easy read

How the NHS uses our personal health information
An easy-read guide

Contents

About this booklet

Ab

Blue Words

When a word or phrase is difficult, we have explained it in **blue writing.**

01. 02. 03.

We have split this booklet up into different sections to make it easier to read.

You may want to read it in stages.

Support

You may want support to read through this booklet.

There is more information at the end of this booklet, if you still have questions.

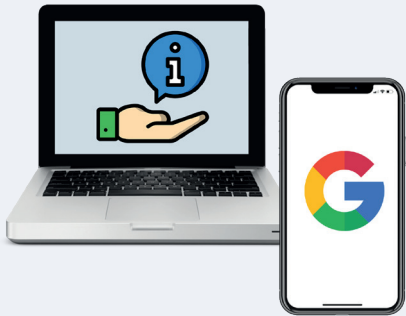# Section 1. **What is Big Data?**

People share information.

We all tell each other all sorts of things.

It helps us all learn.

Now, because of computers and the internet, we can share more and more information – really quickly with other people.

Information stored on a computer is called data.

When lots of it is combined together, it becomes big data.

This can help us to see patterns.

Let's look at an example of a big data pattern.

The London Ambulance Service provides care to 8.6 million people.

In 2019 the London Ambulance Service said it wanted to reduce its 68 ambulance stations.

They said they had looked at all of the journeys of all the ambulances going out on a call.

They said the ambulance journeys made patterns.

These patterns showed where ambulances were going and how long they took.

The data showed that 18 large Ambulance Centres would be better than 68 small ambulance stations.

The data showed that with bigger centres, ambulances would get to patients quicker.

This is an example of how collecting information allows us to improve patient care.
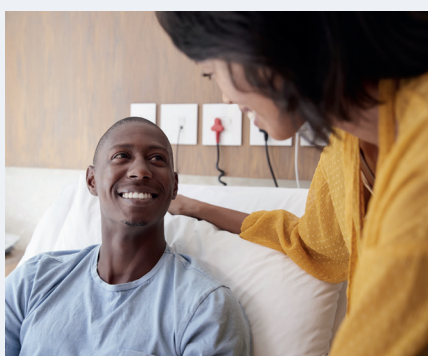
Section 2. **What is Personal Health Information?**

Nowadays healthcare teams in the NHS share a lot of information about us between themselves.

This means NHS managers across the country can plan for what people need, when they need it and in the right place.

Sharing this information helps EVERYONE.

It means we can help more people get better, sooner.

Sharing personal health information allows us to see patterns.

These patterns help the NHS to improve how it cares for our health.

For example: **giving people with the same condition the best dose of a drug for them.**

Connecting | **the different drugs** | **to their different effects** | **with different people**

means the doctor knows which drug is best to use for each person.

For example, the NHS looks after lots of people with Type 2 Diabetes.

There are a number of different drugs for people with Type 2 Diabetes.

The NHS looks at the big picture and collects lots of personal health information about Type 2 Diabetes.
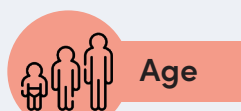

Having looked at the big picture, the NHS helps doctors decide which Type 2 Diabetes drug is right for each patient.

Section 3. Who Can See our Personal Health Information?

The NHS collects information when people visit a hospital, visit a GP or go to any other NHS service.

Age

Sex

Family history

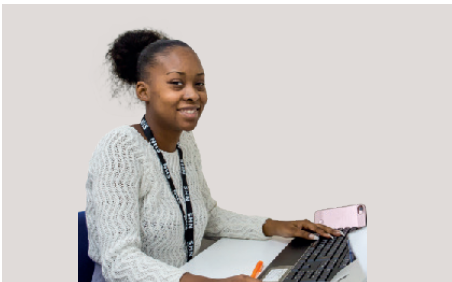There are many differences between individuals such as age, sex and our family history of illness.

