Rijksinstituut voor Volksgezondheid
en Milieu
*Ministerie van Volksgezondheid,
Welzijn en Sport*

The 13-week scan and the 20-week scan

Test for physical abnormalities

Content

What can you get tested?

You are pregnant. You can be tested to see if your unborn baby has a disorder or a physical abnormality. This is called prenatal screening.

There are two types of prenatal screening:
1. Screening for Down syndrome, Edwards' syndrome and Patau's syndrome: the NIPT.
2. Screening for physical abnormalities: the 13- week scan and the 20-week scan. That is what this leaflet is about.

It is entirely up to you to decide if you want to have these scans.

NIPT

A screening for Down syndrome, Edwards' syndrome and Patau's syndrome + choice to screen for incidental findings.

The 13-week scan

A screening for physical abnormalities in the baby early in pregnancy.

The 20-week scan

A screening for physical abnormalities in the baby, (approximately) mid-way through the pregnancy.

When we say an obstetric care provider, we usually mean your midwife or gynaecologist. It may also refer to another care provider, such as a sonographer or a nurse.

This information brochure is about screening for physical abnormalities. Another name for this is the structural ultrasound scan. There is also a brochure about screening for Down, Edwards' and Patau's syndromes.

What are physical abnormalities?

A physical abnormality means that part of the baby's body looks different from what is expected. Examples of physical abnormalities are spina bifida (an open spine), an open skull, hydrocephalus, heart defects, a hole in the diaphragm, a hole in the abdomen, structural abnormalities of the kidneys, and structural abnormalities of the bones.

Making a choice

When you are pregnant you go to your obstetric care provider. At the first visit you will be asked if you want to know more about screening for physical abnormalities. There are two possibilities:
1. You prefer not to know. In this situation you will not receive information about screening, and you will not have the screening scan.
2. You prefer to know. You will then have an in-depth discussion about the screening for physical abnormalities and the screening for Down, Edwards' and Patau's syndromes.

After this session you will then decide what you want to do:

- no prenatal screening,
- screening for physical abnormalities or screening for Down, Edwards' and Patau's syndromes,
- or have both screening tests.

If you choose to have a consultation about the 13-week scan and the 20-week scan.

Tip: before going to the consultation about the screening tests, see www.pns.nl. You can read more about it there. There are also short explanatory films about the screenings on the websites www.pns.nl/13-wekenecho/video-13-wekenecho-20-wekenecho and www.pns.nl/20-wekenecho/video-13-wekenecho-20-wekenecho. If you have any questions, you will be able to ask your obstetric care provider during your appointment.

What are the 13-week scan and the 20-week scan?

The 13-week scan and the 20-week scan are medical examinations. The person who performs the screening test is called a sonographer. At both scans a sonographer will use an ultrasound machine to examine the baby for any physical abnormalities.

The sonographer will also check the amniotic fluid and the growth of the baby. The sonographer is required to inform you of all the findings. This means that you cannot have a partial scan. There is no risk to either the mother or the baby from a screening test.

When is the 13-week ultrasound scan?

You can have the 13-week ultrasound scan from 12+3 up to 14+3 weeks of pregnancy. This means from twelve weeks and three days up to and including fourteen weeks and three days.

When is the 20-week scan?

You can have the 20-week scan from week 18 until week 21 of your pregnancy. This means up to 21 weeks and 0 days of your pregnancy. The best time to have the scan is in week 19 of your pregnancy. That is 19 weeks and 0 days up to and including 19 weeks and 6 days of your pregnancy.

Scientific study of the 13-week scan

In the Netherlands, you can only opt to have the 13-week scan if you are participating in the scientific IMITAS study. This study is investigating the advantages and disadvantages of the 13-week scan. On the one hand, it seems good to know whether the baby has a serious physical abnormality early on in the pregnancy. This will give you more time for additional examinations and to decide what to do considering the results of these tests.
On the other hand, an examination so early in the pregnancy may cause additional anxiety and uncertainty. Taking part in the scientific study means that the researchers can use your data. You will sign an informed consent form for this. If you want to know more about the study and about what happens to your data, please see www.pns.nl.

