Annex 5: Long Term Incentives

Long Term Incentive structures are *hard.* Everything degrades over time.

Farr failed. HDRUK failed. MRC's culture has failed to deliver.

Intransigence, whether from UK Biobank, HDR UK, NHS England or Palantir, takes political capital to maintain. Existing decision makers may accept those costs for now, but leadership changes, and defending the old indefensible is impossible in a supposedly 'new' service.

The one argument for HDRS (and what it should do) is that NHS England as an institution doesn't care about research (gross stereotype, but generally fair).

Such an approach will be especially problematic for devolved administrations, where they have actively chosen to do something different to England for their own reasons, HDRUK (and possibly HDRS) expects to have the remit to be able to interfere in those decisions and will inevitably do so for political reasons.

Equally, DH and NHSE never wanted to implement the National Data Opt Out for existing data flows or for their own uses, but as structures evolve into the Department of Health in England, it will be more difficult not to implement it than it will be to do the right thing.

However incumbents who made and justified bad decisions will remain in place. Progress is not guaranteed, and regression is entirely possible.

Government plans for data may involve doing the wrong thing repeatedly, but eventually they get it right. And if they don't get it right, then it'll repeat.

The line between research and planning is a spectrum, and we've seen no credible way to split the two without creating vast opportunities to disregard patient wishes. Some organisations encourage that confusion for their gain.

The best way to ensure a long term sustainable institution is to maintain the confidence of the patients who will advocate for it to remain and thrive.