

medConfidential comments on the 'Tech Vision'

No patient should be asked to choose between compromising their privacy or compromising their direct medical care. Will the sum of all fears that pervades NHS England (and to a lesser extent other DH ALBs) infect any future conversation on technology?

Transparency, with the primary actor being an informed patient, will also serve as a forcing function for much of the digital uptake work that Matt wishes to see. When patients can see how their data has been accessed and used, for both direct care (SCR) and secondary uses,¹ they can also see how it isn't used. This can provide concrete evidence of disparities in practice which can be addressed without the need for DH to spend limited political capital placing that over other priorities. When doing the right thing becomes easier than not doing it, it aligns incentives across the system. But the system doesn't want to change.

NHS technology problems primarily accrue at and across boundaries. LCHRs might create 'local data pond' for their area, but the complexity will be felt by the patients at the boundaries (whether regions, trusts, clinics, or wards), and ignored by those whose entire incentive is focused within those boundaries. For many reasons, digital projects often make those analogue borders harder, rather than softer or easier for the patient. How does that help?

The latest 'prevention vision' shows those effects in practice. The vision contains little new, but hype in pre-release interviews talked about using patient data. Yet, the applications mooted in the vision barely need patient data at all - the example of a smoker is known from the fact that they're a smoker. Problematically, the NHS using any commercial advertising mechanism to message to those people would provide those networks with state-sanctioned evidence that they were a smoker (etc). Given the goal of prevention, the outreach 'vision' of the Secretary of State can and should be delivered without recourse to patient data - advertising networks have proxies for smokers which can be used for targeting to materially the same effect, and does not provide any additional information.

'Mandating' simplicity

The NHS number in its modern form was a standard from the mid-1990s, made mandatory again by the 'NHS Number' standard in 2008,² made an obligation of NHS funds from the mid-2010s, and was required by law in 2015. It is one thing to start from areas of consensus, quite another to start from areas where the consensus is so broad a Private Member's Bill made it the law some years ago. It is unclear how a rhetorical re-statement of use changes anything.

The simplistic implication that all apps and digital services must use the NHS number is based

¹ Our mockup: <https://nhsapp.experiment.medconfidential.org/#notices>

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<https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/isb-0149-nhs-number>

in a fallacy that is inherently undermining. Some services are prohibited from using the NHS number, and there are individuals eligible for treatment who do not have an NHS number – overseas visitors taken by ambulance to A&E, for example – and many treatment apps in particular environments must handle cases where there is no known identity information for an individual at all (such as an unknown, unconscious arrival at A&E). All of these complex nuances are contained with the existing NHS standard, and are routinely handled by medical professionals and their information systems, yet this concept appears entirely absent from the Secretary of State's vision.

Technology in the NHS is not more complicated than in the rest of the world; it's just harder.³ It is harder principally because the stakes are much higher – unplanned downtime means closing admissions, and affecting life-or-death critical events. Netflix may operate well in a 'cloud first' environment, but the biggest delivery after extra chilling due to service downtime comes 9 months later, and doesn't accrue to Netflix.

A process or a destination?

The NHS is not akin to a startup with an exit strategy. In the conclusion, the 'vision' says "We will know we have achieved our goals when..." and lays out a set of (somewhat) testable hypotheses. Significant but predictable blind spots in those hypotheses will be picked up by other responses, and we do not cover them here.

While many of the areas covered will benefit from high level political attention, the expectation that the vision has an end – rather than needing continual iteration, as the world changes – suggests a fundamental political expectation that the NHS is a temporary phenomenon.

The unintended consequences of grand sweeping gestures can be summarised by the reliance of the Royal National Orthopaedic Hospital on the AI code of Conduct for use of data by a private company co-owned by their CEO.⁴ They appear to have done no other IG, believing the Code of Conduct was sufficient for a researcher to use masses of patient data acquired from the hospital even before the Code of Conduct was published. Perhaps DH would wish to look into that 'shining example' of the Secretary of State's vision...

What the Secretary of State says, and the nuances placed in those documents, matters.

³ <https://russelldavies.typepad.com/planning/2013/01/its-not-complicated-its-just-hard.html>

⁴ https://www.whatdotheyknow.com/request/ai_agreements_with_orthai#incoming-1259566

Patients and informed consent

We are somewhat surprised and disappointed that the vision contains no reference to patients being able to understand how data about them is used – a prerequisite for building the confidence necessary for technology transformations to succeed.

