# Sharing health data:
# What you should know and why it matters

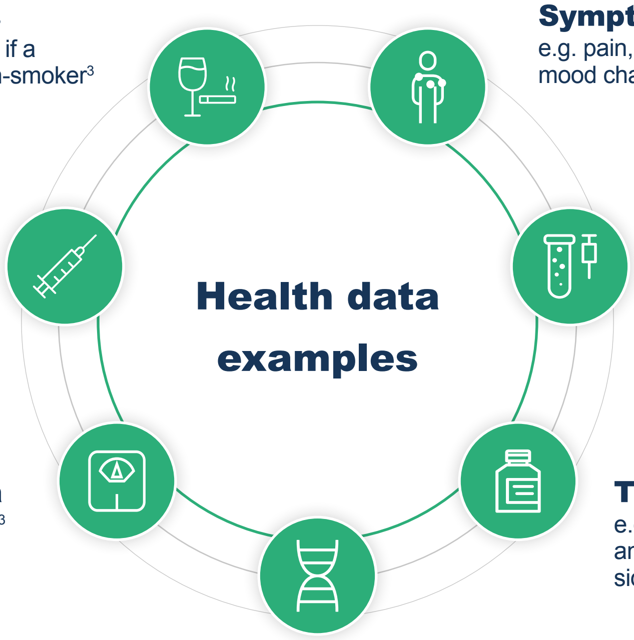
**About this document:** This factsheet aims to increase understanding among patients and patient groups around health data and how it can benefit the patient community. It also addresses potential concerns and issues surrounding health data sharing.

The document is intended to be used alongside the Personalised Healthcare Toolkit to engage patients and facilitate discussions around this topic, in order to help advance towards a data-driven healthcare system in the future.

## What is health data?

Health data, or patient data, is **information that describes an individual's health, healthcare and health issues or diseases**.[1] Health data can be information about multiple people extracted from health records and pooled together, for the purpose of statistics for example (population health data). Or it can be information about one individual (personal health data).[1,2]

There are many different types of health data.[1] Some **examples of health data** include but are not limited to:



**Health data examples**

**Lifestyle choices**
e.g. alcohol consumption, if a patient is a smoker or non-smoker[3]

**Symptoms**
e.g. pain, sleeping patterns, mood changes[1,3–5]

**Immunisation/ disease registries**
e.g. database for reporting, tracking and studying COVID-19 infections and vaccinations[8–10]

**Diagnostic reports**
e.g. blood test and imaging results to help diagnose, stage and monitor disease[3,4]

**Biometric data**
e.g. height and weight[3]

**Treatments**
e.g. medications taken by a person, antibiotic prescription rates, treatment side effects and allergic reactions[2–4,6]

**Genomic/genetic data**
e.g. genomic testing results, inherited diseases[4,7]

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There are many ways health data can be collected. Not only when people are being monitored in a medical setting (examination data), but also by the individuals themselves (patient-generated data).[1–4] Some examples of **collection methods** are outlined below.

## Examination data

Information can be created and accessed by healthcare organisations and healthcare professionals (HCPs) when patients receive care.[1–3] This includes information collected for:

- electronic health records (EHRs)[1,4]
- HCP/site-led patient and disease databases or registries (this data can also be accessed by private organisations, such as private research partners, with appropriate consent)[1,3,11]
- clinical studies[1–3]

## Patient-generated data

Information can be created and accessed by patients and their family members or caregivers.[1] This information can be collected through:

- health surveys and questionnaires[1]
- patient-led patient and disease databases and registries[1,11]
- digital health tools, like prescription and health apps and wearable devices (e.g. smartwatches, fitness trackers)[1]

# Who can access and use health data?

Health data is personal and private and can only be accessed by those with a legitimate health purpose. For a patient's EHR, this includes people involved in their care, both directly (e.g. HCPs) or indirectly (e.g. health administrators).[1,12–15] The data may also be accessed by the patients themselves or family members.[15] Patient consent must be provided if their health data is shared for reasons other than the original purpose for which it was collected for.[1]

