

If you wish to make a request to opt out, you should email [optout.ncardrs@phe.gov.uk](mailto:optout.ncardrs@phe.gov.uk) or write to:

Director,  
National Congenital Anomaly and Rare Disease Registration Service,  
Public Health England,  
Wellington House,  
London,  
SE1 8UG.

### More information

You can get more information by:

- asking your clinical team
- visiting the website [www.gov.uk/phe](http://www.gov.uk/phe)
- contacting ARC UK on 0845 077 2290 or [info@arc-uk.org](mailto:info@arc-uk.org) or by visiting [www.arc-uk.org](http://www.arc-uk.org) for questions on antenatal diagnosis of congenital anomalies
- visiting [www.raredisease.org.uk](http://www.raredisease.org.uk)

The NCARDRS works in partnership with congenital anomaly and rare disease registers in Wales, Scotland and Northern Ireland.

Public Health England  
133-155 Waterloo Road  
Wellington House  
London SE1 8UG  
Tel: 020 7654 8000  
[www.gov.uk/phe](http://www.gov.uk/phe)  
Twitter: @PHE\_uk  
Facebook: [www.facebook.com/PublicHealthEngland](http://www.facebook.com/PublicHealthEngland)

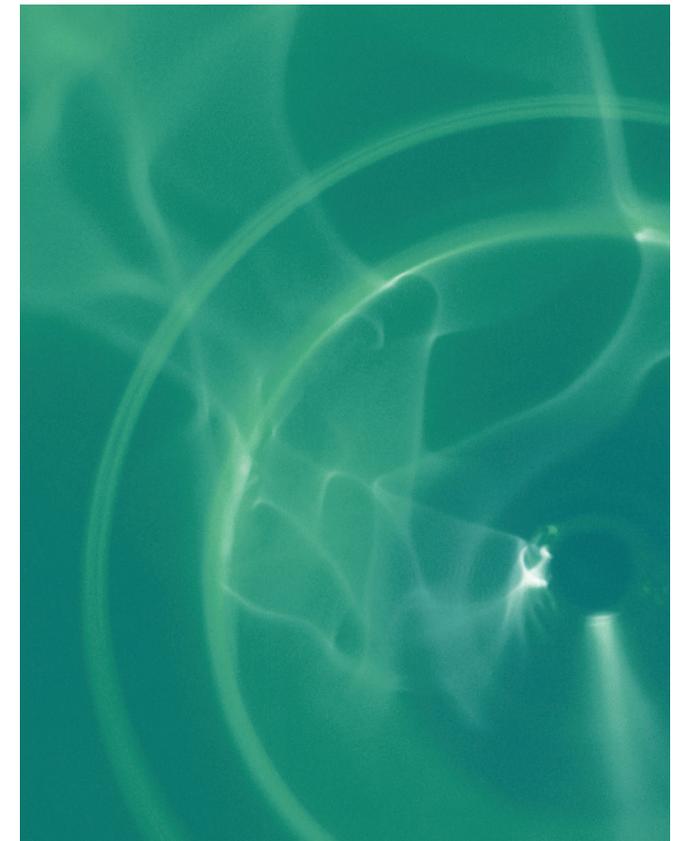


Public Health  
England

Protecting and improving the nation's health

## The National Congenital Anomaly and Rare Disease Registration Service

What it is, the benefits and your options



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**This leaflet explains why information on congenital anomalies and rare diseases is recorded, how this information is used, and how, if you wish, you can see your information or have it removed from the register.**

## Congenital anomalies

Up to 1 in 20 babies are born with problems such as cleft palate, spina bifida or Down's syndrome. These are sometimes called congenital malformations or congenital anomalies. 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 to the general population and, because they are rare, can be difficult to diagnose, treat and/or prevent. A disease is considered to be rare when it affects 1 person in 2,000 or fewer. Collectively rare diseases are not rare. 1 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 suspected or confirmed congenital anomaly or rare disease, your clinical team will pass information about you on to the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS). The service covers England.

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

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 information and may share it with the doctors and nurses who are looking after you or your child.

## The benefits of collecting information on congenital anomalies and rare diseases:

- to look at numbers and trends
- to improve our understanding of congenital anomalies and rare diseases and help research into their prevention, causes and treatment
- to support patients and their carers, through the provision of information relevant to their disease or condition
- to give health professionals information to monitor and improve their clinical practice
- to help plan and develop NHS services
- to monitor and evaluate antenatal and newborn screening programmes

Information held by the NCARDRS helps us make progress in the prevention and treatment of congenital anomalies and rare diseases. Whilst this may not benefit you directly, it could help other patients and families in the future. Registration is the only way we can keep track of how many people are born with congenital anomalies or have a rare disease.

This information is crucial, and is supported by the main UK congenital anomaly and rare disease charities and patient groups.

## Who sees the information

There are very strict regulations controlling access to personal information. This will only be available to clinical staff treating you or your child, and to those who work in the registration service.

Information that might identify you can only be used by researchers if they have your consent or legal and ethical permission to do so.

## Information is confidential

Making sure your personal information is private and confidential is very important. The registration service follows a strict policy on security and confidentiality that is available to the public. The service conforms to the requirements of legislation on data protection.

If you would like to see the information we have about you, we can give this to your doctor for them to share with you.

## Removing your or your child's details from the register

We hope everyone will want to be included on the register, to help us plan and improve services for future generations. However, you can opt out and ask us to remove all of your details from the NCARDRS at any time. This will not affect your treatment or care.