About Screening Discussion Aid for Health Practitioners

The National Screening Unit



About screening HIV screening Down syndrome & other conditions screening Newborn Metabolic screening Newborn Hearing screening

About this resource

Purpose

The resource is designed as a support for health practitioners to help women to make informed choices about screening for themselves and their babies.

While this resource may be used for all women, it has been designed to enhance informed choice in situations where there are communication challenges. This may include women who are deaf or hearing impaired, have low literacy levels, are intellectually disabled, are migrants/refugees, have English as a second language, and some Māori or Pacific women.

Ensuring informed choice includes:

- provision of information about screening
- offering screening in a non-directive manner
- discussions about screening before and during the screening process
- discussions about options following a positive or unclear result
- giving sufficient time to consider options
- documenting discussions and consent or decline to screening
- assuring the woman that whatever choice she makes will be supported.

To aid with informed choice, this resource should be used in conjunction with the relevant practitioner guidelines and consumer pamphlets.

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About screening	HIV screening	Down syndrome & other conditions screening	Newborn Metabolic screening	Newborn Hearing screening

About this resource

How to use this resource:

- The resource is best used as part of a discussion between you and the woman.
- The front-facing pages are for the woman. They illustrate each of the screening steps and the decision points.
- The back-facing pages are for you. They contain prompts/ information for you to use in your screening discussions with the woman. These back pages are not intended to be a script, and can be adjusted to suit your discussions.
- The information in italics contains pointers for you – they refer you to other pages within the document, or sources of additional information that can be used in your discussions.

The resource is in two sections:

- screening during pregnancy
- screening for the baby.

The pregnancy screening section can be discussed with the woman at the first antenatal visit, and the screening for the baby section during the third trimester.

Tips for communicating effectively with women

 To aid with informed choice, this resource should be used in conjunction with the relevant practitioner guidelines and consumer pamphlets.

About screening

HIV screening Down syndrome & other conditions screening Newborn Metabolic screening Newborn Hearing screening

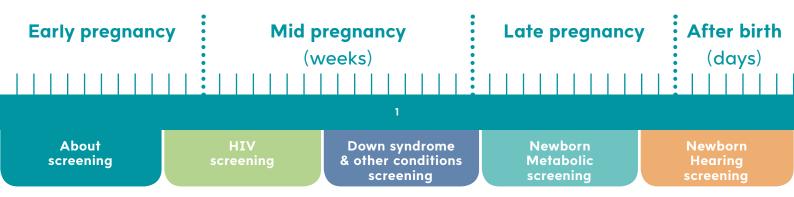
Screening during pregnancy Practitioner Prompts

These screening tests should be discussed during the first trimester or first antenatal visit.



Screening during pregnancy





What is screening during pregnancy? Practitioner Prompts

Screening for you and your baby. The tests can tell you more about your pregnancy and your baby. All pregnant women are offered screening. These tests do not cover all medical conditions.

There are many screening checks during pregnancy. For example the test for diabetes and the check of your baby's heart during ultrasound are both screening checks. Today we are going to talk about two screening checks in pregnancy that particularly involve your choice - HIV screening and screening for Down syndrome and other conditions.

HIV screening in pregnancy is strongly recommended. If you have HIV, you will be offered treatment to help you stay well and to protect your baby from getting HIV.

This screening also involves collecting information about you and the test. This is to make sure that the test results are given to the right person and to make sure that the testing is of the best quality. This information and our discussion will help you decide whether to have screening for HIV as part of the first antenatal blood tests.

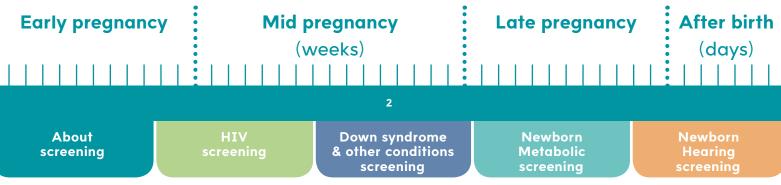
Screening for Down syndrome and other conditions is optional. The test is done to offer you more information about your baby and involves a blood test and a scan up to 14 weeks and a blood test only between 14 and 20 weeks.

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About screening	HIV screening	Down syndrome & other conditions screening	Newborn Metabolic screening	Newborn Hearing screening

What is screening during pregnancy?

- Checks for every pregnant woman
- Screening is your choice





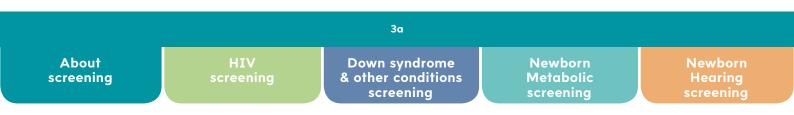
Why screen? Practitioner Prompts

Screening in pregnancy tells you more about you and your baby. For instance it will tell you whether you have a medical condition that needs to be treated.

Some medical conditions can make you or your baby very sick, and others can affect how your baby grows and learns.

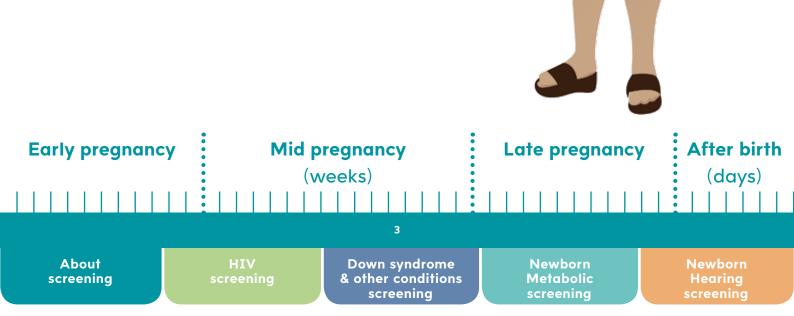
You cannot tell whether you or your baby has one of these conditions without the test.

Finding out early will help you to plan for the future.



Why screen?

- Find out early
- Help you to make choices
- Help you to plan



The screening pathway Practitioner Prompts

Screening finds out the number of people who may be more likely to have a medical condition.

Most women will have only one screening test for each of the conditions that are looked for. Sometimes another screening test is needed if the first test is not clear.

