What's *not* in the white paper?

Every use of patient data should be consensual, safe, and transparent; patients should know how data about them is used, and any ~~coherent~~ arguments for those uses.

This paper is a set of disjoint sections as it represents missing pieces from the 'Integration and innovation: working together to improve health and social care for all' white paper, and those pieces do not necessarily connect – being the rough corners and spurts of future innovation that do not fit neatly into the silos of DHSC...

medConfidential takes no view on the narrowing of the distinction between NHS England and DHSC. When this claimed distinction mattered most, it was largely a fiction anyway. (Having useful things to occupy DHSC's time is probably not a bad thing – if they had more obligations and responsibilities during the pandemic, they would not perhaps have had time to write the whitepaper.)

It is not like NHS England trusts those who deliver care, or DHSC trusts NHSE, or Number 10 trusts DHSC. And their thinking still differs little from that of the consultants who advised mid-Staffs on where they were in the league tables.[1]

DHSC / NHS England expecting to micromanage every bedpan in every hospital from a Palantir dashboard, with Palantir-powered Faculty AIs chasing behind every nurse, is only feasible in the fever dreams of the most-dissociated of pathological SIs.[2] This is not to say that such dashboards will help patients, help care or improve efficiency – though they may give the Secretary of State's minions and Simon Stevens' successor the feeling they can control what is beyond their control.

Data flowing in the interests of patients

A good Shared (or Summary) Care Record accesses data held by a patient's current care providers, who have duties both of confidence and care, not copies; bad SCRs copy data to databases of their own where all sorts of mistakes can happen. The same will also be true for access to Social Care Records, noting this is all for the provision of direct care **only** – with no secondary uses leeching off direct care datasets!

One lesson the Government appears to have learnt from the pandemic is that it needs to build more and bigger databases.[3] That suggests there will be another ~~raiding party~~ 'cross-government-working-group' from DWP showing up at NHSx wanting data held by the NHS,[4] under the guise of "efficiency".[5] Such moves serve to underscore why diverse perspectives must be respected – copying patients' data to DWP may not be against NHSx's interests, but it is certainly not in every patient's interests.

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[1] https://twitter.com/medConfidential/status/1357037423172141061
[2] As both the NAO and Commons PAC reported, digital transformation presents a huge challenge and the NHS "has a track record of failure which it is not learning from": https://committees.parliament.uk/work/479/digital-transformation-in-the-nhs/publications/
[3] https://twitter.com/smithsam/status/1373239462260523013
[4] We understand the civil service wing of NHSx sees no problem with such accesses if DWP 'has a legal basis'. Those with an understanding of patients, confidentiality and medical ethics may take a different view.
[5] https://www.api.gov.uk/dwp/get-medical-details/#get-medical-details

Where patients' interests are already properly aligned, e.g. across NHS bodies, then data and analyses already flow – and COVID-19 has aligned otherwise disparate interests like nothing else in recent history. (Which is not to say that interests will stay aligned.) Where interests and objectives are not aligned, a power grab by, e.g. NHS England undermines both public trust and inter-organisational working. NHSE may think it should have powers to perpetually access data, but this would only have the effect of undermining everything else.

NHS England already has the power to require data; it simply doesn't use it because to do so turns out to be too complex to make work in practice; whether that's at Chorley A&E, or the cross-boundary ICS working in nearby West Lancashire.

Where there are such debates, and there are likely to be many, the Caldicott Principles and the National Data Guardian already provide a mechanism for an independent referee where patient data is not used appropriately – especially in line with Caldicott Principle 7.

There must be patient-visible logs of which organisations have accessed their data and when, which will go some way towards addressing issues such as:

- Creepy Single Doctors
- A centralised dissent function – which will make the inevitable merger of the two SCRs into one easier – a 'Direct Care Dissent from Implied-Consent', replicating the principle of a 'National Data Opt-out' for secondary uses.

The institution of NHS Digital

The proposal that the Secretary of State can move powers around at will must not include the powers of the statutory safe haven – not least because to do so would completely undermine the point of a statutory safe haven. Powers to and around NHS Digital (HSCIC) must remain solely with NHS Digital.

It is notable that NHS Digital had a relatively good crisis, tending to make the right calls repeatedly. While DHSC and NHSx were chasing new and shiny objects that didn't really work, NHS Digital maintained and produced systems that actually did. It would be entirely in character for this Government to undermine NHS Digital for making the right decisions, simply to obfuscate all that DHSC and Number 10 got wrong.[6]

As a progressive rationalisation of NHS data powers, (DHSC and) NHS Digital should request from the Confidentiality Advisory Group at the Health Research Authority an annual view on its advice[7] regarding the dissemination of special category personal

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[6] We cover this further in the 'Data flows of COVID-19' and 'post-COVID landscape' linked from the bottom of https://medconfidential.org/2021/shared-care-records

[7] "In exercising any function under this Act of publishing or otherwise disseminating information, the Information Centre [NHS Digital] **must have regard to any advice given to it by the committee** appointed by the Health Research Authority" - s122, Care Act 2014 https://www.legislation.gov.uk/ukpga/2014/23/section/122/enacted

data[8] versus use of a TRE, with a view to banning the dissemination of *any* patient-level data without a specific view from CAG.

