

National Data Opt Out Information Leaflet – Please keep

<https://www.nhs.uk/your-nhs-data-matters/>

Overview Choose if data from your health records is shared for research and planning

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Information:

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.

[Read NHS Digital's response to the false information about the national data opt-out](#)

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.

This information is also available in [other languages and formats](#).

Information:

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. Find out [how to make your choice](#). 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 Choose if data from your health records is shared for research and planning

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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

Research bodies and organisations can request access to this information. This includes:

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

Information:

[Find out how GP data is used for planning and research on the NHS Digital website](#)

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.

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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.

[Read more about when your choice does not apply \(page opens in new window\).](#)

Make your choice Choose if data from your health records is shared for research and planning

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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). [Read more about the extension to the compliance deadline for national data opt-out.](#)

Any choice you make will not impact your individual care.

Before you start

You must:

- be aged 13 or older
- have access to your email or mobile phone
- have your NHS number or your postcode registered with your GP surgery

Where can I find my NHS number?

An NHS number is a 10 digit number, like 485 777 3456.

You can find your NHS number by logging in to a GP online service or on any document sent to you by the NHS, such as your:

- prescriptions
- test results
- hospital referral letters
- appointment letters

Ask your GP surgery for help if you cannot find your NHS number.

Start now <https://your-data-matters.service.nhs.uk/>

Register your Type 1 opt out Preference

The data held in your GP medical records is shared with other healthcare professionals for the purposes of your individual care. It is also shared with other organisations to support health and care planning and research.

If you do not want your personally identifiable patient data to be shared outside of your GP practice for purposes except your own care, you can register an opt-out with your GP practice. This is known as a Type 1 Opt-out.

Type 1 Opt-outs may be discontinued in the future. If this happens then they may be turned into a National Data Opt-out. Your GP practice will tell you if this is going to happen and if you need to do anything. More information about the National Data Opt-out is here: <https://www.nhs.uk/your-nhs-data-matters/>

You can use this form to:

- register a Type 1 Opt-out, for yourself or for a dependent (if you are the parent or legal guardian of the patient) (to **Opt-out**)
- withdraw an existing Type 1 Opt-out, for yourself or a dependent (if you are the parent or legal guardian of the patient) if you have changed your preference (**Opt-in**)

This decision will not affect individual care and you can change your choice at any time, using this form. This form, once completed, should be sent to your GP practice by email or post.

Details of the patient

Title										
Forename(s)										
Surname										
Address										
Phone number										
Date of birth										
NHS Number (if known)										

Details of parent or legal guardian

If you are filling in this form on behalf of a dependent e.g. a child, the GP practice will first check that you have the authority to do so. Please complete the details below:

Name										
Address										
Relationship to patient										

Your decision

Opt-out

I do not allow my identifiable patient data to be shared outside of the GP practice for purposes except my own care.

OR

I do not allow the patient above's identifiable patient data to be shared outside of the GP practice for purposes except their own care.

Withdraw Opt-out (Opt-in)

I do allow my identifiable patient data to be shared outside of the GP practice for purposes beyond my own care.

OR

I do allow the patient above's identifiable patient data to be shared outside of the GP practice for purposes beyond their own care.

Your declaration

I confirm that:

- the information I have given in this form is correct
- I am the parent or legal guardian of the dependent person I am making a choice for set out above (if applicable)

Signature

Date signed

When complete, please post or send by email to your GP practice

For GP Practice Use Only

Date received		
Date applied		
Tick to select the codes applied	Opt – Out - Dissent code: 9Nu0 (827241000000103 Dissent from secondary use of general practitioner patient identifiable data (finding))	
	Opt – In - Dissent withdrawal code: 9Nu1 (827261000000102 Dissent withdrawn for secondary use of general practitioner patient identifiable data (finding))	