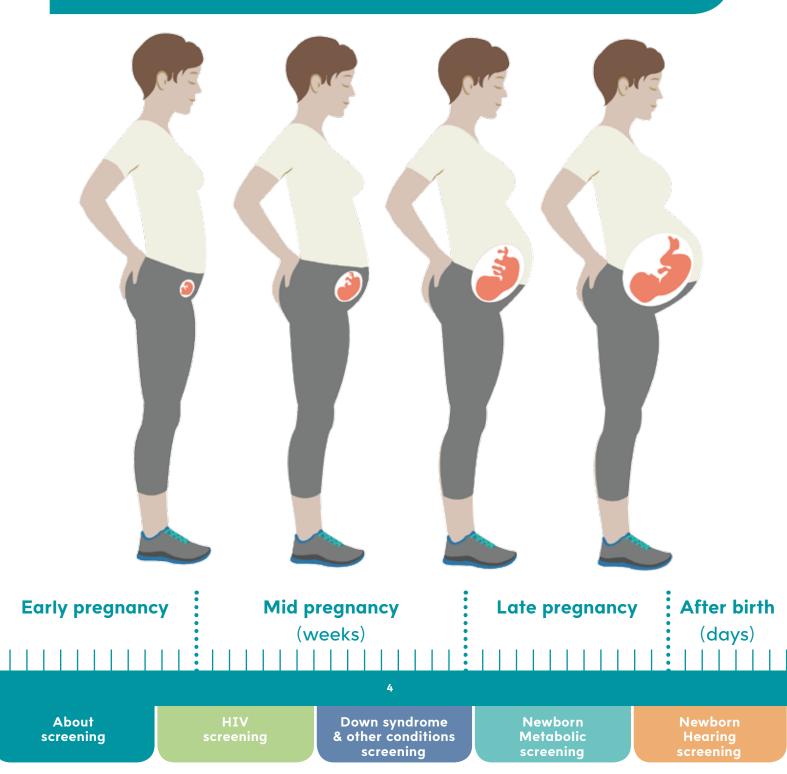
Other tests will be needed to tell you for sure if something further is needed.

Screening usually finds all the people who may have the condition but sometimes it doesn't.

Whenever you have a test, there may be other decisions that you need to make along the way.



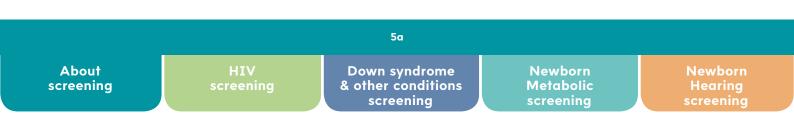
The screening pathway



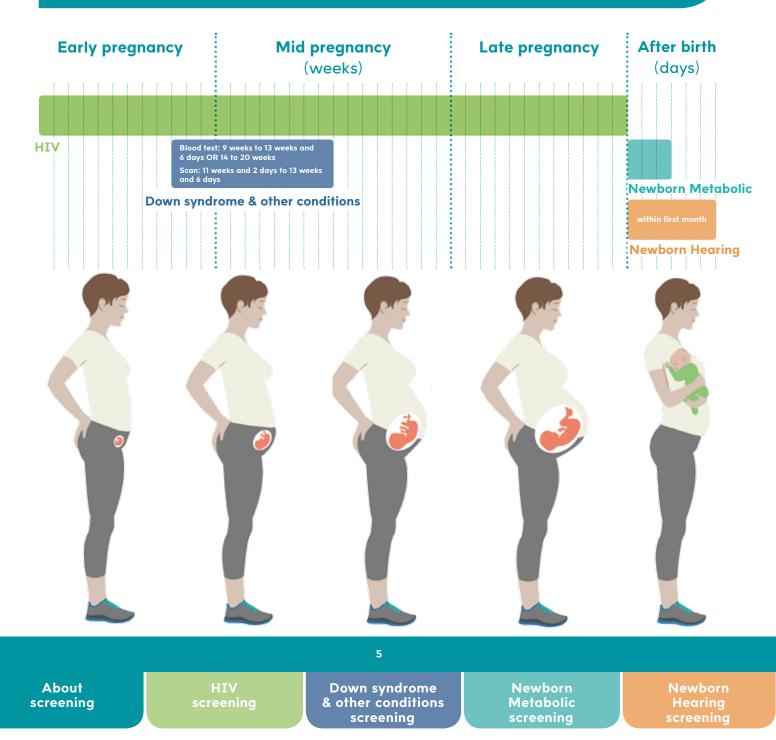
When are the pregnancy checks done? Practitioner Prompts

HIV - at the first pregnancy visit or anytime during your pregnancy

Down syndrome and other conditions - between 9 and 20 weeks



When are the pregnancy checks done?

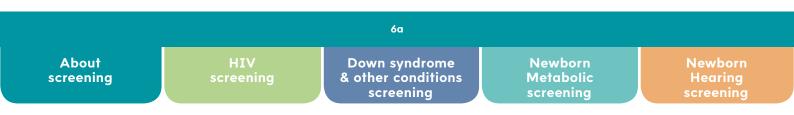


Screening is your choice Practitioner Prompts

Do you have any questions?

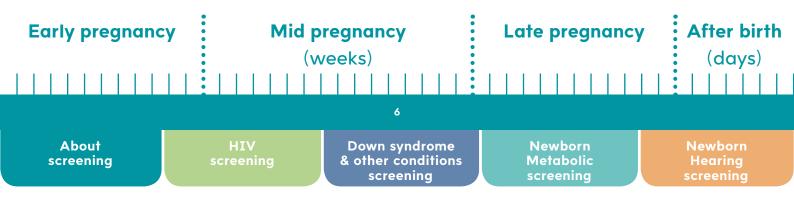
Check understanding

- Screening is my choice.
- Screening is a test to find out more about me and my baby.
- Sometimes further tests are needed.



Screening is your choice





Relevant resources and guidelines

For health practitioners

See the National Screening Unit website: www.nsu.govt.nz

- Guidelines for Maternity Providers offering Antenatal HIV Screening 2008 (HP5045)
- Antenatal HIV Policy and Quality Standards
- 6 online courses for health practitioners: http://www.nsu.govt. nz/health-professionals/3332.aspx and http://learnonline. health.nz/course/category.php?id=5)

For pregnant women

Available from your local authorised health education resource provider, or the HealthEd website: www.healthed.govt.nz

- HIV testing in pregnancy: part of antenatal blood tests (HE1832)
- HIV testing in pregnancy: part of antenatal blood tests (HE1901). This resource has the same text as HE1832, but there are no photos. Also available as web-only translations in: *Chinese* simplified (HE1932), *Chinese traditional* (HE1931), *Hindi* (HE1930), *Korean* (HE1929), *Māori* (HE1925), *Swahili* (HE1928), *Samoan* (HE1926) and *Tongan* (HE1927).



HIV Screening

Antenatal Screening free health checks during pregnancy HIV testing in pregnancy



part of antenatal blood tests

About screening

HIV screening Down syndrome & other conditions screening Newborn Metabolic screening Newborn Hearing screening

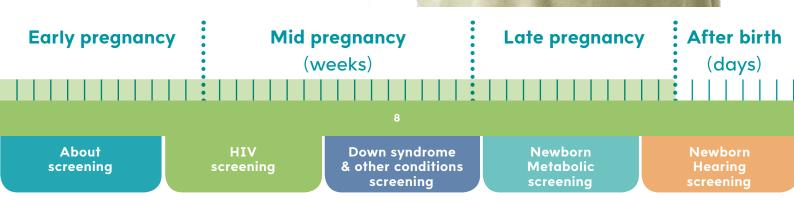
HIV Practitioner Prompts

- HIV is a virus that can make you and your baby very sick.
- You can have HIV for a long time without knowing it.



