New Health Data Research (UK?) Service – issues of Centralisation and Trust

The Prime Minister has announced a potential Health Data Research Service for the UK.

The Service *could* be consensual, safe and transparent for all those patients whose data is included, but we have seen no evidence that it will be. Below is some of what that will mean, which of the various parts can be changed, and which of those parts are likely to be insisted upon by England:

- **Westminster politicians will decide how the medical notes are used,**
- **There will need to be an equivalent to the English NHS National Data Opt Out,**
- **Data will flow into Palantir,**
- **Despite not doing direct care, all data in the service will be (re)identifiable,**
- **Westminster is already making decisions that will apply UK wide,**
- **HDRUK leadership breaks promises they're bound by,**
- **HDRUK is a toxic model for the HDR(UK) Service,**
- **All processes get gamed, and devolved administrations have deep experience of malicious compliance by Westminster,**
- **Promises of transparency get broken.**

The structure of the proposed Service has been announced as a government-owned company, not a normal public body; the job advert is now live for a Chair and CEO. Decisions have already been made, some actively and explicitly, but mostly in implicit silent ways that may prove impossible to change (it is already a govco…)

Current Service planning assumes an "England plus three" arrangement with an evolution of current English practices in ways that NHS England and the Department of Health in England deem to be in the best interests of the Department of Health in England. What England does with English patients' data will be done to the people of Wales, Scotland, and Northern Ireland if they participate. Sometimes in the past this has not been entirely well received; but, as with the views of English patients, the Department of Health in England does not necessarily care about that.

The Wellcome Trust has put initial funding in place so that the Trust can steer benefits in line with their own vision, but that funding is temporary. The existing HDRUK organisation argues strongly that it should run the HDR(UK) Service however it sees fit. NHS England believes that the new service should act like NHSE already does. It is notable that the Trust funded the first period of HDRUK's activity, but declined to fund it beyond. It's a mess. The Service as proposed is effectively the HDRUK model with more data and less transparency.[1] It'l be the same people and the same culture, and it will have the same landlord, but there'll be an extra letter in the new organisation's name.

We strongly advise that any agreement to provide data to this new HDR(UK)S is made watertight against the malicious compliance routinely shown by NHS England in delivery of agreements over time, some of which are detailed below. For a topic that is directly and entirely in the HDRS remit, DHSC has "no plans to work with devolved administrations".

[1] When HDR complains about medConfidential again, ask them for what they've produced and what the total budget was. Was this a good missed opportunity cost?

Westminster politicians will decide how the medical notes are used

Within scope today is all data available to the national NHS bodies, and other departments (DWP, DfE, etc[2]) and companies (e.g. loyalty card data[3]) who wish to share data as well.

The Department of Health in England has also announced the concept of a "single patient record" which will take data controllership of patients' medical notes from registered medical professionals with direct duties of care and confidence in General Practice and place it in the hands of the Secretary of State, to do with as he wishes.

The reason for this is to allow the Secretary of State to run AI and algorithms over patient records, and to share them as he sees fit. The proposed Single Patient Record will include all of the medical notes made by every GP in every consultation since their systems were computerised in the 1990s, and the entirety of that data (and all subsequent data entered onto such systems) will be made available to the new service.

It is the policy of the NHS in England that all data flows will go through their "Federated Data Platform", provided by Palantir - and NHS England will ("graciously") offer to provide the data infrastructure for the new HDRS, meaning that all of the patient data of the devolved nations will have to go through Palantir. (This will be achieved by using what NHS England calls a "instance" for different ICB areas or hospitals – in effect each devolved nations would be a tenant of the English platform) What Palantir features get offered or mandated to devolved administration would be a decision of the NHS in England, including the Westminster fetish of replacing doctors with algorithms provided by the lowest bidder, or from companies who have made politically convenient noises which change with the political winds. UK Life Sciences Champion John (no-Nobel) Bell has recently been in the media talking down the UK approach to life sciences industry while neglecting to mention that he was embarrassed into resigning from his last job as "President" of the Ellison Institute when he lost the confidence of the billionaire backer. The NHS has long seen how fickle and temporary billionaire visionaries can be – they close services as they move on to the new new thing, and the NHS picks up the pieces. Bell's other goal talks about replacing GPs with his club where the entry fee is DNA and lifetime medical history, with the perk of membership being you can get miracle drugs made by his partners offered in a tent in the car park of a local large employer.

Others will need an equivalent to the English National Data Opt Out (or similar)

The Westminster Parliament has been told that "access to data for direct care purposes is not one of the Health Data Research Service's planned capabilities" meaning, patients can object to their data being used in the HDRS.

England currently has an "NHS National Data Opt Out" which tells patients they "Choose if data form your health records is used for research and planning". It is currently unclear whether this opt out will be applied, or whether patients in England will have to opt out again from this new Service. Will a UK-wide service require the other nations to create such an opt out?

