Article by Understanding Patient Data

"A new approach to decisions about data"

Publication date: 8 July 2020

Response from use MY data

31 July 2020

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 of 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

Once submitted this document will be published on our website - www.useMYdata.org.uk

How this response was formed

Noting that feedback was being sought on the article "A new approach to decisions about data", we circulated the details to use MY data members in the weekly Newsletter on 9th July and asked for any feedback by the end of July.

The following is the collated feedback from use MY data members response.

Summary

- The paper was well written and well argued. There was a common view that the paper was good
- We would absolutely support the principle of shifting from governance as a barrier, and agreed with the five advantages you noted in your closing summary

- Examining any process at a single point in the pipeline is not ideal. It is inevitably subject to a restricted view and restricted time. Such factors can therefore result in risk-averse decisions
- We agree that mechanisms which eliminate the potential for a tokenistic patient view should be applauded

Some specific comments from members

As with all our responses, we take the words directly from our members, and present these in a structured manner, although we sometimes collate several similar comments into a single one.

Some thoughts from our members are shown below:

“I think it’s a very good paper. It staggers me that it is not a statement of the obvious which was implemented years ago but actually, compared to practice, breaks some new ground.”

“I fully support that governance should move towards being an enabler rather than a blocker and I agree greater collection and use of feedback is key to that. Feedback is required to inform future decisions and I am really surprised that this is not already a major part of the processes in the areas I have been involved in. It is fundamental to assessing the effectiveness of research, to directing research towards the more productive areas, to cost-justifying the data collection processes, to learning from mistakes and to ensuring transparency and accountability of the data governance bodies.”

“To make this effective, feedback would be required from researchers supported by an expert objective but hopefully brief, quick and cheap view of whether the claims match the reality. It amazes (and frustrates) me that bodies controlling release of data do no not make it a fundamental requirement of data releases that the researchers must deliver feedback on the outcomes measured against the ‘promises’ and add that as a column on the data release register. It would be important that outcomes are not just measured in terms of the number of peer-reviewed papers but also the real-world benefits delivered or opened up. I would also advocate collection (definitely) and publishing (with a slight ?) of the researchers’ views on the effectiveness and efficiency of the data release process and an ‘if only’ column – if only that additional piece of data were available or these two items of data could be joined up or this data was available more promptly then …….

It was further noted that:

“This would enable patients to be more effective advocates for using data to improve world health or to reduce healthcare costs or better still both. We must also recognise that it is critical that patients must participate to ensure data is not unreasonably used. This also requires feedback on anything that went wrong in that context so those mishaps can inform future decisions and processes.

On the principle of the learning system, a point was raised about the time which many research studies will take to complete, which could mean that feedback and learning from results would take many years.

There were some specific points of challenge from our members.

“It was interesting to note that the article does not cover what might be considered to be ‘patient and public representatives’ in the first place. Certainly, looking at CAG, IGARD and the endorsed METADAC committees based on their websites, I count a total of 59 members of which I would consider only 4 to be truly lay members (i.e. 6.7%). So rather than arguing that the involvement of patient/public can be tokenistic, I would argue that it has not even reached those relatively dizzy heights. All METADAC members are ones which even THEY do NOT consider to be lay despite having a mere 33 members on the committee!”

In terms of learning elements within the data access process, and echoing a regular desire for data access processes to be made clearer, faster and transparent, another thought was:

“I see no comment on tracking of applications through the various stages up the date of the data actually being made available for access. The greatest challenge currently is in delay to data access. What is critical in resolving this challenge is accurately (i.e. not what NHSD do) tracking (and the results made public) the progress being made through the process. In this way sticking points can be identified. Having a more intelligent approach to assessment once it reaches a ‘committee’ may not add too much value, if at all, in reducing delay, merely in the ‘quality’ of the assessment decision. The data access committees ought to be more robustly challenging unnecessary delays in the process.”

Commenting on the wider information governance landscape, and the emerging role of HDR-UK, it was noted that:

“Where the HDR Gateway approach is probably more appropriate, it would be good to get feedback on the quality of the data provided. I am working on one healthcare data project where after waiting over 1 year to get their hands on some data (which cost them £50,000 to get access to) 3 people spent a further 13 months trying to address the data quality issues. So overall, a 2-year delay to the project and total cost before they can actually start any actual research work in excess of £250,000+.”

A useful summary from one member simply said:

“….I think the blog is a good starting point but feel it should go further in the amount of feedback available to the patients who are involved in the processes and I think it should be strengthened to recommend a closer working relationship between patient advocates and researchers to drive together the availability and productive use of patient data for patient benefits.

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.

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