

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

## Acknowledging and raising awareness of 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.

### Overview

Patient data is extremely important, not only in the care and treatment of individual patients but also for research into medical conditions and their treatments. The benefits of using patient data became particularly apparent in the handling of the COVID-19 pandemic.

To keep realising the benefits of using patient data it is important to communicate the message that patient data underpins research, care and epidemic/pandemic response.

One way to help achieve this is to include our Patient Data Citation on all publications and stories that would not have been possible without access to patient data:

**This work uses data provided by patients and collected by the NHS as part of their care and support.**

### How our Members should support the use of the Patient Data Citation

- Make any organisation that you are working with aware of the citation.
- If you come across an organisation using the citation, please let the Secretariat know, so that we can promote this.
- If you find an organisation that is using patient data without acknowledging this, please bring the citation to their attention and let the Secretariat know.

## **More about use MY data's Patient Data Citation**

The citation was created by the Members of use MY data. They felt that the citation would be both a recognition of the benefits of using patient data, highlighting how their data has been used and an acknowledgement of the patient contribution to research and analysis.

The history of the creation and development of the patient data citation is available here <http://www.usemydata.org/citation.php>. This includes details of the adoption of the citation by Understanding Patient Data, who were instrumental in helping to spread the message.

The citation is now widely used across a range of outputs and publications from large numbers of academic institutions and commercial organisations. It has been adopted by national bodies, including the National Institute for Health Research, Health Data Research UK, Public Health England, the Office for National Statistics and many research charities.

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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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