HIV

- A virus
- Can pass it to your baby



Why screen for HIV? Practitioner Prompts

- If you have HIV, you will be offered treatment to help you stay well and to protect your baby from getting HIV.
- HIV screening is strongly recommended.



Why screen for HIV?



What is HIV screening? Practitioner Prompts

A blood test.

This test is done at the beginning of your pregnancy, after your first visit with me.

The test is done at a community lab.

I will get your results in about a week. We will talk about your results together and what they mean for you and your baby.

Most times the results are negative. In a very few cases (about 1 in every 6000 women), the test results are unclear. If this happens you will need another test – these test results usually show that you don't have HIV.

Very few women have a positive test. If the results show you may have HIV then another blood test will be needed to be sure. If you do have HIV you will be seen by a specialist doctor and given treatment to make sure that you and your baby stay well – which involves taking medicine and usually having a caesarean and not breastfeeding the baby.

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About screening	HIV screening	Down syndrome & other conditions screening	Newborn Metabolic screening	Newborn Hearing screening

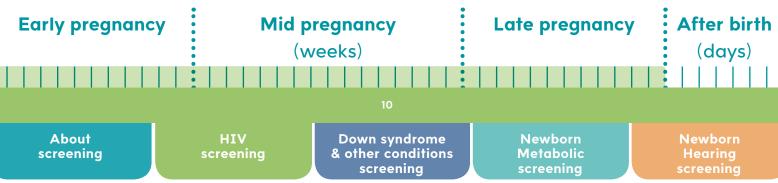
What is HIV screening?











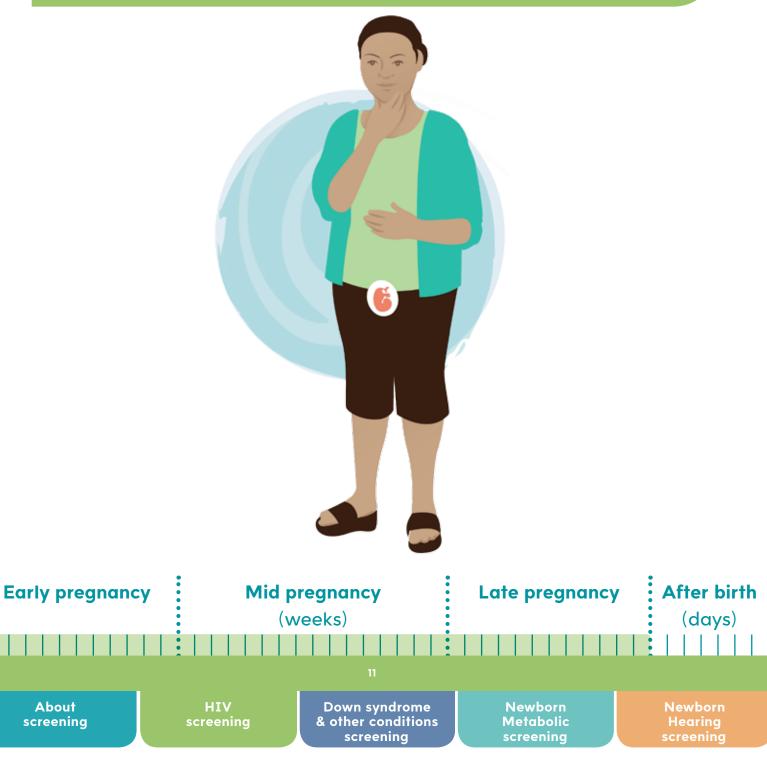
Do you have any questions?

Check understanding

- HIV screening is a blood test that is done when I am pregnant.
- I may not have any symptoms so may not know that I have HIV infection. It can pass to my baby.
- If I have HIV, I can be treated while I am pregnant. Treatment helps to keep me and my baby healthy and helps stop my baby from getting HIV.



HIV screening is strongly recommended



Down syndrome and other conditions Practitioner Prompts

Relevant resources and guidelines

For health practitioners

See the National Screening Unit website: www.nsu.govt.nz

- Antenatal screening for Down syndrome and other conditions: Guidelines for health practitioners (HP5409)
- 6 online courses for health practitioners: http://www.nsu.govt.nz health-professionals/3332.aspx and http://learnonline.health.nz/ course/category.php?id=5)

For pregnant women

Available from your local authorised health education resource provider, or the HealthEd website: www.healthed.govt.nz

• Antenatal screening and testing for Down syndrome and other conditions (HE2382)



Down syndrome and other conditions

Antenatal screening and testing for Down syndrome and other conditions – *in pregnancy*

> Optional screening – your choice – your decision

About screening

HIV screening Down syndrome & other conditions screening Newborn Metabolic screening Newborn Hearing screening

What is Down syndrome? Practitioner Prompts

Down syndrome happens at the time when the baby is made (conception).

Nothing that you have done causes Down syndrome.

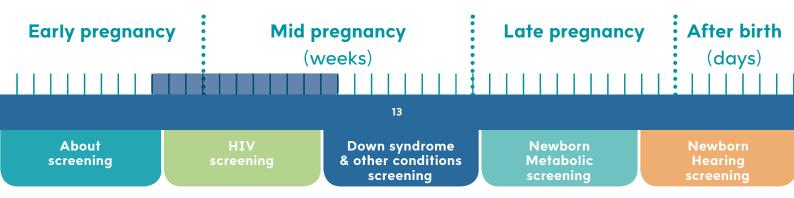
Down syndrome affects a baby's learning and development.

Any woman can have a baby with Down syndrome.



What is Down syndrome?





Why screen for Down syndrome and other conditions? Practitioner Prompts

Gives you more information about your baby and the pregnancy.

Screening will tell you whether you whether you have a low chance or an increased risk of Down syndrome (trisomy 21), trisomy 18 (Edward syndrome), trisomy 13 (Patau syndrome) or some other rare condition. [If appropriate, use the consumer pamphlet to discuss the other conditions.]

If you have screening and have an increased chance result you will be offered further testing to see if your baby has one of the conditions.

Screening doesn't pick up everything, or every baby with one of the conditions.

