

COVID-19 Preface [added 6th April 2020]

The content of this document was written prior to COVID-19 being declared a pandemic. This preface aside, we have deliberately left it as a reflection of the Vision as-was. We note some aspects of the Vision, and some choices of NHSX, have stood up to recent events better than others...

NHSX Tech Vision: a consensual, safe, and transparent vision for data?

Not yet, no.

The NHSX Tech Vision covers a lot of ground across the entire NHS and parts of the care system, but is deliberately structured so as to advance certain aspects of legacy DHSC policy that are disconnected from other areas of the Vision. This is a vision document, so we note there is no expectation of *delivery* prior to 2024, but certain steps are still needed before further steps are possible.

The Vision looks to build on data and infrastructure, some of which is entirely missing or currently built on sand. It is notable that the deadline for interoperable health records continues to be delayed at the rate of one year per annum, while a core record for social care is barely on the radar. The choice of a [gambling executive](#) as CTO of NHSX is also notable, especially where the NHS wishes to “nudge” patients into different pathways.

Data

The Vision introduces a clear articulation of what the LHCR programme has become, which is the creation of a “longitudinal health and care record platform” (page 99 of the NHS Long Term Plan); a lifelong record for every patient, linked across every care setting for direct care purposes, but then shared for commercial use via the [Digital Innovation Hubs](#), NHS Digital, and LHCRs themselves .

medConfidential welcomes the direct care aspects, and supports legitimate, ethical research that respects patients’ choices – but where NHSX seeks to promote purposes beyond direct care, there must both be full transparency on how data is used, and patients must:

“...understand how their info is used, and [have] confidence in its uses, and understand how to exercise their information rights” (Tech Vision, p3)

While this statement is welcome, it is no more than a restatement of existing policy – which itself utterly fails to deliver on existing legal obligations, let alone serve as a vision for the future. Despite many assertions and assumptions about “What Good Looks Like” (p14), there is no example from NHSX of what good looks like in this critical area.

Which means that currently, and for the foreseeable future, the only place you can easily see how data about you is used is at [TheySoldItAnwyay.com](#).

To deliver the Vision: DHSC/NHSX must maintain and publish a DH-wide data release register (akin to the existing NHSD register), and then use the NHS Login to allow a patient to see how data about them has been used, for both direct care and for secondary uses.

To deliver the vision of a “life long record” where “data can be safely shared, where it is appropriate to do so”, there must be full transparency to the patient of every way that data about them is used. (This might also avoid perverse consequences in implementing lines such as “population data allows them to be treated as individuals” – which can mean whatever someone wants it to mean, even if that isn’t what NHSX meant.)

By definition, no “life long record” can be anonymous and so, to comply with the “information rights” of each patient, secondary uses of any data from such records should be subject to dissent within the National Data Opt-out. To see why, one has only to compare the steps taken by the academic longitudinal research studies and the reckless disregard for data subjects by DHSC and NHSE/I/X & D, in their eternal desire to use data however they wish. It is also unclear whether the Vision has considered the effects it might have on *bona fide* academic longitudinal data-driven research.

To deliver the Vision: no patient who has already expressed a National Data Opt-out (or a ‘Type 1’ opt-out at their GP practice) should be required to take any other step to avoid having their “life long record” being used for any purposes beyond direct care.

Regarding analysis, and given the wholesale mandated privatisation of health data analysis by HDR UK in its Digital Innovation Hubs, “Analysts... sharing data and code” (p4) is potentially problematic.

‘PFI for data’ is already a bankrupt model – any vision not grounded in building ‘native’ NHS and UK research capacity has a skewed, myopic view of both “proper value” and data economics. Investments of public money and of the public’s “curated” data that leave the NHS paying again and again, in perpetuity, will no doubt be seen as perpetually unwise.

To deliver the Vision: any population analysis funded by NHS or DHSC budgets must have *open outputs* and code – those outputs having data controls subject to those of the data controller, in line with the existing open access mandate on publicly funded research.

Similarly, while the Vision talks about the problem that “[hospital] doctors cannot access GP records or test results without phone calls and faxes”, this is not simply a ‘secondary care vs primary care’ issue, but a problem that goes in multiple directions. (While GPs may see test results, they cannot see what hospital doctors are doing – and, as the Vision itself states, “In large parts of the system patients struggle to see their own records. And one can draw a veil over what can and cannot be seen across social care only for so long...)

