

Mythbusting social media posts about the national data opt-out

A number of posts are circulating on social media about the national data opt-out, containing incorrect information. This page looks at these claims and gives you the facts you need to make your choice.

GP Data for Planning and Research

This page has information on common misconceptions about the National Data Opt-out. We have a separate page of answers relating to [GP Data for Planning and Research](#).

You can opt out at any time - there is no deadline

We only share data to improve health and care

Health and care data helps the NHS respond to emergencies like the coronavirus outbreak

There are lots of protections in place to make sure patient data is used securely and safely



We do not sell health and care data

We do not share data with marketing and insurance companies

We support anybody who wants to register an opt-out and will respect your wishes about your data, but please read the myth busters below before you decide. We want to make sure that you have accurate information to make the right choice for you.

I've read on social media that if I don't opt-out of sharing my health data by 30 September 2021 I won't be able to

This is not true. You have the choice to register a national data opt-out at any time. This will stop your health data, also known as your confidential patient information, being used for planning and research. There is no deadline.

You can check or change your choice at <https://www.nhs.uk/your-nhs-data-matters> at any time, or by calling 03003035678.

Type 1 Opt-outs

You can also opt-out by registering a Type 1 Opt-out.

We will not collect data from GP practices about patients who have registered a Type 1 Opt-out with their practice.

The improved General Practice Data for Planning and Research (GPDPR) data collection will start on 1 July 2021 so if you do not want your data to be shared with NHS Digital from your GP practice please register your Type 1 Opt-out with your GP practice by **23 June 2021**.

More information about Type 1 Opt-outs is in our GP Data for Planning and Research Transparency Notice, including a form that you can complete and send to your GP practice.

If you register a Type 1 Opt-out after this collection has started, no more of your data will be shared with us. We will however still hold the patient data which was shared with us before you registered the Type 1 Opt-out.

You can register both a National Data Opt-out and a Type 1 Opt-out.



I have been told you will sell my medical record

NHS Digital never sells data and only shares it when it will help health and care and it is safe, ethical and legal to do so. We only share the least amount of data required and we do so in the least identifiable way possible.

The information we share helps researchers and experts to find new treatments and to plan services. For example, our data has been used to find the first treatment for people seriously ill with coronavirus and is being used to support research to find a vaccine.

We do expect organisations who receive data to cover the cost of producing the information they request. We publish details of every time we share data so that the public can see exactly how health data is used and why.

I want to opt-out now because I've read on social media that the NHS will share all my details with anyone who wants them unless I opt out

This is not true. There are very strict rules about how the NHS can use your data or share it.

Health and care staff are only allowed to use your confidential patient information to help with your treatment and care. This is known as direct or individual care. For example when you visit your GP, they might look at your records for information about your health.

Your confidential patient information is never used for marketing or insurance, unless you specifically request this.

It may also be used to

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

If you do not want your data to be used in this way you can opt-out. There is no deadline or final date for when you can opt-out.

You can find out more information about what the NHS can and cannot share here: www.nhs.uk/your-nhs-data-matters or by calling 0300 3035678.

I've heard that the NHS will share my data with anyone whether I opt out or not?

This is not true. A national data opt-out is always upheld by NHS Digital, in line with the policy.



Why is there a deadline of 30 September 2021 for the national data opt-out ?

There is no deadline for patients or public to opt-out of sharing your data for planning and research. The deadline of 30 September 2021 was only ever for health and social care organisations, which need to get ready to manage national data opt-out requests from patients.

Since the launch of the national data-opt-out in May 2018, NHS Digital and a number of other organisations have been upholding the opt-out.

Why have I not heard about the national data opt-out before?

When the national data opt-out was launched in May 2018 there was a full public campaign. This included national media activity and posters and leaflets in a range of health settings including GP practices, dentists, hospitals and pharmacies. These posters and leaflets are still available in these settings. There is also a section on the public-facing NHS website here: nhs.uk/your-NHS-data-matters

Read more information on what you can opt out of sharing on the NHS Digital public facing website.

If I register an opt-out will it stop all of my information being shared by NHS Digital?

Currently national data opt-outs will be considered on a case by case basis but may not apply during the emergency period due to the public interest and legal requirements in sharing certain data. For example, in the case of the Shielded Patients List, the opt-out was not applied due to the public interest in those patients receiving advice and support - we thought it was important that at-risk patients are protected.

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