

What is patient data and how can it be used?



What do we mean when we say health data?



Health data – or patient data – refers to the information about you that is routinely collected when you interact with the health service.



Information about you

- Contact details
- Date of birth
- Address



Information about your health

- Medical conditions
- Medication history
- Test results



Information about your lifestyle

- Smoking
- Alcohol consumption
- Physical activity



Administrative information

- Waiting list status
- Appointments booked



What is a health record and how is it stored?

Your health records include information such as your:

- Name
- Address
- Date of birth
- NHS number
- Medical conditions
- Medication history
- Test results such as blood tests or MRI scans

Your health records are primarily stored digitally (though some are on paper), and different NHS organisations such as your GP, hospital or other services hold their own health records for each patient.

Hospital Record



Name: Alex Brown
Date of birth: 04-04-2004
NHS number: 967 698 8743
Gender: Male
Next of kin/carers: Michael Brown (father)
Suzanne Brown (mother)

Org code: RBT

Emergency admission date: 2017-07-22

Reason: J45.9 asthma, unspecified

Length of stay: 1 day

Treatment: 79/ oxygen therapy

GP Record



Name: Alex Brown NHS number: 967 698 8743
Date of birth: 04-04-2004 Gender: Male

History

Chesty cough and wheeze.

Examination

Chest bilateral scattered crackles basal wheeze
heart sounds normal.

Medication

Amoxicillin 500mg capsules one to be taken
three times a day.

Comments

Book to see nurse for spirometry



Who holds health data in the NHS?



Whilst each provider holds their own records, a **summary version** of your health record is held digitally which provides healthcare professionals involved in your care access to your data for **individual care**.

Depending on where you live, there may be local or regional systems to consolidate records and share data within a given area.



Others, such as NHS and public health analysts, can also access your data in certain instances to **improve the nation's health**.

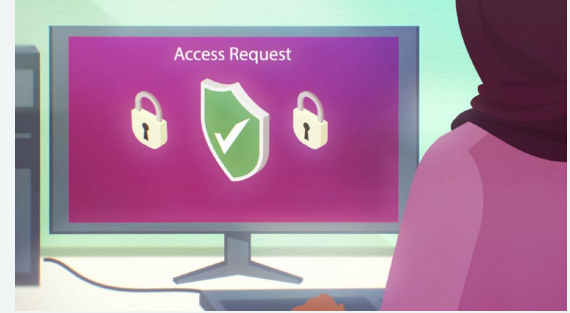
For instance, organisations like NHS England collect information from providers to create national datasets to document things like how many patients visited A&E in a given month.



What is health data used for?



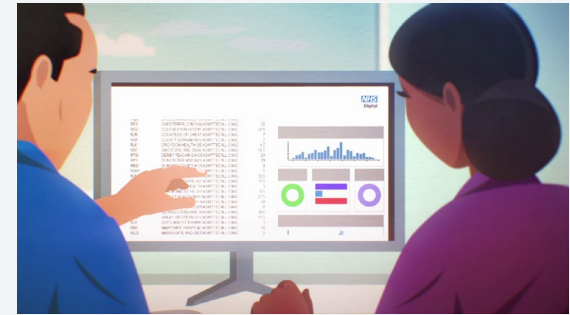
Individual care



Research



Planning



Population health



How is patient data used?

Whenever someone interacts with the health service, such as during a GP or hospital appointment, information is collected about them, their health, and their lifestyle and stored in their patient record.

This data is important to providing the best **individual care** as different medical professionals need to have access to information about a person to help make decisions and provide medical care. Data is shared across the NHS for individual care via things like Summary Care Records and Shared Care Records, but not all data is shared in a timely and consistent way.

The image shows two NHS patient record forms side-by-side. The left form is a 'Hospital Record' for Alex Brown, born 04-04-2004, with NHS number 967 698 8743. It lists his next of kin as Michael Brown (father) and Suzanne Brown (mother), his org code as RBT, his emergency admission date as 2017-07-22, his reason for admission as J45.9 asthma, unspecified, his length of stay as 1 day, and his treatment as 79I oxygen therapy. The right form is a 'GP Record' for the same patient, showing his history (Chesty cough and wheeze), examination (Chest bilateral scattered crackles basal wheeze, heart sounds normal), medication (Amoxicillin 500mg capsules one to be taken three times a day), and comments (Book to see nurse for spirometry).

The image shows a computer monitor displaying a 'Summary Care Record' for Ann Jones, born 16/11/1932, with NHS number 935 678 2547. The record is divided into sections: 'Allergies and Adverse Reactions' (Adverse reaction to Codeine, Problem: drowsiness, dated 05-Apr-2004), 'Acute Medication' (Oxycodone for joint pain - must not be taken with paracetamol, dated 23-Feb-2013), and 'Medication'.