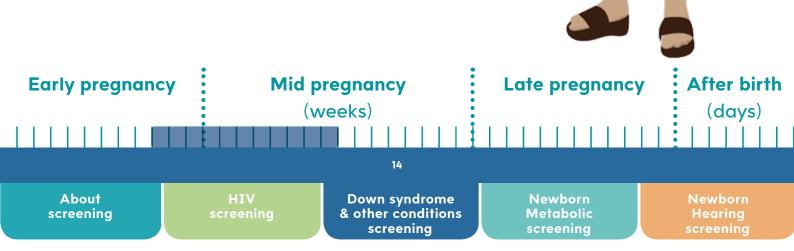
It is up to you whether you would like screening for Down syndrome and other conditions. It is optional and quite ok if you do not want to have it.

If you do have screening there may be some decisions that you need to make – especially if screening shows your baby is more likely to have a condition. These decisions are around further testing and how much information you would like to know about your baby.

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About screening	HIV screening	Down syndrome & other conditions screening	Newborn Metabolic screening	Newborn Hearing screening

Why screen for Down syndrome and other conditions?

- To find out early.
- To help you make choices.
- To help you plan.



When is the screening check done? Practitioner Prompts

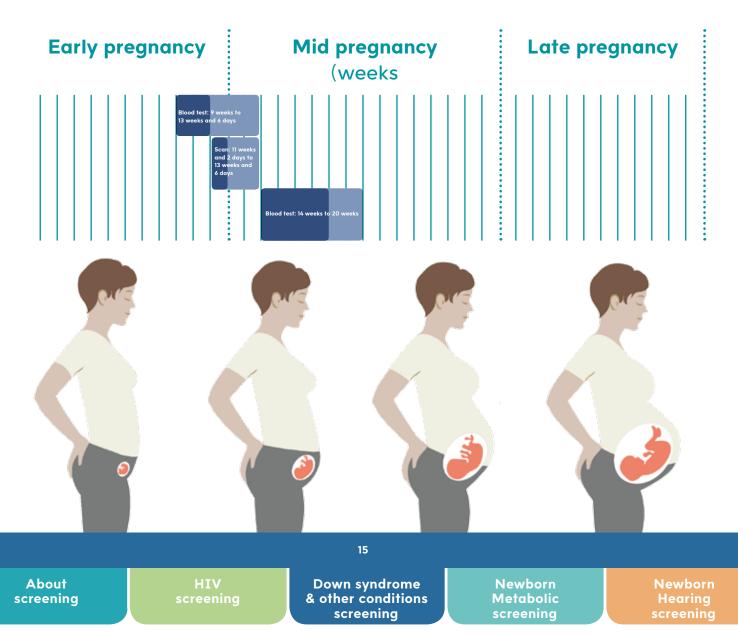
There are two options, depending on how many weeks pregnant you are – before 14 weeks or after 14 weeks – you may hear these terms called the first or second trimester.

On the following page (page 15), the boxes in the timeline show when the screening checks can be done. The best time for screening is shown in dark blue.



When is the screening check done?

- 9 weeks to 13 weeks and 6 days pregnant
- 14 weeks to 20 weeks pregnant



What is screening for Down syndrome and other conditions? Practitioner Prompts

Less than 14 weeks pregnant

If you are less than 14 weeks pregnant, screening is:

- a blood test from your arm
- an ultrasound scan of your baby.

If you would like to have this screening, we can work through the dates of when you should have the blood test and the ultrasound scan. The best time will be at 9–10 weeks for the blood test and around 12 weeks for the ultrasound scan.

The ultrasound scan can also tell you other things about your baby and how it is developing.

You will have to pay extra for the scan, usually \$_____ (health practitioner should give info based on local practice). There are a number of places that you could go to have the scan.

I will receive the results after you have had the blood test and the ultrasound scan. We will discuss the results together.

The results will tell you whether your baby is more likely to have one of the conditions. If this is the case, then you will be offered further testing to see if the baby definitely has one of the conditions. It is your choice whether you want the further tests.

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About screening	HIV screening	Down syndrome & other conditions screening	Newborn Metabolic screening	Newborn Hearing screening

What is screening for Down syndrome and other conditions?

Less than 14 weeks pregnant



What is screening for Down syndrome and other conditions? Practitioner Prompts

14–20 weeks pregnant

If you are 14-20 weeks pregnant, screening is:

• a blood test from your arm.

The best time is when you are 14–18 weeks pregnant, but it can be done up until you are 20 weeks pregnant.

We will discuss the results together.

The result of the test will tell you whether your baby is more likely to have one of the conditions. If this is the case, then you will be offered further testing to see if the baby definitely has one of the conditions. It is your choice whether you want the further tests.



What is screening for Down syndrome and other conditions?











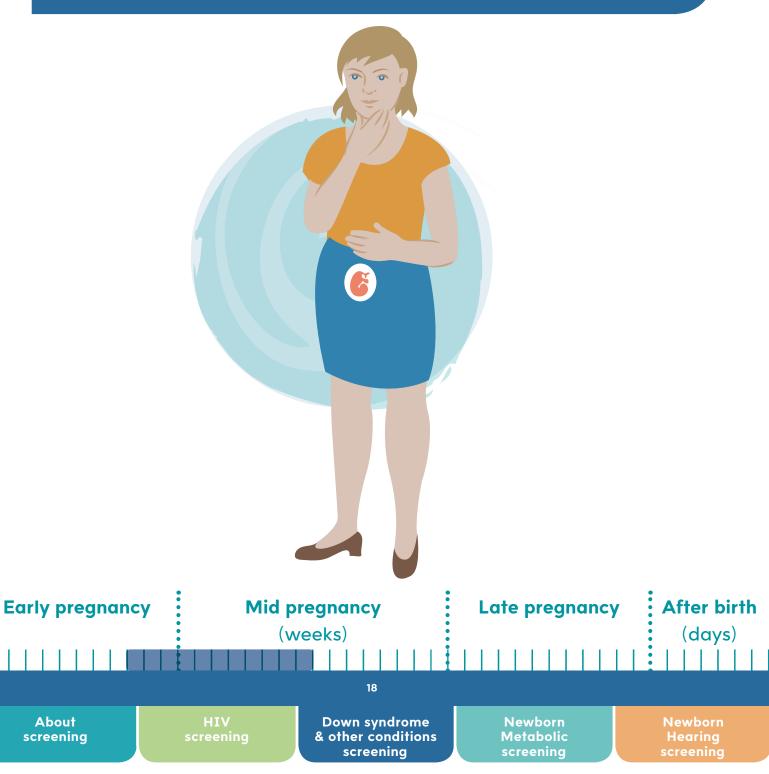
Do you have any questions?

Check understanding

- The condition happens at the time the baby is made.
- Screening is a blood test and a scan / screening is a blood test [Note: The answer depends on which screening the woman may have.]
- Screening will tell me if my baby is more likely to have a condition.
- Screening is my choice.



