

Annex 4: UK Biobank

[Ongoing questions about UK Biobank are in Annex 4B](#) – many of which were published previously, and last updated in late March 2026.

UK Biobank shares a culture with HDRUK (which we cover in Annex 1).

When the Biobank Direction was [published](#), what had Biobank told their supporters about what they were being asked to advocate for?

When UK Biobank moved to disable downloads, we understand Biobank told their funders and others that ceasing downloads was done without notice to users – despite the fact that Biobank did notify users in advance, and it was [in the headline of a puff piece](#). What did the funders know and when? Was it accurate?

It remains unclear which projects have been given exemptions to UK Biobank’s research environment mandate. Why is that list not made available to Biobank members, and why does Biobank keep secret who has been granted access to what data? Has Biobank [fully considered the contents](#) of [the data](#)?

UK taxpayers and Biobank’s charitable donors continue to subsidise UK Biobank users, which include committed eugenicists, entities sanctioned for links to the Chinese military, and Chinese undergraduate students. (UK Biobank’s assessment of nationality appears to accept without question the information provided by applicants, with no checks – treating “TikTok” as a US company, when the company named is the Cayman Islands holding company, and the named researcher is based elsewhere...)

Three years in, what has changed?

Its CEO’s angry denial that there was any problem with insurers having access to Biobank data was followed by an admission to the cohort that the policy would change, with the only disclosure buried in a newsletter.¹ (Whether that has resulted in any change in practice is an entirely different matter.) Such complete lack of perspective is not unusual in a novice PI or a temporary appointment without regard for external opinion; it is rare to find it applied in an institution, albeit one that disregards the future in favour of short term gain.

Assessing UK Biobank over three years after medconfidential began to do so, the most notable thing is how *little* institutional change there has been. Some words may be different, but a persistent attempt to maintain practices and outcomes is maintained. Safeguards promised in theory are undermined in practice, and the bluster and arguments remain pretty much the same.

¹ Page 19:

ukbiobank.ac.uk/wp-content/uploads/2025/05/Participant-newsletter-2024-25-from-data-to-discovery.pdf

Biobank claims to be running a TRE, seemingly without output checking, but there has been no independent assessment of whether it satisfies the Five Safes model – or whether UKB have simply decided that the words can mean whatever they want them to mean (as with HDRUK) and that anyone who wants an exception from the TRE can have one.

Many UKRI longitudinal studies recognise their commitment to their cohort is paramount – and if individuals have engaged every few years for decades, clearly there is a level of bilateral trust. Such trust and respect is not matched by those who put themselves and their own interests before those of their cohorts.

The future

Cleaning up UK Biobank will take time and deep reform of Biobank's board and senior staff – both are packed with loyalists to the longstanding outgoing CEO. There continues to be great value in a [trustworthy](#) UK Biobank, but the current leadership has decided they are indispensable. Whatever the model is for UKB should act as a precedent for OFH when they inevitably run out of cash.

Trustworthiness must be *demonstrated*, not asserted or demanded – and the sheer volume of unanswered questions around UK Biobank suggests a fundamental incompatibility of the current leadership with trustworthiness.

UK Biobank and HDRUK may have convinced Ministers that 'bullying their way through' and having GPs lie to patients is a good idea, as is running a campaign to tell the 3% of patients who have a GPDOO to "opt back in" – but are the research community and institutions so sure of UKB's insistence upon the inaccuracies cited in this Annex that they're willing to put their own projects at risk?

Data projects work when the system is trustworthy. OpenSAFELY and the pandemic dataset both were – and OpenSAFELY still is – but as we've seen twice now with the pandemic dataset, trustworthiness can be undermined by a desire for short term gain.