The new Health Data Research Service could be good

Where does the NHS spend money today, the same way the UK spent money on fossil fuels in the 1990s? What are the equivalents of solar panels and wind?

Everyone wants their own pet project to be prioritised by HDRS – many of whom are going to be disappointed.

Each HDRS annual report should include a list of challenges to the NHS, with a reference to the short list of strategic respondents whose alignment (or otherwise) should be evident to those challenges. Cure Parkinson's is implementing an NHS playbook (and Prostate Cancer UK is gearing up to copy them). Those still trying to figure it out can read "Breath From Salt". Some of that will involve picking champions (or noting the lack of obvious leadership), but also ensuring previous leaders continue to act in the interests of patients – all of the choices around treatment pricing for cystic fibrosis have been rational, at immense financial cost.

In the history of everything that works there was a time that it didn't

HDRS needs to stimulate an environment for better patient outcomes. Big bets have clearly been made on AI discovery, on mRNA, and a few other technologies. Progress on Dog Cancer suggests this was a good choice

Human cancer blood tests ('grail') are starting to work for some cancers; mRNA vaccines for cancer are starting to work for some cancers; the HPV vaccine eliminates cervical cancer in women who've had it, or in men it stops them infecting their partners who haven't. mRNA may cure some cancers in your cat (or dog, note: *may*), but if it might, it's untenable that your vet may be able to save your cat and the NHS has no pathway to offer the same to your grandma.

UK Biobank receives hundreds of thousands in fees from 'longevity' companies; Our Future Health wants to replace your GP with a chatbot and their pharmacist. That's the 'visionary' thinking going into DH. Maybe they'll even eventually be right, or like alchemists of old, they'll keep trying to find a serum for immortality until they die trying.

We know the prize, which can be achieved by research projects that are consensual, safe, and transparent, or fail because they lost public confidence after not being one of those things

Consensual, Safe, Transparent?

The new Health Data Research Service could be good; it could be consensual, safe, and transparent. But there's reasonable grounds for concern that it will not be.

HDRS should decide that it won't process data on any patient who has opted out of research – but as it stands HDRS will be told this is a DH decision and they must process any data DH decides. So much for HDRS autonomy if that's how it goes.

Consensual

The first critical decision point for HDRS is whether people who have opted out of data being used for "research and planning" will have their data be used by HDRS anyway. There need be no conflict between good research, good ethics and good medical care – DH/E can make the decision to respect patient wishes or they can decide whether to ignore them.

If the wishes of patients who have opted out of their personal data being used in research are overridden by politicians and HDRS, if they have their data used in research against their wishes, then that will likely go as well as some of the pre-u-turn decisions of this government. HDRS have the opportunity to get it right from day one, but we see little sign of DH/E allowing them to do that – the job ad for the Chair/CEO of HDRS said that decisions will be "directly accountable to Ministers".

Safe

The extent to which HDRS delivers on the goals, delivers for patients, or does neither of those things depends on decisions not yet officially made. The *ongoing* Biobank mess is a particularly brutal way for HDRS to realise their dear and valued partners will lie to them.

HDRS must not be yet another brand for a cartel to hide accountability for the public to whom they have made promises – where are the outcomes from these projects? Do they deliver what they say they will deliver? There will be much wailing of overpromoted academic mediocrities that their self-important silo is not being prioritised at the expense of everyone else, at the expense of research outcomes, and at the expense of patients.

Transparent

Not everything is HDRS's fault, but much will become HDRS's responsibility

The post-merger Department of Health in England / NHS release register must include HDRS (and HDRUK, and regional SDEs, and… etc etc etc) and must show what data goes where, creating a single consolidated register of all data uses, and declare a clear and unequivocal end to the deceptions and doublespeak in HDRUK's hall of mirrors and NHSE's legacy of confusion continues across the data landscape.

Every use in the new HDRS should be consensual, safe and transparent. That should be table stakes, but who knows what the decisions will be.

A new baseline or more of the same old messes?

HDRS can offer a new baseline – a National Data Opt Out that meaningfully opts people out of "research and planning", transparency on how data is accessed, and safe environments that are meaningfully safe not deception and coverup of a cartel. Such a policy will make public communications very simple: All the data in the Single Palantir Record safely made available for research, unless you have a national data opt out when none of it is available, and a full list of everywhere data has gone: consensual, safe, and transparent.

Is the model for HDRS going to be patient confidence, or placating old cartels of researchers with little interest in consequences for others and patients?