Screening is your choice



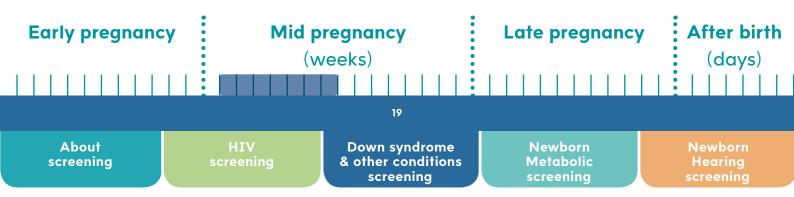
Your screening results Practitioner Prompts

We will discuss the results together.



Your screening results





Low chance Practitioner Prompts

A "low chance" result means your baby is less likely to have a condition.

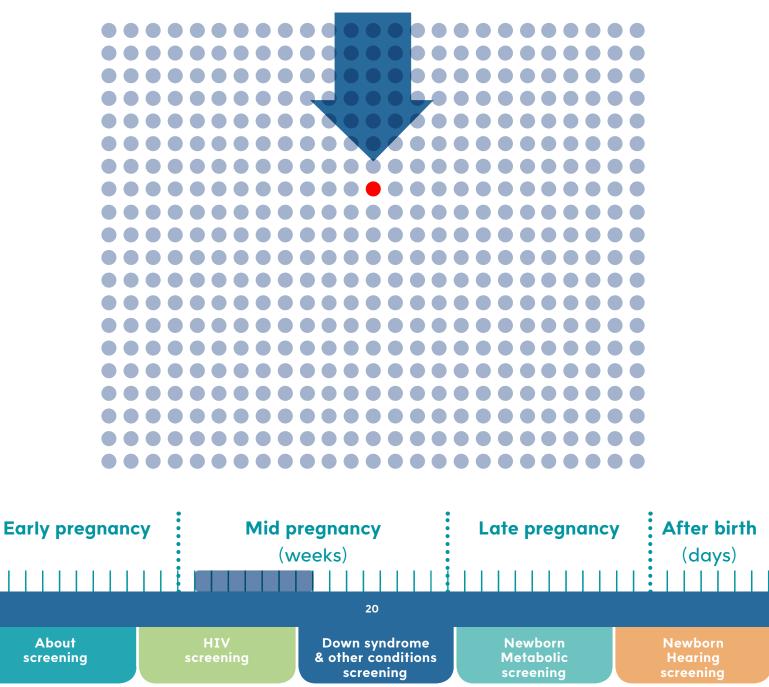
If your results are 1:500 for example, it means that for every 500 women who have the same result as you, 1 woman has a baby with a condition.

There is a very small chance that the screening test has missed a baby with one of the conditions.



Low chance

1 woman out of 500



Increased chance Practitioner Prompts

An "increased chance" result means your baby is more likely to have a condition. It does not mean your baby has a condition.

If your results are 1:50 for example, it means than for every 50 women screened and have the same results as you, 1 or more women has a baby with a condition.

If you have an increased chance result, we will talk about further testing that can tell you for sure whether your baby has one of the conditions.

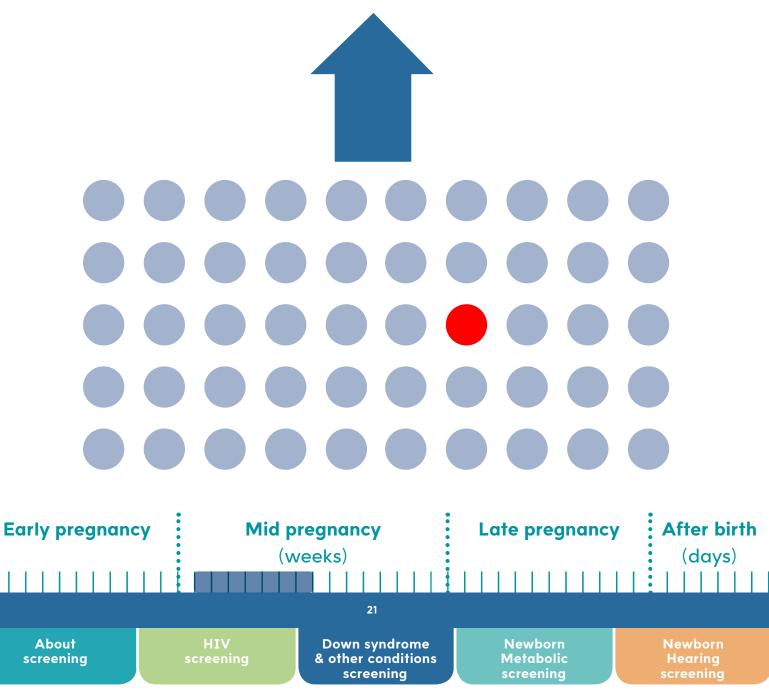
You will be offered an appointment with a specialist to have further testing and they will talk with you about your results and your choices.

You can choose not to see the specialist or to have further testing. We will continue with your regular pregnancy care.



Increased chance

1 woman out of 50



What is diagnostic testing for Down syndrome and other conditions? Practitioner Prompts

Diagnostic testing is offered if you have an increased chance result from screening.

It is the only way to know for sure if your baby has Down syndrome or another condition.

An amniocentesis (amnio) or CVS (chorionic villus sample) are the names of the procedures that collect a sample of fluid from around the baby (amnio) or a sample from the placenta (CVS). A thin needle is placed through your belly to collect the sample.

The procedure has a small chance of miscarriage because the needle goes into the uterus, around 1–2% (for every 200 women who have the test, 1 or 2 will have a miscarriage).

You will be given support to make decisions about testing and can have someone with you at all times.

Your results will be available in about 2 weeks.

Whatever the outcome, we will support you with information to help you to make the decisions that are right for you.



What is diagnostic testing for Down syndrome and other conditions?



Diagnostic testing is your choice Practitioner Prompts

Do you have any questions?

