

Sex assignment in newborn babies

Information for children, families and carers

We have given you this factsheet because when your baby was born, their external sex organs (private parts) did not look as expected and it was not immediately clear what their sex assignment was.

This factsheet explains what sex assignment is and what happens when a baby's sex cannot be assigned as soon as they are born. We hope it helps to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

What is sex assignment?

Sex assignment is the process of deciding whether a baby is male or female.

Why has my baby's sex not been assigned yet?

Sex of a newborn baby is typically assigned at birth based on the appearance of their genitals.

If a baby's body has developed in a slightly different way and their genitals appear different to the genitals of a typical male or female baby, this is known as a 'variation in sex development' and further tests are needed to determine a baby's sex assignment.

Varied genital appearance is common, but there are 40 or so known patterns of sex development that are quite rare.

What causes a variation in sex development?

A variation in sex development can happen for many reasons and does not necessarily mean your baby has an underlying health condition.

What tests will my baby need to have?

Your baby's healthcare team will make a detailed assessment of your baby's sex development. As part of this assessment, your baby will need to have some or all of the following tests:

- an ultrasound scan of your baby's tummy and pelvis to look at their internal structures (your baby's insides)
- a blood test to look at your baby's genetic information
- a blood test to check your baby's hormone levels (we cannot check this until your baby is at least three days old)
- a urine sample to check your baby's hormone levels (we cannot check this until your baby is at least three days old)

We understand that this can be a very difficult and confusing time for you and your family and you will meet lots of different healthcare professionals. We have included the table below to help explain who we all are and how we can help support you and your family.

Healthcare professional	Specialises in:
Consultant paediatric endocrinologist	<ul style="list-style-type: none">• investigations, medication management and co-ordination of care relating to children's hormones
Endocrine nurse specialist	<ul style="list-style-type: none">• co-ordination of care, nursing and medication management relating to hormones
Clinical psychologist	<ul style="list-style-type: none">• offering emotional and psychological support to those with a health condition
Consultant child psychiatrist	<ul style="list-style-type: none">• helping children and families understand the diagnosis (at age-appropriate stages)
Consultant neonatologist	<ul style="list-style-type: none">• the medical care of newborn babies
Consultant geneticist	<ul style="list-style-type: none">• the medical study of how genes cause certain conditions and how certain characteristics are inherited (passed on from parent to child)
Genetics counsellor	<ul style="list-style-type: none">• providing information on genetic testing• offering emotional support and advice to families who are waiting for or who have received a genetic diagnosis
Consultant urologist	<ul style="list-style-type: none">• testing, diagnosing, treating and managing conditions relating to the bladder, kidneys, urinary tract, genitals and reproductive system (the tissues, glands, and organs involved in producing children)
Consultant gynaecologist	<ul style="list-style-type: none">• testing, diagnosing, treating and managing conditions relating to the female reproductive system (this includes the uterus, ovaries, cervix and vagina)
Consultant radiologist	<ul style="list-style-type: none">• examining and interpreting x-rays and scan images
Research nurse specialist	<ul style="list-style-type: none">• providing information about any potential research studies that you may wish to take part in

When will I receive my baby's test results?

We understand that waiting for your baby's test results may be an incredibly stressful time for you and your family. Your baby's named consultant will inform you of your baby's test results as soon as they can. It is important that they have all the test results before they make a definitive diagnosis, as individual test results can be misleading. This can take up to 10 days but can sometimes take a bit longer. Your baby's clinical nurse specialist and named consultant will keep you informed during this time. You may find it helps to make a list of questions you wish to ask while you wait for the results of the tests.

What will happen after I receive my baby's test results?

Your baby's named consultant will explain the results of the tests to you and explain what this means for your baby now and in the future.

It is important that you fully understand how your baby's body has developed so that you can:

- explain this to them as they get older
- answer any questions they may have
- help them to make any decisions regarding treatment and surgery in the future (if needed)

Your baby's healthcare team and our child psychology team can help to support you with all the above. Please contact us if you have any questions or concerns or would like some advice at any stage.

What happens if my baby is diagnosed with a specific condition?

If your baby is diagnosed with a specific condition, a specialist member of your baby's healthcare team will:

- explain the condition to you
- discuss the different treatment and management options with you (including the benefits and the risks)
- answer any questions you may have

Treatment and management options may include:

- growth monitoring (routine measurements to detect abnormal growth)
- hormone treatment (replacing missing hormones with man-made versions)
- further investigations (including genetics)
- fertility planning (understanding future fertility options and different ways to have a family, if desired)
- surgery

What should I tell my family and friends?

New parents often want to announce the birth of their baby with the sex and a weight, and sometimes a name. If the sex of your baby is not clear, you may want to let family and friends know that your baby is staying in hospital for tests. You may also wish to consider avoiding using social media at this time or using it carefully. However, some parents may want to tell their close family and friends everything about their baby's assessment and any medical concerns. We can help you find a way to explain your baby's situation in a way that suits you.

When can I name and register my baby?

Many parents prefer to wait until their baby's variation in sex development is understood before making a final decision about their baby's name. During the assessment phase, some parents choose to give their baby an informal name and ask the hospital staff to use it too. We can help you with this decision.

It is important that you wait to formally register the birth of your baby until a decision has been reached regarding their sex. Your baby's birth certificate can be changed later if needed, but it is a complicated process. You have up to six weeks to register the birth of your baby, so you do not have to do it immediately after they are born.

Glossary

Genes

Genes are coded messages which send instructions to almost every cell in the body about how to function. For example, what colour your baby's eyes will be and how tall they will grow.

Chromosomes

Chromosomes are bundles of genes.

Sex

Sex is biological (male or female). It's based not only on the genes we inherit from both our parents, but also on how our external and internal sex and reproductive organs work and respond to hormones. Sex is the label that's recorded when a baby's birth is registered.

Gender and gender identity

Gender refers to our internal sense of who we are and how we see and describe ourselves.

Gender identity is a way to describe a person's sense of their own gender, whether male, female, non-binary or other. A person's gender identity may not be the same as the sex they were registered with at birth. A person's gender identity can also change over time.

Gonads

Gonads are the primary reproductive organs (the testes or the ovaries).

Hormones

Hormones are chemicals produced by the body that travel around in the bloodstream. They carry messages to different parts of the body to control how it works. The body produces many different types of hormones, including hormones that affect a child's growth and sexual development.

Phenotype

Phenotype is a person's physical appearance.

Further information

If you would like to discuss your baby's care in more detail or you have concerns at any stage, please contact a member of your baby's healthcare team and they will be able to arrange a suitable time to meet with you in clinic or arrange a telephone or video call.

We have included some topics below that you may wish to discuss. For example, you may wish to know how your baby's variation in sex development will affect their:

- general health
- physical, psychological, and emotional development
- future relationships
- fertility

Contact us

If you have any questions or concerns about how our team can support your family, please contact us.

Child psychology team

Telephone: **023 8120 4657** (Monday to Friday, 9am to 5pm)

Email: childpsychology@uhs.nhs.uk

Useful links

www.bsped.org.uk

www.dsdfamilies.org

www.nhs.uk/conditions/differences-in-sex-development

Information adapted from University Hospitals Bristol and Weston NHS Foundation Trust with kind permission.

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit www.uhs.nhs.uk/additionalsupport

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