

Patient Data Toolkit



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Recent introduction of data legislation means the way that organisations collect and use your data has changed. In the toolkit, we focus on how your patient data is used to improve NHS services and future treatments and the options you have when it comes to your data.

What is patient data?

Patient data can be generated by you, such as through health apps or fitness trackers, or collected during clinical trials or studies that involve external organisations to the NHS e.g. university researchers or pharmaceutical companies.

Within the NHS, every person has a unique NHS number and associated to this will be their health records, date of birth, and contact information. This data will be collected by your GP, hospital, dentist or other NHS professional.

Health records can include information, such as medications you are taking, allergy details, and results from tests or procedures you may have had. It could also include records from surveys you have taken, for example on lifestyle habits.

Why is patient data used?

Not only does your own data help to inform the care you are receiving, but your data can also be used to improve healthcare and NHS services.

Using pooled data from many patients, it is possible to identify patterns or anomalies within data. This can then be used to help with:

- 1) Understanding disease
- 2) Improving diagnosis
- 3) Treatment and prevention of diseases
- 4) Individualising care
- 5) Patient safety
- 6) Planning NHS services
- 7) Evaluating policy

A series of 'data saves lives' animations have been produced to demonstrate how patient data has been used to make changes in the care of asthma, cancer, dementia, diabetes and heart attacks. These can be found here: understandingpatientdata.org.uk/animations

The 'data saves lives' motto summaries how using patient data can significantly better outcomes for future patients, by improving knowledge of disease, treatment of disease and NHS services.

Example: Patient Reported Outcomes (PRO) or Quality of Life (QoL) data

In recent years, there has been a shift from focussing on clinical outcomes to a patient-centred care approach. This has included the introduction of patient reported outcomes (PROs), that measure the impact of a disease or treatment as reported by the patients in surveys.

Patient reported outcome measures (PROMs) are being used in routine practice, for example, before and after hip or knee replacements. The results indicate outcomes and quality of NHS services, which is then used to select which providers should be commissioned by the NHS to continue doing the procedure.

Clinical trials are also increasingly incorporating patient reported outcomes. The data collected from these, can then be used to inform clinicians and future patients on the symptoms and quality of life that patients have while on treatment. Thus aiding treatment decisions. The data can also help to support the clinical evidence during regulatory approval that a new treatment or therapy is safe and beneficial to patients compared to those previously available.

Who can use my NHS data?

Only NHS professionals involved in your care have access to your full medical records and there are strict protocols for the way digital and paper notes are handled and stored to protect your confidentiality.

Other organisations can use your data, but strict controls are in place to ensure that your data is safe:

1. An independent review must approve that there is solid reasoning for using the patient data.
2. Identifying information (name and contact details) is removed, unless the patient has given specific consent for this information to be provided.
3. Legal contracts are written and

signed before data is shared

4. Secure IT systems must be in place.

Organisations that use patient data include: Government health bodies, charities, university researchers or external companies partnering with the NHS to provide care or research.

Data is never shared for marketing or insurance purposes.

Can my data be used without my consent?

Under the new EU General Data Protection Regulation (GDPR) your personally identifiable data cannot be used without your consent.

The new regulation means that organisations must make it clear how your data is being used and must have your explicit consent to collect, store and use your personal data.

Explicit consent means that you have been given clear choice to opt-in to your data being used by the organisation.

You can find out more about GDPR here: <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/>

National Data Opt-Out

In the NHS, there is a requirement to store your personally identifiable data for use in your individual care, however, the new National Data Opt-Out is being implemented to give patients the right for their data not to be used for the purposes of research or NHS service planning.

It is important to note that patients who do not opt-out have not actively given their consent for their data to be used. Therefore, if identifiable data is going to be used, there must be reasoning that satisfies the criteria of the Data Protection Act (DPA) and the Common Law Duty of Confidence (CLDC).

This includes:

- Consent. Whereby the person has given explicit consent for their information to be shared and waived their right to privacy.
- A mandatory legal requirement. For example, in a safeguarding case The Children Act of 1989 requires information to be shared
- A court order. Whereby a judge has ordered that specific and relevant information to a case is provided
- Public interest. In which using the data is of significant benefit to the public and outweighs an

individuals right to privacy.