Any attempt by HMG to remove patient dissent by legislative means is likely to prove exceptionally controversial. Particularly given the systemic failures of NHS Digital to facilitate families with children expressing their dissent, it would be wrong and contemptuous for Matt Hancock to presume that every parent cares about the medical histories of their children to the same degree that the Prime Minister appears to care for his...

The critical importance of independent decision-making on secondary uses of patients' data must be protected. When at Public Health England, the cancer registry was beset with cronyism and arrangements that acted as a slushfund[9] – one reason why the cancer registry is now within NHS Digital.

Similar to PHE, NHS England may think it did a good job on data and dashboards in the planning for 'care.data 2', but that is only because it has not told anyone who might point out its mistakes what is going on. In the midst of COVID pressures, did NHSE hand patients' data to a sham organisation because it was under political pressure to be quick rather than careful? Those mistakes will emerge through 2021/22...

Data vs statistics in decision-making and 'PFI for data'

The use of patient-level data directly within decommissioning decisions should be banned.

While commissioning and decommissioning should of course be evidence-based, and while Commissioning Boards should be able to *specify* the statistics and measures they wish to use to make such decisions, and to have those statistics *created* and *published*, no-one – especially NHS England – should be in a position to be able to torture a dataset so as to get the answer that is politically most palatable. This will be even more important as DHSC wants additional powers to Direct NHSE.

If patients' data is to be used in decommissioning decisions, the questions and statistics should be available to all – not cherry-picked to make a case that cannot be supported by *published* statistics. NHS Digital has successfully used Tableau to create dashboards for COVID-19, suggesting that NHS England's desire for Palantir is not solely due to its dashboard capabilities.

While largely obfuscated out of the white paper, the Government's proposed 'PFI for data projects' will fail. It will cost just as much money as Government can be persuaded to pour down that particular drain, and the data quality will not change after the pouring stops. Which is not to say that various interests will not profit from the pouring; they almost certainly will.

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[8] Noting HRA itself must brush up on the law, and correct what it describes as "anonymous health information" where it at high risk of being identifiable in real world practice rather than in a contrived example: https://www.hra.nhs.uk/covid-19-research/guidance-using-patient-data/

[9] https://healthdatainsight.org.uk/category/directors/

Solving social care in the long term

Successive Governments have avoided the 'social care problem', and this Government is no different. However, there is an opportunity right now to use scientific research to reduce the much longer term *demand* for social care.

Repeating Genomics England's research vision but for *for any condition where a post-out test may **become** useful* – covering cancers, Alzheimers, Parkinsons, etc. – established as more of an infrastructure for research and researchers initially than as a clinical tool for today, but with the strategic goal of creating practical and effective diagnostic tools and clinical infrastructure for tomorrow.

Some post-back tests for cancer exist already. Others will not reach diagnostic value for a while, but all of them will be better if provided with better infrastructure. And even for some *partially* useful tests, being able to detect at least *some* biomarkers may help with the prioritisation of some amount of backlog that would otherwise not exist. For sub-clinical uses, such tests have only to work well enough to help.

Again repeating Genomics England's approach, work must be done to make the tests effective and useful as part of normal care. If COVID breaks out again, this work can be deferred for as long as COVID testing has to be ramped up again.

Understanding Patient Data did a recent analysis[10] of press coverage about health data; someone (DHSC or maybe UPD again) should do a similar analysis of the impacts of the white paper on public debate around those issues. The public really does care about their health records.

We are finishing this document the day after the Government announced it believes structural and institutional racism are no longer relevant, within days of when the NHS is waiting for its new non-COVID GP data collection to drop – without either DHSC or the NHS properly informing patients about the collection or their choices. Amongst the all of the wider decisions of Government, both of these may come to inform the views of all communities about the centralised collection and onward copying of data about their religion, their ethnicity, and their entire medical history.

medConfidential, April 2021

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[10] https://understandingpatientdata.org.uk/news/how-are-stories-about-health-data-covered-uk-media

Additional to this paper, are four related others:

- [Specific note on the Direction powers in the white paper](#)
- [Available uses of the Testing infrastructures](#)
- [Available next steps for a trial of a Post-COVID Summary Care Record](#)
- [Why a single cloud EPR cannot work](#)