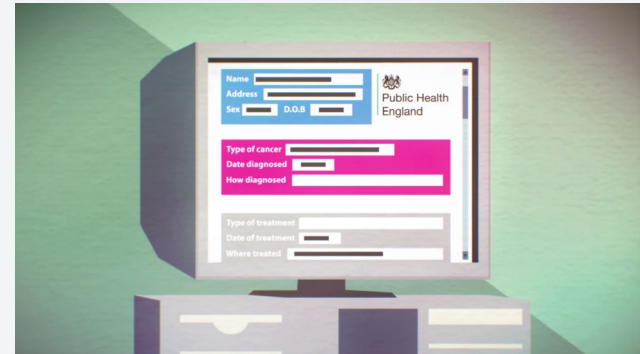
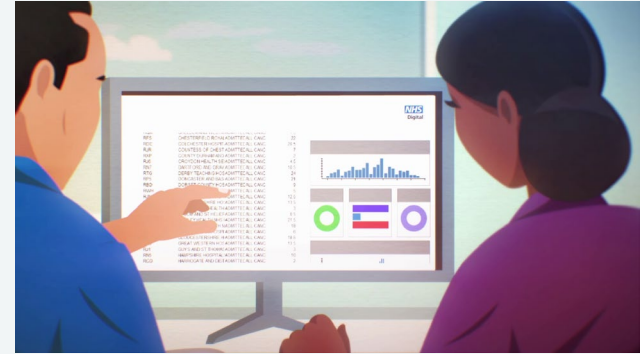
For more information, visit our [guide to how patient data](#) is used and find out more on our [website](#)



How is patient data used?

In addition to providing the best medical care for an individual, patient data is collected and used for other purposes. For instance, approved researchers sometimes access patient data to conduct **research**, for instance to understand the cause of diseases or develop new treatments.

Patient data is also used by the NHS and Government to help with **planning** – e.g. evaluating how services are performing – and to improve **population health** – e.g. understanding the prevalence of risk factors of ill health in an area to be able to provide the right resources.



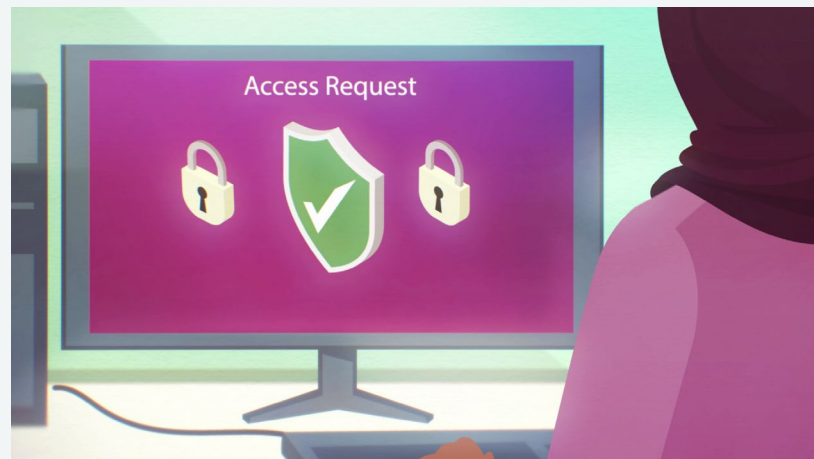
For more examples of how patient data may be used, visit our [case studies](#)



Who outside the NHS can access health data?

In order to conduct research into diseases and develop new treatments, and improve health service planning and population health, some NHS data can sometimes be accessed by organisations outside the NHS.

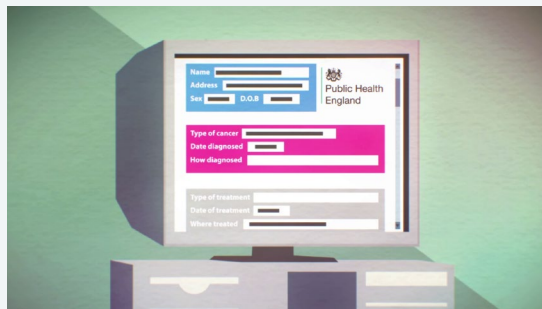
Protections around the use of patient data hold that access needs to be for a **specific purpose** in the **public interest**, by **authorised researchers** and analysts, using the **minimum amount of data** necessary to achieve the outcome.



Anyone wanting to access patient data must request access from the organisation that holds the data and demonstrate that their use of data is safe, secure, and ethical.



