

Wendy Harrison
Senior Lead - Data Governance
Deputy Head of Corporate Information Governance
NHS England & NHS Improvement

21 July 2021

Dear Wendy,

NHS COVID-19 Data Store - Access and Release Register

We are writing on behalf of the members of [use MY data](#), a growing patient-led movement, to seek the publication date of the Access and Release Register from the NHS COVID-19 Data Store.

As you are aware, we wrote to NHSX on 7 October 2020 following our webinar on ‘The COVID-19 exit strategy - what next for patient data?’. We wrote reflecting the request from patients, relatives and carers for the publication of a register showing the details of data access and data releases from the NHS COVID-19 Data Store.

We have worked actively and supportively with NHS England & NHS Improvement (NHSE/I) in the ten months since that point to encourage this publication. Despite this the register has not been published.

We have always recognised that work would be complex, and that pandemic-related work would at times take precedent, but after ten months we are disappointed that the register is yet to be published, and we are losing confidence that this is going to happen.

The lack of any proposed publication date is of particular concern.

The continued absence of the promised published register may fuel the current culture of mistrust and suspicion around the use of patient data. The impact of the lack of transparency and not respecting the views of patients is demonstrated by the recent announcement on the delayed rollout of the GP Data for Planning and Research (GPDPR).

The first of three key underpinning points in the draft NHSX Data Strategy for Health and Social Care highlights the need to “build understanding on how data is used and the potential for

data-driven innovation, improving transparency so the public has control over how we are using their data”. That stated intention is not being backed up with action.

We urgently request a publication date for the Access and Release Register or the reasons why publication is being held back.

We look forward to your response.

Please share or use the contents of this letter in any ways that you feel will help you set a date for the publication and indeed to publish the register. We will publish the letter on our website for transparency and so that our members know that we have acted on their behalf to reflect their growing concerns on this matter.

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
Coordinator
use MY data



Chris Carrigan
Expert Data Adviser
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.

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