When picking the standards worthy of reference in a key piece of advocacy by the Secretary of State, it is striking there was no reference to the fact that all providers of technology and information systems should expect to be required to provide functionality – integrated with others and primary providers – so that patients should know how data about them is accessed and used. Systems must be required to keep track (although that may be on the API server side of a FHIR gateway, rather than on the API consumer side).

When the last major strategic work was done by NHS/DH, from 2012-2013, FHIR did not exist. FHIR was first launched in 2013, and iterated rapidly to reach the current version in 2017. That it has received such widespread support so quickly from so many suppliers and care providers shows that it delivers on user needs in practice. FHIR allows application developers to build tools that work with any provider that supports the standard – which is generally expected to be on every hospital system.

While there are many opportunities for such an ecosystem to thrive, there is also the need to prevent predatory behaviour by large suppliers. No hospital should be permitted to purchase or use an app which may *only* be used with that particular supplier's FHIR service. So, for example, while the DeepMind 'Streams' app claims to meet FHIR standards, the contract that goes along with that app requires it only to be used with FHIR servers run by DeepMind – thereby requiring DeepMind to have a full copy of the hospital's data, for no real reason. Such predation of NHS providers must be prohibited, and the prohibition enforced.

As with many political documents, there is an assumption that all parties involved will always act benignly, and that their publicly stated intents are sufficient to encompass all actions. Current and growing levels of public concern about data use suggests such political optimism ignores the lived reality of many, if not most. With regard to patients' data, NHS Digital's audits of data recipients show this problem to be pervasive.⁵

The suggestion that "data trusts" would or should have access to NHS patients' health data is founded upon the assertion on the part of those making the suggestion that they believe the NHS itself cannot be trusted, nor expected, to get data dissemination correct. This would be a dramatic admission.

⁵ <https://theySoldItAnyway.com>

Registers and APIs

This section of the vision would benefit from significant additional clarity and explanation. There is a fundamental need for a piece that explains what registers are (and aren't), and how they fit together in an NHS context.

In a health context, people may for example (as in the vision document) be referred to as "registered blind". If this term doesn't change in the data context, it must be explained clearly – including the fact that data registers contain or are about things, and never people – and that they are unauthenticated, and (generally) don't involve the non-published or non-permanent state of an object. Information about people and states are to be found in authenticated APIs. An upgrade of TRUD⁶ to allow freely downloadable registers for all is overdue.

Registers of objects and physical resources are a good thing; registers (as they appear to be conceived in the vision) should be published and accessed *without authentication*, and be understood as such.

Information on people and current state should only ever be available via *authenticated* APIs, with all those making requests being subject to audit. Information about those who access patient-level data should be available to that patient – initially showing only the organisation/department they represent, with individual-level information being available should questions be raised.

There is a temporary fascination with projects like Trillian from DeepMind. This is a necessary prerequisite technology for DeepMind's research into general AI; that they use Trillian for accessing health data for now is simply 'marketing fluff'. If a care provider does not have basic integrity and audit checks on all of its data structures (as pretty much all modern information processing systems should provide), then they have bigger problems. DeepMind's work to provide cryptographic guarantees are due to the future needs of its own research, rather than the NHS' current needs. If the NHS cannot trust a supplier to respond honestly to enquiries and investigations, then it should not be a supplier to the NHS. Trillian, and other blockchain technologies, simply make it impossible for anyone to deny tomorrow what they did yesterday.⁷

The novel aspects of blockchain (and Trillian) arise in the context of the absence of trusted institutions. It would be a surprise if DH felt this was a desirable future for the NHS. As an aside, but from a similar perspective, we note NHS England's public statements around blockchain and similar technologies use examples that are underpinned by NHS England's evident lack of confidence in the accuracy of information they receive from NHS Trusts.

Technology is politics, and while hope may temporarily override experience, culture and momentum are strong forces to overcome.

⁶ <https://isd.digital.nhs.uk/trud3/user/guest/group/0/home>

⁷ See paragraphs 65-68 of our evidence to the AI Select Committee of the House of Lords <http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/artificial-intelligence-committee/artificial-intelligence/written/75844.html>

Delivery?⁸

Accepting a technology too early can also incur technical debt; until FHIR was widely available, it remained unclear that a monolithic approach was the way to go – for reasons FHIR advocates now advocate. DH should encourage infrastructure to serve all – such as the ‘patient postbox’ – and to allow interfaces to systems to be chosen by the specialist groups that use them, while key parts are defined by standards.