We welcome the Vision’s expectation to “require every system to” talk to each other (p18), but that expectation cannot be delivered safely if audit information does not also flow back along the system to NHS Digital, and onwards to the patient.

To deliver the Vision: whenever systems share patient-level information beyond the legal boundary of the current data controller, each system must report to NHS Digital that it has done so, and to where the data was shared.

Individual patients should then be able to see those records of access / sharing, and NHS Digital should be able to publish statistics about where systems are not interoperating in practice – even if they could in theory. Those statistics, combined with information to patients on how *their* data was accessed, will allow areas of the NHS and care system which *don't* access other care records to be examined, both at national level and by their own patients and service users.

Do things once - the NHS App, NHS apps, and the NHS Apps Library

Allowing clinicians to talk to each other is necessary for hospitals to function – and that means “digital” in a health context must always mean “...where clinically useful and safe”. This being the case, NHSX should update NHS England’s guidance on using instant messaging in acute clinical settings, in line with previous discussions back in 2018.¹ Aside from the inclusion of [Hospify](#) in the Apps Library in March 2020, very little has changed since NHS England published its guidance – although the political level in DHSC has moved in this direction for their own reasons.

medConfidential expects plans for the ‘independent assurance’ of apps in the NHS Apps Library to be even more exploitative to patients than the process run by NHS Digital and NHSX. Given NHSX has been unable or unwilling to stop predatory advertising within apps, we don’t see how this accountability shift can possibly be better for patients. Grenfell remains a monument to the failure of such approaches. And after 7 years, evidence of clinical efficacy – much less effectiveness – is a baseline standard yet to be met.

The political fudge of a “thin” NHS App is dysfunctional; we question how NHS111 will be able to do video calling to patients, or whether that is something that NHSX has decided will never come to NHS111, because of a policy decision made to appease commercial interests.

It is entirely unreasonable for a patient to have to install a third party app in order to call NHS111, and there are cases where this has clear *clinical* value. Third party app providers have access to work-arounds so they can create video calling ‘within’ the NHS App; the NHS App should offer this as a core feature (potentially building on existing commercial offerings, where they are in use, but without requiring patients to install a second app).

NHSX hiding a “commercial market” excuse behind a “user experience” focus is unsustainable, especially in an App which allows third parties to execute arbitrary HTML and javascript. For a parent or carer worried about the health of their sick child, the NHSX “user experience” fallacy about video calling is demonstrably disingenuous – and appears as a deliberate choice to push patients to private services, the only merit of which is that they don’t make such political decisions.

¹ <https://medconfidential.org/2018/instant-messaging-in-clinical-settings/>

Inequalities

Where “primary care will be able to gain insights into how their decisions impact downstream costs and services”, will that also apply “upstream” of primary care, to decisions by DHSC and NHSE?

To deliver the Vision: as a starting approach, and to stimulate external interest, NHS England should commit to publishing the spreadsheets which it uses to calculate and inform primary care workload.

We welcome the Vision’s requirement to monitor inequalities in digital services, as aligned with the Conservative Manifesto. We would recommend NHSX consider commissioning an equivalent report to that written by Dr Byrom² for HMCTS/MoJ³ on what measures are necessary to measure in health. Without such an authoritative independent report, with widespread support and buy-in, it is unclear that there will be a consensus view on “What Good Looks Like”.

Such efforts may also create opportunities to introduce signposting of ‘health justice’ services within digital pathways, and to relieve the burden on the NHS of chronic effects of a lack of ‘access to justice’.⁴ Well designed for and in a digital world, such services may be far more effective than in an offline environment; for a range of complex cases across the public services, it may be that a lawyer resolving a problem is more effective than doctors having to manage the health effects in the longer term. This may be especially so where services elsewhere are causing failure demand to land on the NHS.

In closing, DHSC, NHS Digital, and NHSX have all argued that the current process for a family to express their “information rights” under the ‘digital-first’ National Data Opt-Out is “not inappropriate”. If that is “What Good Looks Like” within this Vision, then the Vision will simply not be worth the paper it wasn’t printed on.

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² <https://www.thelegaleducationfoundation.org/articles/the-legal-education-foundation-is-today-publishing-a-blueprint-for-digital-justice>

³ <https://www.gov.uk/government/news/hmcts-publishes-response-to-report-on-use-of-data>

⁴ <https://www.ucl.ac.uk/laws/news/2020/feb/prof-dame-hazel-genn-delivers-workshops-health-justice-developing-health-justice>