The national data opt-out does not cover the use of anonymised patient data, which can be shared without consent.

There are strict procedures in place, however, to ensure that patients cannot be identified from anonymous data (see below).

Learn more about the NHS National Data Opt-Out here: <https://digital.nhs.uk/services/national-data-opt-out-programme>

Is my data publicly available?

Any data that is published to the public domain must be anonymised. This not only means

that names and contact details are removed, but patients should not be identifiable from the data.

For example, if there is 1 person diagnosed with leukaemia in Worcester and data was published that included the city patients resided, it is very likely that someone would be able to identify the patient and their associated data even if names are not provided.

Therefore, if a patient can be identified from the data it cannot be made publicly available.

Spectrum of identifiability



‘Identifiability spectrum’ by Understanding Patient Data is licensed under CC BY.

Processes are in place to ensure that publicly available data does not identify patients. Below is an example.

Example: The Get Data Out project

The Brains Trust wanted to make data available from the National Cancer Registry on routes to diagnosis, treatment types, and survival for brain tumour patients.

To do this, NCRAS (National Cancer Registration and Analysis Service) ensured that patients were not identifiable by setting a group size limit of no less than 100 patients.

They maintained groups of >100 patients by only revealing the following information about patients:

- Gender
- Age at diagnosis in 10-year intervals (e.g. 30-39 years old)
- Site of the tumour
- Region in England (i.e. London, North, South or Midlands).

So, for example, there would be at least 100 patients who were: female, diagnosed between the age of 20-29 years old, with a malignant brain tumour, and were from the North of England.

You can see the outcome of their

work here: <http://brainstrust.org.uk/brain-tumour-data/>

Are there any risks of sharing my data?

There are several perceived risks of using data which could affect:

- 1) The individual** - The main concerns are around loss of privacy for the individual sharing their data, or unintended reidentification from sharing data in the public.
- 2) The community** - Here the question is raised about whether sharing community data could lead to stigma or discrimination, for example sharing data on crime incidents could lead to areas being labelled 'violent hot-spots', or communities could lose local health services.

It is important to establish that data sharing should offer greater benefit to the public and outweigh the risks. This means seeing tangible actions from the data being provided.

For example, data demonstrated that the UK is more likely to diagnose cancer later than other European countries, which led to strategies being developed and implemented to improve early diagnosis across the UK.

Strict procedures are in place

before external organisations can access patient data and there must be sound reasoning for using identifiable data instead of anonymised data. This being one example that minimises the risk of sharing patient data.

Can I access my own data?

You can have access to your medical records and learn more about the data the NHS holds on you if you so wish.

Many GP surgeries now offer online access to view certain parts of your patient records, which you can discuss with your surgery. There is also nothing preventing you from informally asking to view your records.

All patients have a legal right to view their health records from the NHS under the Data Protection Act of 1998. You must submit a formal request in writing, called a Subject Access Request, to the healthcare provider.

You can find out more here:

<https://www.nhs.uk/chq/pages/1309.aspx?categoryid=68>

You are also legally able to request to see what information an organisation holds about you.

To find out more about patient data visit:

- [understandingpatientdata.org.uk/](https://www.understandingpatientdata.org.uk/)
- [usemydata.org/](https://www.usemydata.org/)

Further questions?

If you have any further questions about Patient Data, then you can contact our Campaigns and Advocacy team.

They are available Monday to Friday from 9:00am – 5:30pm. If you would like to speak to them, you can:

- Call our office line on 01905 755977
- Send them an email at advocacy@leukaemiacare.org.uk
- You can also call the help line, free of charge on 08088 010 444. The team will pass your enquiry onto the Campaigns and Advocacy team.

Please note that our Campaigns and Advocacy team are unable to provide:

- Detailed medical advice or recommendations
- Legal advice
- Advocacy for a course of action which is contrary to the aims and objectives of Leukaemia Care