Health Data Research UK

Academic infighting is distractingly irrelevant, except when it undermines patient confidence in trustworthiness of data infrastructures. HDRUK have created an echochamber to benefit their friends and to undermine the concept and design of Trustworthy Research Environments – because they can no longer ignore safe data practices, they attempt to undermine them.[1] HDR's convenient fiction of "popup SDEs" are a shorthand for letting users manage the evidence of any misdeeds, unnecessarily continuing the risks of dissemination in a "SDE" world and undermining the entire point of "Trustworthy Research Environments".

HDR's culture[2] and leadership excludes good people, as explained with insightful scientific objectivity by [Katalin Karikó], the [co-inventor of the mRNA technology] (described as "[the weird nerd comes with trade offs]"): success in political institutions requires political games, which is entirely different to doing good science. HDR promotes those games, possibly because their other output appears less than the sum of the parts.[3] Researchers shouldn't need to subordinate their research to HDR's politics, as it is hard for good scientists to beat mutually supporting sockpuppets, especially when the organisation behind the sockpuppets acts to control research funding priorities and research infrastructures.

Change?

HDR grew and thrived in the era of Tory cronyism when favours for friends were the norm while truly believing their choices are good (just like Baroness Mone). [Biobank] and HDR share a culture and ethos that is unsustainable where regard is given to service, to due process, and to ethics. HDR was formed to provide a 'single voice' of health data research, and then chose to do so by using cash to reward friends and denial to stifle dissent. HDR aggressively promotes the outputs from their own sockpuppets without disclosing they all share offices and report up to the HDR CEO. HDR and HDR culture prioritises what's best for HDR, not for science. All this must change.

HDR's CEO insists that as HDR are 'not a grant giving body' any conflicts of interest are managed and due process obligations do not apply[4]. However, according to the [Register of Charities], HDR "Makes Grants To Individuals, Makes Grants To Organisations, Sponsors Or Undertakes Research". Income and outgoings of HDR in their Annual Report suggests that money flows *through* HDR, despite HDR saying it doesn't. HDR's claims are whatever feels easiest today.

HDR has been one small step in the long chain of evolving health research structures in the UK since the Human Genome Project and since before the HGP. It is time for the structures to evolve once again. The Farr (HDR's predecessor) devolved into infighting, and HDR has degraded into cronyism. Rather than giving the (captured) MRC another unrestricted go at designing a new model, UKRI should seek views from other funding bodies on how an [actually-independent] assessment should be made.[5] The HDR logo/brand itself should become a logo promoting the outcomes of UK health data research, as "Britain is Great" does for trade. HDR staff were not

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[1] There have been many attempts to undermine change, improvements most recently outlined in the [Goldacre Review] which called for a small number of TREs with a high standard of trustworthiness. HDR is advocating for a large number meeting HDR's own low standard with inherent backdoors and risk by design.
[2] As shared with biobank.
[3] A full net assessment of HDR and the opportunity costs of the previous-Government status quo is probably useful after HDR have written their own hagiographic retrospective.
[4] HDR asserts that the CEOs conflict of interest with Arhidia Ltd are managed. Perhaps it's even true?
[5] Our submission to that process would be towards some form of collaboration capable of highlighting both the consensus and divergent views in the manner HDR has never achieved.

wrong to create a strong brand, the problem is that is the main creation at the expense of *other* good health data research. HDR was conceived to manage up, and their practice epitomising the "baboon paradox"[6] implements what they think they were asked to do: look friendly even if they deliver less than the sum of the constituent parts.

HDR publishes both an Annual Report (formally to Companies House and the Charities Commission) and an "Annual Review" (for promotional purposes).[7] The biggest indication you'd find that the Wellcome Trust walked away from funding HDR in 2023 is the "QQ1" parentheses in the funder list, with no definition of what "QQ1" meant – the loss of 50% of core funds. HDR currently says it is supported by "nine of the largest government and charity research funders in the UK", which is down from twelve named in 2021. HDR often laud their range of funders – yet in QQ1 all except Wellcome were different pots of public (HMT) funds.[8]

HDR merely say whatever is useful to a current audience – hiding what might be inconvenient. Like many assurances from HDR, assurances of DARE's independence were untrue – not that it mattered to a Tory government awash in cronyism. It may matter now.