Who outside the NHS can access health data?



Government departments



Pharmaceutical industry researchers



Charity or academic researchers

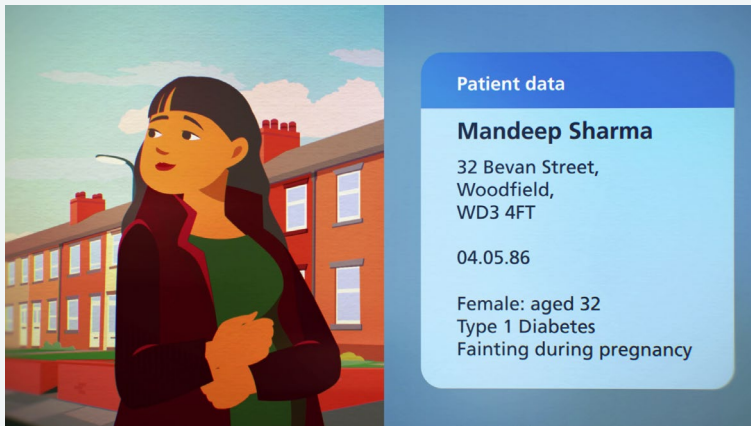


Other data extractors



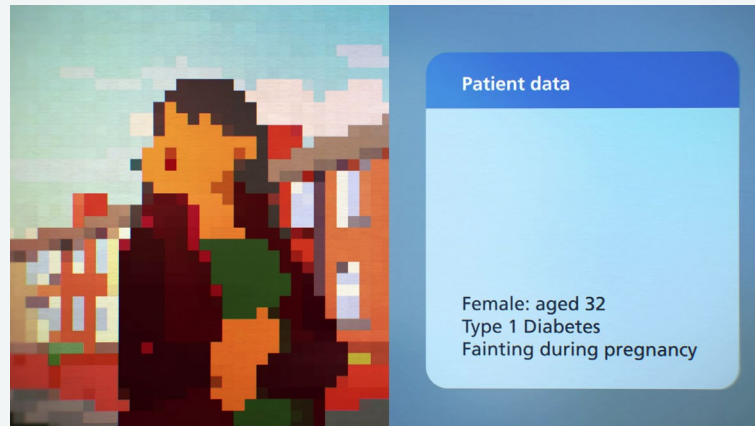
Identifiable vs de-identified

Identifiable Data



- Includes information such as your name, address and date of birth
- Also known as Confidential Patient Information when combined with information about your health or treatment

De-identified Data



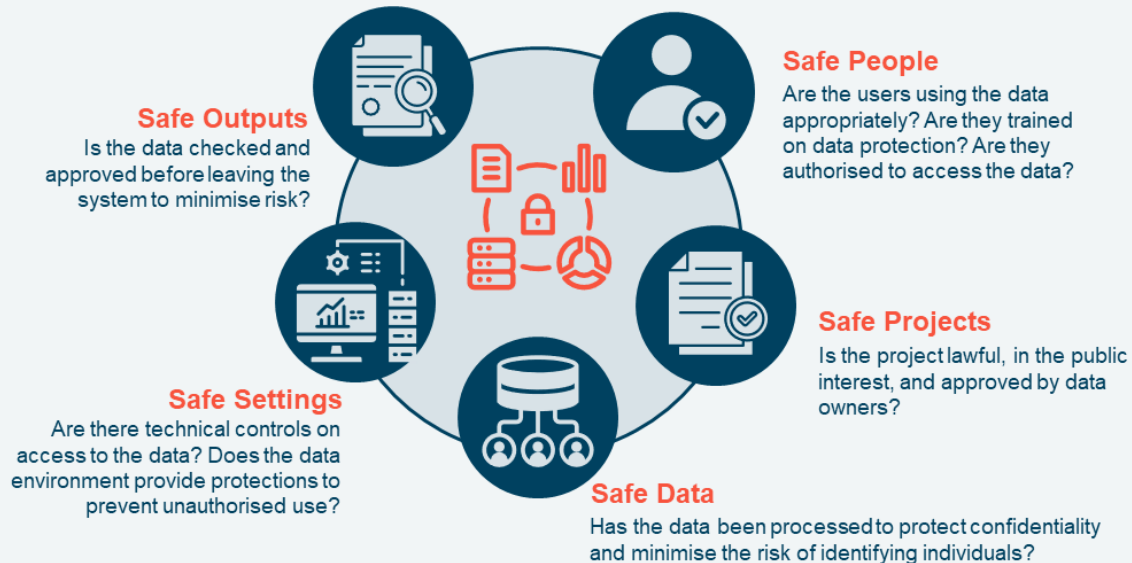
- Information that could directly identify you, such as name or date of birth have been removed
- Sometimes all identifying information has been completely removed, and sometimes a unique marker is used to replace identifying information



