

Our NHS Data and how it will be used is at a critical juncture.

During Covid 19, the government has entered huge contracts with mega tech companies, such as Palantir and Faculty AI. Although this 'covid19 datastore' was said to be a temporary measure during the pandemic, some of these contracts have already been extended.

For a clear explanation of the dangers from these contracts that we face, listen at 1 hour 8 minutes to the [**People's Covid Inquiry | #7 | Profiteering from the People's Health?**](#) where Rosa Curling (a Director of [Foxglove](#) and a UK-qualified lawyer, formerly of Leigh Day Solicitors) talks about the unprecedented collation of data, the 'Covid19 datastore', NHS data in general and the battle over privatisation.

Our NHS data, held by GPs, is being gathered centrally. It is an enormous data set and of huge social value, but also potentially of huge financial value. If we knew that this data were to be used solely for NHS research, for public health and for planning, gathering this data would be a great exercise in the public interest. But we do not know this. Nor have we been consulted about its use now and in the future.

The organisation, [Foxglove](#), has been monitoring and challenging these tech contracts. On May 11th, [Foxglove asked](#): 'Why is the UK government hiding its NHS data deals with private companies?':

In late March 2021, [the NHS announced](#) that it was working with a number of private companies to develop a "covid19 datastore". Some of the companies most of us will have heard of: Google, Amazon, Microsoft. They're companies with expertise and technology, for sure – but they also have a history of not being willing to pay their fair share of tax to fund the NHS. And they don't have the greatest of reputations when it comes to respecting our privacy.

Some of the other companies involved are less well known, but even more worrying. Palantir is a US security and data-mining firm which cut its teeth helping the CIA in Iraq and Afghanistan. More recently, it has become notorious for the links between its owner, Peter Thiel, and Donald Trump – including providing support for Trump's aggressive deportation policies towards immigrants. Palantir is [reported to be charging only £1](#) for its work on this project – raising the question, as a profit-driven company, of what financial return it does expect to make.

Another lesser-known company is Faculty AI. They made a name for themselves doing data work for the Vote Leave campaign. They've got strong links to Boris Johnson's government.

[Read more](#)

On May 19th [Foxglove](#) gave an 'Update: our legal challenge to secrecy surrounding NHS data deals with private companies':

'So far, nearly 9,000 people have joined our campaign with openDemocracy, to end government secrecy on the massive NHS data deal. That's an incredible response, and growing by the day.

Foxglove received a further reply to our original request under the Freedom of Information Act, which we had submitted back in April. The government's failure to respond to this request within the original timescale was one of the things which had prompted openDemocracy and Foxglove to team up to start legal proceedings. Under pressure, the government has now replied. They now say:

'I am writing to inform you that the Department's consideration of the balance of the public interest with regards to your request is not yet complete and requires further time to complete in line with Section 10(3) of the FOI Act.

The Department is currently assessing the public interest in release under Section 43(2) - commercial interests.

We anticipate this process will take no longer than a further 20 working days to complete. We therefore aim to respond fully to your request by 12 June 2020.'

In other words, we may have to wait weeks longer whilst they decide how to balance 'commercial interests' of big tech firms against the 'public interest' of transparency about how they're using our data.

This raises a few important questions. What 'commercial interests' could these private companies have for keeping their deals with the NHS hidden from the public? What justification could there be for the "commercial interests" of these companies outweighing our right to know what they're doing with our personal information? How does this fit with the pledge made, back when the datastore was first announced, that "established principles of openness and transparency remain at the core of everything we do"?

Given that the government has now admitted this is a case of "public interest" vs "commercial interests", the fact that large numbers of members of the public have joined the campaign is hugely valuable. If you haven't already, please join the campaign by signing up on the openDemocracy site. government misuse of tech, COVID-19'.

NHS Digital, GPs, and the opt-out choice

On May 12, NHS Digital issued a Data Provision Notice to GPs to enable a new data collection process to begin from 1 July, 2021:

Digitalhealth May 12th 2021 reported:

'NHS Digital announces new primary care data collection service.

NHS Digital has announced it is setting up a new primary care data collection service with the aim of giving planners and researchers faster access to pseudonymised patient information.

For the last ten years NHS Digital has been collecting data from GPs via the General Practice Extraction Service but it is now to be replaced with their new General Practice Data for Planning and Research (GPDPR) service.

On May 12, the organisation issued a Data Provision Notice to GPs to enable the new data collection process to begin from 1 July, 2021.

NHS Digital confirmed it has been legally directed by the secretary of state for health and social care to establish a new strategic system to collect and provide access to near-real-time data from GP practices for planning and research purposes.'

Everything written on NHS Digital about this process is to re-assure the public that this data will be safely used and can only be used to improve research and planning.

e.g.: [digitalhealth](#)

Any data which directly identifies an individual will be pseudonymised and then encrypted before it leaves a GP practice. Data will only be shared with organisations who have a legal basis and meet strict criteria to use the information for local, regional and national planning, policy development, commissioning, public health and research purposes.

However, the devil may be in the detail – e.g. what are 'strict criteria'? The public has not been consulted, and there is almost nothing in the mass media about the contracts with private data harvesting companies. The government has failed to explain its continuing contracts with private data harvesting companies beyond the pandemic - as [Foxglove explains](#).

If you do not *opt-out*, your (anonymised) medical information held by your GP will be automatically entered into the new General Practice Data for Planning and Research (GPDPR) service on July 1st 2021.

Medical practices may claim that this whole issue has been covered on their website. Check their 'privacy' sections. Some may mention GDPR and also opt-out, but without an update on the new Data Provision Notice to GPs to enable the new data collection process to begin from 1 July 2021. 'Opt-out' needs updating and explaining, with clear guidelines as to opt out if patients choose to do so.

It would be helpful if as many KONP members as possible could raise this matter with GPs and any concerns about NHS data deals with private companies.

If you decide to opt-out, you can also opt-in afterwards.

[You can opt-out at the National data opt-out website on NHS Digital](#)

The website makes it hard to do, as it states that you are only withdrawing from research and planning. And it gives lots of reassurance as to how safe the data will be.

'The national data opt-out is a service that allows patients to opt out of their confidential patient information being used for research and planning'.

and on its 'Mythbuster', it claims:

You can opt out at any time - there is no deadline

We only share data to improve health and care

Health and care data helps the NHS respond to emergencies like the coronavirus outbreak

There are lots of protections in place to make sure patient data is used securely and safely

We do not

We do not sell health and care data

We do not share data with marketing and insurance companies

.....

See also Byline times. May 19th 2021, which rightly questions all these statements:

Although it states that “there are lots of protections in place to make sure patient data is used securely and safely”, it is not doing the safest thing – which would be to not let its customers have copies of patients’ data at all.

Like the Office for National Statistics and Genomics England, NHS Digital does now have what is known as a ‘safe setting’ – a secure data processing facility with layers of rules, approvals, protections and monitoring. But the Government has not made it mandatory for patients’ GP data to only be accessed via this highly secure, heavily audited environment. And so, in all likelihood, NHS Digital’s customers will continue to buy copies.

Furthermore, although NHS Digital says you can opt out at any time, it does not explain how you can withdraw your data once it has been collected after July 1st 2021.