What are the differences between the 13-week scan and the 20-week scan?

The 13-week scan and the 20-week scan are very similar. At both scans a sonographer will use an ultrasound machine to see if the baby has any physical abnormalities.
What are the differences?

13-week scan

- Early in pregnancy. The baby is smaller and less developed.
- Some (severe) abnormalities can be seen. If follow-up diagnostic testing is necessary, you will have more time to decide what to do considering the test results.

- The sonographer does not look to see if the baby is a boy or a girl.

20-week scan

- Later in pregnancy. The baby is bigger.
- More details can be seen. If follow-up diagnostic testing is necessary, you will have less time to decide what to do considering the scan results.
- The sonographer can usually see if the baby is a boy or a girl. You will only be told this if you ask.

The NIPT and the 13-week scan

Like the 13-week scan, the NIPT is a test that you can have early in pregnancy.
However, it is important to know that the NIPT and the 13-week scan are two different tests, screening for different disorders and abnormalities.
These examinations are not interchangeable:

- The NIPT is a screening for Down, Edwards' and Patau's syndromes, which are chromosomal abnormalities.
- The 13-week scan is not intended for this; it is a screening for physical abnormalities.

The sonographer can sometimes see abnormalities on the 13-week scan that may occur in a baby with a chromosomal abnormality (or another congenital disorder). You may then choose to have follow-up diagnostic testing at a Centre for Prenatal Diagnosis, which is a department of a university hospital. If you want to find out if your baby has Down, Edwards' or Patau's syndrome, then you should choose to have the NIPT.

Should you take the NIPT into account when planning the 13-week scan?

You can have the NIPT starting from 10 weeks into pregnancy. You can have the 13-week scan between 12 weeks and 3 days and 14 weeks and 3 days of pregnancy.
You can have NIPT done earlier than the 13-week scan. Ultimately, the order is up to you.

It’s entirely up to you whether or not you have a scan

The 13-week scan and 20-week *scan are not compulsory. It is your decision whether you want to have tests for physical abnormalities, and what to do considering the test results. You can also withdraw from the screening test at any time.*

If you do decide to have the 13-week scan and the 20-week scan, in most babies the sonographer does not find any physical abnormalities. In this case the result of the scan will put your mind at rest. However, there is also a chance that the result might worry or scare you. For this reason, it is very important that you consider carefully whether you want to have the physical abnormality scan.

The results of the scan may confront you with some difficult choices. It could be that your baby has a physical abnormality. In most cases the hospital cannot treat the abnormalities that are found. In some cases, however, such as heart defects, treatment is available. This is not always clear in advance. Further, the sonographer cannot see all possible abnormalities on the ultrasound scan.

The following questions can help you decide whether or not you want a scan for physical abnormalities.

- How much do you want to know about your baby before it is born?
- The results of the scan could show that your baby possibly has a physical abnormality. In that case, would you want to have follow-up diagnostic testing?
- The results of the follow-up tests could show that your baby does have a physical abnormality. How would you prepare yourself for this? It is sometimes important that you give birth in a special hospital.
- What are your views on the possibility of terminating the pregnancy if your baby was found to have a serious physical abnormality?

Need help deciding whether to get screened?

This may help you to make a choice:

- Fill in the questionnaire on www.pns.nl This questionnaire will give you insight into your thoughts and feelings.
- Talk about it with your partner, or with another person that you trust
- Ask any questions that you may have during the discussion with your obstetric care provider.

A discussion about whether or not to have screening: a counselling session

Did you mention during your first visit to your obstetric care provider that you would like to know more about the screening tests for physical abnormalities? If so, you will have an in-depth discussion about this.

The discussion with your obstetric care provider is also known as counselling. The person you have the discussion with is called a counsellor. You will also be able to ask questions.

Take someone along with you

Two people hear more than one. So it's a good idea to take someone else with you to the counselling session. It could be your partner, for instance, or a trusted friend, or one of your parents. Avoid bringing children with you. That way, you will have the chance to talk without distractions.

