Consultation by MHRA

"Seeking views on how we engage and involve patients and the public in our work"

Consultation date: September 2019

Response from use MY data

3 October 2019

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

General Feedback

Due to the nature of the consultation, and the particular interests of use MY data, we have focused much of our response on the role of the Clinical Practice Research datalink (CPRD).

A key overarching point would be that we would strongly support greater transparency on the CPRD data sources, their processes for use of data and the beneficial results. In that context we would highlight the need for increased transparency, in such areas as:

- The processes that they apply in release of data to third parties for research and planning purposes

- The beneficial results that have been achieved from use of CPRD data by CPRD and third parties

- The releases that have been made in the last five years and the date from first request by the third party to release and the performance indicators that CPRD use to measure their performance in that regard. Their results against those performance indicators

- Data requests that have been refused and the reasons why

- Data requests that are in process, the date of application and the current status

- Their plans, if any, to become a repository of relevant data from all GP Practices and a positive enabler and encourager for access to that data for valid requests.

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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www.useMYdata.org.uk
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@useMYdata

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