



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

Expectations of organisations which use our 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

To ensure openness and transparency about how patient data is used, and to build trust in the uses of patient data, we expect any organisation that uses patient data to explain their data uses, including how they use data to deliver benefits for patients: **Say what you do, do what you say and how you will do it.**

We also expect organisations to be clear and open about how they respect any choices which patients have made about their data use.

Principles which we would expect organisations to publicly adopt (when communicating via website, press releases, reports, contacts, etc.)

Individual Choice

1. Describe clearly how you have respected the wishes and preferences of patients regarding use of their data
2. Respect the wishes of patients in the National Data Opt-out* and any patient-choice mechanisms that Trusts have adopted*^{England only}

Societal benefit

3. Be explicit that the primary focus must always be on benefit to patients, relatives and carers
4. Demonstrate the benefits of what you do, and what you have done, and publish this openly

Patient Voice

5. Embed patient voices in all parts of the organisation and be responsive and accountable to them
6. Recognise the use of patient data by adopting the Patient Data Citation¹
7. Be open to questions, and answer these questions openly, clearly and fully

Transparency

8. Be clear how you are delivering fair value to the NHS in what you do with patient data, and how you do it, and publish your assessment of fair value
9. Be proactive - say what you do, how you do it, and publish this for transparency in plain language suitable for its intended audience

Security

10. Ensure the security of patient data held in digital and other formats

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 working in this way, and if not, highlight the areas which they might want to look at
- Let the Secretariat know about any concerns that the organisation may 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

¹ Patient Data Citation: <http://www.usemydata.org/projects.php?project=3>

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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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