Check against delivery

Notes for Westminster Health forum

The single patient record means all your medical notes will be visible wherever the NHS logo is seen, and it will all be shared to the previous speakers under the HDRS banner and reform.

Dr Byrne was right this is about trust, FDP, HDRS and opt out reform comes down to one question: Will patients who don't want their medical records used in research and planning be forced to have their medical records used in research and planning? Some feel any privacy of your medical notes is an inconvenience they can ignore, and they want to force patients into the new programmes telling the public the bits that are good and not talking about the bits that aren't. So lets go into those.

The best example of what will happen to patient data under the new HDR Service is to look at what the shared culture of Biobank and HDR does today.

Government is in a rush, and those with the most plausible sounding quick wins will be those who lie about complexity or are outright crooks.

Normally we ignore HDR's DARE project as a Boris Johnson style distraction that's not worth anyone's time, only relevant because HDR's culture remains perfectly adapted to the standards of integrity and accountability of the Boris Johnson administration. And we know how that went. The good version is in Emily's slides, the other version will be in the chat after I stop talking.

So what's the new HDR Service and COPI reform for?

Let's use the example of HDR's foresight. GP data was made available during the pandemic for covid purposes because that was obviously the right thing to do. Like other aspects of the pandemic response, the review process assumed that people involved were honest. It was not supposed to be the free-for-all that HDR took patient data to be. The researchers and press release make claims far beyond the "covid only" remit disclosed to NHS England and the public.

I'll drop all the citations in the chat when I stop talking, but HDR ran that project, promoted that project, and broke the rules as a deliberate coverup. There seem to be over 100 other such projects. You can't find those 100 projects in the NHS England Data Uses Register - because they're not there. There's only one project listed for "cardiovascular disease and covid19", that started under covid-only rules in 2020, and is a far cry from the fiction in the press release. Patients have to be able to see how their data is used, facts not opinions, and process not coverups.

Patients and the public were lied to by HDR, and NHS England are refusing to investigate properly. Jim Mackey wasn't wrong to say that patients and their rights are seen as an inconvenience that can be denied – It's easier to be complicit in a coverup rather than be transparent to patients.

HDR and share a culture with UK Biobank

Chapters 6 and 8 of the new book by the journalists who uncovered where Biobank sent data goes into detail of what Biobank has ignored. It shows that the recipients of half a million people's genetic data are the new company structures of what historically was known as the "Pioneer Fund". Now, Nazi is a very overused term, often used devoid of real meaning, but the Pioneer Fund was set up in the 1930s to support things like eugenics, and it was around in the 1940s, when it received awards from as-then-Germany about which it remains very proud. That is who Biobank gave data to. When the people who ran it back in the 1940s finally died recently it got a new name that wasn't on any of the Biobank blacklists, so Biobank continues to argue they should have access to Biobank data, even after Biobank knew all of these details.

The best example of what HDRS will do tomorrow is what HDR and biobank do today.

When you run a good TRE, you need to know who your customers are – you can change your mind when you find out about the nazi medals, but Biobank continues to give the eugenicists access to Biobank's servers, servers donated by AWS as a tax writeoff. The London SDE has agreements with commercial companies for projects they agreed they would never make public – their former CEO left by agreement after mismanagement, but is now a number 10 health advisor. It's always falling upwards –

maybe HDR will give him a Review to write about why HDR is so wonderful.

The new HDR and the existing HDR Sudlow Review wants more of biobank style recklessness, with Sudlow claiming Biobank have "one of the best systems" for getting data out in "days" by not checking the paperwork – like checking is this a shell company or not, or asking questions like has the company gone bust?

That is the culture of secrecy HDR wants to build and expand. They've got another big data application pending which won't be in the NHSE secure environment because HDR doesn't like that NHSE suspended a project when rules were broken.

[[To conclude]]

Rebranding the old NHS Digital as the new HDR Service is largely irrelevant – the name and logo of the public body handling data matter very little - it matters what they do, and it matters what they are seen to do. And we've seen what they do. The single patient record is another data grab which solves none of the causes of previous failures and so far none of the inherent tensions have even been considered.

As DH consumes NHS England, will any lessons be learned? or does HDR want more people to act like Baroness Mone? with narrow gain from exploiting data – I should say here that each of Baroness Mone, HDR, and

Biobank all deny any wrongdoing. Because of course they do.

The shared culture of HDRUK and Biobank has led to data misuse, and to an institutional culture where decision makers take no responsibility for their actions. Is that what we want for NHS data as the single patient record?

And with that, back to <<chair>>