

Moving Parts: Current and imminent Government plans for your medical records

[This is long and detailed – shorter versions of parts of it will appear in due course. [You can join our free substack to get an email whenever we post something](#)]

The current Government is infamous for making decisions that offer short term benefits for one group at the expense of the many – here's how Mr Mandelson's political protégé has decided to give away your medical notes to those who write long briefing papers assuming that patient views don't have consequences.

There are currently many overlapping, related, and similar moving parts in Government where Mr Streeting wants to be able to decide how to use your medical records in whichever way they wish.

1. Both government and the public endure, while Ministers are temporary. All Ministers must be honest about revoking promises previously made to the public, even if it was a different Minister of the Crown who made them. When Secretaries of State decide what they will and won't do, they must be completely open with everyone about the effects. Mr Streeting is breaking unambiguous promises his predecessor(s) made for very good reasons, which he's decided he doesn't have to care about – he quite clearly doesn't want to be in this job by the end of this Parliament, and he may not even be there by the end of the ~~week~~ summer.

Impacts of non-pandemic re-uses of pandemic-only GP data

2. Mr Streeting has chosen to re-use “pandemic only” data for new purposes because it fits with his plans, and because he himself didn't make the promise that it wouldn't be used in this way. Once implemented, the precedent of such re-use cannot be undone – and re-use can be repeated for whatever someone else lobbies for tomorrow. (A process that has already begun.)
 - a. In 2020 GP medical records were copied into a “pandemic only” dataset – the legitimate fear with any such programme being that once the data is copied for a single purpose it will get re-used; assurances given in a national / global emergency that this would never happen were believed. Even within the breach of trust, and while the [GPES Data for Consented Research Directions 2026](#) appear to be narrow, the enclosed specification is much wider:
 - i. Compare [paragraph 4](#) of the Direction, on “Purpose”...
 - ii. with [section 3](#) of the Specification, on “Information in Scope of the Direction”
 - b. It is vital that promises made in the **next** pandemic [can be believed](#).
 - c. Breaking promises has wider effects too. As stated in the [Goldacre Review](#), “*The NHS must maintain trust and active enthusiasm from patients and the public*”, which is true for all data uses. Spurious claims that data has been safely ‘anonymised’ for reuse fall apart for all the reasons detailed in Chapter 4 of the Review, from “Privacy risks in detailed health data”...

Your GP has been told there is nothing they can do

3. While GPs have been told they need to take “no action”, they *must* take action and update their patient-facing information – otherwise they will be held responsible for DH having broken their promises, which GPs passed on in good faith. “No action” implies that some GPs will indeed take no action, and NHS England decided not to even ask GPs to confirm that they have (and are) correctly informing their patients.
 - a. [We have some wording for GP practices here.](#)

Who is responsible?

4. The main advocates for this breach of trust are UK Biobank – who want GP data and don’t care how they get it, because they believe the consequences will fall on others.
 - a. Biobank received GP data covering 45% of their patient volunteers; they continue to sell that data, and still have nothing to show for it – where are the academic papers? Where are the discoveries?
 - b. In 2024, Biobank stopped publishing details of new projects, and didn’t start again for a calendar year. They kept *approving* new projects and kept *starting* new projects, including from sanctioned entities – they just didn’t *disclose them publicly*. The only way that Biobank allows you to see what Biobank changed last month is to look at the individual webpages of each of the 6700+ projects and check what's changed ([which we do](#)). These are just a sample:
 - i. <https://medconfidential.org/2024/biobank/> (updated several times since it was first published in 2024)
 - ii. Guardian investigation on access by China: <https://www.theguardian.com/technology/2025/apr/15/revealed-chinese-researchers-access-half-a-million-uk-gp-records>
 - iii. Eugenicists: <https://investigations.hopenothate.org.uk/biobank-access/> and <https://investigations.hopenothate.org.uk/race-science-inc/>
 - iv. Insurers (albeit with a U-turn ~15 months later, see [page 19](#)): <https://www.theguardian.com/technology/2023/nov/12/private-uk-health-data-donated-medical-research-shared-insurance-companies>
 - v. Shell companies registered in the office that (also) serve as fronts for QAnon conspiracies: <https://www.wired.com/story/epik-domain-registrar-new-owner/>
 - vi. When people signed up to Biobank, did they think they would be [sending their DNA and medical history to an undergraduate course in China](#)?
 - vii. We still have a [long list of questions for Biobank which remain unanswered](#).
 - c. Biobank and OFH are “consented” cohorts – the people involved supposedly gave consent for what Biobank does. And Biobank argues that NHS England has signed off on everything Biobank does...
 - d. Time will tell.

