

Information on the anomaly scan

The 20-week ultrasound
May 2019

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1 What can you get tested?

During pregnancy, you can have screening tests to find out whether your unborn baby has a congenital disorder or any physical abnormalities. This is called prenatal screening. There are two types of screening tests:

1. prenatal screening for Down syndrome, Edwards' syndrome and Patau's syndrome, and
2. screening for physical abnormalities (anomaly scan).

It's entirely up to you to decide whether or not you want to take these screening tests. This leaflet contains further details about the 20-week anomaly scan.

There is also a leaflet about the prenatal screening for Down syndrome, Edwards' syndrome and Patau's syndrome.

What is the anomaly scan?

The anomaly scan is a medical examination. Another name for it is the structural ultrasound scan. The aim is to find out whether the baby has any physical abnormalities. These include spina bifida (an open spine), anencephaly (where most of the brain and spinal cord is missing), hydrocephalus (water on the brain), heart defects, diaphragmatic hernia, abdominal hernia, either absent or abnormal kidneys, abnormal bone development, and abnormalities of the arms or legs. The sonographer also checks whether the baby is growing properly and whether there is sufficient amniotic fluid.

If you are expecting more than one baby, the sonographer will examine each one individually. When making an appointment for the anomaly scan, you should say that you are expecting more than one baby.

The anomaly scan is not used to find out the sex of your baby. However, if the sonographer does happen to notice the sex of your baby, they will only tell you if you ask them to do so.

When is the anomaly scan carried out?

You can have an anomaly scan from week 18 to week 21 of your pregnancy (which is 21 weeks and 0 days into your pregnancy). It should ideally be in week 19 of your pregnancy (which is 19 weeks and 0 days to 19 weeks and 6 days into your pregnancy).

Are there any risks involved? The scan does not entail any risks for the mother or the baby.

What costs are involved? You do not have to pay for the anomaly scan as it's covered by the basic health insurance.

During your first visit, your obstetric care provider will ask you if you would like to know more about the anomaly scan. What if you don't want this information? In that case, your obstetric care provider will not tell you anything about the anomaly scan. This means you have decided not to have your baby screened by means of an anomaly scan.

Would you like to know more? If so, then you will have an in-depth discussion. This is called a counselling session. After this session, you are free to choose whether or not you want an anomaly scan. During this session, your obstetric care provider will also discuss prenatal screening for Down syndrome, Edwards' syndrome and Patau's syndrome

The obstetric care provider will usually be your midwife, but this role could also be performed by another care provider, such as a gynaecologist, sonographer or nurse.

Where can you find more information?

We recommend that you take a look at www.onderzoekvanmijnongeborenkind.nl beforehand. If there is anything you don't understand, please feel free to ask about it during the session.

2 It's entirely up to you whether or not you have an anomaly scan

An anomaly scan is not compulsory. It's entirely up to you to decide whether to have the scan and what should be done based on the result. You can also withdraw from the screening test at any time.

Most babies show no signs of physical abnormality. In these cases, the result of the anomaly scan may help to put your mind at rest. But there is also a chance that the result might worry you or scare you. For this reason, it is important for you to carefully consider whether you want to go ahead with the anomaly scan.

Questions that can help you to reach a decision.

The result of the anomaly scan may force you to make some difficult choices. Some abnormalities – such as certain heart abnormalities – can be effectively treated. Others cannot. This is not always clear in advance. You should also remember that the anomaly scan cannot (yet) show up all types of abnormality.

Here are a few questions that can help you to reach a decision:

- How much do you want to know about your baby before it is born?
- The anomaly scan could show that your baby may have a physical abnormality. In that case, would you want to have follow-up diagnostic testing?
- If the follow-up diagnostic testing shows that your baby does indeed have a physical abnormality, how can you prepare for this?
- Imagine that your baby is found to have a severe physical abnormality. What are your views about terminating the pregnancy?

Help with choosing

There is a questionnaire at www.onderzoekvanmijnongeborenkind.nl that can help you to organise your own feelings and thoughts on the matter. There are also tips on how to discuss this topic with your partner or others. You will also find the personal stories of various women who had to choose whether or not to go ahead with these screening tests. You can always put your questions to your midwife or gynaecologist.

