

Letter sent by email to Andy Moody,
Senior Data Policy Advisor, NHSX

07 October 2020

Dear Andy,

Data releases from the NHS COVID-19 Data Store

Firstly, thank you again for taking part in our recent use MY data webinar, looking at issues and opportunities for data, and the move towards a COVID-19 exit strategy. use MY data is driven directly by the views and requests of its members; patients, relatives and carers, and this was an important topic that they wanted to discuss with you.

Further to the webinar, and following discussions with our Advisory Group, we would like to follow up with you about a particular point raised during the webinar by delegates. This was that details of data releases from (and access to) the current NHS COVID-19 Data Store are not yet published. As a movement focused on the benefits of data usage, transparency and building trust amongst patients and the public, this is something that we would like to see addressed urgently.

Following our webinar, we have noted that the COPI Notices issued to NHS England and NHS Improvement and NHS Digital differed slightly in this area.

The [letter to NHS Digital from the Secretary of State](#) stated that it “requires NHS Digital to publish details of the organisations with whom it has shared confidential patient information under this Notice and the purposes for which it was shared in the NHS Digital Data Release Register.”

In contrast, we note that the [letter that was issued by the Secretary of State to NHS England and NHS Improvement](#) on 20 March 2020 was not as specific, merely stating that “A record should be kept of all data processed under this notice”.

For reasons of transparency, we would see the requirement to publish a register of data releases to be equally important to NHS England and NHS Improvement as to NHS Digital. We believe that this is much more in line with the reasonable expectations of patients - a view we heard clearly on the webinar. And this is critical to retain and build patient trust.

We have informed our webinar delegates and our membership that we are writing to NHSX to request publication of the register.


use MY data is keen to bring a strong and direct patient voice to all conversations about patient data. Please let us know if the patient voice can assist the release of the register.

We look forward to hearing from you. Thank you.

Yours sincerely,



Chris Carrigan
Expert Data Adviser, use MY data



Alison Stone
Coordinator, use MY data