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15 April 2025

Dear Secretary of State,

Welcome to Government. We only write to you when it matters. medConfidential is an independent non-partisan organisation campaigning for confidentiality and consent in health and social care, which seeks to ensure that every flow of data into, across and out of the NHS and care system is *consensual, safe, and transparent*. medConfidential works with patients and medics, service users and care professionals; draws advice from a network of experts in the fields of health informatics, computer security, law/ethics and privacy; and believes there need be no conflict between good research, good ethics and good medical care.

The 2022 Goldacre Review described "no new emergency" for data, and steps forward like OpenSAFELY are undermined by steps backwards that undermine public trust.

GP Data – OpenSAFELY

OpenSAFELY has worked until now because all those involved recognised all perspectives have value and progress is possible when no one is unheard; we hope this will continue.

medConfidential supports OpenSAFELY because it respects patient dissent and has inherent transparency. However, NHS England's usual communications about patient data only cover the NHS National Data Opt Out, reflecting NHS England's long term deliberate omission of the GP Data Opt Out when telling patients what choices they have about their data.[1] Past policy can be incoherent in the context of a new service, and so NHS England has so far refused to permit the NDOO to apply within OpenSAFELY – ie every project which has chosen to respect NDOO (to maintain public confidence in their work) would be prohibited from using the service at all. Both MHRA's CPRD and the "regional SDEs" respect the NDOO which is the comparator that patients will see, but NHSE see something else. NHSE's inability to update a policy they're implementing blindly is partially why you're abolishing NHSE, an abolition which creates an opportunity to do better what all patients want: use data in ways they wish, and not if they don't. As you are 'looking for growth', respecting patient choices is the low conflict way to get growth.

GP Data – UK Biobank

Biobank and their allies are begging you to tear up the promises made by your predecessor about the pandemic GP dataset – that GDPPR would only be used for the pandemic. It would be futile for the immediate goal, harmful to both research more widely, and undermine your priorities as Secretary of State, yet Biobank are bragging to the press that they not only expect you to do so, but are giving press briefings as if you already have done so.

Promises made by the Secretary of State can only be broken by the Secretary of State.

[1] DH/E are currently conducting a series of focus groups pushing attendees towards both dropping the GP Data Opt Out and castrating the NDOO to not apply to the work of DH/E.

Many organisations will claim they run a Trusted Research Environment (because *they* trust it, and they say they do research), but to actually be trustworthy requires independent decision making to ensure "safe people" are doing "safe projects" with a trustworthy process around "safe outputs". It is unclear how Biobank's eugenicists and sanctioned users can satisfy those "five safes", but they may pass the tests HDR have designed to allow unsafe uses (it appears HDRUK have been handed the "HDR Service", which will waste more time and money).

Biobank have painted themselves into a corner on GP data, a corner they are begging you to get them out of. For as long as Biobank refuses to answer simple and reasonable questions (in footnote 1) about their processes and actions it is impossible anyone to have substantive confidence in the answers. There is no dispute that Biobank has not answered our questions – Biobank merely insists they don't have to answer any of them. Questions covering what Biobank have done with the GP data they received on an "unclear" legal basis prior to 2017 which, according to Biobank's documentation, is data they still make available. We understand NHS England's early 2025 audit will cover *some* questions on what data Biobank has sent where, but we understand it does not cover all of them. It is only a start.

If you decide it is convenient to reuse pandemic-only data for non-pandemic purposes, how can HMG make believable "pandemic only" promises during the next pandemic? Breaking the "pandemic only" promise once means it can be broken again – all *your* future promises are called into question because clearly you don't expect them to be kept. We hear Biobank argues that any opt outs that occur as a result of your reuse decision are not important, which may be true for Biobank but it is unclear if it is more widely shared by the research community. What you do with GP data for Biobank is the best signal of your intent for the Central Care Record data: do you expect your successors to keep promises you make?

GP Data for direct care towards a Single Central Care Record

Any implementation of a single central health and care record requires patients and the public to believe that promises made will then be kept. The best evidence patients and the public have about the Single Care Record tomorrow is to look at what DHSC and NHS England say they will do today for the Federated Data Platform, and examine whether they then actually do it – unfortunately, they don't.

