

The Goldacre Review into use of health data for research and analysis

Response from [use MY data](#)

22 March 2021

Introductory Note

This response has been coordinated by the Secretariat of [use MY data](#), on behalf of members.

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 from members, and all these views are included in our response. We believe that there is strength in presenting a complete range of views.

Contact details and follow-up

Our members are happy for [use MY data](#)'s 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

Our comments are provided below and relate to areas outlined in the Terms of Reference for the review, as detailed at <https://www.gov.uk/government/news/new-review-into-use-of-health-data-for-research-and-analysis>, preceded by some general points of feedback.

Background

Given the short timescales we contacted the [use MY data](#) Advisory Group Members asking for comments on the areas identified within the Terms of Reference. We also advertised the application process for the workshop for expert patient and public representatives.

General Feedback

Our overall comments are very much guided by the principles of [use MY data](#) and include the key points that:

- We do not see this as a technical problem
- We have seen unreasonable timeliness of 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 Environments¹ 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
- Clear communications are vital and needs careful design and funding
- We subscribe to the philosophy that data saves lives. We would therefore argue that not using data costs lives.
- Getting a patient’s own data into one place for their own benefit, will in turn benefit research
- Allowing patients to add data or comments about their own conditions will aid research
- Engagement with the public and patients on the benefits of data sharing but also the privacy assurances will be vital - building on the successes of the pandemic
- All analytical and research outputs should adopt the Patient Data Citation².

Some of the specific comments from our Members are summarised below.

1. “You ask for comments but it’s hard to comment against a blank canvas.” (This reflects that this consultation has felt somewhat different to previous consultations to which we have responded).
2. “I think it would be worthwhile to recommend to Ben Goldacre right away that patients should be part of the Steering Group or whatever the governance structure is.”
3. “Could they start from the premise that they are seeking to use (general, deidentified etc. etc.) patient data for patient/public/system benefit, and that includes (suitably approved/regulated) research, as opposed to their traditional first step of ‘We must never share anything ever’.”
4. “One of the biggest problems we face is that people have different strategies and different interpretations and different processes, and all of that causes delays (at best) in sharing data.”
5. "Data controllers need to publish their interpretation of the law when they share (or don't share) data."
6. “Health data research has historically been dominated by research cohorts and data distribution.”
7. “Trust comes from improved transparency but also from improved patient comprehension and familiarity with their own data. This is not helped by lack of support to assist in understanding codified data. My experience of getting my data from

¹ Views on Trusted Research Environments, webinar; <http://www.usemydata.org/webinars.php?webinar=2020-11-25>

² Patient Data Citation; <http://www.usemydata.org/citation.php>

secondary care was effectively a ‘data dump’ with no explanation of the data variable or values. Lessons need to be learnt from the NCRAS (National Cancer Registration and Analysis Service) approach to data access requests.”

8. "The principles of the Five Safes are key steps in ensuring data is protected, managed and used ethically."
9. "Trusted Research Environments need to be trusted by those that are effectively donating their data - patients."
10. "I would like NHSX to fix the better joining up of hospital & GP data..."
11. "There is a view that data-sharing within the UK is likely to prove more difficult than between the UK and Europe, especially if we assume that the UK and EU will reach a new data-sharing agreement later this year, as seems likely. We have heard a frustrated researcher argue that it already is more difficult here."
12. "Obviously, it depends what data is wanted and for what purpose, but it is interesting to see the numbers of groups now springing up to promote data-sharing, especially in cancer research, where data that was shared easily a few years ago now takes months to be released, if it gets released at all."
13. "Inclusion of patients in all decision-making processes not only because morally this is the right thing to do, in our role as taxpayers and as end-users of services (i.e. patients) but because being seen to include patients provides additional credibility in the eyes of fellow patients and the public."
14. "Should Subject Access Requests really be the way that patients are forced to use, if they want to see their healthcare records?³ No."
15. "One specific way forward would be for improved communication of data case studies/patient stories which demonstrate that sharing and using data helps identify relevant questions and often the appropriate solution. This in turn can lead to improved, smarter, kinder treatments and better outcomes for patients. It is not always about ‘saving lives’ (other than in the widest meaning of that phrase)."

The overall feeling of our Members was articulated well in a particular quotation from one, which simply said:

“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.”

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

³ Show me my data! webinar; <http://www.usemydata.org/webinars.php?webinar=2021-03-03>

About use MY data

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.

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.

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 provide learning resources for patient advocates on patient data issues, including:
 - hosting workshops for patients and the public, focussing on topics related to patient data
 - a library of resources of data security, consent
 - narratives from individuals about how collecting, storing and using data can help patients.
- ❖ 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.

www.useMYdata.org.uk
getinvolved@useMYdata.org.uk
[@useMYdata](https://twitter.com/useMYdata)