Check understanding

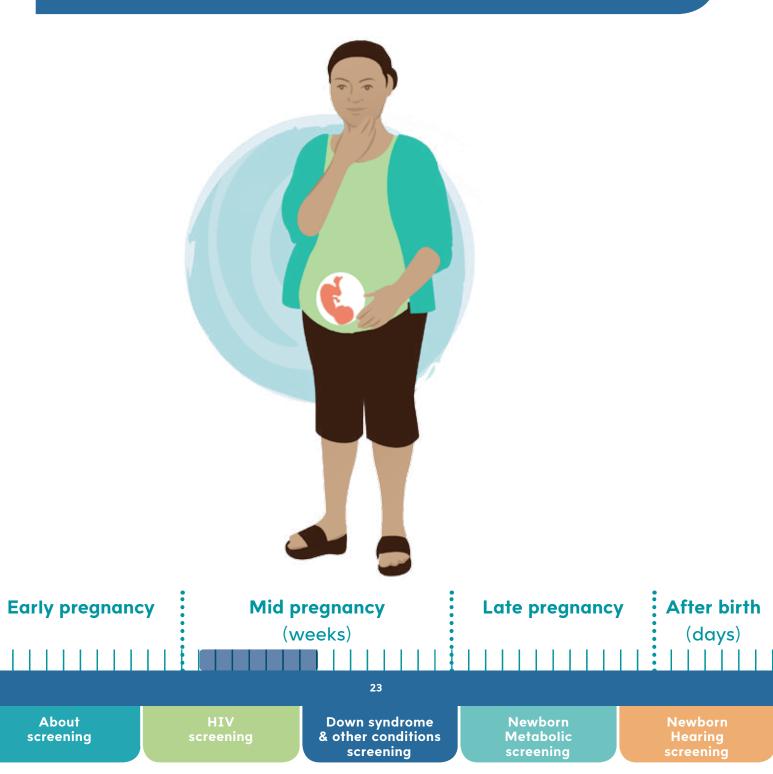
- Diagnostic testing is offered if I have an increased chance result.
- It's the only way to confirm if my baby has Down syndrome or another condition.
- You will talk with me about further testing if it is offered.
- There is a risk of miscarriage from the test (amnio/CVS).
- It's my choice.

You will be offered an appointment with a specialist to have further testing and they will talk with you about your results and your choices.

You can choose not to see the specialist or to have further testing. We will continue with your regular pregnancy care.



Diagnostic testing is your choice



Screening for your baby Practitioner Prompts

These screening tests should be discussed during the latter stages of pregnancy.



Screening for your baby

About screening

HIV screening Down syndrome & other conditions screening

Newborn Metabolic screening Newborn Hearing screening Screening checks of your baby that are done after he or she is born.

Today we are going to talk about:

- Newborn metabolic screening
- Newborn hearing screening.

I strongly recommend that you have these checks.

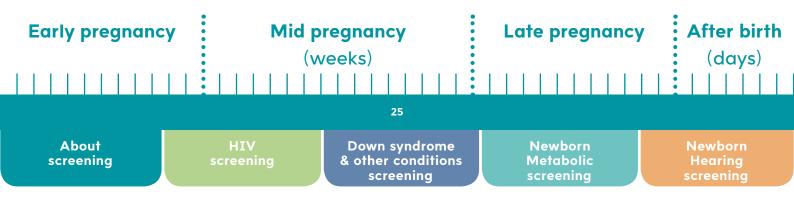
These screening checks collect information about you and the test. This is to make sure that the test results are given to the right person and to make sure that the testing is of the best quality.

This information and our discussion will help you decide whether to have these screening checks.



What is the screening?





Why screen? Practitioner Prompts

Can tell you if your baby has a hearing loss or a medical condition that needs to be treated.

Some medical conditions can make your baby very sick, and others can affect how your baby grows and learns.

You cannot tell whether you or your baby has one of these things without the test.

Most babies will have only one screening test for each of the conditions that are looked for. Sometimes another screening test is needed if the first test is not clear.

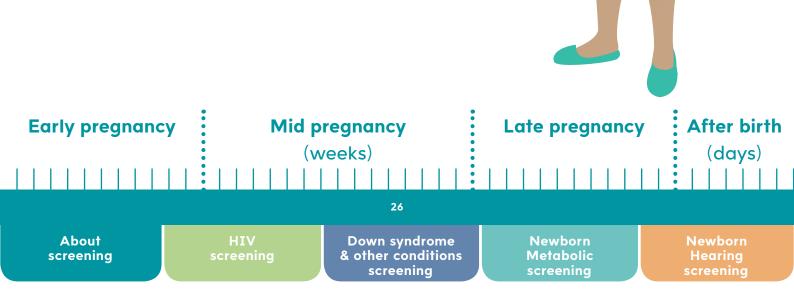
Other tests will be needed to tell you for sure if something further is needed.

Finding out early will help you to plan for the future.



Why screen?

- Find out early
- Help you to make choices
- Help you to plan



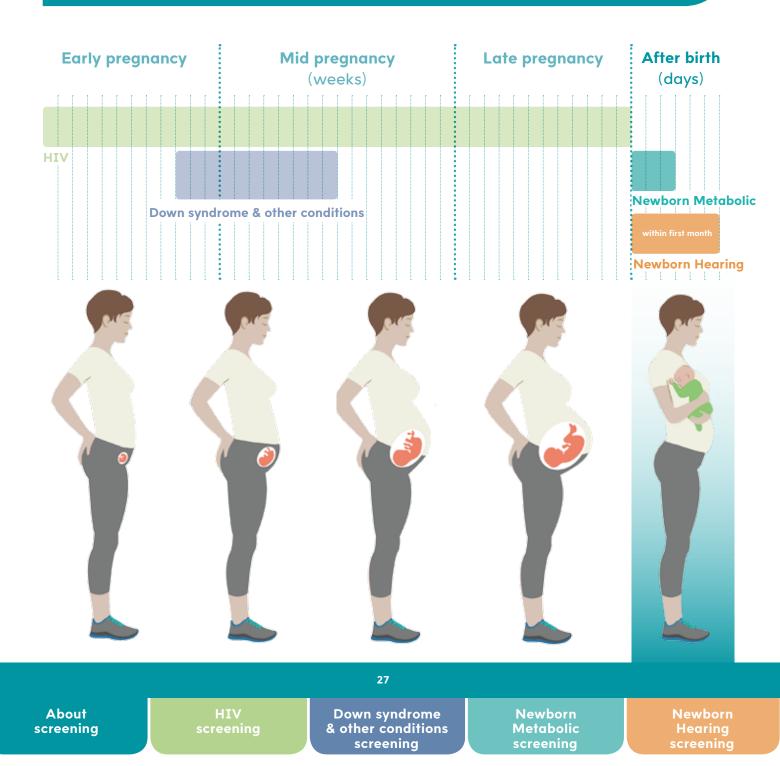
When are the screening checks done? Practitioner Prompts

Newborn metabolic - once baby is 48 hours (2 days) old, or as soon as possible after that.

Newborn hearing - soon after birth or within the first month.



When are the screening checks done?

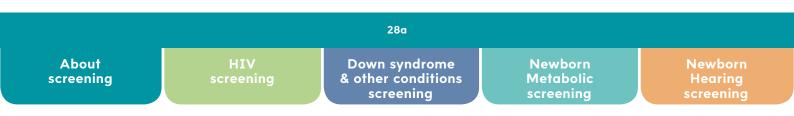


Screening is your choice Practitioner Prompts

Do you have any questions?