The traditional project management methodology, PRINCE2, is based on the idea that there is nothing to learn in the midst of delivering a real world project; the belief that everything those driving the project wish to know by the end they already know at the start. Unfortunately this is also often true of civil service decision-making.

‘Agile’ digital methods assume that a team will learn something in the course of implementing a project. Political cultures and promises, and unstated contradictory Whitehall commitments, make that potentially impossible – especially when a project crosses multiple NHS bodies, and also DH. Agile methods assume there will be as many iterations as needed, which can be true in the private sector, but public sector projects come with harder deadlines and the civil service is excellent at running out the clock on issues with which it doesn’t wish to deal.

In May 2018, the Department of Health and the NHS launched the new ‘National Data Opt-out’ to allow a patient to dissent from their data being used for purposes beyond their direct care.⁹ The digital process for registering a choice only works for individual adults – no mechanism was delivered for dependent children who cannot, legally and practically, use the online service.¹⁰

The most ‘digital’ Secretary of State the NHS has ever had continues to propose the process be a paper form and multiple documents sent by post, because the incentives of his department and arm’s length bodies are perverse; the most ‘Agile’ method of solving the problem was to drop the ‘user need’ of serving England’s families, and instead serve only individual adults with internet connections.

The online process verifies an adult’s identity sufficiently to allow them to make a choice, but does not ask them whether they have any children for whom they wish to express a choice.¹¹ Forcing families through separate processes for adults and children is a digital service failure

⁸ Parts of this are taken from our longer evidence to the Digital Government Inquiry of the Commons Sci/Tech committee:

<http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/science-and-technology-committee/digital-government/written/91683.html>

⁹ <https://www.nhs.uk/your-nhs-data-matters/>

¹⁰ https://assets.nhs.uk/prod/documents/Non-Digital_Parental_Request_Opt-Out_Form_v20.pdf

¹¹ Adults who make a consent choice online, by definition, have had their identity verified against the details held by the Personal Demographics Service (PDS). The digital process could therefore ask if they have any dependent children living at the same address for whom they wish to express a choice. It doesn’t. Each dependent child will already have an entry in PDS for their NHS number, and the existing address / contact details in PDS for the child can be checked with those recorded for the verified adult.

by Government. There is insufficient information currently available to know whether this is a failure of imagination, delivery, management, or oversight – or a combination or all of these. However, for successful digital projects, it is becoming necessary for each level to catch the failures of others. In contrast with previous advisory groups on such issues, such as the care.data Advisory Group (CDAG) on which medConfidential sat,¹² there were no digital or privacy experts on the National Data Opt-Out Programme advisory group.¹³

It is entirely rational – and possibly common – for one department, directorate, or individual desk to make a choice that undermines the goals of another in Government, whether that decision is fully informed or made with a justifiable lack of awareness. The perverse priorities the Home Office enforces around immigration are possibly the most obvious example – but this happens day in, day out, in many petty feuds up and down Whitehall, across all its silos and fiefdoms.

The civil service approach to digital government extends to a digital NHS – initially through the Department of Health and Social Care, and thence into the Health and Social Care Information Centre, or, to use its trading name “NHS Digital”.¹⁴ NHS services are traditionally provided by care providers; in a digital world, they are increasingly being provided by DH bodies under direction from the Secretary of State.

That one of this document’s flagship standards was a standard a decade ago – and made law in 2015 – raises questions as to what it is this new announcement adds. The Secretary of State has a clear political intent behind his vision, which requires implementation and delivery by others. Will improvements in care be delivered in the real world? Absent a route to delivery, this document may prove little more than a policy ‘chew toy’ for ALBs with regard only for pieces within their own silos, an NHS vision that will deliver less than the sum of the parts.

In any event, should DH build a ‘Bonfire of the Faxes’, printing out this (or any) policy document to act as kindling is probably best avoided... again.¹⁵

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¹² <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Lords/2015-12-15/HL4600/>

¹³ http://digital.nhs.uk/binaries/content/assets/website-assets/corporate-information/transforming-care-domains/ndop/20180419_national-data-opt-out-programme-advisory-group_minutes_v1.0.pdf

¹⁴ <https://www.gov.uk/government/news/hscic-changing-its-name-to-nhs-digital>

¹⁵ twitter.com/tkelsey1/status/639015598744322048
twitter.com/digitalhealth2/status/639388002712748032