

EVIDENCE STATEMENT: FOXGLOVE

Thank you very much for inviting Foxglove to address this Inquiry.

Foxglove was set up by me, Rosa Curling, Cori Crider and Martha Dark during the summer of 2019. We are a non-profit. We use a mixture of investigation, campaigning and litigation to try and make technology fair for everyone. One of the issues which have been working on repeatedly over the last year is NHS data.

I am going to tell you about two legal cases Foxglove and openDemocracy took concerning the NHS Covid19 datastore. And then I would like to end by raising some concerns about the steps being taken now by the Secretary of State in relation to NHS data.

First, a word on NHS Data. The NHS currently holds the largest set of machine-readable health data on the planet. It has an estimated value of £10bn / year. It is being eyed up by all the tech giants across the world.

The pandemic saw the normal rules about data protection and procurement being cast aside. These emergency arrangements shouldn't become the norm without our consent. Corporations like Palantir, Google, Amazon should not be allowed to embed themselves into the NHS via the backdoor.

At Foxglove, we believe if were to happen, the trust that is so crucial to the successful operation of the NHS, will be broken.

The Legal Cases

The Covid19 Datastore was announced in an NHS blog on 28 March 2020. This blog said that several US tech giants Amazon, Microsoft, and Google, plus Faculty and Palantir, were being brought in help create this Covid 19 datastore, a datastore which it said was going to be a "*single source of truth*" about the pandemic.

For the first time, health and social care data from various sources was going to be collated on a national level and held in a single place. Whitehall sources described it as "*unprecedented*". And yet despite that the government released virtually no details about the deals reached with the private corporations or the types of data that was going to be stored in the Datastore.

We were concerned. The tech companies chosen exist to aggregate and monetise data. And press reports suggested that the companies chosen hoped to bed down with the NHS for the long haul.

Serious questions arose:

- (a) Had these companies earned the public trust necessary to have access to all our most sensitive, confidential information?
- (b) And to be working with the NHS?

- (c) Should all our most sensitive data be collated on such a mass scale and held in one place?
- (d) What security was in place to protect it?
- (e) Who would have access to it? On what terms?
- (f) How would the government ensure the Covid19 Datastore came to an end when the pandemic resolved? It is clearly in the companies' interests for their products and services to be used in the long-term, for purposes other than the response to Covid. But that may not be in the interests of the public or the NHS more generally.

Our journey, with openDemocracy, trying to figure out what was happening began.

We started with FOIA requests, both to NHS England and the Department for:

- a. Copies of data sharing agreements with the 5 private companies
- b. Copies of the data protection impact assessment(s) (DPIA) completed regarding these agreements and contracts.

The FOIA response deadlines came and went. And so openDemocracy made clear that if no response was received, it would make an application for judicial review in the High Court seeking an order for the documents to be published without further delay.

We set a deadline of Friday 22 May 2020. By this time, we understood the datastore to have been in operation for approximately two months. We believed it was essential that the details of the data deals were made public so some form of public debate could take place, not least because the public had not been consulted about the creation of the datastore itself.

As openDemocracy was preparing to issue, on 5 June 2020, the contracts were finally released. The initial DPIA came afterwards, having been completed after the fact. On 11 June 2020, we asked for the risk assessment underlying the DPIA. That was provided on 15 June 2020.

It therefore took us almost three months of concerted pressure and legal threats to obtain copies of these contracts. A precedent which does not provide us with much comfort moving forward.

Now, turning to the contracts themselves. The response we received from NHS England showed the terms of the deal reached between NHS England and Faculty were changed after initial demands for transparency were complied with. The company had originally been granted intellectual property rights and allowed to refine its software and profit from its emergency access to NHS data.

Following the request for transparency, an amendment to the contract reversed this.

The contracts did not appear to be temporary. The contracts with Faculty and Palantir referred to an “*overarching project of which the services [in the contract] form a part*” and an “*NHS AI Lab*” which will run for at least 12 months.

So, during the summer of 2020, our letters started again. And by September 2020, we had received a reassurance from NHS England that the “*overarching project*” was the COVID-19 datastore. And that the datastore was about the Covid19 response only.

It was also disclosed to us during this time, that NHS England had in fact signed another, second contract with Palantir, two months previously, in June 2020, for an initial period of 4 months, which was in the process of being extended for a further two months until 11 December 2020.

Fearing another contract was going to be signed, openDemocracy wrote to NHS England again warning that it would issue court proceedings to prevent any long term contract with Palantir unless a proper procurement and consultation process took place beforehand.

On the same day as we sent that letter, NHS England quietly entered into a third contract with Palantir, worth up to £23 million, to run the datastore for a further two years. This contract, as we feared, went beyond the pandemic.

On 4 December 2020, a very short response was received from NHS England, stating that no public consultation was required and the data protection impact assessment completed previously “*will be reviewed and updated from time to time*”. In other words, no DPIA had been completed in relation to this new two year long deal. And this was despite the fact the Datastore was now envisaged to go beyond the pandemic itself.

