medConfidential note to the NHS "E&I and X and D"[1] review

NHS Digital – or to give it its legal name, the Health and Social Care Information Centre – is the statutory safe haven for the NHS in England and it should operate as such, which includes being the primary safe setting (aka 'Data Access Environment', 'Trusted Research Environment') for NHS patients' health data.

The COVID-19 Data Store therefore should move from NHSE/I to NHS Digital and become a disease register, held like any other data or register in the statutory safe haven, with the highest standards of information governance, utility, and professional ethics (including a duty of care and duty of confidence).

We note HDR UK's desire to become data controller for COVID data sets, and expect that "to end badly" – especially given the clear conflict of interests at HDR's core. We further note that NHS Digital is not empowered to delegate its statutory responsibilities.[2]

When considering how to structure and prioritise digital projects, especially around social care and NHSX, we draw your attention to Martha's Talisman:[3]

> "Apply the following test. Recall the face of the poorest and the weakest, the most digitally-disengaged patient whom you may have seen, and ask yourself if the step you contemplate is going to be of any use to them? Will they gain anything by it? Will it restore them to a control over their own life and destiny? Will they have the information to make an informed decision?
> – with apologies to Gandhi and Martha Lane-Fox [4]

Going beyond our newly-published net assessment of NHS Data, this note considers how to move forwards specifically in terms of public bodies and what they do.

The EDIX of NHS bodies

medConfidential sees both advantages and disadvantages to the NHSD/NHSX split.

If nothing else, the temporary existence of NHSX will have been a positive step, because it shook up what was a complete mess, and at least made it an accountable jumble in practical terms – rather than accountable only in theory. We acknowledge there are political and bureaucratic benefits to having a small entity that makes policy decisions and which is focussed on political priorities and user experience, with an entirely separate organisation

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[1] https://www.hsj.co.uk/technology-and-innovation/business-chief-brought-in-to-review-turbulent-nhs-it-landscape/7028109.article

[2] "The HSCIC has statutory powers to collect, process, and store identifiable data that NHS England, as a commissioner, has no legal basis to undertake itself. Therefore, NHS England is reliant on the HSCIC to conduct these functions when it directs the HSCIC to do so."
https://www.england.nhs.uk/wp-content/uploads/2015/01/item7-board-290115.pdf

[3] https://medconfidential.org/2017/remember-marthas-talisman/

[4] https://www.england.nhs.uk/2015/12/martha-lane-fox/

focussed on long-term delivery and maintenance of infrastructure; such entities will eternally be in tension, and not necessarily unhelpfully so. However, and while this would be true to some extent of any Secretary of State, Matt Hancock is possibly not the stereotype you would want to be determining the sustainable national technical infrastructures underpinning A&E.

There's not an app for that.

NHS Digital has performed markedly well during the pandemic, with its singular vision of supporting the NHS. NHSX, meanwhile, has performed variably – in a similarly evolving and challenging (but not identical) environment, supporting the Secretary of State. There is, and always will be, a clear continuing need to manage the Critical National Infrastructure of the NHS by an organisation that is insulated to some extent from the short-term priorities of the Secretary of State.

How NHSX and NHSD work together has always been a complex issue, and NHS Digital's current culture – due in part to key staff immigrating to the NHS from the Home Office – has been more insular and less empathetic than the NHS norm,[5] and not always as honest.

One model proposed – that of merging NHSD and NHSX into NHSE/I – is fundamentally toxic and unworkable. The body that makes commissioning and decommissioning decisions cannot credibly claim to both make decisions based on evidence **and** be the statutory safe haven for medical records, without patients equally credibly believing *their* records were used to close *their* hospital, even if such a belief is incorrect.

Many of the issues around [OKRs and targets that we cover elsewhere](#) also apply to public bodies with NHS in their name.

Another rename? Not yet

We would suggest that 'care.data 2' – i.e. the "strategic" GP collection, for beyond COVID-19 "tactical" purposes – is fully implemented before any new name is launched. HSCIC was renamed in large part because it got blamed for NHS England's failures in the first care.data programme, though its own behaviour with hospital data didn't help.

The toxicity of the NHS Digital brand lies in its defence of the Home Office MoU before that was shut down; reactivation of that or anything similar, and NHSD's ongoing failure to respect the law and promises made to patients[6] pose similarly existential questions that should be resolved first.

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[5] e.g. https://digital.nhs.uk/news-and-events/latest-news/nhs-digital-statement-on-health-select-committees-report-into-patient-data-sharing noting the defensive use of polling in an attempt to support the unsupportable, and refusal to rule out wider (mis)use: https://www.mirror.co.uk/news/politics/nhs-chiefs-wont-rule-out-12198409

[6] http://theysolditanyway.com/

Substantive steps available to NHS National Bodies

1) Patients should know how data about them is used:[7]

   a) 'Data Release Statements' as built by NHS Digital should be launched on the NHS App at the earliest opportunity. (Their launch on NHS.UK will need to wait until after NHS Login has been launched on NHS.UK, but there is no other reason for delay);

   b) PHE's Patient Viewer (now 'owned' by NHSD after the cancer registry move) should launch, potentially as part of COVID-19 Data Store response – especially given the ability it provides to annotate the official record, and to detect where the official record (according to NHSD) is missing parts of the official record according to others, where a data link has failed.

2) Patients' consent choices should continue to be implemented *to their full extent*, in both the spirit and letter of the law – and this must include any and all HDR datasets which are not fully consented.

3) Routine publication of statistics should be increased, with far less reliance on *ad hoc* 'flows' and analyses – with a published pathway to move from the latter to the former. (Potentially via openSAFELY running under the enhanced 'GPES data for COVID-19 planning and research' data access and IG model; noting that DARS / IGARD is still subordinate to HRA CAG.)

4) The public body that is the statutory safe haven for health and social care data must be an independent creature of statute, operating primarily in response to Direction from statutory policy bodies and the Secretary of State. It must be accountable both to those bodies *and to the patients whose data it holds*.

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   September 2020
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[7] We note the National Data Guardian's comments in her latest Annual Report about the consequences of the push-poll NHS Digital ran to undermine the case for its work on transparency.