medConfidential note on Gavin's Terms of Reference and Evidence to UK Covid19 Inquiry[1]

Gavin is an undisputed clear expert on the data flows of government, and our comments cover areas of his (already long) evidence which show why that isn't enough. At some point, it's necessary to understand the context of the NHS (as Gavin himself acknowledged). While the expertise is not directly akin to asking a divorce lawyer to handle your tax tribunal, there are some specialties that were not covered and it is unclear if any other experts will have picked up these issues.

The CMO is a Permanent Secretary in the DHSC

The Covid Inquiry evidence (and hearings so far) insufficiently addresses[2] the fact that the Chief Medical Office is also a Permanent Secretary in DHSC. It's understandable that external expertise missed that fact, because it was insufficiently recognised by DHSC and Government during the pandemic.

That the Chief Medical Officer is also a Permanent Secretary at the Department of Health, means they are not only in a position to instruct the NHS about actions, but does (or, at least, should) have equal authority (as perm sec) to instruct the "rest of government" too, where appropriate. This can be addressed.[3]

The powers of the CMO to the medical institutions wearing their health hat(s) should be mirrored by equivalent powers to civil service institutions wearing their 'permsec hat', and CMO authority can bridge perceived divides – perhaps CMO should also be a permsec in CO/CCS. The placing of some services on "gov.uk" vs "NHS.uk" sometimes seemed more down to delivery capacity than anything else, but it also appears never to have mattered in practice.

It is reasonable to expect that government departments help each other out with burden sharing at times of crisis.

Health data

Your medical record is created and stored to provide you care.

Your GP record is collected to treat you in the practice, so the next time you come in, there can be continuity of care and the doctor you see at your next appointment can see the important information from the previous visits. Those who wish to use that data for other purposes, however noble they may be, complain that they must use the data that exists which is not quite the data that they would *like* to exist.

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[1] Formally INQ 000260629 at https://covid19.public-inquiry.uk/documents/inq000260629-expert-report-by-gavin-freeguard-for-the-uk-covid-19-public-inquiry-titled-module-2-political-and-administrative-decision-making-in-relation-to-the-covid-19-pandemic-dated-26-09-202/, C19 evidence is published as scans, here's an OCRed PDF https://medconfidential.org/wp-content/uploads/2023/10/INQ000260629-gavin-freeguard-inquiry-evidence-OCRed.pdf

[2] It was most covered in the discussion about "independent SAGE".

[3] https://medconfidential.org/wp-content/uploads/2023/12/cmo-dea-alternatives.pdf

Similarly, for hospital data, the dataset used the majority of the time is the Hospital Episode Statistics which covers all hospitals, and has less detail on certain topics than some analysts expect. Of course, there's always less detail than analysts would like – no data analyst is satisfied with the data available, there are always more questions to which the answer is "more data".

There is always a need for more data, more contingency, more context, more resources; even if every contingency of every exercise had been fully implemented, covid would still have posed new unforeseen challenges: Technology evolves, things move on. One department will always complain that another department doesn't collect the data it now wants with the accuracy it now wants. Crises mean needs change.

What did work in 2020, and will work again next time, is committed public servants working to address emerging challenges as they evolve.

NHS England justified the creation of the Covid-19 Data Store and Palantir platform, both stood up to respond to the challenges of covid. Both could have been setup in February 2020, or late January, but in any event, were responsive to events.

Those tools do not need to be in constant service. If "wartime" returns, the best available tools should, once again, be deployed to fight it. As Dame Kate Bingham describes, the goal of wartime is to get back to peacetime.

As Palantir demonstrated in March 2020, these tools can be deployed rapidly, if needed, in a future crisis.

[But FDP is outside of the Inquiry's scope.]

In the face of an imminent crisis, medics will do what is necessary – the sacrifices of NHS staff seem indescribable here, but describable by the Inquiry.

If asked in January 2020 how long it would take to reconfigure the NHS in London, the right answer would have been "about a decade". In March 2020 the right answer was "a weekend". Medics saw the value of the RECOVERY trial, and even under the hardest of circumstances at the height of the pandemic, did the extra work to make the trial successful, with world improving consequences. An example from peacetime is the Deepmind / Moorfields project[4] and the consequential discoveries.[5]

The 'what' and 'why' of additional data collections need to be clear, and real, to those doing the work. Too many NHS data projects are structured akin to the joke that goes something like:

1. You do some work
2. ???
3. I get the benefit

(Government departments often take that 3 step approach and wonder why their projects fail.)

Covid created a unity of purpose, whether it was the NHS frontline, schoolchildren not physically going to school, or teenagers not going to parties, everyone knew roughly what they were not doing, and why.