The third contract refers to several other uses for the Datastore, including the “*EU exit*”, the NHS’s workforce plans, “*related pandemic[s]*”, flu vaccinations and other “*business-as-usual*” activities.

It also allows for other uses to be added over the life of the contract. The datasets were redacted from the version of the contract published and made available to the public.

In February 2021, openDemocracy therefore wrote once making clear that, with this third contract now almost two months old, the NHS’s failure to undertake a new DPIA regarding the proposed non-Covid uses of the Datastore was unlawful and judicial review number two began.

I want to take a minute to explain why a proper DPIA and a consultation process are not merely legal formalities. These processes really matter.

The public has a right to be consulted about how their medical data is used, and with whom it is shared. The secretive approach adopted by NHS England throughout the course of both these cases is extremely worrying and to be frank unacceptable.

The stakes with healthcare data are high. The rewards of proper data use in the public interest are potentially lifesaving, while the risks involved range from minor

embarrassment to a total corruption of trust in the medical profession. That, in turn, would lead to worsened patient outcomes, where patients do not trust their practitioner enough to give them critical information.

When the UK government is engaging in concerted efforts to fight vaccine hesitancy and wider health misinformation the importance of building and retaining trust in public health institutions cannot be overstated. DPIAs are about ensuring accountability. It cannot just be assumed that it is in the interests of the public for something that is believed to have been helpful in an urgent situation to become a business-as-usual way of working.

Private companies know the NHS, with its highly centralised system and unique mass of health data, provide extraordinary opportunities from which to profit. This creates incentives that may well be at odds with the public interest, and/or the best interests of patients. That is why public engagement is critical.

Trust is undermined by a sense that contracts are awarded to parties for reasons other than the public good. Since the beginning of the pandemic, there have been numerous exposes about major public contracts being awarded to politically connected donors, allies, or large firms without competition or public scrutiny.

Above all, the NHS needs the public's trust to operate and be effective: to persuade people to take vaccinations, to share their health information, and to use NHS services with confidence. Meaningful consultation and democratic assent are the only ways to retain the public trust on which our collective public health depends.

A failure to win the public's trust around the centralisation of this data will undermine the government's own public health objectives. Look at the debacle we saw in 2014 regarding care.data.

In March 2021, in response to openDemocracy's court application, NHS England in essence conceded the claim. It agreed that no non-Covid data processing would take place until a data protection assessment and the public consultation process that involves, had been undertaken including via patient juries.

What's Next?

While delighted with this concession, the public engagement process about the datastore is only a small step towards what is needed.

Unless we demand it, Foxglove fears emergency arrangements put in place for Covid are going to become the norm without our consent.

Just last week, on 12 May 2021, NHS Digital issued a Data Provision Notice to all GPs to enable "*new and improved data collection process to begin from 1st July.*"

NHS Digital explains the new arrangement as follows:

"NHS Digital 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...The new General Practice Data for Planning and Research (GPDR) service, a broader general-purpose collection will enable faster access to pseudonymised patient data for planners and researchers.”

There is an opt-out, which is welcome. But that is only effective if people are in fact aware this mass transfer of their health data from their GP practices to NHS Digital is in fact about to happen.

Can it be correct that your patient identifiable data can be shared by your GP with NHS Digital without your consent; simply on the basis of a lack of opt-out. We are not sure how that accords with the requirement for “explicit consent” under data protection laws and intend to consider this question further over the next few days.

Also, we need to know urgently what limitations NHS Digital considers themselves to be subject to once the data is received by them.

This is crucial: are there strict limits on the purposes for which this collated data can be accessed and used, meaningful consent frameworks that permit patients to differentiate between say academic and for-profit access?

If data is to play such a key role in our health service moving forward, surely the NHS needs to build up its technical expertise in-house? Otherwise, it will be at the behest of private corporations.

Is it right the NHS should involve US tech giants, like Google and Amazon, in our national health service at all?

If these huge tech multinationals are to become involved in NHS data management and infrastructure, how do we ensure patient data is protected? And that NHS data remains a public asset, for the public good, rather than exploited for private profit?

If private tech companies are going to partner with the NHS, who is suitable partner?

These partners need to be chosen carefully, if at all.

For example, Palantir. This company was founded and chaired by Peter Thiel, a Silicon Valley billionaire and major donor to Donald Trump.

Is this company an appropriate partner for our health service?

Palantir has built software accused of fuelling racist feedback loops in the hands of the Los Angeles police, and has been criticised by its own staff over its role in the US Immigrations and Customs Enforcement (ICE) agency’s harmful policy of family separations. We question whether such a partner will, in the long term, undermine confidence in the health service amongst the very communities where the government now seeks to shore up trust.

The future of NHS data is being determined now. We can shape its future, but we must demand our say.

Our experience regarding the Covid 19 Datastore tells us, without concerted public pressure, potentially sweeping changes to our health service will be made without our consent and without a democratic mandate. We need to, and can, make sure that does not happen.