Until HDRUK (note, HDRUK not HDRS) decided to tear up the status quo for no measurable benefit, there had been a decade of coherent informed debate about uses of national NHS data. NHS England published their data use registers, which were the canonical reference for data uses. There may have been discussions about what use *should* have been, but there was no surprises in what data use *was*. HDRUK tore up that arrangement by having their own list with less information than NHS England provided because they believed rules did not apply to them. Hence, HDRUKforesight collapsed only after HDRUK issued a press release about it – because no one had any evidence in advance of what HDRUK had chosen to do. HDRS should commit to never making that mistake again – all data should be in a single up to date register accessible to the public, and a monthly spreadsheet to act as the canonical reference for a particular publication date.

Biobank and their allies are most distraught over whether an extra 2% of data from GPs will make any difference at all. If 2-5% more data is the reason a project failed, it would have failed anyway. Those whose model fails argue that the entirety of the research ecosystem should be turned to ash because UKB/HDR's shared legacy culture insists on using data on people who didn't want it used. Is the 2%-5% of patients with an opt out really worth burning down an entire new programme?

HDRS can choose not to process data it doesn't want to process – legitimate researchers always respect patient wishes. The failures of legacy institutions are well documented, the only question is whether HDRS will join them in failing mediocrity, or whether it creates something better for everyone – there need be no conflict between good research, good ethics and good medical care.

Those who want their data used in research should have it used; those who don't want their data used should have none of it used. The current fudge harms *everyone*.

The new Health Data Research Service could be good; it could be consensual, safe, and transparent. But there's reasonable grounds for concern that it will not be – the first critical decision point for HDRS is whether people who have opted out of data being used for "research and planning" will have their data be used by HDRS anyway.

The Regional SDE network is a mess

The SDE programme is working on showing the performative motions of trustworthiness while undermining and evading the point of trustworthy use of patient data – that's what the SDE programme is incentivised to do. It had insufficient remit to do otherwise.

The London SDE – covering roughly every patient in London – takes GP data for direct care (so opt outs don't apply), and also takes mental health notes (also ignoring opt outs), and refuses to disclose who they sell access to the whole lot to because that'll reduce the amount of money they make from selling access to the data. This secondary use should be subject to the opt out(s), but it isn't because they had got the data already and chose to reuse it – it's such a mess the ICO is having a difficult job figuring out who is liable. Then their business model failed, and they ran out of cash, and it's unclear how they continue to operate – but it probably involves cash from somewhere that benefits from opacity around their only asset, which is sensitive NHS data on people who have said they don't want their data used…

HDRS will take over the national Secure Data Environment network for research projects that receive NHS-sourced data, it should continue OpenSAFELY, and it should close the failing 'regional SDE network' apart from those SDes which otherwise would exist (Manchester, Liverpool, maybe London). But those are all table stakes. Smaller environments will always be put under funding and political pressures to weaken their own rules for gain.

Annex 1: Health Data Research UK

HDRUK shares a culture with UK Biobank (which we cover in Annex 4).

Unreformed, HDRUK remains perfectly adapted to the notorious standards of integrity and transparency of the Boris Johnson administration. It is in need of a reset for similar reasons. As we have chronicled over time, the arrangement that follows the closing of HDRUK should learn from the failures of the Farr Institutes and HDR.[1]

As it is today, HDRUK hosts many supposedly independent organisations whose privacy policies all disclose that the data they collect is controlled and managed by HDRUK, and whose "leaders" are line managed by HDRUK's CEO – they are little more than sockpuppets parroting HDR's corporate line designed to deceive others into believing that HDR has a broad base of support.

The cognitive dissonance is so strong that page 163 of the HDR/Sudlow Review argued there was a shortlist of organisations to be treated as the experts on trustworthiness; all were HDR sockpuppets. There is no official list of all of the sockpuppets that HDRUK has created to lobby for HDRUK policies – they need not be recorded anywhere other than on the HDRUK payroll as they are not legal entities.

With a track record of failures of delivery, HDRUK is seeking (and may now have received) a multi-million pound bailout – using NHS patient data as the reason they should get the cash – while lobbying DSIT Ministers (and others) to give them another opportunity to attempt to do what they have failed at so far.

We had a decade with an agreed evidence base about how national NHS data was used, until HDRUK's Data Science Centre decided to tear up the status quo for no measurable benefit; NHS Digital (now absorbed into NHS England) published their data use registers, which were the canonical reference for data uses. There may have been discussions about what uses *should* have been, but there was no surprises in what data uses were.

HDRUK tore up that arrangement by having their own list with less information than NHS England provided, because they believed the rules did not apply to them. As a result, HDR Foresight collapsed only after HDRUK issued a press release about it – because no-one had any evidence in advance of what HDR had chosen to do. HDRUK's response to scrutiny was to look for a more accommodating environment where HDR cash will speak louder than promises to patients, and seems to have found it in SAIL.