Consequences: HDR spend public money on HDR sockpuppets talking *to* other HDR sockpuppets *about* yet more HDR sockpuppets

HDR makes use of sockpuppets, different logos claiming independence but with staff reporting to the HDR leadership. The most notable example is DARE, where HDR funnels public funds to their friendly institutions via processes it says to critics that it does not control, so conflict of interest, ethics, and propriety rules do not apply. HDR is data controller for DARE and HDR line manages DARE staff. MRC is aware of this – when MRC wrote a letter about the performance of DARE (which resulted in the first DARE lead leaving abruptly), MRC wrote to HDR due to the line manager relationship and the flow of funds – HDR controlled the money and linemanaged the DARE project head, and filled the role with the HDR CEO's chosen deputy, who had received most funds from the DARE project, at the HDR CEO's former institution.

When MRC/UKRI ask for input, their processes are pre-shaped such that they only give weight to those who already agree with HDR and what HDR is already doing. HDR may argue that they supported MRC to create a call for projects where MRC gave money to PEDRI to assess DARE projects working with others. However, from the annual reports and legal structures, it appears in fact HDR advised MRC to give funds to HDR which HDR then guided to HDR (as sockpuppet PEDRI[9]) to assess HDR (as sockpuppet DARE) collaborations with other HDR projects. As with the quinquennial review which resulted in Wellcome walking away, HDR says HDR is doing swimmingly. Of course they do…

HDR misuse their influence and secrecy to undermine competitive bidding processes. The general belief of interested academia is that if the project an academic wanted to do didn't kickback cash to the feted friends, it was unlikely to get funded. It is beyond our scope to conduct a full assessment

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[6] everyone above sees a smiley happy face; everyone below sees an asshole. https://www.prospect magazine.co.uk/culture/53959/the-baboon-paradox-why-bosses-look-so-ugly-from-behind.
See also our note on The baboon paradox of HDR.
[7] Annual Reports: 17/18, 18/19, 19/20, 20/21, 21/22, 22/23;
Annual Reviews: 18/19 is just a bunch of php errors, 19/20 , 20/21, 21/22, no annual review in 22/23.
[8] BHF also gave HDR restricted funds to be spent on the BHF centre. We'll come back to this in the final footnote of this document.
[9] PEDRI doesn't seem to have a privacy policy or any form of legal identity other than as part of HDR.

on the accuracy, substance, and consequences of the seemingly contradictory statements.[10] Reflecting the cronyism shown graphically on page 18 of the 19/20 Annual Review (the earliest Review that is still available), Scotland was always the most feted guinea pig, from Dundee's recklessness to dataloch, to having all data in "co-connect" and the majority of projects in DARE having participants who were 'friends of Andrew[11]'.

The "Health Data Research Alliance" (another HDR sockpuppet) gives preferential access to HDR projects and parrots HDR's narratives to the NHS and health research ecosystem, while claiming independence when HDR feels it beneficial,[12] and claiming subservience when HDR wishes to take the credit.[13] As with many of the sockpuppets, many "Alliance" materials are also co-branded HDR.

Consequences: HDR acts to undermine Secure Data Environments and Undermine TREs

"Privacy enhancing technologies" themselves aren't enough – the tendency is to use a single PET and say "we are now privacy enhancing" ignoring everything else that the system does. Secure Data Environments and Trustworthy Research Environments are not a panacea – they can be implemented terribly. Good TREs work, but bad TREs can also appear to work unless someone checks all the details.

To use the words of the HDR / DARE flagship project (formerly known as TREEHOOSE[14]) in Dundee: "Code is encrypted, **inaccessible to TRE admins**" – if environment admins can't see the code, they can't know what the output is beyond trusting the user who has every incentive to lie. HDR has a pattern of behaviour that is not in the data subject's interests and is not in the data controller's interest, but is designed to benefit HDR and HDR's interests only.

