



coordinator@medconfidential.org

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Dear Sir Jim,

The only difference between NHS England's largely-heretofore-uncontroversial GPPR dataset and the trainwreck of the cancelled GPPR (2021) programme is the "pandemic only" promise – a promise NHSE has apparently been Directed to decisively break.

medConfidential understands¹ NHS England has received but has not yet published a Direction from the Secretary of State to break the "pandemic only" promise covering uses of the GP Data for Pandemic Planning and Research data collection, with data controllers being told they will not / do not need to inform patients that anything has even changed – let alone that the "pandemic only" promise is being torn up.

As a consequence, GP practices, etc. will still be telling their patients the collected data is for "pandemic only" uses, which will not be true and will be a *deliberate* deception Directed on behalf of the Secretary of State.² **In effect, DHSC has chosen to Direct NHS England to actively lie to patients; it only remains to be seen what NHSE will do.**

We understand that Biobank had arranged for media coverage celebrating that UK Biobank, along with Our Future Health Ltd and Genomics England,³ will benefit from this Direction. It is deeply concerning that several of NHS England's data customers expected to be crowing in the press that NHSE has been Directed to lie to patients, solely on the basis that it would save DH/E some paperwork and some time.

Other concerns include the fact that NHS England appears to have accepted a Direction without Board approval and without considering it sufficiently (again); that there remain unaddressed broad and systemic flaws in both the transparency and governance of the processes at Biobank as they [wave away festering controversies](#) about their practices in the existing DPN, and the culture they share with HDRUK (who themselves have previously broken "pandemic only" promises because overlapping HDR / Biobank leaders decided they could do what they chose⁴); and that the approach taken in the Direction breaks the "no surprises" principle of the NDG. This list is likely to grow when we see the Direction.

We understand via footnote 1 that the Direction has been issued and signed without the informed consent of the Profession to whom any consequent Notice will apply.

¹ From Biobank's botched comms operation. All mistakes are theirs, in more ways than one.

² medConfidential has a long-standing concern that Directions are issued with an image of a scrawl as a "signature", but no name – making it unclear who actually issued a Direction from DH: [one example](#)

³ We have no reason to believe OFH/GeL knew the extent of Biobank's activities, in much the same way Biobank cannot know the activities of users they've exempted from using their supposed "SDE".

⁴ Despite the opinion of NHS England's Advisory Group for Data on 12th June, NHSE's 'scrutiny' process seems to have gone something like this:

NHSE to HDR: "We gave you this data only for Covid purposes. You did keep to that, right?"

HDR: "Erm... sure!?"

NHSE: "OK then. Case closed. We definitely won't look at the 100+ other projects."

None of the problems of which we have warned your staff over recent years have been resolved, and Biobank once again seems to have assumed that no one would notice the consequences. (Even though they seem to have tried to place a story in the FT!)

If the Direction *has* been signed and received but is not yet in force, it should be published immediately – as received, pending acceptance – with any implementation paused until a decision on its acceptance is taken at the next *public* NHS England Board meeting (which alone formally accepts Directions) and any other engagement processes have concluded.

The Federated Data Platform requires trust and patient confidence. Whether it runs on NHS England's "data platform" or not, the Single Patient Record will require trust and confidence. The [proposed HDRS](#) will depend on trust and confidence, yet it seems that the decision of the DH/NHSE Joint Data Policy Unit is that patients and data controllers can be lied to, misled, or simply ignored in the interests of the Secretary of State. It's unclear if this is tenable in even the short term – let alone in the context of DH/E's desire for "opt-out reform" to further widen the loopholes in opt-out policy. Is this the type of process that doctors, patients, and the public should expect from the SPR and HDRS?

Why should patients believe political promises made about protecting their medical notes if guarantees given by the NHS in a global crisis are shown to be *this* meaningless? The trust and confidence that patients have in the NHS should not be squandered by this Secretary of State, or any other.

NHS England knows their data uses *can* meet medConfidential's three tests – i.e. that they are consensual, safe, and transparent – although it often chooses not to satisfy those tests. We continue to support the OpenSAFELY platform which can and does satisfy those tests, and where deceptions such as those in this letter cannot occur in secret. It is clear that NHS England remains the 'blocker' on DPN acceptance in failing to answer simple questions that practices asked almost immediately after the OpenSAFELY DPN was issued; responses that practices continue to wait for, over 3 months later.

Yours sincerely,



Phil Booth, medConfidential



Sam Smith, medConfidential

P.S. Jim, your technology suppliers will often tell you that the way to get more efficiency is to give more money to your technology suppliers; DH/E and the Office of Life Sciences call this work "business models for data". [Here is an alternative approach](#) (with several years of accumulated evidence / case studies) that could take ever less NHS budget, not ever more.