Ongoing projects should be able to demonstrate benefit from their efforts

HDRUK Leadership dreams of their researchers coming up with something so novel and so groundbreaking that they must immediately contact all doctors in the country directly, to tell them to change how they treat patients: do an analysis, find a 'cure' for cancer, and knock

[1] HDRUK have read this assessment, and internally have a response – which is a list of all the things medConfidential have said about HDRUK. If you're in a position to ask for a copy, it's very funny.

out a draft of a preprint; doctors will gawp at the brilliance, and the Nobel committee will wake them up the next morning instead of their alarm.

This is the sort of ego-driven thinking you get from data analysts who don't ever deal with patients. It is also quite common at the Department of Health in England – medical ethics, NICE guidelines, and barriers to reidentification are simply hurdles to get over on the way to Stockholm.

Where are the papers?

The main reason that any academic project should continue is entirely missing in the case made by HDRUK. There should be a pile of published papers containing high quality research outputs that could only have been done (using HDR infrastructure) by academics who are **not** receiving HDR funding to work on HDRUK projects that are the topic of the papers.

This question can be answered with citations, so where are they?

Where are the benefits?

If all the cheating of the Covid-only rules was as beneficial as HDR decided it was, where are the benefits? Where are the outputs? And what has ended up actually helping patients? The RECOVERY trial followed the rules, published their outputs, and medicine improved. *Where are the outputs from HDRUK's various activities that have led to practical benefits for patients?*

Where is the evidence of anything that could only have happened because HDRUK exists? Is there any infrastructure in use that allows research that can only happen because HDRUK continues to exist? HDRUK (and DARE) are supposed to have been providing infrastructure, but where are the publications? *Where are the discoveries that would have been impossible without that infrastructure?* *crickets*

What was the money spent on?

HDRUK poured over £24 million of public funds into its DARE programme, and has nothing to show for it. We have seen no independent analysis on how much money has gone to HDR's Leadership and Home Institution teams via DARE laundering, circular funding, and kickbacks to HDR partners that were implicitly necessary to get any funding.

It's impossible to know from the outside what money went where. DARE is entirely managed and led by HDRUK, and HDRUK convinced MRC to de facto depend on HDRUK for decision making about DARE strategy and spending – e.g. an "open" call for applications in which UKRI will channel public funds to the "single collaborative bid" HDR chooses to support.

UKRI will continue to pour good money after bad until MRC accepts there is a need to restructure HDRUK the way that UKRI has accepted is necessary for the Turing Institute.

Multiple Farr Institutes devolved into petty rivalries and academic bickering, and the single all-powerful HDRUK centre has apparently devolved into a den of nepotism and grift. Having spent £24m of public funds, where are the citations for research papers that were possible only because of that investment? How many papers are from research conducted by an organisation that **didn't** receive any of the £24m themselves?

What is there to show for the money?

By comparison, £24m is a third of the annual core AHRC budget, a fifth of ESRC's – and one third of the £75m freezing order placed on the assets of Michelle Mone, who took a similar view of pandemic purposes as HDRUK took with their Foresight escapade. UKRI and MRC allowed HDRUK to pre-vet preferred applicants for MRC cash in HDRUK-influenced programmes and spent £24m on them. What does UKRI have to show for HDR's cronyism?

Annex 2: Genomics England will cease to exist

It is medConfidential's assessment that, after DHSC has eaten NHS England, and with the Whole Genome Sequence of all babies going into their Single Patient Record in Palantir, the political and institutional direction of travel is that Genomics England will cease to exist as an independent entity in the medium term. That outcome would be in the interests of the bureaucracy – even if it is utterly terrible for privacy, for patient confidence, and for care.

In 2026 it would make no sense for there to be an "X-Rays England" to be run by DHSC; there is a belief by the Department and their technology providers that genomics is going the same way.

The NHS Genomic Medicine Service will continue as a routine NHS service, in the same way the NHS has many routine medical services. GeL has done that job admirably. GeL has also run a trusted research environment for years, but NHS England has one of those now too. And there's no space for nostalgia in the Treasury's Spending Review.

The Department of Health and NHS England expect the whole genome sequence of babies to go into their Single Patient Record in Palantir – where they can and will do whatever the Secretary of State, as data controller, decides.

After data is ingested, data held in GeL today will be treated as any other data held by DH/E. Genomics will become just 'part of the government' like digital ID, and the genome of every resident will be shared the way any government Department shares any data. Such sharing would even be covered by DH/E's proposed expansion of data sharing under the Digital Economy Act – an expansion that would destroy the business model of Our Future Health. DHSC will inevitably make the data available to police and the Home Office; not necessarily on day one, but the forces of State can be patient when temporarily refused...

