

The baboon paradox:

By Karen Moloney April 14, 2010



One face for your boss, one for your team

If there is one thing about which the pandemic has given the public a greater understanding, it is that scientists working with the best will in the world, and with the latest, most extensive but incomplete evidence can come to different conclusions.² This is just as true beyond COVID.

HDR UK³ was created to obscure that discussion from funders; to “unite the UK’s health data”⁴ and be “the national institute for health data science”,⁵ acting as “the voice” of health research in the UK to funders, and to manage down – implementing the Baboon Paradox.⁶

The predecessor Farr Institute was a loose conflation of several independent entities, which did not speak with one voice.⁷ It appears medical research funders reacted no better to a range of views than some national newspapers did to the range of views on COVID response.

¹ COVID transformed many things, including this piece of work, from a historical look at what was – the Farr Institute – to an explainer on what is, i.e. HDR UK, and why it is broken the way it is.

² e.g. wearing masks in the early stages of the pandemic, or models for re-opening in mid-2021; there are also areas where scientists have unanimity, of course, such as the effectiveness of vaccines.

³ HDR could be “Farr 2”, just as whatever replaces HDR is likely to be, initially, deemed “HDR 2” or “Farr 3”

⁴ <https://www.hdruk.ac.uk>

⁵ <https://www.hdruk.ac.uk/about-us/>

⁶ <https://www.prospectmagazine.co.uk/arts-and-books/the-baboon-paradox-bosses-ugly-behind>

⁷ For those referred to this document from the ESRC consultation response, think ARDC-E – which no longer exists for similar reasons.

FarrInstitute.org

Like many academic side-projects when those involved have moved on, whoever registered the Farr Institute domain was no longer funded to keep it, so let it lapse – it now belongs to someone else.⁸ The replacement for Farr in the UK had an initial budget⁹ of £37.5 million over five years,¹⁰ but no-one felt it worth the £10 a year it would cost to keep the domain?¹¹

Announcing the job search to lead Farr's successor in 2016, MRC said:

The UK institute for health and biomedical informatics research will transform the UK medical informatics research landscape. It will be a world leading interdisciplinary research institute, capitalising on the UK's unique research strengths and data assets.

It will be founded on the mission to develop the capacity and methods to accelerate the pace and scale of health and biomedical data science. It will drive discovery research aimed at improving health and care for patients and the public, and grow capability and economic opportunity in the UK. It will be independent, open and inclusive.

implying that these are things which the Farr didn't do, or didn't achieve. By comparison, in 2013, Farr itself was announced as follows:¹²

This investment will support the safe use of patient and research data for medical research across all diseases. The Institute's independent research will support innovation in the public sector and industry leading to advances in preventative medicine, improvements in NHS care and better development of commercial drugs and diagnostics ...

It will also provide new insights into the understanding of causes of ill health which in turn will guide new biomedical research discovery ...

In addition to health benefits for patients and UK citizens, the Institute will help to cement the UK's reputation as a world leader in research using large electronic health data ...

The concentration of funding in developing UK health informatics research base will provide a focus for collaborations with IT and pharmaceutical companies, attracting inward investment into the UK economy ...

The Farr Institute has secure structures in place to protect patient privacy. The Institute will engage closely with the public to identify current and future concerns for research using personal data, ways of safely addressing these issues and ensuring the benefits of this type of research are visible to patients and the public.

Did Farr do what it set out to do? And what *did* it do?

⁸ An 'Institute' in America named for broadly the same reasons: <https://www.farrinstitute.org/publications/> which, in August 2021 when we write this, has "sexual health supplements" as its monthly promotion.

⁹ This figure does not include supplementary funds.

¹⁰ <https://mrc.ukri.org/documents/pdf/director-recruitment-pack-uk-institute-for-health-and-biomedical-informatics-research/>

¹¹ Twitter may be more ephemeral than many things, but the Farr twitter account outlasted both the Institute and its official website: <https://twitter.com/farrinstitute>

¹² <https://mrc.ukri.org/news/browse/20-million-for-new-health-informatics-research-institute/>

The Farr Institute published four annual reports: for 2013/14,¹³ 2014/15,¹⁴ 2015/16,¹⁵ and 2016/17,¹⁶ plus a final report.¹⁷ Read consecutively, they paint a picture of curing disease and harmonious progress.¹⁸ One needs only to read the announcement of HDR UK to see that is not the only view.

Farr Final Report

The most notable thing about the final report from the Farr¹⁹ is that it was not published by the Farr, or by its successor, but was rather an academic paper looking (mostly) at *authors*.

Of the top ten papers (Table 2a) it is notable how *few* of them are obviously delivering on what Farr *was funded to do*. Indeed, it's hard to see how some of them connect to Farr at all. That's not to say high quality researchers don't do high quality research, of course they do – but the point of Farr (and now HDR) is supposed to be something else.