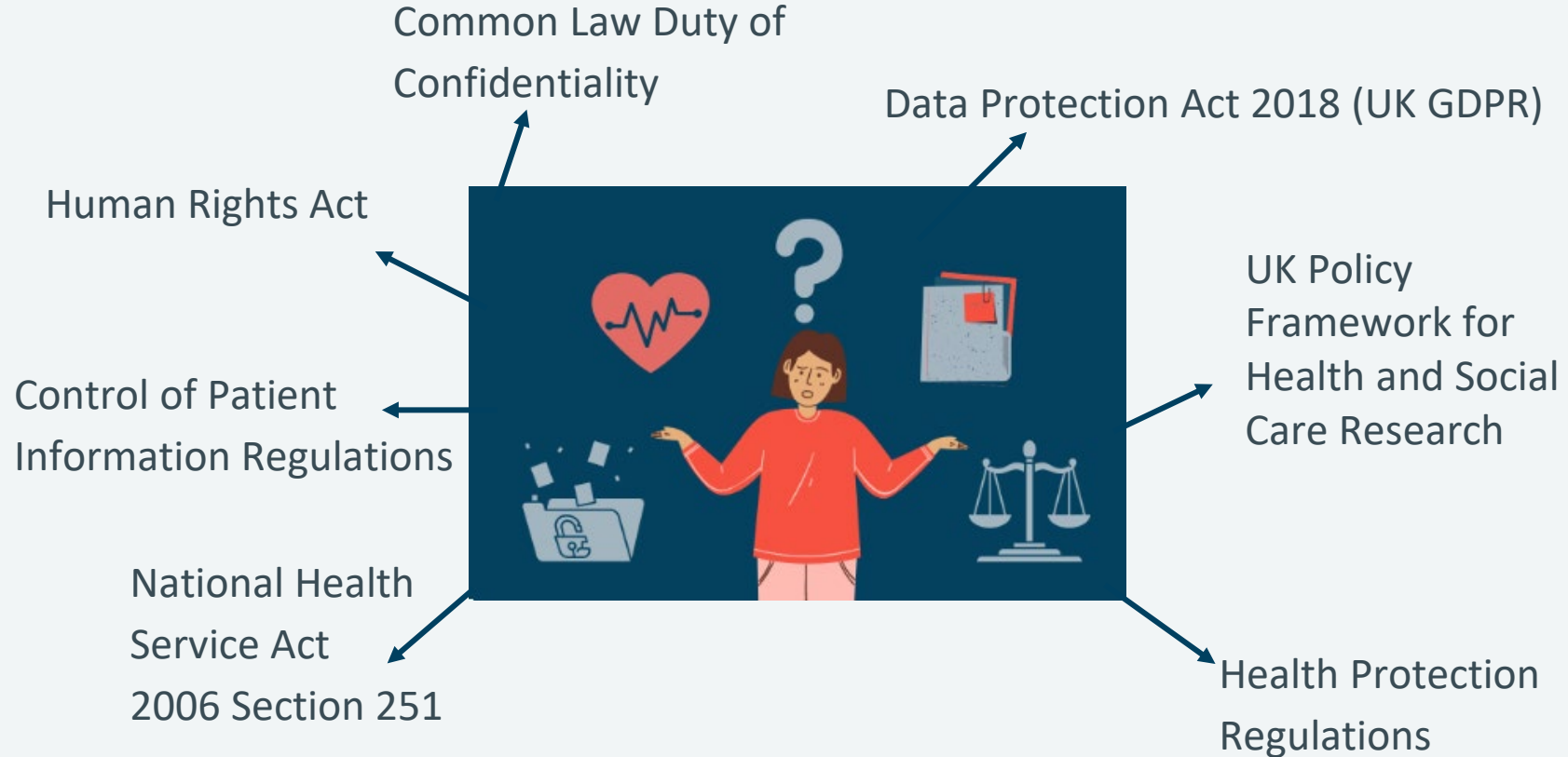
How is data kept safe?

One model for thinking about how to keep data safe is the 'Five Safes' framework. Originally developed by the Office for National Statistics, these principles are a useful way of thinking about how health data is kept safe.

Individual organisations (such as your GP) are legally responsible for keeping your data safe. Your health data is governed by data protection laws and the Information Commissioner's Office is tasked with ensuring people's rights are protected.



Laws and regulations protecting patient data



Questions? Get in touch!

Contact us at hello@understandingpatientdata.org.uk



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