

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

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.

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.

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.

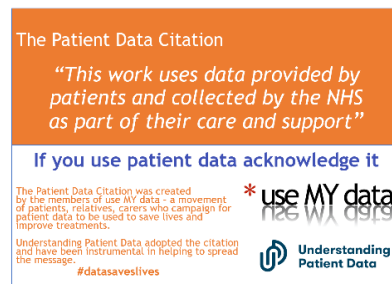
- Our **Advisory Group** is drawn from **use MY data** Members. The Advisory Group defines the priorities, actions and activities of **use MY data**, representing its Members and advising the Secretariat on the Members' behalf. Please visit the Advisory Group page [here](#) for details about the Advisory Group, including current Members.
- Our **Secretariat** supports the work of **use MY data**. The Secretariat comprises a Coordinator, Data Adviser and Events & Website Manager. These are the only funded roles within **use MY data** and all of the roles are funded part-time.
- Details of our **status** and **funders** are published on our website [here](#).

"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

What we do

- We promote the benefits of sharing and using data to save lives and improve patient outcomes with sensible safeguards against misuse.
- We host patient data events for patients and the public. The wide-ranging programmes are devised by our Members and bring together a wide range of stakeholders to discuss all things 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.
- We developed the Patient Data Citation, which acknowledges that patients are the source of the data. Details are published [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 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 act as a conduit between organisations and our Members.
- We are building a library of patient stories where patient advocates speak direct to camera about the positive uses of patient data. The library is available [here](#).
- We work to bring a patient voice to all conversations about patient data. This includes our Members speaking at events, sitting on national organisation's panels and responding to patient data consultations, to ensure the patient voice is included.



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. Please join us - it's free and there is strength in numbers!

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.

To join (and/or request further information) please email - join@usemydata.org.uk.