

07 October 2020

Dear Delegate,

Thank you for attending our webinar **The COVID-19 exit strategy - what next for patient data?** on 9 September.

Following discussion with our Advisory Group we are in touch to follow up on points that were raised by delegates, either during the session or in the feedback.

Webinar practicalities

It was clear that many delegates found the topic useful, though complex. Several delegates highlighted that the use of acronyms made the conversations difficult to follow. Please accept our apologies for this.

We always provide briefings for our speakers, requesting that they do not use acronyms and that they speak in plain English. These are key points of principle for us, in order for our events to be as inclusive as possible.

The webinar was planned as a session with one speaker, followed by questions and answers. Unfortunately, and probably reflecting the complexity of the topic, the speakers were increased in number shortly before the webinar began, from one to four. This meant that the additional three speakers did not receive a briefing, and that their information did not meet the needs of all delegates. For future events, we will ensure that all speakers are briefed before they take part.

Due to the late addition of the speakers, it appeared that the format of the webinar was a panel and that patients had not been included. Please accept our apologies for this. Our policy is always to include a patient on a panel and we will ensure this happens at our future events.

Following up with NHSX about data access

It was clear from the speakers that significant steps have been made to use data more effectively in the response to COVID-19, and we heard that many benefits have been seen. However, a serious point highlighted during the webinar was the need for NHSX to publish details of data which has been accessed or released from the NHS COVID-19 Data Store.

In line with our own [principles of transparency](#), we believe that the access and release details of these should be published. We have written to NHSX to request that this happens. We have included a copy of our letter, for your information.

If you are already a Member or Associate Member of use MY data, we will be including updates on progress in our weekly news round-up.

Membership of use MY data

If you are not part of use MY data, you may wish to consider joining us. Membership is free and open to all:

- Members are patients, relatives or carers from all disease areas
- Associate Members are clinicians, researchers, charities, researchers, public and commercial sector workers. They are united by an interest in sharing healthcare data to improve patient outcomes under appropriate levels of consent, security and privacy.

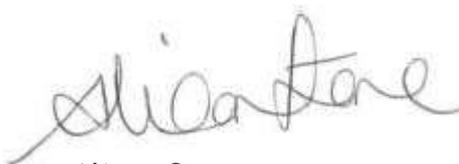
If you would like to join us please email join@useMYdata.org.uk The more members and associate members we have, the stronger our voice becomes in campaigning for patient data to be used to save lives and improve treatments.

With thanks again for your time and contributions.

Yours sincerely,



Chris Carrigan
Expert Data Adviser, use MY data



Alison Stone
Coordinator, use MY data

Enclosure - Letter to 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.

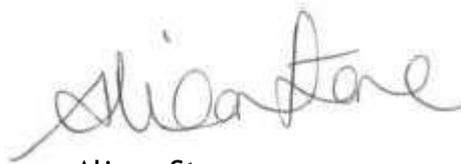
use MY data is keen to bring a strong and direct patient voice to all conversations about patient data. Please let us know if the patient voice can assist the release of the register.

We look forward to hearing from you. Thank you.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'C. Carrigan'.

Chris Carrigan
Expert Data Adviser, use MY data

A handwritten signature in black ink, appearing to read 'Alison Stone'.

Alison Stone
Coordinator, use MY data