Our doctor needs to take these differences into account when deciding which treatment to use.

When lots of our personal health information is combined together it becomes big data.

The NHS shares this big data about our personal health information with:
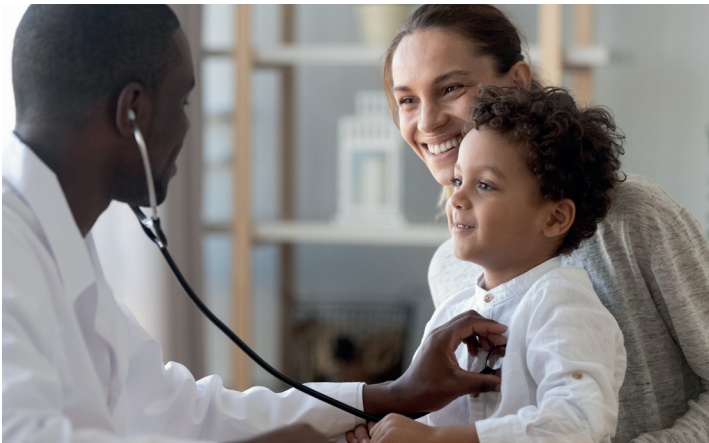
Different health professionals

NHS managers

Health Researchers

NHS This means the NHS can:

Provide the right treatment and care

Improve what it does

Only your NHS health care team can see the information which says who you are.

Before the NHS shares your personal health information with anyone else, it takes out the information which says who you are.

This makes it very hard to see who the individual people are.

It means the NHS can use our personal health information for research and planning without revealing who we are.

The NHS works with private companies.

For example: a drug company testing a new drug.

The NHS only shares information with private companies that cannot reveal who you are.

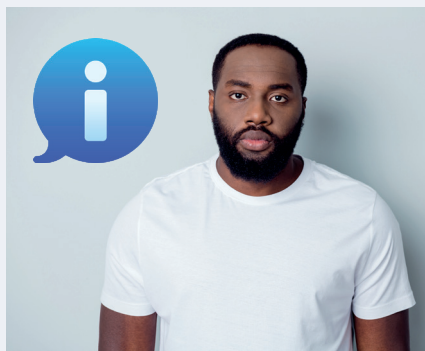# Section 4. Rules About Using Personal Health Information

There are strict rules about using personal health information for NHS research and planning.

You can choose to stop your health information being used for research and planning.

This is called an opt out.

Even if you opt out, there are still health emergencies when your health information is used.
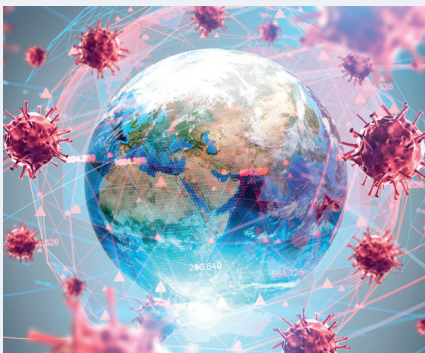
For example:

During an epidemic where there might be a risk to you or to other people's health.

An epidemic is an outbreak of a disease that spreads quickly and affects many people at the same time.

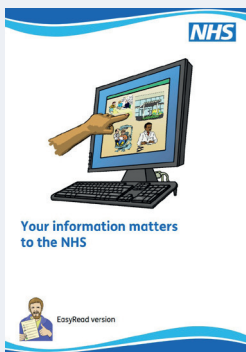**An epidemic which goes across several countries or continents is called a pandemic.**

Covid-19 is a pandemic.