It's your decision

After the counselling session, it's entirely your choice to decide whether or not you want to have the scan for physical abnormalities. Are you still unsure? Then you may discuss it with your obstetric care provider again. This may help to make things clearer for you. Have you decided that you want to have a scan for physical abnormalities?
Then you can make arrangements for this immediately.

What does the screening test involve?

Only specially trained sonographers are authorised to do the 13-week scan and the 20-week *scan. For this reason, you will usually have to go to a special sonography centre for the scan. However, in some cases your own obstetric care provider will be able to perform the scan.*

The scan takes about 30 minutes. The sonographer will take the time to examine your baby in detail. The scan is usually done via the abdomen:

- You will lie on your back while the sonographer is doing the scan. You will expose your abdomen. Some gel will be spread on your abdomen. It can sometimes feel a bit cold.
- The sonographer will move the transducer over your abdomen. The sonographer can now see your baby. You will usually be able to see this yourself on a screen.

The 13-week and 20-week scans are safe for you and your unborn child. The examination doesn't hurt and your unborn child will not feel anything.

The sonographer has to concentrate carefully during the screening test, and you would probably not want anyone to distract you. For these reasons you may only bring one person with you. Do not bring any children.

A vaginal scan

Sometimes the sonographer cannot see everything clearly. This could be because a woman is above average weight, due to a scar on the abdominal wall or because the baby is lying in an awkward position. The sonographer may suggest doing a vaginal scan. If you want to have this, the vaginal scan will be done at that moment, during that same appointment. If you don't want to have a vaginal scan, you can decline to have it.

The result

You will be given the results of the scan immediately after the screening test. What do the results mean? How certain are the scan results?

The results are not certain

- Sometimes the sonographer sees something that could be an abnormality. An international study has shown that at the 13-week scan possible abnormalities were seen in 5 out of 100 pregnant women. Another scientific study has been set up to investigate this further. At the 20-week scan, about 5 out of 100 pregnant women show signs of potential abnormalities.
- What if the sonographer sees something that is an indication for an abnormality? It is not always clear if it really is an abnormality, how serious it may be, and what it means for your baby. For this reason, you will always be offered follow-up diagnostic testing.
- The sonographer cannot see all possible abnormalities at the 13-week scan and the 20-week scan. This means that even if the results are normal, your baby may still have an abnormality.

Chance of 5 out of 100

In 5 out of 100 pregnancies there are indications for abnormalities.
In 95 out of 100 pregnancies there are no indications for abnormalities.

Scientific study of the 13-week scan

The 13-week scan is part of a scientific study. One question researchers want to answer is, how often do sonographers see something which could be an abnormality? Based on international research, we currently think that possible abnormalities are seen at the 13-week scan in about 5 out of every 100 pregnant women. This number could be slightly higher, or lower.

The results of the 13-week scan

The following results are possible:

No visible indications of an abnormality.
This is the result for about 95 out of 100 pregnant women (this is an estimate, see the information on the previous page).

No follow-up diagnostic testing is necessary.

The sonographer has checked the baby but could not see everything clearly.
This doesn’t always mean that there is something wrong with your baby. It could mean that your baby is lying in such a position that it cannot be seen clearly. Further, it can be more difficult to perform a scan on women who are heavier.

No follow-up diagnostic testing is necessary. If you have chosen to have a 20-week *scan, the sonographer will look again at the next scan.*

There are indications of an abnormality.
If the sonographer sees something out of the ordinary, or is unsure about the findings, this is the result you will get. Further tests are necessary for a diagnosis, and to find out what this means for you and your baby.

You may choose to have follow-up diagnostic testing at a Centre for Prenatal Diagnostics. This is a department of a university hospital.
It is your choice whether or not you want to have these follow-up tests.

The results of the 20-week scan

The following results are possible:

There are no visible indications of an abnormality.
This is the result for about 95 out of 100 pregnant women.

No follow-up diagnostic testing is necessary.

The sonographer wants to repeat the scan.
This is the result you will get if the sonographer cannot see the baby clearly. It doesn't necessarily mean that there is something wrong with your baby.
It could mean that your baby is lying in such a position that it cannot be seen clearly.