Hand-wavy explanation of secure enclaves
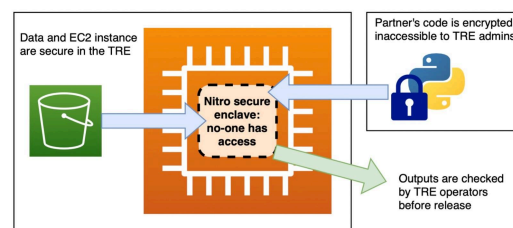
HDR claim they are "Committed to earning trust in how health data is used"[15]; their actions contradict their claim.
HDR's convenient fiction of "Popup SDEs" are a shorthand for letting users destroy the evidence of any misdeeds, unnecessarily continuing the risks of dissemination in a "SDE" world undermining the entire point of "Trustworthy Research Environments". When the organisations get to mark their own homework, all but the last argument from Understanding Patient Data's benefits of an SDE are undermined.[16] It remains to be seen how the shared culture of biobank and HDR affect biobank's move to TRE only data use.[17]

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[10] E.g. 20/21 Annual Report, pg 40 says "All protocols, code and analysis is available in the public domain via the BHF Data Science Centre webpages, the Gateway GitHub repository, and open access publications." The 2022 Goldacre Review looked for them and couldn't substantiate the claims

[11] Not the Prince.

[12] "An independent alliance of leading healthcare and research organisations" says the front page, https://ukhealthdata.org/

[13] "The Alliance is managed by Health Data Research UK (HDR UK) and funded as part of HDR UK's 2023-2028 core work" says HDR itself:

https://www.hdruk.ac.uk/access-to-health-data/uk-health-data-research-alliance/

[14] First TREEHOOSE, then SATRE, and will get renamed again for phase 2 if it goes ahead

[15] report 18/19, page 5

[16] And the last one can apply whether you use a TRE/SDE or not.

[17] https://community.ukbiobank.ac.uk/hc/en-gb/articles/19968506179485-Why-can-I-no-longer-download-data

The TRE/SDE concept requires public confidence and integrity at every step of the process. Hiding features in systems is a terrible idea, hiding features designed to allow commercial partners to hide what analyses they do on data undermines every other claim made about the work.

The culture of coverup runs deep – the sense of doing whatever someone wants because it might allow more research in the short term, the sort of culture that epitomises current contents of the Thames. As with the water companies, at some point the stench becomes too noticeable to ignore, no matter the political connections. The Post Office claim that Horizon was trustworthy and robust long after impartial findings others – HDR have made a similar choice to perpetuate denial.

There should be a high bar for a research project becoming core NHS infrastructure – digiTrials has passed it, OpenSAFELY has passed it – but that should not be a decision made by HDR deciding what it doesn't wish to fund any more. The practice in HDR to externalise costs is deeply woven into their culture, knowing they have many sockpuppets who'll defend whatever HDR want.

A small number of SDEs are necessary, but they need a strong coherent reason to exist, not simply covering "Kent, Medway and Sussex". Small SDEs will get gamed the same way weak data dissemination practices ended badly. The previous government's arrangements mean that the "regional SDEs" are being run with no model for sustainability, created by a DHSC which funded HDR to advise on what they should look like, using software HDR is paying to build by paying HDR constituent parts (who determine the HDR worldview) to build, but HDR avoids taking responsibility for the toxic design and funding choices. While sometimes MRC follow their own guidelines on independence, sometimes they mysteriously don't, when it would allow any self-dealing (corruption?) to be hidden behind the fact that HDR took UKRI money claiming it is building something the NHS wants while telling DH that UKRI/MRC funds this idea, because HDR grantees and friends influence the "independent" MRC funding committees which rate projects based on HDR drafted criteria. Michelle Mone would be proud.

We often see claims of "broad" support for something being pushed by HDR where most of the evidence is their sockpuppet logos lined up feigning autonomy.[18] HDR's misplaced sense of support is typified by the "open letter" HDR drafted in support of the doomed "GPDPR" programme in 2021. The number of junior staff at (HDR stalwarts) Dundee and Edinburgh who signed the letter was notable and unusual, not least because the programme only harmed England, but was described in the most recent annual review (21/22) as:

> "HDR UK further enhanced its reputation as the leading voice in the health research community in response to debate around the implementation of General Practice Data for Planning and Research (GPDPR). The communications team successfully built on an existing #DataSavesLives mini campaign to support the case for GP data use in research, built around a Joint Statement that was signed by over 250 leading health researchers,[19] as well as maintaining a drumbeat of increasing activity around key HDR UK and national moments…
>
> The campaign received overwhelming positive feedback from members of the UK health research community, for helping to redress the balance of the debate in the national media and put forward the positive case for the secure, trustworthy use of health data for research in the face of negative headlines."

