

The only independent UK movement of patients, relatives and carers focussed on the use of patient data to save lives and improve outcomes

Highlighting the benefits of using patient data

use MY data endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care and well-being for all.

use MY data supports and promotes the protection of individual choice and privacy in the sharing of healthcare data to improve patient treatments, outcomes and experience.

use MY data aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service design and improvement, and in research, aimed at improving clinically informed patient decision making, treatment and experience.

What do we mean by ‘patient data’?

Patient data is health care information recorded about an individual patient. This may include medical data relating to our past and current health or illness, our treatment history and that of our family, and lifestyle choices, e.g. smoking or alcohol consumption. This information, held by GPs and hospitals and other care providers, is primarily used to inform our choices and help guide decisions about our current and future care and treatment.

Using patient data for research

Our patient data can also be used in research to help identify (more) smarter, kinder treatments, monitor the safety of medicines, generate new understandings and knowledge about the causes of disease and disability, and how to identify and overcome unmet health needs.

Also, the findings of research based on patient data can be used to estimate the impacts of living with illness and injury and dying prematurely and enable health service planning decisions, including the obtaining of new treatments, services and health-related technologies.

Highlighting the benefits of choice

It is important that we, as patients, have control over how and know where, our data and our tissue samples, collected during testing and medical interventions, are used. We should be able to make informed decisions and be given the opportunity to opt out of sharing our data, if we wish. Within this, it is crucial that

we are aware of both the benefits and the risks of data sharing. It is after all our own unique personal data.

There are significant safeguards to manage the potential risk of data usage

Firstly, we support and promote the consistently safe, transparent and informed sharing and use of patient data, while respecting any individual patient's choice to opt out of sharing the data but to continue to use NHS services.

We also recognise and support the several ways that our privacy is shielded when our healthcare data is shared for research or for the benefit of the NHS or other patients. For example by removing any information which directly identifies us, by using an independent review process for data sharing, by ensuring strict legal contracts are in place before data is transferred to another party, and by implementing robust data security standards. These are contained in the principles of the Five Safes¹.

1. Safe data: Does the data itself contain sufficient information to allow confidentiality to be breached?
2. Safe projects: Is this use of the data appropriate, lawful, ethical and sensible?
3. Safe people: Can the user be trusted to use it in an appropriate manner?
4. Safe settings: Does the access facility limit unauthorised use or mistakes?
5. Safe outputs: Is the confidentiality maintained for the outputs of the management regime?

There are significant benefits of using patient data for research

The benefits of sharing and using patient data are not always understood or communicated well.

But most treatments and care provided by the NHS are based on data and information from patients. Using this data improves health care and treatment, advances medical research and ultimately saves lives and improves outcomes.

A key benefit is that researchers can analyse millions of people's health in this 'real world' data. This allows them to study rare diseases that affect small numbers of people, or side effects of treatments that are serious but don't occur very often, but without identifying any individual patients, because the data is anonymised, and our privacy is protected by law and by regulators.

¹ The Five Safes: <https://blog.ons.gov.uk/2017/01/27/the-five-safes-data-privacy-at-ons/>

How our Members should adopt and use these principles

- For any organisation that you are working with, make sure they are aware of these principles
- Find out whether the organisation is open about highlighting the benefits of data usage, and if not, highlight the areas which they might want to look at
- Let the Secretariat know about any concerns that the organisations have, or that you have
- If you need advice on taking this forward, contact the Secretariat and we will either help you directly, or put you in touch with another Member who can help

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Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

About use MY data

- **use MY data** is a movement of patients, carers and relatives.
- **use MY data** endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.
- **use MY data** supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.
- **use MY data** aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

What we do

- We promote the benefits of collecting and using patient data to improve patient outcomes with sensible safeguards against misuse.
- We work to bring a patient voice to all conversations about patient data.
- We have developed the Patient Data Citation, which acknowledges that patients are the source of the data. Details are available [here](#).
- We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
- We provide learning resources for patient advocates on patient data issues, including:
 - Hosting events for patients and the public, focussing on patient data topics
 - a library of resources of data security, consent
 - narratives from individuals about the value of collecting and using patient data.
- We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

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