The independent and trustworthy structures and culture of Genomics England are the best option for a rapid NHS response to the demonstrations of mRNA treatments that we address in Dog Cancer and related pieces.

The HPV vaccine eradicated cervical cancer in women who've had it. There's a decent chance that, by the end of the current Parliament, it will be possible for your vet to cure cancers in your dog or cat, and it's politically untenable for the NHS not to do the same for your grandma – subject to clinical trials, compassionate use, etc.

GeL deserves to survive as an independent entity; patient confidence will be better if it does, but political priorities override patient confidence when Palantir gets involved, and politics beats patients every time.

In all future scenarios – confidence, culture and consent-wise – it makes complete sense to appoint the Chair of GeL as the Chair of the Health Data Research Service. As a consequence, if the primary legislation necessary to make the Secretary of State data controller for the Single Palantir Record does not pass, but the SPR continues regardless, a merged GeL/HDRS may be in an ideal position to become the public body that is the data controller as a new 'Information and Innovation Service'.

Annex 3: Our Future Health

Our Future Health Ltd remains a company owned by a Charity.

The UK has a non-commercial Biobank whose governance failed under scrutiny, whereas OFH exists to help "kick start" the life sciences industry with a company selling access to data and a charity doing marketing and publicity for the company. Their letters are optimised to be confusing to those who receive them.

We previously said "It does not seem unfair to describe Our Future Health as two steps away from offering a chocolate bar in return for DNA and lifetime data access", and since then OFH has begun asking people to give up their DNA, their full medical history, and over time all other data held by Government, in return for a one-off £10 gift voucher. (Sometimes they don't even offer that.)

There is a historical analogy. In the 1990s, there were two competing "genome projects": the Human Genome Project was supported by the public purse and committed to public knowledge; a private competitor – the 'Venterpillar' – tried to privatise the lot, and went bust. Sir John Bell helped the Human Genome Project succeed, but switched sides to capitalise on the "life sciences strategy" he wrote.

Professor Sir John Bell CH subsequently learnt the fickleness of billionaire sponsors. Sir John Bell, founder and prime mover behind Our Future Health, got his CH recently. What questions would the Palace ask before William/George would sign up to OFH? What are the answers? And why isn't that information available to everyone?

When the CEO of OFH said the following on the "NHS Confed podcast", how many of these things have they actually done over 2 years later? (And how many did they start and then withdraw quietly due to failure?)

> "We're not just giving people information that cannot be acted upon, as that's not good for them, neither physical nor mental health. Initially, we'll feed back information on disease where there are existing programmes for them to be dealt with, so for example, diabetes, ischaemic heart disease, heart disease, we have the existing NHS health check programme for people aged 40-74. What the additional information will gather through OFH is people will have more accurate information about their disease which can be dealt with when they go for their health check. Additionally, diseases like breast cancer, where we have a screening programme, being able to identify women who are at higher risk of breast cancer based on their genetic risk who are not identified, so who are not part of the screening programme, that will have to be done in close coordination with the NHS screening programmes as well. The whole programme is being done in partnership with the NHS, but its implementation, once the research phase is over, the implementation phase is a key challenge which we are aware of."

Since our 2023 questions, some things have moved on – Our Future Health has unlocked millions of pounds of public funds by sending ever more junk mail with an NHS logo on the envelope. (The NHS-related letters were sent when working with the NHS; OFH is now sending different "dear household" letters to addresses it is buying from junk mailshot companies.) Some of the technology and policy questions for OFH overlap with those to UK Biobank given the competition and overlap between the two entities.

In the world of Wes Streeting's Single Patient Record, data available from the NHS will beat OFH on every metric other than blatant commercialism.

Prof Sir John Bell's Our Future Health may fail in its quest to sell 5 million people's data, but in doing so he may have encouraged the Blair Government in-exile to cause the same to happen to the data of everyone in England. He'd probably take that tradeoff.

Annex 4: UK Biobank

Ongoing questions about UK Biobank are in Annex 4B – many of which were published previously, and last updated in late March 2026.

UK Biobank shares a culture with HDRUK (which we cover in Annex 1).

When the Biobank Direction was published, what had Biobank told their supporters about what they were being asked to advocate for?

When UK Biobank moved to disable downloads, we understand Biobank told their funders and others that ceasing downloads was done without notice to users – despite the fact that Biobank did notify users in advance, and it was in the headline of a puff piece. What did the funders know and when? Was it accurate?