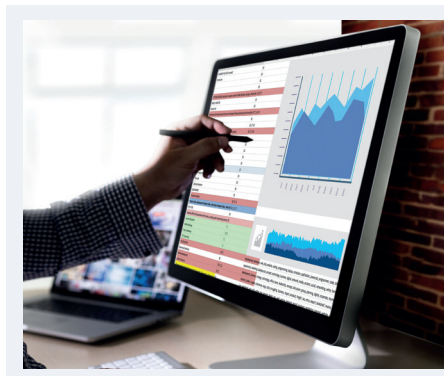You can choose to stop your personal information being used for research and planning. This is called an **opt out.**

There is an easy-read booklet which explains more about **opt-out.**

Click on this image to read the opt-out easy-read booklet.

Section 5. **National Healthcare Datasets**

We said that information stored on a computer is called data.

When you put lots and lots of information onto a computer this is called big data.

This can allow us to see patterns.

The NHS has the best national healthcare datasets in the world.

National healthcare datasets are electronic records which store patient information collected by the NHS.

An example are **The Cancer Registries.**

The English Cancer Registry healthcare dataset started collecting cancer patient information in the early 1960's.
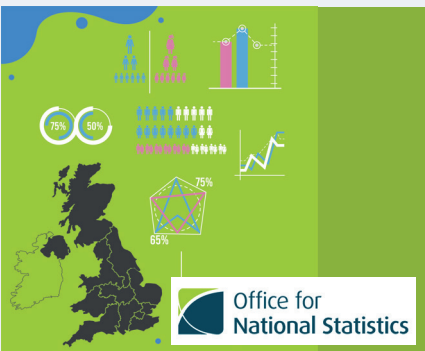
Click on the image to visit the Macmillan Cancer Support website which has more information about The Cancer Registry.
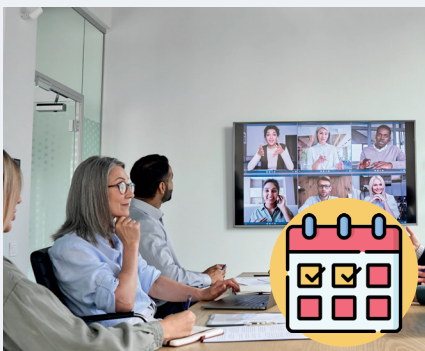
Two other national healthcare datasets are:

A hospital dataset shows when and where a patient went to hospital, what for and what happened.

The ONS dataset shows deaths broken down by age, sex, area and cause of death.
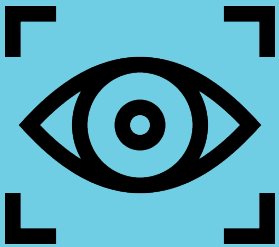
ONS means Office for National Statistics.

These hospital and ONS datasets are used for planning public services such as the NHS.

Section 6. More Information

> ❗ It is important to make uses of personal health information

👁	**1** *More visible*
🤝	**2** **Trustworthy**
💡	**3** **Understandable**

On this page we have shared links to some animations about personal health information.

The Bigger Picture:

https://youtu.be/fJ2hyXCOOyQ

Asthma:

https://youtu.be/iVRTjZ30KBo

Cancer:

https://youtu.be/y0P2qriA5dw

Dementia:

https://youtu.be/-X_LZp8J9qA

Diabetes:

https://youtu.be/vYCUSSperMo

Heart Attack:

https://youtu.be/iVRTjZ30KBo

Record Sharing:

https://youtu.be/oDY9dGAV9NQ

NHS Digital

NHS Digital collects our patient health information.

'Your Data Matters to the NHS' by NHS Digital has helpful information.

Click on the image to go to the NHS Digital website.

A Leicester co-production group created the content. We wanted to make patient health information accessible to everybody.

This guide was made in partnership with Understanding Patient Data.

We created this document as people who are:

"Clever, smart and intelligent" Rachida
"Clever, smart and helpful" Sharifa
"Organised, caring, respectful, motivated and empathetic" Jacqui
"Curious and helpful" Bharti
"A passionate learner" Dhwani
"Smart, active, helpful and am independent" Shmoyl

To find out more visit our website: thinklusive.org
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