[2] HDR/Sudlow Review Page 123
[3] HDR/Sudlow Review Page 103

In practice, the current English opt out is ignored over half the time, and patients who do not wish to have their data used for research (or planning) have it used anyway. Patients are told they can opt out, they exercise that right, and then their opt out is ignored. Will a UK-wide service impose this English subterfuge onto other nations as well?

For Northern Ireland in particular there may be particular sensitivities around the creation of an analogue of the Single Patient Record containing every patient's written medical notes and prescriptions, with reasons – including details of the most sensitive treatments, going back many years – all then being shared with anyone who can set up a shell company broker or intermediary. Decisions on who gets access will be made in England.

The Department of Health in England is currently conducting a public engagement process on removing patients' ability to opt out of 'planning' uses. It is unclear as yet whether NHS England's communications and implementation of the National Data Opt Out are compatible with the forthcoming Hillsborough Law, and while NHS England may grandfather in their doublespeak (which is how they got into this mess), that will not be an option for devolved administrations.

Data will flow into Palantir

It is unclear whether this new Service will be a "thin" layer added around existing NHS England processes, or a new data lake with its own separate data infrastructure. Either option would have significant consequences. HDRUK want it to be a continuation of HDRUK, and DHSC want it to be a continuation of NHS England.

It is the policy of the Department of Health in England that all data infrastructures are to live within NHS England's "Federated Data Platform", supplied by Palantir. Therefore, if any data is added by devolved nations to this type of "thin" service, it is likely that NHS England will expect devolved nations to supply all of their citizens' data to Palantir. This model is most compatible with the vision described in some Parliamentary answers (contradicting others).

The Tony Blair Institute has recommended that their partner/funder[4] Oracle should be used instead of Palantir. If it doesn't go to Palantir, where does it go, and who will be responsible for it? The govco is not being structured to do that…

Despite not doing direct care, all data in the service will be (re)identifiable

Proposers of the HDR(UK)S want to reidentify patient data because they don't trust the NHS. Just like HDRUK, they prefer centralised theoretical simplicity to the complexity of medical practice and so would deploy shortcuts to circumvent "inconveniences" like data protection.

[4] And overlapping board member; Oracle being founded by Larry Ellison who gave his money to the Ellison institute and then decided the UK Life Sciences champion was a poor choice to lead it.

Contrast this with the RECOVERY trial for covid. Finding dexamethasone was the start, but the approach was not to micromanage and second guess doctors around the country or the world, but rather to write a paper, draw attention to it, and let clinicians make informed decisions about their patients.

That system worked because everyone understood what and why. If it really matters, the researchers can do the work to tell people what's there and why it matters, rather than tossing their incomplete research back to the clinicians to deal with without sufficient information. If it's not published, it's not yet research, but it can be a politically motivated press release.

Westminster is already making decisions that will apply UK wide

With a Whitehall-based politician as the proposed data controller, decisions like this can be made for such reasons. While the Secretary of State will be the data controller for England only, the system itself will by default assume that decisions made for England apply everywhere else and expect that data to be provided. As the job ad for the Chair/CEO of HDR(UK)S states, decisions will be "directly accountable to Ministers".

NHS England is doing public acceptabliity testing of "regional" decision making on data, supposedly so that decisions are made closer to patients - but for national-level data the decision of any one region (which may say yes to almost anything for its own reasons) will apply to patient data from across the country. We therefore expect HDR(UK)S to treat the devolved nations as if they were simply English regions, noting that the CEO job advert only requires experience in "central government controls".

Devolved nations know how Westminster treats promises; HDRUK already does the same. HDRUK is perfectly adapted to the standards of integrity and transparency of the Boris Johnson administration, and is in need of a reset for similar reasons.

HDRUK leadership breaks promises they're bound by

The most obvious precedent for such 'devolved decision making' is the HDRUK/foresight project in which Health Data Research UK (HDR UK – this summary is from a year ago) took "covid19 only" data collected under extraordinary powers during the pandemic and used it to train a large language model, on the basis that the model would include the period of the pandemic, so the data could be used. NHS England and HDRUK both insist they did nothing wrong, and data guardians tell us they have accepted at face value the "it was covid" excuse.

Individual academics did what the system was set to to allow them to do – they filled in the forms they were asked to fill in, and seem to have done so honestly. It was the HDRUK leadership which institutionally decided that promises about how data would and wouldn't be used simply shouldn't apply to them. The GP dataset, for example, was supplied to NHS England on the basis that any data projects using it would be subject to approval from the GP Profession – a condition HDRUK decided to ignore and NHS England decided it doesn't want to enforce. When NHS England sent a selection of those projects to its independent Advisory

Group for Data, the majority of the projects were not supported by the independent advisors (item 5.1 – they didn't bother to ask anyone else what they thought).