HDR "enhanced its reputation" by supporting a programme as it was being shut down in disgrace?

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[18] The Health Data Alliance is a particular example.
[19] what is claimed to be "240+" "individuals in support of this statement", of which those who have their affiliation as HDR, Edinburgh or Dundee appeared as over 25% of the signatories (possibly one third due to multiple affiliations). Some also appeared fictitious.

Consequences: HDR's failure to support the HDR hubs failed their topic areas

The hubs showed promise until they got dumped. HDR dumped the costs of continuing digiTrials onto the NHS budget, and in the same way expects to dump the SDE costs back onto the NHS.

When Wellcome ceased supporting HDR, the annual report implied that CRUK replaced them ("QQ2 only"), yet the cancer "hub" was cut loose by HDR and left to find other sources of funds as it was not refunded. The details of that are unclear.

Whatever happens with HDR, sustainable and high quality hubs deserve the opportunity to continue without subservience to HDR politics. Taking the framing of the new Government, perhaps the hubs should become "missions" to progress research as best for each topic funded by MRC, rather than HDR interceding to pick from their friends.

Consequences: Epitomising HDR's culture, HDR's "Gateway" is pretty but dangerous

Using HDR's flagship gateway, anyone with a (free) linkedin account can use gateway's intended features to do disclosive analyses on any data that HDR allows to be used in that way, which includes the health details of the entire population of Scotland.[20] HDR framed it as a positive for research, being silent about the risks imposed on others that did not fit with HDR's preferred narrative.

Whatever becomes of the gateway, all metadata held should be open access for specialists to build their own tools for custom audiences. HDR's efforts to standardise the access methods to data can be helpful – divergence for the sake of it is unnecessary hassle for everyone – but the shared culture of biobank and HDR resulted in biobank taking the NHS's 30 page application form and turning into 3 pages, insisting it was fine until it became eminently clear that it wasn't. That also sums up HDR[21].

medConfidential

PS – We cover separately some available next steps for research after HDRUK

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[20] 22/23 annual report page 14.
[21] With the final mention of HDR in this document, we note HDR have compiled a dossier on all the things we've said about them over the years that they don't like. When HDR respond to this with their usual dismissal, you should ask for the dossier; it's funny… We'd have FOIed it, but HDR weren't a body subject to FOI in their first five years, but depending on the exact detail of the current funding and ownership arrangements, it may now be covered by Section 6 of the Freedom of Information Act.

Appendix: Related Past Assessments: (listed in reverse chronological order)

Biobank and HDR UK share a culture, and the most toxic HDR projects (TREEHOOSE, COCONNECT) are laundered under the DARE sockpuppet:

- Biobank: [part 1](#) (2023), [part 2](#) (2023), [part 3](#) (May 2024)
- [HDR and sockpuppets' consultation on Public Participation standards](#) (Mar 2024)
- [HDR's Co-connect is like storing landmines in a playground](#) (Nov 2022)
- [Deception by design – HDRUK's TREEHOOSE project](#) (key evidence is in the annex) (Dec 2022)
- [Shaky and unsafe foundations of data infrastructure – DAREUK](#) (Dec 2022)
- [Questions for health data custodians after TREEHOOSE, CO-CONNECT, and DAREUK](#) (Dec 2022)
- [Letter to stakeholders on the dangers of HDR's CO-CONNECT project](#) (May 2022) – Co-connect has since been integrated into the HDR "gateway" and exposes data on everyone in Scotland, but it seems no public body in England has so far accepted the risks beyond various HDR sockpuppets and grantees.
- [What should replace HDR as it replaced Farr?](#) (April 2022)
- [A retrospective on the Farr, and the baboon paradox of HDR](#) (August 2021)
- [PRUK as a sockpuppet](#) (August 2021)
- [Data as a zero sum game – note to NHSX in 2019](#). Shortly afterwards there was a followup (then private) note about making data into a [positive sum game](#).