If the sonographer has any doubts, you will be asked to come back for another scan.

Something out of the ordinary has been seen. Follow-up diagnostic testing is necessary to confirm the findings.
You will get this result if the sonographer sees anything out of the ordinary. Further tests are necessary for a diagnosis, and to find out what this means for you and your baby.

You may choose to have follow-up diagnostic tests at a Centre for Prenatal Diagnostics.
This is a department of a university hospital. It is your choice whether or not you want to have these follow-up tests.

There is an indication of an abnormality. No follow-up diagnostic testing is necessary.
You will get this result if the sonographer sees something that is not serious, and that usually goes away naturally.

You will have another scan later in your pregnancy. The sonographer will then check if the small abnormality has disappeared.

Deciding whether or not to have follow-up diagnostic testing

Has the sonographer seen an indication of an abnormality, and follow-up testing is necessary for more clarity? Then the sonographer, midwife or gynaecologist will tell you about the diagnostic tests you can have.

It is your choice whether or not you want to have these follow-up diagnostic tests. You may choose to do nothing. If you do choose to have the tests, then you will decide for yourself what to do considering the results of the follow-up tests.

These are your options:
• You do nothing. You remain pregnant, do not have any follow-up tests and give birth to your baby.
• You get follow-up diagnostic tests. These will tell you conclusively if your child has an abnormality.

The choice is yours
If you want more information about follow-up testing, you will get an appointment at a prenatal diagnostic centre. After that, you can make your choice. You can also choose not to get follow-up testing.

What does follow-up diagnostic testing involve?

Follow-up diagnostic testing usually involves a morphology scan in a specialist hospital. Sometimes the doctor will also suggest another test:
• A blood test.
• A chorionic villus sampling test. The doctor will take a small piece of the placenta and examine it. This can be done after week 11 of the pregnancy.
• An amniocentesis. The doctor will remove a small amount of amniotic fluid and test it. This can be done after week 15 of the pregnancy.

After these follow-up tests you will know for sure if your baby has an abnormality. The chorionic villus sampling test and the amniocentesis both carry a small risk of causing a miscarriage. Miscarriage occurs in 2 out of 1,000 women who have these follow-up tests.

The results of the follow-up diagnostic tests

The doctor will tell you the results of the follow-up diagnostic tests. The results may show that there is nothing wrong. However, there is also a chance that the tests will show that your baby has a physical abnormality. News like this can make you feel anxious or sad, and you will probably have a lot of questions. For this reason, you will have a counselling session with one or more doctors soon after getting the results. This may be a gynaecologist, a clinical geneticist or a paediatrician. The types of specialists you will talk to will depend on the type of abnormality that has been found.

Extensive support

One or more doctors will be present at the counselling session to help you and to give you more information. You will be given the following information:

- How this will affect your baby's life.
- The consequences that the abnormality will have for your baby.
- If your baby's abnormality can be treated.
- Where you can find more information about the abnormality. For more information you can find details of the most important organisations and websites listed on Page 25 of this brochure.

You and your partner can ask any questions during the session.

Help in deciding what to do considering the results

After the counselling session you are often faced with a difficult choice, because you have to decide what to do considering the results. The experts at the Centre for Prenatal Diagnosis will help you with this. What are your choices?

- You can continue with your pregnancy and have the baby. You will then be able to prepare for the arrival of a baby with a disorder or abnormality. You will also be able to arrange extra care for your pregnancy and the birth of the baby.
- In some abnormalities the baby may not survive the pregnancy, the birth, or for very long after being born. If this is the case, your obstetric care provider will give you careful guidance.
- You can also choose to terminate the pregnancy. The baby will then die. Talk about this with the midwife, gynaecologist, paediatrician or clinical geneticist. And ask any question you want to. You can also talk with other experts. For example, a psychologist or a social worker. Have you chosen to terminate the pregnancy? This can be done up to 24 weeks of pregnancy.

It is often very difficult to make a decision. For this reason, make sure to ask your obstetric care provider all of your questions. You can also ask the other doctors who were present at the session to discuss your results.