Who else is complicit?

5. UK Biobank and HDRUK share a culture:

- a. One rogue HDRUK purportedly “Covid” project decided that research which covered “before and after Covid-19” meant they could do any project they wished. When they got caught, they doubled down. The NHS independent advisors on data didn’t let the majority of exemplar projects through ([item 5.1](#)) and required a rewrite – but even then they knew HDRUK was probably lying to them about governance. The single project that got caught [breaching the rules](#) remains suspended on NHS England servers.
- b. In response HDRUK has decided they do not want NHS England to review their projects and are moving their data environment to Wales, as HDRUK in London thinks it can bully Wales into covering up their actions – cf. [Item 4.1 of these minutes](#).
- c. HDRUK is trying to grab data controllership of the data at the same time as the new Health Data Research Service (HDRS) is trying to sell access to the same data. England risks having two organisations racing to the bottom on how data can be sold off...
- d. Even with all this cheating, HDRUK has nothing to show for it beyond more demands for more data. What has HDRUK actually *delivered*? Where did this £25m go, and what is the public benefit from those funds? Perhaps as significantly, what was the opportunity cost?

6. The recent HDRUK / Sudlow Review advocated for greater reuse of data, and that data from ‘the rest of government’ be expanded to include health data:

This would expose it to the same “Digital Economy Act” powers that HMRC used to immediately stop families’ Child Benefit to encourage people to get in touch with them (because they couldn’t feed their kids). The data grab culture that started with your health records wants everything else any part of government knows about you, and then [data from private companies](#) you engage with too.

- a. At the launch of the [HDR/Sudlow Review](#), the lead author who was previously responsible for the UK Biobank access processes then proclaimed Biobank should be “[used as widely as possible](#)” as it had “[one of the best systems](#)” for giving data out in “[days](#)”. (Sudlow was then appointed to the [Advisory Board for the National Data Library](#) which calls into question the entire [culture](#) around the NDJ). The application form at the time was just [three and a half pages](#) long (replaced by a [one page](#) form that hides most questions).
- b. This was *after* it had been disclosed Biobank sold their data to [eugenicists](#); the former-UK Biobank senior staff learned nothing because it’s in their interests to learn nothing. (The same senior staff responsible for the [cheating of other Covid-19 data](#)...)

- c. Biobank claims to some people that they enabled their “secure environment” with no notice to their customers / users, which doesn’t match with Biobank emailing their users about it – so the users could download everything – nor with them doing press interviews to signal the change was coming, thereby fundamentally undermining the point of a safe environment.
- d. UK Biobank and those with whom they share a culture see patient safeguards as something to evade. These organisations write self-interested briefings to Wes Streeting, and he doesn’t bother to consider whether the promises made are credible and outmatch the risk. What could go wrong?

What can patients do?

- 7. [Your GP Data Opt Out and your National Data Opt Out currently work](#). But while you can [use them today](#), we can’t make that promise for tomorrow – because Wes Streeting is acting on the same culture as his political mentor Mr Mandelson’s Epstein culture with regard to your medical rights.
 - a. How does all (or any) of this, and Mr Streeting’s Direction, fit with “[building public trust and transparency at the forefront of our ambitions to harness the power of data for the future of health and care](#)” – will Events show those reassurances to be fiction?
 - b. [The current impact of opt outs is low](#). The GP Data Opt Out rate is currently at around 2%, and the National Data Opt Out rate is 5%. But [when independent polling asks people](#) whether they *think* they’ve opted out, the number is closer to 20% – and up to 50% of people say they would opt out when you talk to them about how data is actually being used. (All of these figures are from before this next mess happened....)
 - c. Despite this all being known, UK Biobank and its friends are considering running an “awareness” campaign to have people *undo* their opt outs so Biobank can sell their data to their customers.

What comes next?

- 8. NHS England is being swallowed into the Department of Health, so the politician acting as Secretary of State can give clear and immediate instructions about how the NHS is run, and how your medical notes are used. Mr Streeting’s first use on taking office was to deliver on ideological commitments about [restricting care](#) to groups he felt shouldn’t have it.
- 9. DH may choose to collectively punish everyone – especially groups who have opted out “too much” – by taking away everyone’s ability to opt out, so that the government can use patient data for its own goals. This is *precisely why* groups which don’t trust the system have good reason not to trust the system. Whether it’s to do with what’s in your record or closing your local hospital, the Government wants to use your medical notes however it chooses, without you having a choice.

