

Screening tests for you and your baby: babies in special care units

Public Health England (PHE) created this information on behalf of the NHS. In this information, the word 'we' refers to the NHS service that provides screening.

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

We understand this is likely to be a stressful time for you and your family. This information will help you and your health professionals to talk through how newborn screening tests fit into all the other parts of your baby's care. This information should support, but not replace, discussions you have with health professionals.

It explains some important differences in the way 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 and can be found at www.gov.uk/phe/pregnancy-newborn-screening.

The screening tests covered here should ideally be completed before you take your baby home.

If your baby was born very prematurely, before 28 weeks, you may need to wait a few weeks for some tests. Newborn hearing screening testing can only happen once a baby reaches 34 weeks corrected age.

Corrected age is the number of weeks after becoming pregnant, rather than the number of weeks after birth.

For example, a baby born after 28 weeks of pregnancy would need to wait 6 weeks after birth to have their newborn hearing screening test.

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 information.

Eyes, heart, hips and testes (physical examination)

The purpose of the screening test

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

How the test is 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 to 8 weeks of age, as some conditions can become apparent later.

Blood spot

The purpose of the screening test

The test is to find out if your baby has any of 9 rare but serious health conditions. These are:

- sickle cell disease (SCD)
- cystic fibrosis (CF)
- congenital hypothyroidism (CHT)
- 6 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 screening is 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.

How the test is 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 weeks.

Hearing loss

The purpose of the screening test

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

Why screening is different for babies in special care units

1 to 2 babies in every 1,000 are born with a permanent 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 corrected age before having their hearing screening test. The screening test should ideally be carried out within the first few weeks of birth and should be done when treatment 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 the test is different

If your baby has been in a special care baby unit for more than 48 hours, they will need to have 2 types of hearing screening tests.

These are an AOA (automated otoacoustic emission) test and an AABR (automated auditory brainstem response) test.

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

Finding out about hearing loss early gives babies a better chance of developing language, speech and communication skills.

Screening does not pick up all types of hearing loss, so it is important to check your child's hearing as they grow up. If you have any concerns about your child's hearing, you should tell your health visitor or GP.

Infectious diseases

The purpose of the screening test

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

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

How follow-on care is different

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 before 28 weeks) may need their breathing monitored for 2 to 3 days after their first vaccination.

Vaccinations should take place:

- within 24 hours at birth (and immunoglobulin)
- 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 also need to have a blood test at their final vaccination at one year to check if infection has been avoided.

More information

Details of organisations that can provide support for parents when their baby needs special care are available on NHS.UK at www.nhs.uk/conditions/pregnancy-and-baby/baby-special-intensive-care

The NHS Screening Programmes use personal information from your NHS records to invite you for screening at the right time. Public Health England also uses your information to ensure you receive high quality care and to improve the screening programmes. Find out more about how your information is used and protected, and your options at www.gov.uk/phe/screening-data.

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