, as some conditions can become apparent later.



Blood spot

nhs.uk/bloodspot

What is the screening test for?

To find out if your baby has any of nine rare but serious health conditions. These are:

- sickle cell disease (SCD)
- cystic fibrosis (CF)
- congenital hypothyroidism (CHT)

Inherited metabolic diseases (IMDs):

- 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)

Early treatment can improve your baby's health and prevent severe disability or even death. If you or a family member already has one of these conditions, please tell your baby's health care team straight away.

Why is screening different for babies in special care units?

The blood spot sample is usually taken when a baby is 5 days old. However, the timing is different when a baby is ill and in a special care baby unit.

Blood spot

How is the test different?

The blood spot sample needs to be taken as soon as possible after your baby is born to screen for SCD. This is in case your baby needs a blood transfusion – the test for SCD would be inaccurate if a sample for screening is taken after a transfusion.

Another blood spot sample to screen for the other conditions will then be taken when your baby is 5 days old. If your baby has a transfusion, this test might be delayed until they are 8 days old.

If your baby is born before 32 weeks of pregnancy, another sample should be taken to test for CHT. This should happen when your baby is 28 days old or when you take your baby home (whichever comes first).

Getting my results

You should receive your baby's results by letter or from your health visitor within 6 to 8 weeks.

Hearing loss

nhs.uk/newbornhearing

What is the screening test for?

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

Why is screening different for babies in special care units?

About 1 in every 900 babies has hearing loss in one or both ears. This number increases to about 1 in every 100 babies who have spent at least 48 hours in a special care unit.

Your baby will need to be at least 34 weeks gestation before having their hearing screening test. The test can be carried out up to 3 months of age and should be done when treatment and intervention is complete and your baby is well enough. Your baby's health care team will advise the most appropriate time for your baby's test to take place.

How is the test different?

If your baby has been in a special care baby unit for more than 48 hours, they will need to have two types of hearing screening tests. These are an AOAE (automated otoacoustic emission) test and an AABR (automated auditory brainstem response) test.

If the screening test results do not show a clear response an appointment will be made with a hearing specialist. About 9 babies in every 100 cared for in a special care unit for more than 48 hours 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. It is very important that you attend the appointment in case your baby has a hearing loss.

Infectious diseases

nhs.uk/infections

What is the screening test for?

During pregnancy we offer women a blood test to screen for hepatitis B, HIV (human immunodeficiency virus) and syphilis.

Premature babies born to mothers who have tested positive for hepatitis B may need special monitoring and care.

How is follow-on care different?

Follow-on care is different if you have hepatitis B, regardless of the status (extent) of your infection.

Babies born weighing less than 1500g need immunoglobulin (antibodies that fight infection) and the hepatitis B vaccination.

It is very important premature babies have all 6 recommended hepatitis B vaccinations at the right age. Very premature babies (born under 28 weeks) may need their breathing monitored for 2 to 3 days after their first vaccination.

Vaccinations should take place:

- within 24 hours of birth
- at 4 weeks of age
- at 8, 12 and 16 weeks of age (part of routine childhood immunisation schedule)
- at one year of age

Babies may need an injection of antibodies (hepatitis B immunoglobin) at their first vaccination. Babies also have a blood test at their final vaccination at one year to check if infection has been avoided.

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Web address	www.gov.uk/phe/screening-leaflets
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