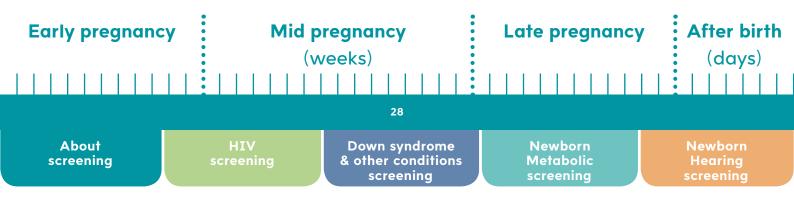
Check understanding

- Screening is my choice.
- Screening is a test to find out more about my baby.
- Sometimes further tests are needed.



Screening is your choice





Newborn metabolic screening Practitioner Prompts

Relevant resources and guidelines

For health practitioners

See the National Screening Unit website: www.nsu.govt.nz

- Guidelines for practitioners providing services within the Newborn Metabolic Screening Programme in New Zealand – February 2010 (HP4968)
- Newborn Metabolic Screening Programme Policy Framework June 2011
- Newborn Metabolic Screening Programme: key messages and questions and answers
- *Best Practice for Health Practitioners DVD*, available from http://www.nsu.govt.nz/health-professionals/1099.aspx
- 6 online courses for health practitioners: http://www.nsu.govt.nz/ health-professionals/3332.aspx and http://learnonline.health.nz/ course/category.php?id=5)

For pregnant women

- Your newborn baby's blood test (HE2310), available from your local authorised health education provider or from the HealthEd website: www.healthed.govt.nz
- *Heel prick information for parents DVD*, available from http://www.nsu.govt.nz/current-nsu-programmes/1316.aspx



Newborn metabolic screening

Your newborn baby's blood test



The Newborn Metabolic Screening Programme

About screening HIV screening Down syndrome & other conditions screening Newborn Metabolic screening Newborn Hearing screening

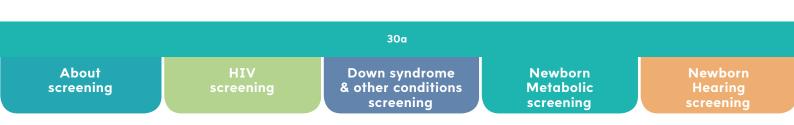
What are metabolic disorders? Practitioner Prompts

Rare conditions that may lead to sickness in your baby. Finding out early means your baby can be treated before they become sick.

There are over 20 medical conditions that are looked for. [If appropriate, use the consumer pamphlet to talk through the conditions.]

About 45 babies each year are found and treated through this screening.

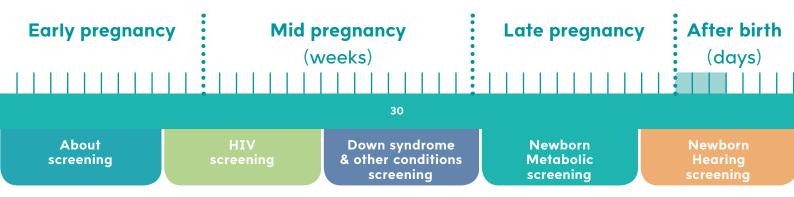
[Advise link to DVD for the woman to watch at home.]



What are metabolic disorders?

- Rare conditions
- Your baby can get very sick or die





Why screen for metabolic disorders? Practitioner Prompts

If your baby has a disorder, finding out about it early and treating it can stop them from getting very sick or dying.

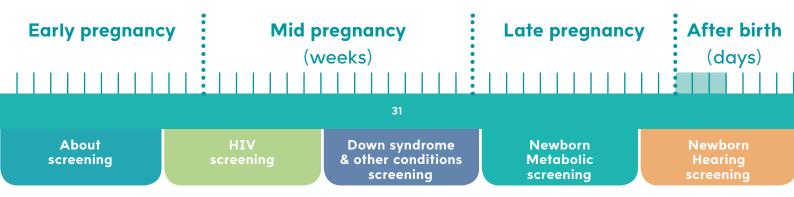
I strongly recommend this test.



Why screen for metabolic disorders?

- Find out early
- Start treatment before baby gets sick





What is screening for metabolic disorders? Practitioner Prompts

A small prick is done on the baby's heel to collect a small amount of blood onto a card. This happens to your baby is 48 to 72 hours (2 to 3 days) old.

You may still be in hospital, or it may be taken by your midwife at home.

The blood spot card is then sent to the laboratory for testing.

I will discuss the results with you as soon as they are available – in about 10 days' time [described on page 33 below].

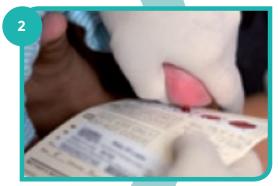
You also need to decide whether you would like to have the blood spot card with the left over blood returned to you after testing is finished. We will discuss more about this soon [described on page 34 below].



What is screening for metabolic disorders?











Your baby's screening results Practitioner Prompts

Results will be available in about 10 days. I will talk about these with you.

Most babies have a negative result - they do not have a disorder.

Sometimes the sample comes back with an unclear result and another test is needed.

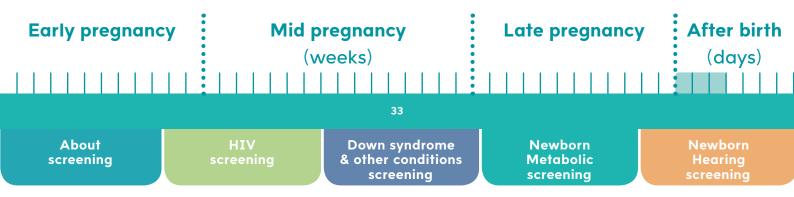
A few babies will have a positive result. If this happens, another sample of blood is needed and/or referral to another doctor to talk about what the result means for you and your baby.

If your baby does have a disorder they will be given medicine or special food to stop them from getting sick. You will be given advice and information about the disorder.



Your baby's screening results





The blood spot card Practitioner Prompts

You can choose to have the blood spots returned to you after testing is finished or the blood spot card can be stored by the laboratory.

The laboratory stores the card so that the blood can be tested again in the future if needed:

- if your baby is found to have condition in the future
- to help find out what caused an illness or death in your family

The blood spots may also be used for research for the benefit of all New Zealanders.

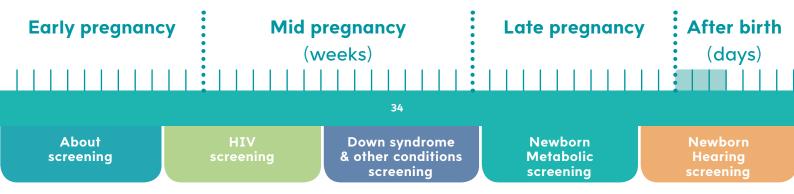
The blood spot card is stored in a secure place with limited people having access.

It's your choice whether the blood spots are returned to you or stored.