3 An in-depth discussion: counselling session

During your first visit to your obstetric care provider, did you tell them that you would like to know more about the anomaly scan? If so, you will have an in-depth counselling session with your midwife or gynaecologist about the screening. You will also be able to ask questions. This is called counselling. The person you will be talking to is called a counsellor.

Take someone along with you

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

It's entirely up to you

After the in-depth discussion (counselling session), it's entirely up to you to decide whether or not you want the anomaly scan. What if, after the counselling session, you are still not sure whether you want to go ahead with the screening? In that case, you can discuss this again with your midwife or gynaecologist. This may help to make things clearer for you. If you do decide to go ahead with an anomaly scan, you should make an appointment immediately

4 What does the screening test involve?

Only specially trained sonographers are authorised to do the anomaly scan. You will usually have to go to a specialised sonography centre to get the screening test. In some cases, your own midwife or gynaecologist will be able to do the anomaly scan. The whole screening test takes about 30 minutes.

The sonographer will make an ultrasound scan of your baby, and will take the time to examine your baby in detail.

What happens during the anomaly scan?

- You will lie on your back during the anomaly scan. You will have to expose your belly. Some gel will be spread over your belly. That can sometimes feel a bit cold.
- The sonographer will move the transducer probe (a kind of wand) over your belly. The sonographer will now be able to see your baby. You will usually be able to see this yourself, on a screen.
- Ultrasound scans don't hurt. Your baby will feel nothing, and it is perfectly safe for you and your baby.

The sonographer has to concentrate carefully during the screening test. And you won't want to be distracted either. So avoid bringing any children with you, and bring as few other people as possible (no more than one or two).

5 The result of the anomaly scan

You will be given the result of the anomaly scan immediately after the screening test. But what do the results mean exactly? Does the anomaly scan provide absolute certainty?

What do the results mean?

- In about five out of every 100 pregnant women, the sonographer sees something that might be an abnormality. It is not always clear whether or not something really is an abnormality, nor how bad the abnormality is and what it might mean for your baby. In such cases, you will usually be offered follow-up diagnostic testing.
- The anomaly scan cannot show up all types of abnormality. This means that, even if the results are good, your baby may still have an abnormality.

What sort of results might you get?

There were no visible abnormalities.

In about 95 out of 100 pregnant women, the sonographer sees no abnormalities at all. In these cases, no follow-up diagnostic testing is needed.

The sonographer wants to do another ultrasound scan.

The sonographer may not be able to see your baby in sufficient detail. That does not necessarily mean that something is wrong with your baby. For instance, it may just mean that the baby is not lying in a favourable position. In the case of heavier women, it is sometimes difficult to do the screening test. When in doubt, the sonographer will ask you to come back later for another anomaly scan.

Something out of the ordinary has been seen. Follow-up diagnostic testing is not necessary.

Occasionally, the sonographer will see something in the anomaly scan that is usually not considered to be serious. Something that will eventually disappear naturally. However, the sonographer may well want you to return for another anomaly scan, later in your pregnancy. She will then check that whatever it was she saw last time has indeed disappeared.

Something out of the ordinary has been seen. Follow-up diagnostic testing is needed, just to be sure.

Sometimes, the sonographer will see something that is out of the ordinary. In that case, further screening tests will be needed to find out exactly what the problem is, and to determine its consequences for your baby. To be absolutely sure, the sonographer will send you to a Centre for Prenatal Screening (which is a department in the hospital).

6 Deciding whether or not to have follow-up diagnostic testing

Has something out of the ordinary been seen? Also, is follow-up diagnostic testing needed to find out more about this? If so, the sonographer, your midwife or your gynaecologist will always discuss every detail of the follow-up diagnostic testing options with you. Follow-up diagnostic testing is not compulsory. You could decide not to take any tests and to just carry on with the pregnancy, it's up to you. If you do decide to go ahead with follow-up diagnostic testing, what you do about the results is entirely up to you.

What does follow-up diagnostic testing involve?