10. Mr Streeting has also decided you must have what he calls a “[Single Patient Record](#)” in which he will control all of your medical notes – the details from every appointment you have across the NHS. The SPR is, in effect, a patient-facing and doctor-facing rebrand of the existing Federated Data Platform which has become an analogy for Palantir. When the NHS launches the “NHS AI platform”, it will be the [Palantir AI Platform](#) behind a facade of NHS blue.
- a. Mr Streeting’s [10 year plan proposes](#) that microphones record and AIs transcribe every word you and your doctor share (supposedly in confidence) in one of his Neighbourhood Health Centres; that being the case, the transcriptions (and eventually the recordings) will need to be kept in case the lawyers need to blame a patient for something – all of which will make their way into the Single Patient Record, brokered by Palantir.
 - b. Mr Streeting was [keen to highlight](#) the [AI monitoring](#) of maternity and babies in intensive care, which will require all of their data being made available to the AI. Recognising the controversy, that detail was omitted from the 10 year plan but [included in the press release made a few days before](#).
 - c. Mr Streeting’s Plan also expects that every baby born in the NHS will have their entire genome sequenced and stored in their Single Patient Record. Successive UK Governments have kept the blood spots of babies born [since around 2011](#), and the only reason to retain them is to be able to sequence every baby born since 2011 into Palantir’s databases (and potentially police databases during a moral panic).
11. Shortcuts taken on data flows mean that consented cohorts are not getting all the data they should – specifically consented patients with an NDOO / GPDOO are missing – while dubious organisations are able to gain more data than they should on those who *have* opted out. The flows should be simple, directly from NHSE, without unconsented intermediaries who can make their own decisions away from public accountability and transparency (e.g. HDRUK in [item 4.1](#)):
- Those who have given specific consent should have data provided in line with that consent
 - Those who have an NDOO or GPDOO should have no data provided unless they have given overriding consent
- The morass of indirection and deception, the hallmarks of HDRUK (who while they share a culture with Biobank, do not share a consent model with Biobank) will make things worse. DH are playing temporary politics, not solving problems sustainably.
12. Every step in this sequence builds on steps before. Breaking pandemic promises once means they can break them (and others) again. And do so again and again. Sequencing a person’s genome *once* and putting it into Palantir means they’ll do that *for everyone eventually*. The future of the NHS is whatever Mr Streeting’s advisers want it to be, and some of those advisers are thinking about their next job in a very different way than how patients think about their next interaction with the NHS. [Palantir’s advertising tagline is “Making Americans Irreplaceable” to the NHS](#).
13. DH/E claims to want to hear from ‘experts by experience’ – those whose lived experience of the NHS can help the future. The Single Patient Record, accessible across DH/E prompted

[a warning for experts by experience](#) as DH/E will be data controller for their entire record held in Palantir's Single Patient Record. Meetings with the Secretary of State will be meetings with the data controller for the data that may not be entirely accurate. Patients and those in the public eye at high risk with an "S-flag" on their record will have it ignored to [take a copy of those records](#), and he'll sell those records [in ways which can identify you](#). Some will assume that 'going private', away from the NHS, may save them from this – but the ability to privately prescribe without the Government being notified will incrementally go away too, the same way private treatment is politically curtailed for other groups. Or, as Mr Streeting's ally and funder of the Blair Institute put it, "[constant surveillance and you'll be on your best behaviour](#)".

Returning to what you can do about this now, given that Wes Streeting has clearly decided to take your medical notes and use them how he chooses. The future of your NHS medical notes could be consensual, safe, and transparent to you; but it could also be as abusive, reckless, and secretive as the protege of Peter Mandelson can envisage.

[Opt outs still work today \(here's how\)](#), and watering down decisions millions have already acted upon will be hard – but he *will* try because, as should now be abundantly clear, Streeting has a very Mandelson view of patients. Mr Streeting may make you opt out again – he can do that, and he's planning to change the law anyway – but if you want to minimise the impact on you, do what you choose now and let the lawyers argue about it later.

No reuse will take place until around the last week of March 2026, so there's no urgent need to panic. If you believe you have done a National Data Opt Out, it would certainly be [worth checking](#) (you are told what your current setting is before you decide if you want to change it).

We and others are doing our best to dissuade DH and the Secretary of State from this course of action, and the fact that Biobank weren't entirely honest with Wes would make a politician who valued public opinion think twice, but Mr Streeting is the mentee of Peter Mandelson.

Take some time to digest all this, and make your own decision; it is as straightforward to opt back in as it is to opt out, if you later change your mind.

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