Of the six “TREs” cited in Table 2b of the Farr final report only SAIL still exists in a recognisable form (and perhaps EDRIS in Scotland). Any trustworthy TRE infrastructure must be seen to exist indefinitely – the continued existence of SAIL is, in effect, assured by the Welsh Government²⁰ – something UKRI will never be in a position to assure, due to the vagaries of HM Treasury. Any “HDR UK TRE” will exist only as long as HDR UK exists, and “Farr 3” could have the same disregard for current projects as “Farr 2” chose for its predecessor's. UKRI should therefore fund NHS Digital's TRE development, or fund capacity in it for the exclusive use of UKRI-funded researchers,²¹ as resourcing NHS Digital is likely to be a more efficient use of Research Council resources.²²

We had intended to look at each paper cited in the reports, and to examine each from the perspective of *papers* whether they cited Farr and related funding – or whether that citation was retroactively added due to affiliations in the (usual) end-of-grant panic. However, due to the paywalls that still restricted access to research for some of that time, it proved a biased sample – suggesting some end report affiliations may have been less than contemporary.²³

¹³ <https://medconfidential.org/wp-content/uploads/2020/07/The-Farr-Institute-Annual-Report-2013-2014.pdf>

¹⁴ <https://medconfidential.org/wp-content/uploads/2020/07/The-Farr-Institute-Annual-Report-2014-2015.pdf>

¹⁵ <https://medconfidential.org/wp-content/uploads/2020/07/The-Farr-Institute-Annual-Report-2015-2016.pdf>

¹⁶ <https://medconfidential.org/wp-content/uploads/2020/07/The-Farr-Institute-Annual-Report-2016-2017.pdf>

¹⁷ https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3312791

¹⁸ We exclude the wider effects of the network of both HDR and Farr, the PhD students they trained etc.

¹⁹ https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3312791 a

²⁰ And EDRIS was backstopped by the Scottish Government.

²¹ For which there is ESRC precedent in the ONS environment.

²² We note that HDR UK will likely disagree, without reference to the fact that it reduces HDR resources...

²³ There is probably an academic paper in here for those with academic journal access, although it would likely not win you many friends in the current management of HDR UK, though it might perhaps influence whatever could be described as “Farr 3”.

Into HDR UK

Farr was a loose collaboration of university research groups which focussed on their own priorities. It was not intended to be a single coherent whole, and it was not funded to be; many institutions were excluded. And some funders were less than happy with the multiple perspectives that came from funding multiple independent teams.

HDR UK was created to act as a layer between academics doing research, and the institutions who funded medical research. In effect, HDR UK has positioned itself as the ‘voice of research’ without the burden of incorporating the voices of those it does not fund.

That the first round of HDR sites had nothing between Birmingham and the Scottish Border was notable. When HDR UK funded its “hubs”, Oxford’s bid failed to make the initial cut, so John Bell complained to Number 10 and Oxford got its money, while the NHS does all the hard work²⁴ and everyone else continues to fight over table scraps. How Very Oxford...

The 2021 spending review

UKRI and its major grantees, including HDR UK and ADR UK²⁵, are currently going through a refunding round as part of the spending review. HDR clearly believes it is doing what it was asked to do, and that any change must come from the funders.

We have covered DARE (and PRUK) elsewhere,²⁶ and HDR is proceeding with a set of sprints to determine what it should spend money on. We have no doubt the process will be run in line with UKRI’s guidelines on competition and anti-corruption, but looking beyond process²⁷ to outcomes, would anything have been different had HDR officers just bunged the money to their mates?

“Uniting” health data is a reasonable mission,²⁸ but HDR is also attempting to “unite” the *users* of the data behind the single ‘vision’ HDR espouses... with HDR UK at the centre.

If the focus is to be **science**, then that should be enhancing the diverse views and approaches of researchers – not the narrow interests of institutions which claim to represent them.²⁹

²⁴ <https://digital.nhs.uk/services/nhs-digitrials#what-the-service-will-offer>

²⁵ ADR UK’s approach is adjacent to this paper, and largely covered in the documents linked at the bottom of this 2020 blog post: <https://medconfidential.org/2020/data-misuse-as-missed-use/> – since which time little appears to have changed.

²⁶ http://medconfidential.org/wp-content/uploads/2021/08/PRUK_DARE.pdf

²⁷ Cummings et al, *ad longitidinum*...

²⁸ And, as both useMYdata and medConfidential advocate, the best research possible *should be done* on those who haven’t objected to their data being used for research.

²⁹ During the largest health data controversy of recent years, HDR UK (and ADR UK) managed to get only “240+” signatures to an open letter so bland and irrelevant to the situation as to be unobjectionable for what it did say – by ignoring all of the key issues of controversy, and anything where HDR’s input would have been relevant.

In creating HDR UK, perhaps unintentionally, UKRI took the choice not to be directly involved in key debates around the priorities of science; this now seems fundamentally unwise.

Where UKRI is unwilling, Table 2b of the Farr report clearly makes the case that HDR UK *has no ability*³⁰ to govern long-term infrastructure. Neither has HDR UK managed the dual role of funder and designer any better than Farr did – but, by design, it has made funders *feel* happier, without the burden of producing better research.

In light of COVID-19, the optimal formulation of SAGE for long-running events may be reviewed; the research community may wish to consider the same hypothesis for HDR UK.³¹

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³⁰ Including governance: HDR UK apparently believes it is outside FoI and transparency obligations, claiming to act as an academic entity – but lacking both academic rigour and oversight.

³¹ A simple analysis can be conducted to inform that debate: for anyone with work published by the SAGE secretariat during the pandemic, as the sampling frame, which funding sources have been cited in their outputs since Farr ended? This can be assessed for comparison against the top ten publications in Table 2a of the Farr final report.