

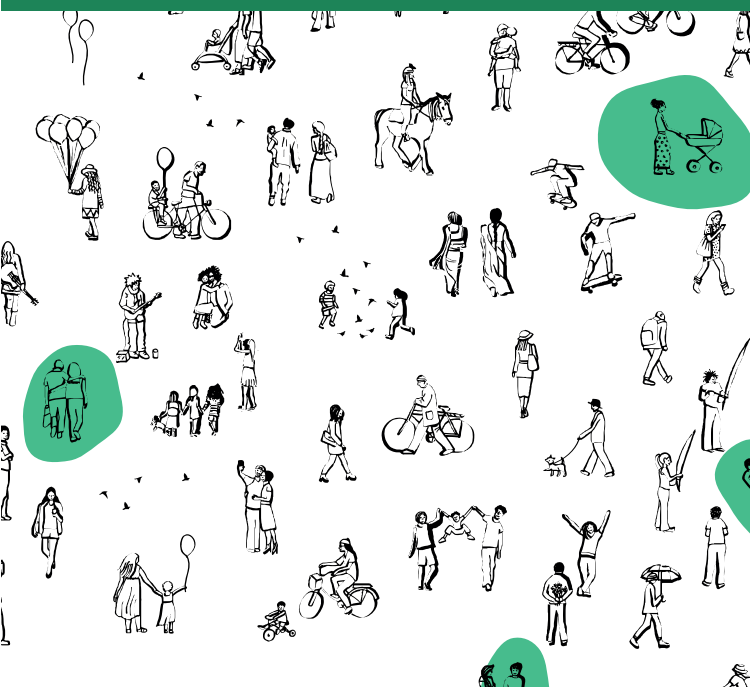


NDRS

NATIONAL DISEASE REGISTRATION SERVICE

The National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Why it matters and what you
need to know



This leaflet explains what information is recorded on congenital anomalies and rare diseases and why. It tells you how you can see your information and how you can have it removed if you wish.

Congenital anomalies

One baby was diagnosed with a congenital anomaly for every 45 births in 2020 in England. This is the term used to describe conditions such as cleft palate, spina bifida and Down's syndrome. A congenital anomaly is sometimes detected during pregnancy, but may also be found at birth, or only becomes obvious as a baby grows older.

Rare diseases

Rare diseases affect a small number of people, which means they can be difficult to diagnose, treat or prevent. A disease is considered rare when it affects no more than one person in 2,000. But collectively, rare diseases are not rare – one in 17 people will be affected by a rare disease at some point in their life. This is equal to about 3.5 million people in the UK.

The National Congenital Anomaly and Rare Disease Registration Service

As part of the NHS, we have special permission from the Government to collect and use personally identifiable information about people with congenital anomalies and rare diseases. This is because it is in the public interest to use this information to further improve the way these conditions are diagnosed and treated.

The information collected about congenital anomalies and rare diseases could help you and other patients and families in the future. The national register is supported by the main UK congenital anomaly and rare disease charities and patient groups.

What information is collected?

The personally identifiable information shared with us includes you and your child's name, address, date of birth and sex. The information also includes physical health and genetic data, including genomic test results, and information about you and your child's diagnosis and treatment. This information is included in the national congenital anomaly and rare disease register.

Why does registration matter?

Collecting information helps us better understand congenital anomalies and rare diseases, to help make sure that people living with these conditions receive the best possible individual care.

The national register is also used for research and planning by helping us to:

- look at numbers and trends
- improve health, care and services for people with these conditions
- support patients by providing information about their condition
- give the NHS information to help it further improve the services it provides
- make sure that safe and effective antenatal and newborn screening programmes are provided across England

Is my or my child's information confidential?

We take the protection of the personally identifiable information we hold about you and your child very seriously. There are strict controls on who can see this information to protect you and your child's identity – only a small number of our trained staff use the information to make sure that you and your child's details are correct.

Most of the work we do looking at numbers and trends is done using de-personalised information (in other words, it does not identify you and your child). We will never publish any information that could identify you and your child. We will only ever share personally identifiable information about you and your child with other organisations who have a valid reason to access the data for the purposes of health research.

Can I access information about me or my child?

Yes. If you would like to see the personally identifiable information we hold about you and your child, we can give this to your healthcare professional for them to share with you.

Can I ask you not to use my or my child's information?

We hope you will want to be included on the national register to help us plan and improve services for you and others. However, you can choose to opt out of us holding your or your child's personally identifiable information at any time. This will not affect the individual care you and your child receives from the NHS.

If you would like to opt out of the national register, please email: NDRSoptout@nhs.net or write to:

NDRS Data Opt-Out
5th floor
The Government Hub
23 Stephenson Street
Birmingham
B2 4BH

Where can I get more information?

For more information about the national register, accessing your or your child's information, or opting out of the register, visit our website: <https://digital.nhs.uk/ndrs/about/ncardrs>

For more information about congenital anomalies and rare diseases, speak to the specialist providing your care.

- for support before, during and after antenatal screening, contact ARC UK at info@arc-uk.org or by visiting www.arc-uk.org
- for information about rare diseases and support, visit www.geneticalliance.org.uk

NHS England is the data controller of the National Congenital Anomaly and Rare Disease Registration Service. You can find more information about fair and lawful processing of personal information on our website at:

<https://digital.nhs.uk/ndrs/patients/your-rights-and-privacy>

If necessary, data is also collected about family members. We collect this data from across the NHS. You can find out more information about genomic testing and how your data is protected on the NHS website.

<https://www.nhs.uk/conditions/genetic-and-genomic-testing/>

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