The blood spot card

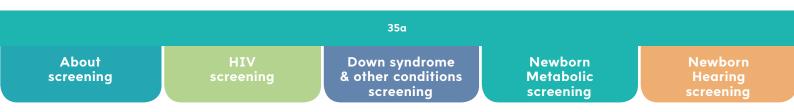




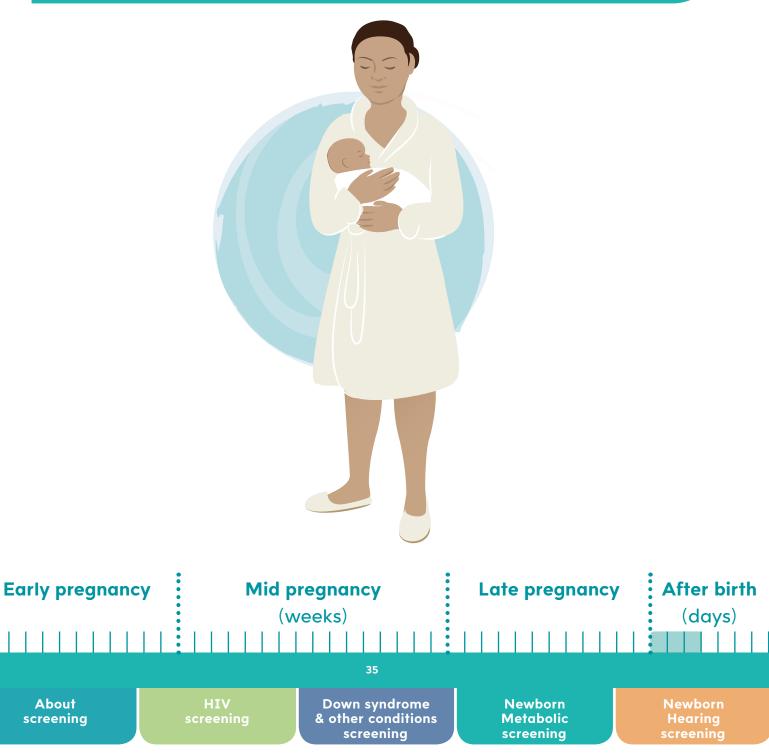
Do you have any questions?

Check understanding

- Finding out early means my baby can be treated before they get sick.
- Screening is blood taken from my baby's heel (a heel prick).
- The best time is 48 hours (2 days) after birth.
- If there is a positive result, another sample of blood is taken from my baby and/or my baby is referred to a specialist.
- Further testing will confirm if my baby has a disorder.
- If my baby has a disorder they will be given medicine or special food to stop them from getting sick. I will be given advice and information about the disorder.
- It's my choice if the blood spot card is stored or the blood spots are returned to me
- If the card is stored, uses may include for future research or to look at an illness in my family.



Screening for metabolic disorders is strongly recommended



Relevant resources and guidelines

For health practitioners

See the National Screening Unit website: www.nsu.govt.nz

- Universal Newborn Hearing Screening and Audiology Workforce
 Strategy and Action Plan June 2008
- Universal Newborn Hearing Screening and Early Intervention Programme: National Policy and Quality Standards (HP5518)
- 6 online courses for health practitioners: http://www.nsu.govt. nz/health-professionals/3332.aspx and http://learnonline. health.nz/course/category.php?id=5)

For pregnant women

Available from your local authorised health education resource provider, or the HealthEd website: www.healthed.govt.nz

- Newborn Hearing Screening Your Baby's Hearing Screen (HE1921)
- Newborn Hearing Screening Results (HE1922)
- Repeat Newborn Hearing Screen (HE1923)
- Newborn Hearing Screening Referral to an Audiologist (HE1924)

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About screening	HIV screening	Down syndrome & other conditions screening	Newborn Metabolic screening	Newborn Hearing screening

Newborn hearing screening

Newborn Screening Free health checks for your baby

Newborn Hearing Screening



Your Baby's Hearing Screen

About screening HIV screening Down syndrome & other conditions screening Newborn Metabolic screening Newborn Hearing screening

Why have hearing screening? Practitioner Prompts

If your baby can't hear, it's hard for them to understand and communicate with you. Hearing is important for their language, learning and social development.

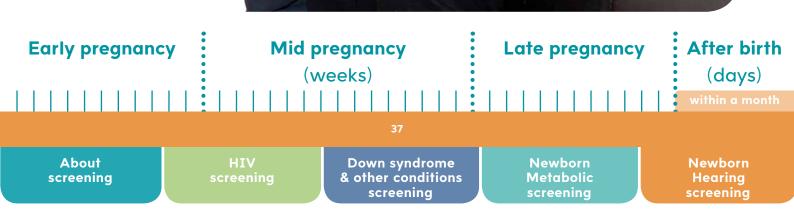
If found early, hearing loss can be managed.

I strongly recommend this screening for your baby.



Why have hearing screening?

- To check if your baby can hear well
- Hearing is important for talking, learning, playing



What is hearing screening? Practitioner Prompts

A hearing screener at the hospital will come and talk to you about newborn hearing screening.

It is done soon after birth, or within the first month after birth.

A soft cup will be placed in or on your sleeping baby's ear. It makes soft clicking sounds.

A computer will show how your baby's ears respond.

It does not hurt your baby.

You will be told the results straight away.

- An ok result means your baby passed newborn hearing screening. Your baby's hearing will also be checked as part of the usual childhood checks.
- Sometimes the results are unclear. This may be because there was too much noise in the room, or because your baby still has birth fluid in their ears, was unsettled or may have a hearing loss.
- If the first test does not give a clear result, a further test will be required. The next test will either be before you leave the hospital or as an outpatient appointment (meaning you need to go to a clinic or return to the hospital for the repeat screen).
- If your baby does not pass newborn hearing screening you will be referred to a hearing specialist (audiologist) for more testing.

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About screening	HIV screening	Down syndrome & other conditions screening	Newborn Metabolic screening	Newborn Hearing screening

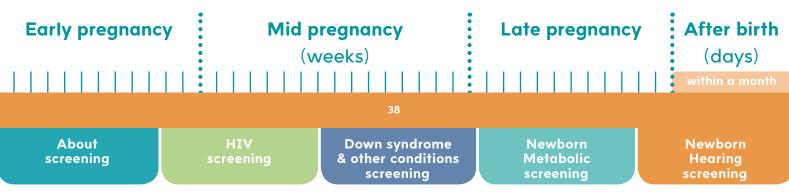
What is hearing screening?











Hearing screening is strongly recommended Practitioner Prompts

Do you have any questions?

Check understanding

- Hearing screening happens soon after birth or within the first month.
- Hearing is important for my baby's development.
- Hearing screening looks for hearing loss.
- If the screening results aren't clear I will be offered a repeat test for my baby.
- If my baby does not pass hearing screening I will be offered a referral to a hearing specialist.





