

Mission statement

use MY data is a movement of patients, carers and relatives.

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 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 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.

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.

Who we are

- Our membership comprises:

Members - patient advocates who are either patients, relatives or carers

Associate Members - who are clinicians, researchers, charity workers, academics, public and commercial sector workers. They are united by an interest in sharing healthcare data to improve patient outcomes under appropriate levels of consent, security and privacy.

- Our **Advisory Group** advises on all aspects of use MY data's work. The Advisory Group comprises use MY data members and there are currently ten members on the Group.
- Our **Secretariat** supports the work of **use MY data**. The Secretariat comprises a Coordinator and Expert Data Adviser. These are the only funded roles within **use MY data** and both roles are funded part time.
- Details of our **funders** can be found at <http://www.usemydata.org/funders.php>

"Knowledgeable patients are already proving they can play a pivotal role. Take the great work of the movement that is "use MY data", harnessing the patient voice to build confidence in the use of data for improvements."

Health Service Journal, Oct 2017

Dialogue with the public

The third principle outline by Dame Fiona Caldicott on her appointment as National Data Guardian

Third, there is the over-arching issue of the need to build a dialogue with the public about how we all wish information to be used. Many interests need to have voices in the debate. They include:

- commercial companies providing drugs and services to the NHS
- researchers discovering new connections which will transform treatment
- those managing the services on which people rely, so that public money is used to maximum value

What we do

- We promote the benefits of sharing and using data to improve patient outcomes with sensible safeguards against misuse.
- We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
- We host patient data workshop workshops for patients and the public. The wide-ranging programmes are devised by our members.
- 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.
- We advise and support organisations who want to collect, store and use patient data for patient benefit, on topics such as consent, audit of clinical practice, security and privacy.
- We have developed a citation that acknowledges the use of patient data. This was adopted by Understanding Patient Data, who helped us to spread the message. Details are here - <http://www.usemydata.org/citation.php>
- We are building a library of patient stories <http://www.usemydata.org/stories5.shtml> where patient advocates talk direct to camera about the positive uses of patient data.



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

Membership

The more members and associate members we have, the stronger our voice becomes in campaigning for patient data to be used to save lives and improve treatments.

The benefits of joining:

- Being part of a community which works to build confidence in the use of patient data.
- Receiving regular updates about patient data matters including: engagement opportunities, event information, patient data developments, opportunity to input into consultations.
- Receiving guidance/support on patient data information and queries (via the Secretariat).
- Direct invitations to use MY data events.

There is no charge to join [use MY data](http://www.usemydata.org). To join please contact coordinator@usemydata.org.uk.

www.useMYdata.org.uk

@ useMYdata