Whatever the result, talk to someone – with your partner, midwife, social worker, psychologist, gynaecologist or GP.

Costs and reimbursements

What do the screening tests cost? Are these costs reimbursed by health insurance? You do not have to pay anything for the 13-week scan or the 20-week *scan.*

Costs of counselling

Your health insurer will pay the costs of your counselling. Counselling is an in-depth discussion about the tests for physical abnormalities. You do not have to pay anything yourself. It will also not affect your health insurance's obligatory deductible excess.

Costs of the 13-week scan

If you are a care user in the Netherlands, you will not pay anything for the 13-week scan. For more information see www.pns.nl.

Costs of the 20-week scan

The 20-week scan is covered by your basic health insurance package. You will usually not have to pay for the 20-week scan, and nothing will be deducted from your health insurance's obligatory deductible excess. If your obstetric care provider does not have a contract with your health care insurer, the costs of the scan will not always be completely reimbursed. For more information see www.pns.nl.

Costs of follow-up diagnostic tests

Has the sonographer seen an indication of an abnormality at the 13-week scan or at the 20-week scan? Then you can choose to have follow-up diagnostic tests. Your health insurer will cover the costs of these. This care is covered by your basic health insurance package. However, you will pay something from your obligatory deductible excess. Ask your health insurer about this. The experts at the Centre for Prenatal Diagnostics can also give you information about this.

The terms and conditions of health care insurers can differ greatly. For this reason, please take into account that the costs may not always be fully reimbursed. For more information see www.pns.nl.

More information about the screening test

There are several organisations, websites and leaflets where you can find more information about your pregnancy, as well as various abnormalities and conditions.

Internet

On www.pns.nl there is information about tests both during and after pregnancy (prenatal and neonatal screening tests).

Other websites that provide information about tests during your pregnancy:
www.erfelijkheid.nl
www.deverloskundige.nl
www.thuisarts.nl
www.degynaecoloog.nl
www.13wekenecho.org (information about the scientific IMITAS study)

VSOP
VSOP is the Dutch national patient alliance for rare and genetic diseases. VSOP advocates for people with rare and genetic disorders and their families and caregivers on behalf of more than 100 member organisations.

The Erfocentrum
The Erfocentrum provides information about inherited disorders. See www.erfelijkheid.nl and www.zwangerwijzer.nl.

Information about specific abnormalities
- Living with cerebral paresis (spasms), CP Nederland: www.cpnederland.nl
- Living with severe multiple disabilities, EMB Nederland: www.embnederland.nl
- Living with spina bifida or hydrocephalus, SBH Nederland www.sbhnederland.nl
- Living with schisis (split lip, jaw or palate), Schisis Nederland: www.schisisnederland.nl

ZeldSamen
The ZeldSamen association collects the knowledge and experiences of parents and care professionals regarding very rare genetic syndromes: www.zeldsamen.nl.

ZON Platform
The ZON Platform connects parents of children with undiagnosed chronic illnesses and exceptionally rare disorders.

Dutch Heart Foundation
For more information about congenital heart defects, see www.hartstichting.nl.

Fetusned
See www.fetusned.nl for information about abnormalities of bones, arms, or legs, and information about possible treatments.

RIVM
RIVM co-ordinates everything related to prenatal screening. This includes information and research, for example. RIVM works on behalf of the Ministry of Health, Welfare and Sports. See www.rivm.nl.

Regional Centres for Prenatal Screening
The Regional Centres for Prenatal Screening ensure that prenatal screening in your area is well organised. For more information see www.pns.nl/professionals.

Brochures containing information about other pregnancy screening tests

You can read more in these brochures:

The NIPT
This brochure can be found at www.pns.nl/folders

Pregnant!
This is a general information brochure about pregnancy. It also contains information about the blood test you have when you are 12 weeks pregnant.
This is the test at which your blood group is identified. It also tests to see if you have any infectious diseases. The brochure can be found at www.pns.nl/folders

You can also ask your midwife, GP and gynaecologist for these brochures.

What happens to your data?