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[4] https://www.moorfields.nhs.uk/landing-page/deepmind-health-research-partnership
[5] e.g. https://www.moorfields.nhs.uk/news/eye-scans-detect-signs-parkinson-s-disease-seven-years-diagnosis and many others

COPI

The COPI *regulations*[6] are long standing regulations used for multiple purposes every day across the health service (both NHS and public health). Regulation 2 covers cancer data, Regulation 3 is "Communicable diseases and risks to public health", and Regulation 5 covers everything else. They should be revisited after 21 years, as should the Public Health Act 1984, but they largely served sufficient for the purpose.

The COPI *Notices* are simply notices that the existing regulations have temporary broader effect due to, in this case, a communicable disease. No one is *obliged* to do anything, but as part of everyone responding to the pandemic, everyone was expected to offer information to others who were also doing their bit.

At this point we should point out that if someone were to misuse the data for non-COVID purposes then it is outside the COPI notice and hence would need another legal basis for handling the data, and probably don't have it.

If someone were to process data that the original applicant didn't agree with, they wouldn't have to provide it. But, in an emergent pandemic situation, everyone was expected to be behaving with integrity in the face of a national emergency. The equivalent is how the DHSC procurement people dealt with PPE suppliers – some checks were done, but everyone was expected to be behaving with integrity in the face of a national emergency. (Oops).

In short, the COPI notices were simply saying that the long standing COPI regulations were in effect. No one had to agree to do anything they didn't want to do.[7]

(The cultural origin of the GPDPR fiasco in 2021 and the FDP can be found discussed from paragraph 88 of Simon Bolton's Inquiry written evidence – because a process worked for one narrow purpose, under exceptional circumstances in an emergency, it was assumed that it would apply for all purposes in normal times. NHS England could not have been more wrong. The module 2 closing submissions from UKSA and the Scottish Government also replicate this mistake – advocating that a pool of data should be created in case it is needed – because while it will be needed when there is a future pandemic, it will be reused for many other purposes in the interim, undermining confidence in the systems needed in that future emergency for the short term gain, squandering public confidence exactly as GPDPR did.[8]

[6] https://www.legislation.gov.uk/uksi/2002/1438/made

[7] The one place that agreement was not given was that GDPPR data should not flow into Palantir without clear explicit approval. In one case, a derivation of one field did flow, even if in that case NHS England didn't quite follow the process for clear and explicit approval.

[8] At the time of writing, the impact of and on FDP is as yet undetermined, and the rest of Government continues to take controversial approaches, as we cover in our evidence to Parliament: https://committees.parliament.uk/writtenevidence/125418/pdf/

NCDR

Mention of the National Clinical Data Repository[9] is missing from the expert evidence, probably because NHS England and DHSC never really talk about it.

If the pandemic had hit 10 years earlier, what would have been built was NCDR; or, in reverse, when the pandemic hit, NCDR was reimagined and rebuilt as the Covid-19 Data Repository with the Palantir adjunct.

NHS England acted rationally – NCDR has had many problems[10] – but it is impossible to understand the approaches to NHS data without knowing that it existed, what it *did*, what it *didn't* do, and what it *couldn't* do.

We concur with NHS England's assessment that NCDR is an artefact of the technology of the time it was built, and in need of wholescale reform and replacement, and do not disagree with NHSE's doing so given the emergent and unclear nature of the pandemic.

NCDR was designed to suck in as much data as it could, and be as opaque as possible with what it was used for. These were design decisions of NHS England, decisions that continued under the pandemic data store and palantir.

As NHS England is today, data projects in NHS England could go to the NHS England DARS process for data, which has transparency and accountability measures built in, as that process also works for external projects. Separately, internal data projects at NHS England could, and can, talk only to NCDR, where they can use data without transparency, possibly[11] without anyone outside the organisation having any idea that the project happened, and possibly without most of those *inside* the organisation knowing it happened either.

The parallels with the lack of transparency about the Covid 19 data store are self-evident.

No transparency, no accountability, and the expectations of secrecy, are continuing policy decisions of NHS England, policy decisions that predated and persisted into the Covid19 data store, and seem to persist forwards into the Federated Data Platform.

Had NCDR had half a billion pounds thrown at it, it too could have been updated to do what Palantir is now expected to do; although if you throw half a billion pounds at almost anything, you can make it do what Palantir is now expected to do.[12] Palantir is not magic, it's just expensive, and being expensive, it keeps number 10 happy.

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[9] https://ncdr.england.nhs.uk/

[10] For example, I would have linked to the very informative video that NCDR used to have on their front page about what they do, a video that disappeared shortly after I wondered in a meeting "Is that real data?"

[11] We don't know what the arrangements are. From what we know of the covid data store, one part of NHS England can ask the data and analytics team for anything they say they need.

[12] Since NHS England has already used Excel instead of Palantir, £500m, or even the £150m being spent to start to make Palantir more useful, would make quite a prize pot at the Excel Olympics https://fmworldcup.com/excel-esports/microsoft-excel-world-championship/