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BRIEFING

How health data have been used during covid-19, and whether the changes are here to stay

The pandemic has rewritten the rules on accessing and using health data. **Chris Stokel-Walker** looks at how covid-19 has changed what is allowed, and whether things will go back to normal after the crisis has abated

Chris Stokel-Walker *freelance journalist*

“Covid has changed the conversation,” says physician Saira Ghafur, who leads digital health at the Institute of Global Health Innovation at Imperial College London. “It’s trite to say that we’re in a new normal, but the pandemic has changed approaches to the use of patient data.”

The data driven response to the pandemic—using private health data and personal contacts of those going about their everyday lives—has been crucial in attempts to contain SARS-CoV-2. In the UK, for example, the NHS has used records to identify their most vulnerable patients to advise them to shield, and patient histories have been used to prioritise those most in need of early vaccination.

What changes has the pandemic brought about?

The biggest change was the triggering of a regulation set up nearly 20 years ago.

Since 2002 the UK Health Service (Control of Patient Information) Regulations have given the health secretary the ability to access and use health data—everything from time and dates of admission to hospital to x ray or blood sample results—to respond to health emergencies.¹ Section 3(1) of the regulation allows the health secretary to pool data for “diagnosing communicable diseases and other risks to public health,” as well as “monitoring and managing” risks to public health, including “incidents of exposure to communicable disease” and the “delivery, efficacy, and safety of immunisation programmes.”

Current health secretary Matt Hancock triggered that regulation in April 2020.² “We want to ensure that health organisations, arm’s length bodies, and local authorities are able to process and share the data they need to respond to covid-19,” the Department of Health and Social Care (DHSC) said at the time.

“Notices have been given that mean NHS England can do a bunch of extraordinary things that they couldn’t otherwise do unless there was a public health emergency,” says Phil Booth of MedConfidential, a campaign group ensuring patient confidentiality. For example, positive test results have been passed to police forces to ensure compliance with self-isolation requirements.

This isn’t the first time the regulations have been invoked—according to Booth, they’ve been triggered

routinely since 2002 as a legal gateway for Public Health England (PHE) to monitor communicable diseases using confidential patient data. But the pandemic is the first time the regulations have been used so extensively, for such a prolonged period. DHSC has regularly updated the time limited implementation of the regulations over the past year, as the pandemic has dragged on. At the time of writing, the imposition of the regulations is set to expire on 30 September 2021.

Who owns health data, and what are they used for?

“In UK statute, it’s the secretary of state for health that has overall oversight and ‘ownership’ of health data,” says Ghafur, “But, still, there’s the question of whether data belong to patients, to an organisation, to the clinical commissioning group, or to someone else. I don’t think they’ve truly answered that. Whereas if you go into a US hospital, you basically sign your life away as soon as you enter.” (Booth also points out that, legally, there is no such thing as someone “owning” data.)

A list of data custodians in the UK—which includes various parts of the NHS, as well as third parties such as medical research charities—can be found on the website of the UK Health Data Research Alliance, who describe themselves as “a group of leading health, care, and research organisations united to establish best practice around the ethical use of UK health data for research and innovation at scale.”

The alliance was launched in February 2019 by Health Data Research UK (HDRUK), the national institute for health data science, supported by UK Research and Innovation and medical charities such as the Wellcome Trust and the British Heart Foundation. “Our 20 year vision is for large scale data and advanced analytics to benefit every patient interaction, clinical trial, and biomedical discovery, and to enhance public health,” says Alastair Denniston, director of Insight, the HDRUK hub for eye health.

During the coronavirus pandemic, HDRUK’s remit has focused on “uniting” the healthcare system to make better use of data to tackle the virus. “Health datasets of all kinds are valuable in helping us understand the causes of disease, improving clinical care, designing health services, developing new

treatments, and monitoring safety and effectiveness,” Denniston told *The BMJ*.

Any organisation that wants to access health data must make a request to the relevant data custodian. Each custodian has a data access committee, which weighs up applications and decides if they are valid requests and, if so, what level of detail is required.

All requests to use data should adhere to the principles of data driven medical support for patients³ as drawn up by the Office for Life Sciences—in particular, that NHS data not in the public domain must be used only to improve the health, welfare, and care of patients.

Booth says that in practice, however, there is no consistency. “PHE was doing it so badly that the Cancer Registry had to be moved to NHS Digital,” he says, adding that, as the main data controller, NHS Digital, with its remit and expertise, is the only body that comes close to being able to oversee health data properly.

Booth says that, in theory, the UK Information Commissioner’s Office (ICO) ensures that data use rules are adhered to and applied consistently. “HDRUK pretends it can oversee health data, but it’s not a data controller, so it’s got no data of its own to share. The national data guardian is responsible for information governance across health and adult social care. But the ICO and Care Quality Commission have the regulatory teeth.” In short, responsibility and oversight remain unclear.

If patients aren’t keen on their data being used, they can choose to circumscribe their health records from any use other than their own direct care. The national data opt-out system allows patients to prevent their information being used for research or planning purposes within the NHS. Around 1.6 million patients have opted out of the system in the NHS, and the numbers opting out have generally stayed the same during the pandemic.

What happens after the pandemic?

Campaigners worry that as the pandemic abates, some health data will continue to be used as they were at the height of the crisis, even if there isn’t any lawful basis for it.

There are also worries that the pandemic has pushed back key timelines for adherence to data use rules. The national data opt-out system was initially meant to be mandatory for all organisations in 2020—but pandemic responses delayed it, first to 31 March 2021, then to 30 September 2021.⁴ “Rather than a debate about ownership, I want a debate about protections,” says Booth. “We need statutory safeguards in place.”

It’s also vital that healthcare providers better demonstrate how and why data collection improves treatment, says Ghafur. “We need to make sure we’re able to explain to patients and the public what we’re doing with the data, and, beyond that, making sure we’ve got the right legal and regulatory safeguards.” That includes what’s happened during the pandemic: the regulation under which health services are currently processing our data legally requires them to keep a “record of processing,” showing how they used it and why.

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Competing interests: I have read and understood BMJ policy on declaration of interests and have no relevant interests to declare.

1 Health Service (Control of Patient Information) Regulations. 2002. www.legislation.gov.uk/uk-si/2002/1438/contents/made.

2 Department of Health and Social Care. Coronavirus (covid-19): notification to organisations to share information. 1 April 2020. www.gov.uk/government/publications/coronavirus-covid-19-notification-of-data-controllers-to-share-information.

3 Department of Health and Social Care. Creating the right framework to realise the benefits for patients and the NHS where data underpins innovation. 15 July 2019. www.gov.uk/government/publications/creating-the-right-framework-to-realise-the-benefits-of-health-data/creating-the-right-framework-to-realise-the-benefits-for-patients-and-the-nhs-where-data-underpins-innovation.

4 NHS Digital. Compliance with the national data opt-out. 11 February 2021. <https://digital.nhs.uk/services/national-data-opt-out/compliance-with-the-national-data-opt-out>.