Have you chosen to have prenatal screening? Your health care professionals will then keep your data in a medical record. This is necessary to do the test and give you the results. Your prenatal screening data is stored in a national database (Peridos). Only your care providers can look up your data in Peridos.

Only health care professionals are able to see your data. This includes your midwife, gynaecologist, laboratory technician, nurse and sonographer, for example.

What is your data used for?

1. To monitor performance of the NIPT, the 13-week scan and the 20-week scan and to verify that care providers and laboratories are doing their work correctly (quality assurance). This is done by a regional centre. This centre ensures that prenatal screening in

your region is well regulated. The centres are licenced by the Ministry of Health, Welfare and Sports. Regional centre staff can look up and check the data, which may have been anonymised. The system is well secured.

2. To further improve the quality of the NIPT, the 13-week scan and the 20-week scan (monitoring and evaluation). The figures on the studies and on the effects of the studies are used for this purpose. These include figures on how many pregnant women choose to have prenatal screening, and what the results of the various tests are. The researchers cannot see who the data belongs to. Sometimes it is necessary for researchers to know this, for example when investigating new methods. If we want to use your data for this, we will ask you for your permission first.
3. For the IMITAS study and for possible future scientific research: subject to strict criteria, scientific researchers can request data about the NIPT, the 13-week scan and the 20-week scan. Your data can be used in the IMITAS study and in future scientific research only if you give your consent for this.

Would you prefer us not to use your data?

If you don't want us to use your data for quality control and scientific research, please tell your obstetric care provider. Your data will then be removed from the database. This will be done after the date at which your obstetric care provider expects you to give birth. All that will remain in the database is an anonymous report that you have had prenatal screening so that you can be included in the statistics. However, no one will be able to see your personal data.

Want to know more?

If you want to know more about how we protect your personal data, your obstetric care provider can give tell you more about this. You can also find more information on www.peridos.nl and www.pns.nl.

Consent for scientific IMITAS study

Have you chosen to have a 13-week scan? Then you will be taking part in the scientific IMITAS study. This means that researchers can use your data.
You will sign an informed consent form for this. If you want more information about this, see www.13wekenecho.org.

Consent for future scientific research

Scientific researchers may wish to use your data from the 13-week scan, the 20-week scan and/or the NIPT. This also includes data about any follow-up diagnostic tests and about the health of your baby after birth. Note that, in the case of the 13-week scan, this refers to scientific research after the IMITAS study. During your counselling session, your care provider will ask if you consent to your data being used in future scientific research. The choice is up to you. Your answer will be registered in Peridos.

Strong data security

If you give consent for future scientific research, your data will be kept well secured. Scientific researchers will not be able to see your name or address. They will not know to whom the data belongs.
Do you want to withdraw your consent?
If you want to withdraw your consent, tell your obstetric care provider. The Peridos system will notify the IMITAS research group that consent has been withdrawn.

Do you object to storing your data in Peridos?

If you do not want your prenatal screening data to be stored in Peridos for monitoring purposes and/or to improve prenatal screening, tell your obstetric care provider. They will make sure that only anonymous data remains in Peridos after the expected date of delivery. That means you will be included in statistics, but no one will be able to see your personal data.

Who produced this leaflet?

This leaflet was produced by a workgroup. A number of organisations took part in the workgroup.

- An organisation of sonographers (BEN)
- The Regional Centres for Prenatal Screening
- The *Erfocentrum*
- An organisation of midwives (KNOV)
- An organisation of paediatricians (NVK)
- An organisation of gynaecologists (NVOG)
- RIVM
- An organisation of clinical geneticists (VKGN)
- VSOP: an association of 90 patient organisations for rare and genetic disorders.

Colophon

This leaflet was compiled on the basis of current knowledge. The people and organisations who produced this leaflet are not responsible for potential inaccuracies in the leaflet. You can get personal advice from your midwife or gynaecologist.

This leaflet is also available on www.pns.nl, the website offering information about tests both during and after pregnancy (prenatal and neonatal screening tests).

Are you an obstetric care provider? You can order extra brochures from the online PNS shop at www.pns.nl/webshop.

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