

UK Parliament Inquiry

The right to privacy: digital data

Response from [use MY data](#)

21 March 2022

Introductory Note

This response has been coordinated by the Secretariat of [use MY data](#) on behalf of Members. We have drawn from our Members' responses to previous consultations, in particular on the National Data Strategy and the Goldacre Review.

As with all the responses we collate on behalf of [use MY data](#), these may contain contrasting views from Members. It is inevitable that we receive a range of views and all of these views are included. We believe that there is strength in presenting a complete range of views.

We hope these comments are useful and thank you for the opportunity to contribute. If any points need clarifying, please do get in touch.

Contact details and follow-up

[use MY data](#) is happy for this response to be used or shared without restriction.

If you would like to follow-up with [use MY data](#), or ask any questions about our response, please contact the Coordinator, Alison Stone - alison@useMYdata.org.uk

The right to privacy: digital data

Inquiry:

“Effectively sharing data across and between Government and industry has a number of potential benefits, but there are risks to doing so too. A key issue is public trust and the need for transparency with respect to how individuals’ data is used and shared. The Government’s December 2020 National Data Strategy and its more recent draft strategy, ‘data saves lives: reshaping health and social care with data’, address aspects of this. Specifically, the latter sets out an aim to “share anonymous data safely and appropriately across the entire health system”, which has raised concerns amongst patient groups and some privacy campaigners.”

Our key points

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

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.

We recognise that there are areas of concern about the use of patient data, which need to be addressed if public trust is to be improved. We have identified key points in relation to this.

Privacy concerns should not be blockers to approved data access

“We have narrowed the doorway and then put bouncers on the door. We are now trying to negotiate with the bouncers, but what's really needed is to put the doorway back to how it was.” - **use MY data** Member on access to their patient data

- We continue to see unreasonable delays by large data controlling bodies in providing access to data for research
- The benefits of using the data must not be overshadowed by perceptions of risk, or behaviour which is disproportionately risk averse
- Trusted Research Environments should provide a more robust mechanism to enable research
- Transparency must be an essential and integral part of any successful solution - ‘Say what you do and do what you say’
- There must be inclusion of patients in all decision-making processes around data access and release
- Engagement with the public and patients on the benefits of data sharing but also the privacy assurances will be vital - building on the success of data usage as part of the pandemic response
- All analytical and research outputs should adopt the **Patient Data Citation**.

use MY data subscribes to the philosophy that data saves lives and therefore, that not using data costs lives.

Transparency needs to improve significantly, or public trust will be damaged

Transparency is increasingly quoted in conversations about patient data as being essential to demonstrate trustworthy uses of data. However, the rhetoric needs to be matched by actions.

As a patient movement, we have had to work extremely hard to get the NHS to publish basic things such as information about planned data programmes, or data-access and release registers - to show which organisations had used patient data, why they had used it, and the benefits of this use to the NHS and patients.

A recent survey by Health Data Research UK [highlighted the scale of the challenge](#) showed that only 48% of the data custodians and controllers surveyed actually had a public data use register.

The survey also found that “Information on the legal basis for data sharing, as well as the application of the Common Law Duty of Confidentiality and national data opt-outs was the least common, with only two data custodians providing this data”.

From a patient perspective, this is not acceptable. Publishing details of how our data is used should not be difficult. This should be a simple, but mandatory requirement. Details of data releases and uses should be available to the public by default, without having to campaign extensively for this to happen.

Equally, it is as important to publish details of any data breaches, with a clear statement of the impact, where the responsibility lay, the consequences for the responsible agency/agent and what will be done to prevent a future data breach. The principle **Being as pro-active with ‘bad news’ as with ‘good news’** is included in **use MY data’s [transparency principles](#)** for the use of patient data.

Transparency should not be difficult. But a cultural change is needed, which needs to be driven from the top.

There is confusion over ‘Anonymous’ data

There is a fundamental lack of clarity about the term ‘anonymous’. The terms anonymised, de-identified, pseudonymised and anonymous are often used incorrectly, which is confusing, unhelpful and does not aid public confidence in how patient data is used.

Under the definitions of the Data Protection Act 2018 and the General Data Protection Regulation (GDPR), anonymous data is not treated as a personal data. Therefore, no user consent and no particular protection is required.

If data is truly anonymous then it can be shared. In which case the stated intention to “share anonymous data safely and appropriately across the entire health system” would be difficult to challenge.

There needs to be a much wider and better informed conversation, with patients and the public about this area.

Acknowledging the use of patient data will increase public awareness of data uses

use MY data created a Patient Data Citation for inclusion on all research and analyses using patient data, to acknowledge the contribution of patients - **‘This work uses data provided by patients and collected by the NHS as part of their care and support’**.

The Citation highlights how patient data has been used and is a recognition of some of the benefits of using the data.

We would like to see the Patient Data Citation used within national strategy documents for patient data, and a direction that it is used by all patient data organisations.

The benefits of using patient data for research need to be highlighted

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 peoples' health data 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 rare, without identifying individual patients, because the data is anonymised (note, not anonymous) and our privacy is protected by law and by regulators.

Challenges raised by our Members in relation to the National Data Strategy and public trust

Listed here are challenges from some of our Members, in their own words, in relation to the National Data Strategy and public trust.

- “There is a statement in the strategy that says 'we do not sell data for the benefit of private companies' I have heard this statement being challenged by people in the field. I think NHS X/Digital need to absolutely clear in the strategy about when data does change hands for money.”
- “The vision talks about 'increased transparency'. I would have thought total transparency should be the vision.”
- “GPs/BMA opposition”
- “Stove piped data controllers”
- “Misinformation, mistrust, inertia”
- “Failure to articulate and communicate and thus convince stakeholders of the vision and its consequences and benefits”
- “Major ****-ups leading to loss of confidence”
- “Real commitment across the NHS to separating the data layer as the key enabler to achieving the technical/operational goals.”
- “Changes are needed in legislation, accountability and data control. Planning how we make the necessary changes in those areas whilst retaining public and professional confidence so that these are enablers to the ambitions rather than barriers to achieving them.”

use MY data

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

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.

Our mission statement

- **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** 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.
- **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.

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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