

National Data Opt Out Information Leaflet

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Overview

Your health records contain a type of data called confidential patient information. This data can be used to help with research and planning. You can choose to stop your confidential patient information being used for research and planning. You can also make a choice for someone else like your children under the age of 13. Your choice will only apply to the health and care system in England. This does not apply to health or care services accessed in Scotland, Wales or Northern Ireland.

Coronavirus update

To help the NHS respond to coronavirus, your information may be used for coronavirus research purposes even if you have chosen not to share it. Any information used will be shared appropriately and lawfully.

What is confidential patient information

Confidential patient information is when 2 types of information from your health records are joined together.

The 2 types of information are:

- something that can identify you
- something about your health care or treatment

For example, your name joined with what medicine you take. Identifiable information on its own is used by health and care services to contact patients and this is not confidential patient information.

How we use your confidential patient information

Your individual care

Health and care staff may use your confidential patient information to help with your treatment and care. For example, when you visit your GP they may look at your records for important information about your health.

Research and planning

Confidential patient information might also be used to:

- plan and improve health and care services
- research and develop cures for serious illnesses

Your choice

You can stop your confidential patient information being used for research and planning. If you're happy with your confidential patient information being used for research and planning you do not need to do anything. Any choice you make will not impact your individual care.

How confidential patient information is used

The NHS collects confidential patient information from:

- all NHS organisations, trusts and local authorities (including GP surgeries)
- private organisations, such as private hospitals providing NHS funded care
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Research bodies and organisations can request access to this information. This includes:

- university researchers
- hospital researchers
- medical royal colleges
- pharmaceutical companies researching new treatments

Who cannot use confidential patient information

Access to confidential patient information will **not** be given for:

- marketing purposes
- insurance purposes

(unless you request this)

How confidential patient information is protected

Your confidential patient information is looked after in accordance with good practice and the law.

Every organisation that provides health and care services will take every step to:

- keep data secure
- use data that cannot identify you whenever possible
- use data to benefit health and care
- not use data for marketing or insurance purposes (unless you request this)
- make it clear why and how data is being used

All NHS organisations must provide information on the type of data they collect and how it's used. Data release registers are published by NHS Digital and Public Health England, showing records of the data they have shared with other organisations.

When your choice does not apply

If you choose to stop your confidential patient information being used for research and planning, your data might still be used in some situations.

When required by law

If there's a legal requirement to provide it, such as a court order.

When you have given consent

If you have given your consent, such as for a medical research study.

When there is an overriding public interest

In an emergency or in a situation when the safety of others is most important. For example, to help manage contagious diseases like coronavirus and stop them spreading.

When information that can identify you is removed

Information about your health care or treatment might still be used in research and planning if the information that can identify you is removed first.

When there is a specific exclusion

Your confidential patient information can still be used in a small number of situations. For example, for official national statistics like a population census.

Make your choice

There have been posts on social media with false information about opting out of sharing your data with the NHS.

Here's what you need to know:

- There is no 30 September deadline for opting out of sharing your data. You can opt out at any time.
- NHS Digital will never sell your data.
- There are strict rules about how the NHS can use your data. It's only shared securely and safely.
- Shared data helps the NHS. It has been used to find the first treatment for coronavirus and for vaccine research.

Use this service to:

- choose if your confidential patient information is used for research and planning
- change or check your current choice

Your choice will be applied by:

- NHS Digital and Public Health England
- all other health and care organisations by 30 September 2021 (delayed from March 2020 to allow organisations to focus on the COVID-19 outbreak).

Any choice you make will not impact your individual care.