NHS England regularly does not do what it says it will do – actions fail to deliver even the most watered down assurances they try to give. NHS England has only published one overarching Data Protection Impact Assessment for the FDP, despite repeated assurances that NHSE would publish all of the DPIAs underneath it (per product, per use case, etc). A "Privacy Notice" tells the public they can "Access contact details for data protection officers in the NHS trusts using this product" – you only need click the link to see that the thing E tells people they can "access" is simply not there. Similarly, NHS England remains publicly very proud of the "FDP engagement portal" which has had zero visible updates since launch, it encourages people to ask questions but provides no answers, it encourages people to "get involved" but does not then do anything to involve those who sign up. Examples abound, and this culture is part of the reason you're abolishing NHS England, an abolition will make it easier for you to deliver benefits to patients, but which has consequences on accountability that need to be addressed. Patients and the front line have spent a decade on the exciting end of a triple pendulum, without predictability or hope that the system will get better. Abolishing NHSE will make a complex system tractable, hopefully systematic improvements will follow.

The best way to build confidence in your vision of tomorrow is to do what is possible today.

If patients see when/where their record is accessed today, it is entirely reasonable for them to expect the same will happen tomorrow. The difference is minimal between access to all GP written medical notes through a central care record of tomorrow, and to those same notes through GP Connect today. If patients are to have confidence that they will know where their record has been accessed tomorrow, they should be able to know where/when their record has been accessed today, to the extent possible by current systems. NHS England runs the Summary Care Record system, it owns the audit trails for that system, and it runs the NHS App – NHS England can show Summary Care Record audit trails to patients if it chose to; it refuses. Around half of GPs can already use the TPP Online service to show GPConnect audit trails to patients, but NHS England does not show it in the app (and has not asked EMIS to do similar). Abuses of systems are routine – it is so common for doctors to look up the medical history of women they go on dates with, that some will tell their victims they did it because they expect no consequences; the legacy you have inherited means their expectations are accurate. Both as Secretary of State and as data controller for a central care record, whether patients are protected will become your decision.

A patient visible audit trail will help the programme deliver your goals .It has been reported that you are proposing that every diagnosis should be accessible from anywhere the NHS logo is seen, where they can be misused without any patient having any clue they were accessed, or go largely *unused* without that too being visible to patients (an invisible problem today). If you want your grand vision to become reality, patients need the evidence to ask why their records weren't checked at all – a situation far more common than misuse.

Transparency and accountability to patients where/when their records are accessed from outside their care setting is a choice to make, and a choice to maintain, and the legacy of NHS England will again choose the quiet life of coverup unless it is clear that you are on the side of the patients not on the side of abusers. The choice is still yours to make, and you can choose wisely. OpenSAFELY shows that data use with public confidence is possible; the lack of transparent integrity of the Federated Data Platform shows how it doesn't always happen.

As we have said to NHS England over the last decade of previous data projects, a central care record can be done in a manner that is consensual, safe, transparent. We hope that it will be, but we have seen no reason to believe the new Department of Health in England will choose to produce something safe for everyone. Previous attempts were unsafe and then collapsed, and have seen no evidence that DH/E has learnt anything from those experiences. As in all other areas of your role, your predecessors have left a legacy.

Just as your decisions will be used to implement your policy, they will also be used to implement the policy of Governments that come after yours – which may be barriers on access to healthcare or medication on the grounds it relates to gender, ADHD, or PrEP.

As OpenSAFELY has (hopefully) shown, none of these issues are unsolvable. If your new Department of Health in England wishes to follow a better path, there are available next steps on GP data for Biobank and on the Single Central Care Record which create no conflict between good research, good ethics and good medical care (which we're happy to share when we work out which of your staff will be around long enough to implement anything).

Yours sincerely,

Phil Booth, medConfidential

Sam Smith, medConfidential

cc AMRC, BMA, Lord Patrick Vallance.