Follow-up diagnostic testing usually involves an extensive ultrasound scan in a specialist hospital. Sometimes you will also be offered amniocentesis or a blood test. Amniocentesis is a procedure in which a doctor inserts a needle into your belly and takes a little amniotic fluid (the liquid that surrounds the unborn baby in the womb). There is a small chance of a miscarriage. About one in every 1,000 women who have had an amniocentesis suffer a miscarriage. However, the other 999 women do not suffer a miscarriage as a result of the screening test.

The results

The medical specialist will inform you about the results of the follow-up diagnostic testing. The follow-up diagnostic testing may show that there is nothing wrong with your baby. But there is also a chance that these screening tests will show that your baby has a disorder. This type of news can trigger feelings of sadness or anxiety.

You would probably have a lot of questions, too. This means that, soon after the results are known, you will have counselling sessions with one or more medical specialists, such as a gynaecologist, a clinical geneticist, or a paediatrician. Exactly which specialists are involved will depend on the abnormality or condition that has been found.

Extensive support

You can always count on getting suitable support. A gynaecologist, paediatrician and/or clinical geneticist will talk to you about the results, and about your baby's disorder or abnormality. They will also tell you how this will affect your baby's life and whether it can be treated. There will, of course, be plenty of time for any questions that you and your partner might wish to ask. It is important that you get all the answers you need. You will also be told where to find more information about your baby's disorder or abnormality. Details of the most important organisations and websites are listed on page 14.

Help in deciding how to continue

The next step is usually a difficult one – you have to decide what you want to do about the results. It goes without saying that the experts at the Centre for Prenatal Screening will help you with this.

- You can choose to continue the pregnancy. You will then have several months in which to prepare for the arrival of a baby with a disorder or abnormality. You will also have time to tailor the care you receive during pregnancy and delivery, in line with the abnormality or disorder that has been found.
- Some abnormalities are so severe that the baby may die before or during birth. If this is the case, then the midwife or gynaecologist will give you careful guidance.

- If you find out that your unborn baby has an abnormality, you may find it difficult to decide what to do. You might consider terminating the pregnancy, for example. Put your questions to your midwife, gynaecologist, paediatrician and/or clinical geneticist. They will help you to reach a decision that is right for you. You will also be offered an opportunity to talk to a social worker, or other experts. If you opt for early termination, this procedure can be carried out up until the 24th week of your pregnancy.

Whatever the result, you should discuss it with your partner, midwife, social worker, psychologist, gynaecologist or GP.

7 Some other things that you need to know

The cost of an anomaly scan

Your health insurance will cover the cost of the anomaly scan counselling session and that of the scan itself. This will not affect your health insurance's obligatory deductible excess. So you don't have to pay anything yourself.

Please note: the counselling session, the right to reimbursement for the costs of that counselling session, and the anomaly scan will only be available if your care provider has an agreement with a Regional Centre for Prenatal Screening. You should ask about this in advance. You can also check (at www.peridos.nl/zoek-zorgverlener) which midwives or gynaecologists in your region have an agreement of this kind. Also, ask your care insurer whether your care provider has an agreement with them.

Reimbursement for follow-up diagnostic testing

If something out of the ordinary is seen during the anomaly scan, you can opt for follow-up diagnostic testing. The costs involved are covered by your basic health insurance package. However, this may affect your obligatory deductible excess. Ask your care insurer about this.

8 More information

Internet

You can read more about the anomaly scan at www.onderzoekinformatiemijnmijngeborenkind.nl. Are you finding it difficult to decide whether or not to have an anomaly scan? The website's questionnaire may be able to help you with this. There are also tips on how to discuss this topic with your partner or others.

Other websites that provide information on prenatal screening:

www.erfelijkheid.nl

www.deverloskundige.nl

www.thuisarts.nl

www.degynaecoloog.nl

Leaflets containing information about other pregnancy screening tests

There is a separate leaflet with information about prenatal screening for Down syndrome, Edwards' syndrome and Patau's syndrome. You can find this leaflet at **www.rivm.nl/down-edwards-patau/folder**. The leaflet entitled 'Pregnant!' contains general information about pregnancy. It also gives details of the blood test that you will take before you are 12 weeks pregnant. These screening tests are used for various purposes, such as identifying your blood group and checking for any infectious diseases. You can find this leaflet at **www.rivm.nl/folderzwanger!**. You can also ask your midwife, GP or gynaecologist about these leaflets.