Assuming consent is obtained, some information can be shared to various organisations for different purposes,[16] including but not limited to:

| | Potential uses of health data |
|---|---|
| **Patient groups** | Evaluating services and identifying ways to improve care[2,12] |
| **Healthcare providers/ administrators and public health officials** | Monitoring trends in hospital activity, assessing how care is provided and supporting local service planning[1,2,12] |
| **Academic research institutions** | Understanding more about the causes of disease and developing new diagnostic tools and treatments[1,14] |
| **Companies** (e.g. insurance providers, pharmaceutical and tech companies) | Providing care and developing new treatments or digital solutions (smartphone apps and wearables) through partnerships with healthcare organisations[2,16] |

It is important to note that there are **strict controls and legislations** on how health data is used by organisations.[1,12]

# Harnessing the power of data to transform care

Health data has the potential to help improve health and healthcare for everyone.[1] It is vital for:

### Receiving effective and personalised care

Up-to-date health data can help patients and family members make shared decisions with their care team, to ensure patients receive the most efficient, high quality, safe and personalised care, that is based on their individual needs, preferences and lifestyles.[1,2,17–20]

### Improving healthcare services

Health data from many patients that is linked up and pooled, known as aggregated data, can support health administrators in optimising care pathways and more effectively allocating resources. This can help improve patient experiences, outcomes and quality of life.[1,18,19]

Insights obtained from health data can help meet the growing demands for more effective, less costly and smarter care. They may also help people receive more holistic care and support to suit individual needs – this is called personalised care. Harnessing the power of health data has already led to significant advances.[1] Although it might not affect everyone, the potential **benefits of collecting and analysing health data** for some individuals and healthcare services are outlined below, including some real-life examples of how insights obtained from health data are already helping.

| Potential benefit | Real-life examples |
|---|---|
| Health data can show an individual's potential risk of a condition and provide insights that lead to a deeper understanding of how conditions develop. This can help improve screening for earlier **detection** and, where possible, **prevention** of conditions.[21–23] | • Tracking COVID-19 to **prevent the virus spreading**[24] |
| Health data can provide information that supports the development of more effective diagnostic tools and pathways. This can help achieve more **accurate** and **quicker diagnoses**, as well as better use of resources.[1,23,25] | • **Finding a diagnosis for a quarter of patients** who had previously undetected rare genetic diseases[26]<br>• Discovering a new test to **identify Alzheimer's disease earlier**[27] |
| A patient's unique health data can help identify specific **treatment** and **care** options that are **tailored** to them, as early as possible.[22,23,28] | • **Monitoring glucose levels** in real-time, giving patients with diabetes and their families peace of mind and reducing anxiety[29] |
| Data generated from **digital health tools** can help monitor a patient's health status and when analysed, improve understanding of conditions. Based on this knowledge, changes to healthcare approaches can be made, for better quality of life and outcomes.[1,30] | • A platform that can **monitor patients with inflammatory bowel disease in between health visits**, which has shown to improve quality life and reduce costs[30] |
| Insights from health data can help reduce medication errors, reduce adverse side effects and improve compliance to practice guidelines, to help **maintain patient safety**.[22,23,31] | • Spotting the **early signs of adverse events** of heart attacks in a hospital ward[32] |

# What does this mean for patients?

Patients play a key role in achieving the outlined benefits for themselves and others. Once the patient's health data has been collected, it is up to them, or their family members in some cases, whether they want to consent and share it for purposes other than their individual care (i.e. indirect care).[12]

**Data collected** **Patient approval** **Indirect care**

### What choices do patients have?

Consent processes for sharing health data vary between countries.[33] Options available to patients (or others consenting on their behalf) can include:

- **opt-in** – individual actively sign-ups for data to be collected and used[34,35]
- **opt-out** – data is collected and used automatically unless individual actively dissents[34,35]
- **informed consent** – individual provides clear and affirmative action to allow data to be collected and used[34,35]

### What happens to the data?

After patient approval, their health data will be shared with the relevant organisations. Wherever possible, personally identifiable information will be removed, and the minimum amount of information will be shared.[12]

**My Health Data Path** is a useful resource that describes how data might be used and how it is protected – see myhealthdatapath.com for more information.