It remains unclear which projects have been given exemptions to UK Biobank's research environment mandate. Why is that list not made available to Biobank members, and why does Biobank keep secret who has been granted access to what data? Has Biobank fully considered the contents of the data?

UK taxpayers and Biobank's charitable donors continue to subsidise UK Biobank users, which include committed eugenicists, entities sanctioned for links to the Chinese military, and Chinese undergraduate students. (UK Biobank's assessment of nationality appears to accept without question the information provided by applicants, with no checks – treating "TikTok" as a US company, when the company named is the Cayman Islands holding company, and the named researcher is based elsewhere...)

Three years in, what has changed?

Its CEO's angry denial that there was any problem with insurers having access to Biobank data was followed by an admission to the cohort that the policy would change, with the only disclosure buried in a newsletter.[2] (Whether that has resulted in any change in practice is an entirely different matter.) Such complete lack of perspective is not unusual in a novice PI or a temporary appointment without regard for external opinion; it is rare to find it applied in an institution, albeit one that disregards the future in favour of short term gain.

Assessing UK Biobank over three years after medconfidential began to do so, the most notable thing is how *little* institutional change there has been. Some words may be different, but a persistent attempt to maintain practices and outcomes is maintained. Safeguards promised in theory are undermined in practice, and the bluster and arguments remain pretty much the same.

Biobank claims to be running a TRE, seemingly without output checking, but there has been no independent assessment of whether it satisfies the Five Safes model – or whether UKB

[2] Page 19: ukbiobank.ac.uk/wp-content/uploads/2025/05/Participant-newsletter-2024-25-from-data-to-discovery.pdf

have simply decided that the words can mean whatever they want them to mean (as with HDRUK) and that anyone who wants an exception from the TRE can have one.

Many UKRI longitudinal studies recognise their commitment to their cohort is paramount – and if individuals have engaged every few years for decades, clearly there is a level of bilateral trust. Such trust and respect is not matched by those who put themselves and their own interests before those of their cohorts.

The future

Cleaning up UK Biobank will take time and deep reform of Biobank's board and senior staff – both are packed with loyalists to the longstanding outgoing CEO. There continues to be great value in a ***trustworthy*** UK Biobank, but the current leadership has decided they are indispensable. Whatever the model is for UKB should act as a precedent for OFH when they inevitably run out of cash.

Trustworthiness must be *demonstrated*, not asserted or demanded – and the sheer volume of unanswered questions around UK Biobank suggests a fundamental incompatibility of the current leadership with trustworthiness.

UK Biobank and HDRUK may have convinced Ministers that 'bullying their way through' and having GPs lie to patients is a good idea, as is running a campaign to tell the 3% of patients who have a GPDOO to "opt back in" – but are the research community and institutions so sure of UKB's insistence upon the inaccuracies cited in this Annex that they're willing to put their own projects at risk?

Data projects work when the system is trustworthy. OpenSAFELY and the pandemic dataset both were – and OpenSAFELY still is – but as we've seen twice now with the pandemic dataset, trustworthiness can be undermined by a desire for short term gain.

Annex 4B – Questions about UK Biobank

Ongoing questions about UK Biobank are in a separate document Annex 4B – many of which were published previously, and last updated in late March 2026.

Annex 5: Long Term Incentives

Long Term Incentive structures are *hard.* Everything degrades over time.

Farr failed. HDRUK failed. MRC's culture has failed to deliver.

Intransigence, whether from UK Biobank, HDR UK, NHS England or Palantir, takes political capital to maintain. Existing decision makers may accept those costs for now, but leadership changes, and defending the old indefensible is impossible in a supposedly 'new' service.

The one argument for HDRS (and what it should do) is that NHS England as an institution doesn't care about research (gross stereotype, but generally fair).

Such an approach will be especially problematic for devolved administrations, where they have actively chosen to do something different to England for their own reasons, HDRUK (and possibly HDRS) expects to have the remit to be able to interfere in those decisions and will inevitably do so for political reasons.

Equally, DH and NHSE never wanted to implement the National Data Opt Out for existing data flows or for their own uses, but as structures evolve into the Department of Health in England, it will be more difficult not to implement it than it will be to do the right thing.

However incumbents who made and justified bad decisions will remain in place. Progress is not guaranteed, and regression is entirely possible.

Government plans for data may involve doing the wrong thing repeatedly, but eventually they get it right. And if they don't get it right, then it'll repeat.

The line between research and planning is a spectrum, and we've seen no credible way to split the two without creating vast opportunities to disregard patient wishes. Some organisations encourage that confusion for their gain.

The best way to ensure a long term sustainable institution is to maintain the confidence of the patients who will advocate for it to remain and thrive.