Organisations and addresses

The Erfocentrum

The Erfocentrum is the national knowledge and information centre for heredity, pregnancy and genetic or congenital defects.

www.erfelijkheid.nl, www.zwangerwijzer.nl

BOSK

BOSK is an association for people with limited motor abilities, and their parents. BOSK provides information and advice, puts fellow patients in touch with one another, and protects the interests of people with impaired motor skills. One of BOSK's focal areas is spina bifida (both in children and adults). www.bosk.nl

VSOP

The Association of Parent and Patient Organisations (VSOP) is involved in genetic issues. It is a partnership of approximately 75 patient organisations, most of which involve disorders that are genetic, congenital, or rare. For more than 40 years, VSOP has been representing these organisations' common interests in the fields of genetic issues, ethics, pregnancy, biomedical research and care for rare disorders.

www.vsop.nl

Vereniging VG netwerken

Connects parents and people with very rare syndromes relating to intellectual disability and/or learning difficulties.

www.vgnetwerken.nl

Platform ZON

Patient organisation for the parents of children with very rare or unknown disorders, including chromosome abnormalities.

www.ziekteonbekend.nl

Dutch Heart Foundation

For more information about congenital heart defects, see: www.hartstichting.nl

FetusNed

Information about abnormalities in bones, arms or legs and possible treatments:

www.fetusned.nl

RIVM

The RIVM (Dutch National Institute for Public Health and the Environment) coordinates screening programmes for Down's syndrome and physical defects at the request of the Ministry of Health, Welfare and Sport and in cooperation with the various medical professional associations. For more information: www.rivm.nl/down-edwards-patau-seo under 'Organisatie'.

Regional centres

The eight regional centres are all licensed to organise the screenings described above. They maintain contractual agreements with the screeners and are responsible for regional quality assurance. More information about these Regional Centres can be found at:

www.rivm.nl/down-edwards-patau-seo under 'Organisatie'

9 How your data is used

If you opt for prenatal screening, the care providers will record data in your healthcare file. Some of this data will also be held in a national database (Peridos). This is necessary to ensure that prenatal screening runs smoothly. The data in Peridos can only be seen by your care providers (such as the midwife, gynaecologist, laboratory worker, nurse and sonographer).

Each region has its own Regional Centre that is licensed by the Ministry of Health, Welfare and Sport (VWS). These Regional Centres ensure that prenatal screening in your region is organised effectively. They also monitor all of the care providers involved, to ensure that they perform their duties properly. Staff at the Regional Centres occasionally check the data, to determine whether the screening is going well. The system is highly secure, to protect your privacy.

Scientific research

Having national figures about the use and effect of the screening programme is vital, in terms of improving prenatal screening still further.

For instance, we keep track of how many pregnant women use prenatal screening and the results of the various screening tests.

These evaluations and statistics are used by researchers, but the data contains no clues to the identities of the people who took these screening tests.

However, personal data are sometimes necessary for the purposes of scientific research. For instance, when investigating new methods. We would never use your data for that purpose without first asking your permission.

Objection

Would you prefer us not to use your data for evaluation and scientific research? If so, please tell your obstetric care provider. Your data will then be deleted after the expected delivery date. All that will be left is an anonymous report, so that you can be included in the statistics.

Would you like to know more?

Your obstetric care provider can give you more information about the protection of your data. Or go to www.peridos.nl.

You can also find more information on these topics at www.onderzoekvanmijnongeborenkind.nl/privacy.

Publishing details

The contents of this document were developed by a working group. This working group includes the organisations representing general practitioners (NHG), midwives (KNOV), gynaecologists (NVOG), the Regional Centres for Prenatal Screening, ultrasound operators (BEN), paediatricians (NVK), clinical geneticists (VKGN), the Erfo Centre, the Dutch Genetic Alliance (VSOP), regional screening organisations and the National Institute for Public Health and the Environment (RIVM). ©

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RIVM, may 2019