

# A Guide to the National Data Opt Out for Young People

## Patient Information

Information Governance Department



The Patient Information Leaflets page on the Trust website is available on the link:  
<https://www.wvl.nhs.uk/patient-information-leaflets> or scan the QR code.

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## 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](http://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 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 laws which give people more control over their own 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 the NHS helpline. You can use these to change your mind at any time

**0300 303 5678**

**[www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters)**

## 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 [www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters) or call 0300 303 5678**

**To use 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](http://ico.org.uk)**

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## Comments, Compliments or Complaints

The Patient Relations/Patient Advice and Liaison Service (PALS) Department provides confidential on the spot advice, information and support to patients, relatives, friends, and carers.

## Contact Us

Tel: 01942 822376 (Monday to Friday 9am until 4pm)

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## Ask 3 Questions

Become more involved in decisions about your healthcare. You may be asked to make choices about your treatment. To begin with, try to make sure you get the answers to three key questions:

1. What are my options?
2. What are the positives and negatives of each option for me?
3. How do I get support to help me make a decision that is right for me?



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## How We Use Your Information

For details on how we collect, use, and store the information we hold about you, please see patient information leaflet, Ref. **Corp 006** How we use your information, this can be found on the Patient Information Leaflets page on the Trust website, see details on the front cover.

This leaflet is also available in audio, large print, Braille, and other languages upon request. For more information, please ask in the department/ward.

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