

19 June 2025

Dear Rory and Andrew,

You're aware that medConfidential argues that Biobank and HDRUK share a culture. It appears evident in your decision making, it appears evident in your lobbying, and your Patient and Public Involvement and Engagement groups should be asked if it's evident in your PPIE work. Both of your organisations have come into controversy recently, and the causes of both are similar.

For Biobank's [latest argument](#), the only people Biobank quoted were Biobank's founding funders and members of the Biobank patient group, all of whom appear to have been wholly dependent upon Biobank for the (internal) information underpinning their comments (e.g. "anonymised", "procedures for vetting researchers"). Patients can make their own choices, and medConfidential works to ensure that all patients can make informed choices. Do your PPIE groups (and funders) believe no information you knew but didn't share would have made any difference to their views?

Your actions and decisions are your own choices – we understand your personal reasoning for disregarding what medConfidential says, solely because it is medConfidential saying it. Since both HDR and Biobank insist (publicly, at least) that you have nothing to learn from medConfidential's scrutiny, we write to ask you to do one thing: **show this letter to your PPIE groups and hear what they say in return, hear whether they feel they were given full and accurate information, and most perhaps importantly, hear what they think should happen next time.**

Decision making

What do your patient groups think of the original decisions and the information that was provided, given the information that came out later? Biobank insists that all users use their TRE, but keeps secret which & how many users receive the exception to those safeguards (is it anyone who asks?).

- Biobank's recent annual report [says](#) there are "5774 approved projects" with "3,700 underway", in contrast the website lists "4016" projects "[ongoing](#)" – why are these numbers so different? Biobank [claims](#) annual reporting is "mandatory", so why does the public "ongoing" list include [companies that haven't existed for years](#)? Can a project be "ongoing" without a legal entity, without an annual report, and without using the TRE? How many such projects are there? (2074?) Is one of those the startup under the modern umbrella housing the long established US-based Pioneer Fund, who are a 1930s US eugenics outfit who, because they're that old, had received awards in the 1940s from then-Germany for their work, and which carried on until 2023 when they passed the Fund on¹ to people Biobank claim are banned from accessing Biobank. The new company registration is in the same address as QAnon front companies and other "race science" outfits from the same umbrella. [This is who Biobank gave data to](#), choices Biobank asked patients to defend.
- HDR [insists](#) that HDR was legitimate in an HDR internal decision board making "covid only" data available to HDR researchers for non-covid purposes. The HDR/Sudlow Review suggested that as a policy choice, and the Government is assessing that as part of the HDR Service, but HDR decided it didn't like the rules as they are and seem to have ignored them.

¹ As covered in Chapters 6 + 8 of the book Year of the Rat by Harry Shukman, published in May 2025.

HDR insists that making decisions for institutional benefit is appropriate in a pandemic – aka Baroness Mone’s defence. We note HDR proclaims innocence, as Michelle Mone continues to do², yet NHS England [terminated the arrangement](#) immediately upon questions being asked and started the inquiry into one sub-project, taking HDR’s assurance of the minimum possible scope for investigation. Will HDR confirm there are no similar other projects?

- HDR’s DARE project has spent millions on what it calls a “safe environment” despite designing in [back doors](#) for HDR projects and commercial friends. HDR similarly insists that it is entirely legitimate for the various HDR brands / sock puppets to speak without disclosure that they are legally part of HDR. HDR thinks it is so normal to astroturf public debate that the [HDR/Sudlow review](#) recommended HDR affiliates are the *only* groups that need to be heard. We’re aware HDR, Biobank, and friends are lobbying for covid promises to be ripped up “for consented cohorts”, and HDR is simultaneously lobbying for data for unconsented cohorts, (wrongly) assuming the difference will get missed. Do HDR / Biobank’s own engagement groups feel such activity is appropriate, and do members fully informed such that they will not regret whatever activities HDR/Biobank portray them as supporting?

We know it is entirely possible to convince an entirely honest and well-meaning PPIE group that a toxic project is a good thing – you simply tell them the positive parts and don’t tell them anything you think anyone might object to. PPIE groups have to trust they’re not being misled by special pleading. HDR’s priorities are endlessly pushed by HDR, so you would be forgiven for believing [the reckless and unsafe notion of “safe return”](#) has benefits otherwise impossible. Those in any PPIE community wanting to hear wider perspectives may find that [joining UseMyData](#) offers a space to discuss topics with others, and assess the impact of institutional behaviours on wider public and patient confidence.

The [proposed](#) £600m “HDR Service” was envisaged by HDR to run like the existing HDR fiefdoms operate – is that what HDR’s own patient groups think should happen as HDR(S) spins up and HDR(UK) evolves? Were any patient groups with different perspectives taken into account? HDR’s folly with [foresight](#), and the HDR/Sudlow Review, is to believe that only HDR’s goals matter.

Our key question, as current CEO of your respective organisations, will you share a copy of this letter with all of your PPIE members and listen to what they tell you in response? We’re happy to engage with any PPIE groups however they feel useful and appropriate – it is up to them – but we note what has been described to us as HDR conducting a denial of service attack on diaries, due to HDR’s proliferation of meetings between HDR, HDR, and HDR, until HDR gets what it wants. medConfidential can always be reached as below, and we’ve put a copy of this letter online so you can easily share this link:

<https://medconfidential.org/wp-content/uploads/2025/06/biobank5.pdf>³

Best wishes,
Phil & Sam
medConfidential

² When Andrew claims a medConfidential [analogy](#) is “verging on libellous” he clearly understands that it isn’t. HDR says of medConfidential in private what they won’t say in public – internally HDR admit we “do have some valid points” but HDR don’t *like* how we say things (e.g. this letter, and the next footnote).

³ HDR readers may be interested in the [references at the end of this 2024 summary](#) (HDR have a response to the April 2022 note amongst others they may share with you), and Biobank readers in parts 1-4: [biobank.pdf](#), [biobank-again.pdf](#), [biobank-hostile-states.pdf](#), and [biobank4.pdf](#) (in particular q4+5 here).