medConfidential submission to the Spending Review

1. Minimise cost to the public purse of the benefits of NHS data, not “business models”
2. Decommission the “Regional SDE network”
3. Reduce ongoing costs of data governance

It is likely that during the period for this spending review, innovation means you may be able to buy a pill to extend the life of your dog and use an mRNA vaccine to cure the cancer of your cat.[1] The political consequences for the NHS and government of denying life saving treatments to a NHS patient that they could buy for their pet will begin to be known by the next election and perhaps should be avoided.

Minimise cost to the public purse of buying outputs based on NHS data

Moving money between NHS budgets via commercial intermediaries does not boost the nation’s balance sheet and slows down health benefits – every pound added to one NHS balance sheet from the “sale” of algorithms to other parts of the NHS has to be taken away from another NHS budget . The “business models for data” work straddling DSIT’s Office for Life Sciences and DHSC has gone nowhere since 2019, but the flawed assumptions of “business models” thinking have become clear. The CSR should move all the “business models” resources to other topics.

Moorfields (rightly) got worldwide acclaim for the 2018 breakthroughs with DeepMind on AI analysis of retina scans. They published enough information into the public domain that companies who manufacture equipment for opticians were able to improve their products and therefore improve services of every optician in the country. There are people today who would have gone blind without those innovations being rolled out. However, Moorfields themselves have spent the intervening years arguing over how to charge exactly the right amount of money across different NHS balance sheets to satisfy DHSC guidance, and those other trusts have been careful to make sure they didn’t get charged too much, so nothing happened. There are people walking around today who would have gone blind if it was not published until the business models were written down, at far greater cost to HMT.

The goal of NHS data use should be minimal future cost to the NHS, effectively pricing algorithms as commodities, rather than encouraging one Trust to maximise financial extractions from all others. One critical breakthrough like that which saves sight will bring benefits to the UK economy far greater than the sums moving between NHS budgets. An example from this week is to seek the workings of what Imperial/ChelWest think they’ll gain in financial terms after this trial, and the cost to the rest of the public purse of not having it available in every smartwatch/phone with an ECG feature.

Decommission the “Regional SDE network”

NHS England designed their own “regional SDE network” prior to the creation of the Federated Data Platform and OpenSAFELY, or the conception of a National Data Library and

[1] in addition to whatever quackery comes out of the Trump Administration that happens to actually work – some will.

Single Central Care Record. The "regional SDE network" was designed to address research access to data that was not available nationally because of the lack of a single care record.The NHSE National TRE now serves all those functions, in addition to having a single way to access national data (which the regional network is attempting to duplicate at 12x the expense and overhead).

No part of the regional network is fully operational, and even the most advanced silo – London – continues the culture of the previous Government when it fails to deliver on promises of accountability and transparency, undermining the public engagement work they did while claiming to deliver on it, with the only detail in the public domain being an opaque list of titles and organisations, with little idea what they do.

Separately, the assessment from HDRUK/DAREUK that the only organisation which could satisfy the HDRUK/DAREUK authored call for the regional SDE network is the one applicant whose "single bid" would be blessed by HDRUK does not obviously satisfy the requirements of Managing Public Money (as the brands promoted by HDR have HDR as the legal entity).

Data Governance

The assumption by the Department of Health in England that they can sell data on people who have objected to that sale (opted out via the NHS National Data Opt Out) because they dance through a complex justification process adds complexity and undermines public confidence. It should be simpler for all to understand: patients with an NHS National Data Opt Out should not have their data used for purposes beyond direct care. The attempt to use data when people have objected means complexity and delay with consequent expense and barriers to growth throughout the process.