Baroness Mone would be proud of this creativity. This creative redrawing of remit and scope to serve their own convenience are further examples of NHS England's common practice of malicious compliance.

HDRUK and Biobank are a toxic model for the HDR(UK) Service

The HDRUK/Sudlow Review[5] that proposed the new HDR(UK) Service, written by the former chief scientist of UK Biobank who was responsible for getting more data into the Biobank.

The shared toxic cultures of HDRUK and Biobank make decisions that benefit themselves before patients. HDRUK wants to run the new Service, which was conceived in a report written by England's "national institute for health data science"... known as HDRUK. NHS England, DHSC (England) and others deny that HDRUK will lead the new HDR(UK) Service; HDRUK privately argues otherwise. At the launch of that report, the now-former National Statistician stood up and lauded the report, and the report's lead author said that the system she had led at UK Biobank had "one of the best systems" - sending data to applicants in "weeks and days" - and that the NHS should release data just like Biobank. (This being the same Biobank who failed to spot an applicant was a bunch of eugenicists operating out of the same fake office as QAnon websites and other scams...)

At the time of those speeches, Biobank had publicly stated they had suspended "new data" and publicly listed no new projects from July 2024. From July 2025 they published ~1800 new projects that had previously not been disclosed – Biobank simply decided they didn't have to disclose data projects, so for a year, they didn't.[6]

Replacing doctors with academic leaders, algorithms, or hungover researchers

HDR's leadership dreams of their researcher coming up with something so novel and so ground breaking that they must contact all doctors in the country immediately and directly to tell them to change how they treat patients. Do an analysis, find a 'cure' for cancer, knock 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. These are the sort of ego-driven ideas you get from analysts who don't ever deal with patients; they are also quite common at the Department of Health in England - NICE guidelines, medical ethics, and barriers to reidentification be damned.

This will be most problematic for devolved administrations, where they actively choose to do something different to England for their own reasons, HDRS expects to have the remit to be able to interfere in those decisions.

[5] HDR/Sudlow Review
[6] And there appear to be yet more sanctioned entities in the 'secret' list.

All processes get gamed, and areas have deep experience of malicious compliance

All processes get gamed, and the Department of Health in England will game them for English benefit as is the English approach to government. One of the reasons NHS England is being 'abolished' / folded back into DHSC is because NHSE has been equally disingenuous with DHSC. DHSC alone was in a position to do something about this, and all they could do is 'abolish' NHSE. DHSC will however have the same people, making the same decisions, for many of the same reasons under the new 'brand' – and things will go no better for the devolved nations than they did for DHSC.

HDRUK facilitate interference in different devolved decision making – at least 25% of the signatories to HDR's "open letter" in support of the 2021 (English) GP data fiasco were from HDR/Dundee/Edinburgh affiliations (possibly up to one third given multiple affiliations of those involved).

The unique health experiences of different groups, especially those in devolved areas, will be ignored. England will use data as England sees fit, with decisions being made by the Secretary of State for any reason he or she sees fit as they have "no plans to work with devolved administrations" on topics that are within the core of HDR(UK)S.

Citizen identifiers

The linkage of the NHS number as the "unique identifier" for children in schools in England takes a very Whitehall perspective. While the NHS number can be a so-called "children's identifier" to DfE, DfE loses responsibility for each of those individuals at age 16. That each of those people continues to live with the same NHS number for the rest of their life does not matter to them, as that is outside DfE's remit. But the identifier persists.

HDR(UK)S will have to make similar 'boundary decisions' – decisions taken in Westminster for Westminster reasons.

The UK Home Office will potentially have "research" access to the full dataset in future, even if those "research" uses are contrary to devolved governments' policies. This cannot be prevented, even if it means that promises to residents of devolved nations are broken.

Promises of transparency get broken

In England, arguments about what had happened to patients' health data for secondary uses largely went away for a decade from 2015-2025 – this was because NHS England (and its predecessors) published a detailed spreadsheet every month of what data had gone, to where and for what purpose. (The quality of this spreadsheet improved considerably after the care.data scandal in 2014, and thereafter - but declined with the absorption of NHS Digital into NHSE. When the Secure Data Environment was created, they were denied resources to automatically provide the same levels of transparency).

Scandals instead mostly erupted from organisations that decided those standards didn't apply, and the new HDR(UK)S appears designed to be one of those. medConfidential believes that HDR(UK)S *could* be consensual, safe, and transparent - but it will take significant work and eternal vigilance from those who offer data to it.

Things don't get better just because someone says they should.

medConfidential
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Contact: coordinator@medconfidential.org or see medConfidential.org

medConfidential is always willing to provide our support to conversations as deemed useful, we normally limit our focus to England on the basis that how the Welsh / Scottish / NI health services work are primarily a question for those living there.

In the context of an English Politically Controlled Central Care Record, Record, those who currently operate a disease registry or similar may wish to consider their future decision making options and autonomy as akin to that of an NHS region described above.