A guide to the national data opt-out for young people

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nhs.uk/your-nhs-data-matters

Why does the NHS collect info about me?

Info about what happens to patients is noted down every time we use the health service. That's been happening for ages, so that doctors, nurses and other NHS staff can give you the best treatment and keep you safe. To do this they need to take notes down about you – this is for your **individual care**.

This info helps the NHS to find out if its services are working well and whether different medicines and treatments are making people better or not. This is known as **research and planning**.

To find out how data can save and improve lives watch the animations at www.patientdata.org.uk

Who will get their hands on this info?

A small number of people who are working to make healthcare better for patients, such as:

- **NHS staff** that plan and keep an eye on services
- **universities** that are looking for new medicines and treatments
- **charities** that are looking for new medicines and treatments
- **pharmaceutical companies** researching new treatments

Your info will not be given to marketing or insurance companies.

I thought everything I said to my doctor was private. Is that changing?

No. The NHS knows that keeping the info you share with your doctor private is really important. That's why they'll be **protecting your privacy very carefully.**

The people who use the info will have to be **really careful** with it, as there are laws that say how it can and can't be used. This includes new laws from May which gave people more control over their info.

What do I need to do?

If you're happy for your health and care info to be used for planning and research you don't need to do anything.

If you don't want info about you used for research and planning, you can opt out. The decision you make will not affect your individual care and you can change your choice at any time.

You can opt out online or by calling our helpline. You can use these to change your mind at any time.

0300 303 5678

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Can I do this myself?

If you are 13 or over you can make the decision and set your own national data opt-out.

If you are under 13 your parent or guardian will need to make the decision and set a national data opt-out on your behalf. If they set an opt-out for you, this will stay until you make your own choice.

I'm under 13 and someone else made the decision for me. Can I change it later?

Yes. You can change your mind at any time and as many times as you like.

You can find out more about how your health and care information is used at nhs.uk/your-nhs-data-matters or call 0300 303 5678.

To use the Next Generation Text Service (NGTS) dial 18001 followed by 0300 303 5678.

For more information about your data rights please visit the Your Data Matters campaign at ico.org.uk.


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