NATIONAL DISEASE REGISTRATION SERVICE

Your genetic test information: how it is collected, what it is used for and what you need to know

What is the National Disease Registration Service (NDRS)?

NDRS is part of the NHS in England. We collect information about NHS patients with cancer, conditions that might lead to cancer, and rare diseases. If you are diagnosed with one of these conditions, the NHS team looking after you will share information with NDRS about you and the care you receive. This applies to children and adults of all ages. Our work allows the NHS to see a complete national picture of cancer and rare disease diagnosis and care.

Why is collecting this information so important?

By collecting this information, we can support those working to improve patient care and outcomes. For example, our work:

- Generates the official national statistics on how many people are getting cancer, and the survival rates for different cancer types.
- Allows the NHS to understand how well treatments, screening programmes, and awareness campaigns are working.
- Helps inform and improve patient care and highlights any inequalities in accessing NHS services.
- Supports research looking at causes of cancer and potential ways to prevent it or diagnose it early.

About Genetic Testing

Many rare diseases are genetic. This means that they are caused by harmful inherited variants in a gene. In some families, a harmful genetic variant increases their risk of getting cancer.

For example, women who have a potentially harmful variant in their *BRCA1* or *BRCA2* gene have a higher-than-average risk of getting breast and ovarian cancer over their lifetime.

Genetic tests to look for harmful variants are offered to people who might have a rare disease or a higher genetic risk of getting cancer.

What information is collected?

We collect genetic information from two main sources:

- Clinical genetics services providing genetic counselling and diagnosis.
- NHS Genomics Laboratories performing genetic tests.

The information collected includes:

- Your name, sex, date of birth, postcode, and NHS number.
- Exact details of your genetic test, including any harmful or potentially harmful variants identified.
- Your genetic diagnosis, if you have one.
- What sort of screening you might have had, and when you were last screened.

Is my information secure?

Information about an individual's health is highly sensitive. We store it on secure servers and apply the strongest form of encryption. Everyone working with patient information is trained in information governance, and follows strict rules to make sure patient information stays safe.

Information is only shared if the party requesting access has a genuine reason for needing it and meets all legal and ethical requirements; for example, a hospital or University research team. Most information shared is aggregated, meaning that overall statistics can be calculated, but it is not possible to see individual people’s records.

Genetic Information and NDRS

NDRS collects information on genetic tests and their results, and uses the information to support other NHS genetic services, for example:

- Genetic counsellors can check exact details of cancer diagnoses with NDRS (with the person’s consent). Having an accurate diagnosis for each person in the family enables the genetic counsellor to tailor care and offer the most appropriate tests to the family.

- NDRS runs the national registry for people with genetic susceptibility to cancer – such as Lynch syndrome, a condition leading to an increased risk of bowel cancer. We share this information with screening services such as the NHS National Bowel Cancer Screening Programme. Screening increases the chance of finding cancers at an early stage, when treatment is most likely to be successful.

- NDRS shares anonymous national laboratory data with the NHS Cancer Variant Interpretation Group. These NHS genetics doctors and scientists evaluate genetic variants of uncertain significance (VUS) and use evidence to decide whether each variant is potentially harmful.

What the law says about collecting your information

NDRS has legal permission to collect patient information to protect the health of the population under Section 254 of the Health and Social Care Act 2012. The law allows NDRS to collect information about people without obtaining their specific consent. (This is separate from the consent form you sign to allow your genetic test to take place and the test results to be used for the care of you and your family members).

This also applies to people being tested for a genetic variant that increases their risk of getting cancer, even if they do not actually have cancer. Knowing about all the people who carry a particular variant, and whether or not they get cancer, helps us to understand the impact of inheriting that genetic variant.

Additionally, we need to know about people who have had a genetic test but are found not to have a harmful genetic variant. Although these people do not have an increased chance of getting cancer, this enables us to check that genetic testing is being offered fairly and equitably to everyone who is eligible. It also means that we can calculate the percentage of tests in which a harmful variant is discovered.

Key points

- NDRS collects your genetic testing information.
- It is stored securely.
- Collecting your information may benefit your care, and that of your family and other people.
- You can choose to opt out of your information being collected.

Your right to opt out

If you decide that you do not want your data collected by NDRS, you have the right to opt out. You can do this by contacting NDRS at NDRSoptout@nhs.net.

If you opt out, we will be unable to give complete information to NHS genetics teams caring for your family members, or to let you know about screening for which you may be eligible.

The NDRS Genetics Team

The NDRS genetics team is led by professionals who have previously worked in NHS genetics facilities. We understand the importance and sensitivity of your personal medical details and take seriously our responsibilities and legal obligations to safeguard this information.

Further Information

This leaflet has been co-created with genetic counsellors and patient representatives.

If you would like more information about the work we do and your right to opt out, please visit our website: https://digital.nhs.uk/ndrs

Updated June 2024, Version 1.0