

## 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.<sup>1</sup>

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

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<sup>1</sup> 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.

them to change how they treat patients: do an analysis, find a 'cure' for cancer, and 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.

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?