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.