**A patient's choice will not affect their individual care[2]**

# How is health data kept safe?

Patients are demonstrating an openness to contribute to and participate in a data-driven healthcare system, if their **privacy is protected and personal data is secure**.[36] Health data is sensitive and should be protected.[1,12] Sharing and using health data will never be totally risk-free. But there are robust measures and safeguards in place to protect health data and reduce the risks as much as possible.[2,12]

### Removing identifying information

- Details that identify the individual are removed[2,12,37]
- The minimum amount of health data is provided to organisations[2,12]
- This process is often referred to as 'anonymisation'[37] (see definition of key terms below for more information)

### Abiding by regulations

- Regulations are in place which set strict laws about what organisations can do with data, when it must be deleted and what is not allowed[2]
- Different countries have different regulations e.g. the EU/UK follows a right-based regulation called the **General Data Protection Regulation (GDPR)**, whilst the US follows the **Health Insurance Portability & Accountability Act (HIPAA)**[38]

### Independent review process

- In some cases, requests to use health data are often assessed by an independent review committee[2,12]
- The committee checks the reason for using the data is appropriate[2,12]

### Robust security

- Data is stored securely, with controlled access and robust IT systems and processes in place, to keep it safe[2,12]

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**Every patient should be informed on and involved in deciding how their health data is used, including understanding how it can benefit those who receive care and ultimately save lives**[1]

Data Saves Lives Toolkit is a useful resource for heath data literacy, case studies and further learning – see helpful resources below for more information

# Find out more

Common questions patients can ask their HCPs around health data:

- Can I be identified from the data?
- Can I access my data?
- Who has access to the data?
- What will happen to my data?
- Who will see my data?
- What can my data be used for?
- What risks are involved if I choose to share my data?
- What data will be held?
- Where will my data be held?
- What safeguards are in place to protect my data?
- Who will be my point of contact?
- Will my data be shared with third parties?
- How will my data be protected?
- Will I be contacted if there is a security breach?
- Can I access my data or ask for it to be deleted or changed?
- How can I consent to sharing my data?
- Have I given consent for my data to be used for any other reasons beyond my care?
- Can I withdraw my consent at any time?

# Helpful resources

- Data Glossary – Connected Health Cities (a list of key definitions related to health data and their explanations)
- Data Saves Lives Toolkit (provides information and materials to help patient advocates have positive dialogues with their communities about health data and to potentially launch their own health data initiatives)
- Data Saves Lives YouTube channel (hosts multiple educational videos for patients and patient groups e.g. webinars and animations)
- Glossary of terms – Data Saves Lives (a list of key definitions related to health data and their explanations)
- Patient Data: Finding the best set of words to use. Summary of findings – Understanding Patient Data (research findings on the best vocabulary to use when communicating about health data)
- What is patient data and how is it used? – Genetic Alliance (a brief description of health data and what it is used for, with a focus on genetic/genomic testing)
- My Health Data Path website (a website that describes certain situations where health data may be used, to help people understand the value of sharing data)
- Your Data Matters to the NHS – NHS (materials explaining how patient data is used and patient choices for its use in the UK, provided in various formats and languages)
- Quick guide to explaining how patient data is used – Understanding Patient Data (a quick-guide explaining how health data is used in UK health services and beyond)
- Data Resources in the Health Sciences – University of Washington (a collection of resources related to different types of health data and their application in medical research)

# Key terms

| Term | Definition | Also known as |
|---|---|---|
| **Big data** | Large and diverse sets of data that can grow at ever-increasing rates.[1,35] | |
| **Anonymisation** | The process of altering identifying data so that it can no longer be related back to an individual (e.g. removing a name and address). Note, this process does not guarantee that data is no longer identifiable.[35] | |
| **Anonymised data** | Data that is not related to an identified or an identifiable person and cannot be combined with other information to re-identify individuals.[35] | Anonymised in context<br>Masked<br>Non-disclosive<br>Non-identifiable |
| **Electronic health record** | A digital version of a patient's health record that can be shared across multiple healthcare settings. Electronic health records can include demographics (e.g. age, weight), medical history, medication and allergies, immunisation status and laboratory test results.[35,39,40] | EHR |
| **Electronic medical record** | A digital version of a patient's health record that is usually only shared within one healthcare practice or department. Electronic medical records can include medical history, medication and health conditions.[39,40] | EMR |
| **Identifying data** | Information that could identify an individual patient.[35] | Confidential information<br>Confidential personal information<br>Patient identifiable information |
| **Health data** | Information that relates to an individual's healthcare and health issues or diseases.[1] | Medical data<br>Medical information<br>Patient health information |
| **Personal health data** | Information about one individual's healthcare and health issues or diseases.[1] | |
| **Population health data** | Information about a population's healthcare and health issues or diseases.[1] | |

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