Wendy Harrison
Senior Lead – Data Governance
Deputy Head of Corporate Information Governance
NHS England & NHS Improvement (NHSE/I)

10 November 2021

Dear Wendy,

NHS COVID-19 Data Store - Access and Release Register

We were pleased to see the register published on 12 August 2021 on the NHS England website.
We are writing to follow up on behalf of the members of use MY data, to ask two things for clarity.

The first is about your plans for monthly updates to the register. You had previously stated your intention to refresh the register monthly, although the current version is still dated 12 August and the data sharing expiry dates for most of the entries are 30 September 2021. Could you let us know - or better still, publish - your planned refresh schedule, and clarify what arrangements are in place to monitor the delivery of the schedule?

A second point is about the content of the register. When contrasted with a similar register published by NHS Digital, which contained 89 entries, the NHSE/I register contained just 18. Is this because the usage of the NHS COVID-19 data store was largely done by direct access rather than data release? Will you also be including data access in the register, in the interests of openness, transparency and building public trust?

We look forward to your response.

Please share or use the contents of this letter in any ways that you feel will help. We will publish the letter on our website for transparency and so that our members know that we have acted on their behalf to follow up on further improvements to the register.

Yours sincerely,

Richard Stephens

Richard Stephens
Chair
use MY data Advisory Group

Dave Chuter

Dave Chuter
Vice Chair
use MY data Advisory Group

Alison Stone

Alison Stone
Coordinator
use MY data

C. Carry

Chris Carrigan
Expert Data Adviser
use MY data

The only independent patient movement in the UK focussed on patient 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.

www.useMYdata.org.uk
join@useMYdata.org.uk
@useMYdata

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