If you would like to opt out of the congenital anomaly and rare disease register, please email optout.ncardrs@phe.gov.uk or write to:

Director
National Congenital Anomaly and Rare Disease Registration Service
Public Health England
133-155 Waterloo Road
Wellington House
London SE1 8UG.

Where can I get more information?

For more information about NCARDRS, accessing your or your child’s information, or opting out of the register, visit our website:

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

• For questions on antenatal diagnosis of congenital anomalies, contact ARC UK on 0207 7137 486 or info@arc-uk.org or by visiting www.arc-uk.org.

• For information about rare diseases and support, visit www.geneticalliance.org.uk.

The registration service covers England and works in partnership with congenital anomaly and rare disease registers in neighbouring UK countries.

Public Health England is the data controller of the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS). You can find information about keeping to data-protection law in relation to the fair and lawful processing of personal information on our website at:

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

Why it matters and what you need to know
This leaflet explains why information on congenital anomalies and rare diseases is recorded, how this information is used, and how, if you want, you can see your information or have it removed from the register.

Congenital anomalies
One in 50 babies is born with conditions such as cleft palate, spina bifida or Down’s syndrome. Some congenital anomalies are detected during pregnancy, some are found at birth, while others become obvious only as a baby grows older.

Rare diseases
Rare diseases affect a small number of people compared with the general population and, because they are rare, can be difficult to diagnose, treat or prevent. A disease is considered to be rare when it affects one person in 2,000 or less. Collectively rare diseases are not rare. One in 17 people will be affected by a rare disease at some point in their life. This amounts to about 3.5 million people in the UK.

Congenital anomaly and rare disease registration
If you or your child has a congenital anomaly or rare disease, the NHS staff involved in your care will pass information about you to us, the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS).

This information will include your name, address, date of birth and sex, as well as information about the diagnosis and treatment of you or your child.

The registration service has the Government’s permission to collect this information. To get a complete picture, we will also link this information to your (or your child’s) other health records and may share it with the NHS staff who are looking after you or your child.

Why does registration matter?
Collecting information helps us understand congenital anomalies and rare diseases better and make sure that people living with these conditions receive the best possible support and care. Registration helps to:

• look at numbers and trends;
• improve understanding about congenital anomalies and rare diseases and allows research about prevention, causes and treatment;
• support patients and their carers by providing information relevant to their disease or condition;
• give health professionals information to monitor and improve clinical practice;
• inform and improve NHS services; and
• monitor and evaluate antenatal and newborn screening programmes

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

Is my or my child’s information confidential?
Making sure personal information about you or your child is private and confidential is very important. There are very strict controls on who can see your or your child’s personal information. Information is only available to clinical staff treating you or your child, and to a small number of staff in the registration service to make sure that your details are correct.

Most of the work looking at numbers and trends is done without the need to see information that identifies you or your child. We will only ever share personal information about you or your child if organisations asking for information have received your permission or they have appropriate legal and ethical permission. For example, we may share information with NHS organisations or research institutions as long as they have met legal and ethical conditions.

Can I access information held about me or my child?
Yes, if you would like to see information we hold about you or your child, we can give this to your doctor for them to share with you.

Can I ask for my or my child’s information not to be included in the register?
We hope you will want to be included on the register, to help us plan and improve services for you and for future generations. However, you can choose to opt out of the register at any time. This will not affect your treatment or care.