

Data from this pandemic, afterwards

NHS England has taken over all hospitals in England due to the 'level 4' alert for the current pandemic. When that alert is stood down, the powers by which NHSX can use Palantir will cease. Palantir has agreed to destroy the copy of the data it is using.

NHS England will keep its copy, and intends to use it (officials call it the 'PPDS').

That dataset will be useful for multiple things: the public inquiry into decision making and routing of resources; clinical research, and wider operational research; how HMG and NHSE failed, and when, and how many died as a result – both in the NHS, and also those who *had* been in hospital, who were discharged into social care to die.

The COVID-19 dataset is a disease register like any other; it will be vastly more broad, but very time-limited. NHS England should therefore make a public commitment now that, after this is over, it will back-fill all of the NHS procurement data on masks / gowns / etc. into that register, so that usage and flows can be properly analysed. What did national bodies know, when did they know it, and what did they do about it?

As for patients' data, just as other disease registers should respect patient dissent for secondary uses of data – so should this disease register. If DHSC / NHS England intends to make secondary use(s) of this data, HDR UK should immediately commission and fund a matching exercise for all those people who died outside of hospital in the period, and what pre-existing conditions they apparently died from, that excludes them from the NHS figures we currently receive.

NHS Digital will be able to link data to other datasets as it does routinely for disease surveillance. This register should follow the lead of Genomics England and only allow data to be available in the [Data Access Environment](#), where all of the data remains permanently within the NHS's digital boundary.

An ethical, well-managed research dataset for legitimate research purposes will be welcome – there are many things to learn for the next pandemic. Empire building and ass-covering by the operations side of NHS England and DHSC will not only be unwelcome, but profoundly unhelpful.

NHS England may want to keep its data flows running under a perpetual s251, but any belief in such an approach assumes that NHSE will never give up the powers that it has taken to fight a pandemic. NHSE's claim for perpetual data use under "other legitimate arrangements" must be replaced with *bona fide* research governance that is not in any way subject to NHS England's whims. A "COVID-19 disease register" covering all patient and operational data would deliver in practical terms the vision it has long held for 'improving' all disease registries.

The good people of Lewisham support "the NHS", even when NHS England wishes to close their hospital. Support for NHS England's necessary steps in a crisis cannot be used as an

excuse to micromanage their hospital into closure afterwards. From its other actions, NHS England appears to have learned nothing from the data debacles of the last 6 years, about how data should be used. It still seems to think it can do – and tries to justify – in 2020 what it thought was a good idea in 2013, and was proved otherwise in 2014, 2015, 2016, 2017...

There are existing approaches to data for diseases, which address both the diverse needs of research and the diverse needs of patients; it would be a disturbing precedent for NHS England to use the approach it has cobbled together in a crisis to inform or intervene in other areas of treatment.

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