Genomics, Infants, & Children for Life Sciences in the NHS 10 Year Plan

There is a strong need for a moral and long term perspective on NHS tech innovation – the NHS focuses on only what will get it through the news cycle, and that has harmful consequences for patients and the public each time the bill comes due.

The NHS 10 Year Plan says by 2035: “Big Bet 3: In the NHS of 2035, your personalised health journey will begin at birth” as “This will facilitate earlier identification and treatment of rare genetic conditions and allow us to assess the risks and benefits of storing and tailoring care around an individual’s genome over their lifetime” (page 119).

The 10 year plan to store the DNA sequence of every baby born in Palantir will not improve treatment for any baby or adult. The debate is entirely short-term, focused on budgets and economic growth, with no real assessment of the long-term—beyond the belief that DNA sequencing and AI are assumed to work flawlessly, and that more magic must be better. This may become an “expensive distraction”, as favored technologies are assumed to work flawlessly, while alternatives are assumed to remain static through 2035. All innovation continues.

Future Cancer

If a loved one is diagnosed with cancer tomorrow, the NHS already tries to sequence both them and their tumour where clinically relevant – both need to be done on the same machine at (around) the same time to aid in the matching. The matching will always occur, and will need the same machines unless they’re identical between when one is born and when diagnosed (ie a baby is born with cancer).

The NHS is already trialing blood tests for cancer and mRNA cancer treatments (page 71). The principle has been shown to work, the trials are to see how these can be rolled out at NHS scale, and to see where they are more/less effective in practice, but the plan assumes the NHS will learn nothing from the trials and patients will see no benefit.

It is entirely reasonable that, by the time of the next election, some cancers will be curable in your cat via an mRNA treatment, but the 10 year plan does not help those treatments be available for your loved ones.

The plan says “Whole Genome Sequencing is already showing the promise to significantly improve cancer outcomes for patients with more accurate diagnosis and treatment. Whole Genomic Sequencing for cancer involves analysing the entire DNA sequence of a tumour sample to identify every single mutation” (page 119). It could have said more about the claims – which it does for AI>

Babies and maternity

There is an endless push to sequence all babies at birth – it is profitable for those who sequence the babies, it is profitable for those who store the data for decades, it is administratively budget expanding for the organisations who do the work, it is desirable by

the Home Office, it is desired by hostile intelligence agencies, the only people it doesn't help are those being sequenced. The main constraint is budget, and the cost is falling.

If a baby is born tomorrow who would benefit from whole genome sequencing, the NHS will already do it for them. The plan proposes sequencing every baby, not just those who need it. Trials and demonstrators for expansion beyond those who need it, and keep showing negligible results, with an estimated 4-5 babies out of 100,000 showing any benefit, against ~100 false positive results as covered in the summary by Genewatch UK (since NHS/GeL don't publish concrete figures).

In preparation for the day when the cost to sequence every baby is no longer prohibitive, the NHS has taken "parental consent" and retained[1] the blood spot cards for every baby whose parents have consented to screening since around 2016 (they're retained for "at least" five years, but we understand they have all been kept). The cost to sequence is likely to be about the staff time required to do it within the period covered by the 10 year plan, meaning it will not be every baby born after 2035 who is sequenced, but potentially every person born after 2016,[2] which by 2035 will be almost all those who are British aged under 19.

Single Patient Record in Palantir

The "national platform" for NHS data is supplied by Palantir – a controversial US company with a strong ideological commitment. The 10 year plan does not say where the SPR will be hosted (as the delivery chapter is missing), but it does say that one of the earliest projects in the 10YP will be the maternity monitoring dashboards which will use the Single Patient Record. These dashboards had been pre-announced by DH the week before, and *that* announcement said they would be based on the Federated Data Platform. There's a lot more in our recent written evidence to the Commons SIT Committee.[3]

While some parts of the Department claim there will be an open and fair competition for who runs the SPR, other parts seem to have assumed there won't be. It remains to be seen who will be right, but when it comes to Palantir, a journalist has remarked that the most evil option usually wins.

The SPR will contain all medical notes retained by any doctor, even from decades ago, and it will all be fed to summarising AIs.

Sensors and monitoring

Those who carry a smartphone or wear a smartwatch/fitbit (or any other sensors that monitor your health such as continuous glucose monitoring) often want to share some information with their doctors. If anyone wishes to share any data from their device with the NHS, via the

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[1] Final paragraph "research" https://www.nhs.uk/baby/newborn-screening/blood-spot-test/ – the "small chance" is the 2016 assessment of this happening in 2016. Spots have been retained.
[2] Big red box on page 6 of the Code of Practice from 2018: https://assets.publishing.service.gov.uk/media/5aba5b9a40f0b67d64e21955/Code_of_Practice_for_the_Retention_and_Storage_of_Residual_Blood_Spots_2018__March_addendum_.pdf
[3] Parts are touched on in parts 1 and 2 of the medConfidential episodes of Marcus Baw's podcast, and Palantir in part 3 coming "soon" https://www.youtube.com/@EverythingDigitalHealth/videos

NHS app, then they will be required to share all data via the NHS app to the Federated Data Platform, where DH/E can use it for any purpose they like, including resale if any tangent can be found to "benefit the NHS". The position of the Department / NHS is that patients have to choose between sharing data that may save their life or that of their unborn child, and having that data shared onwards linked with the rest of their medical history, or neither of those things.

The norm of the Apple/Android ecosystems is that if you give an app access to some historic data from a sensor, then it presumes you want to grant all of it.

Algorithms running over sensor data can discover many things about a person – your smartwatch can detect pregnancy before you know. Data mining techniques find predictors in surprising correlations. The same monitoring that creates data which helps a pregnant woman with her maternity care is data that can be *retrospectively* analysed to figure out when particular shifts occur and use that knowledge to target ads at the most intrusive times. Companies that sell device "forensics" services to police and other state entities will also be able to implement those algorithms and give law enforcement (or anyone else who gains access to a device) an algorithmic assessment of the user's life. DWP will use that to measure whether people are more active than their last disability assessment suggests; other countries will be more intrusive to some.

Barriers to innovations spreading across the NHS

Digital tools have created innovations before – the Moorfields project with DeepMind published their findings and there are people walking round London today with no vision problems who would be blind without those discoveries. Deepmind published, there is no expectation Palantir will. Indeed, the main complaint from Moorfields about those discoveries is that Moorfields didn't make enough money off them.[4] Palantir won't make that mistake.

The money Moorfields wanted to make from algorithms was selling them to other NHS Trusts – increasing money to Moorfields but not (materially) increasing or decreasing NHS budgets overall, Palantir will take their money out of the NHS family and give it to their shareholders.

Reuse of tooling (in Palantir)

Palantir 's culture and ethos is about building custom tools for one customer that they can then repackage and resell to others. Both Cancer360 and Optica are Palantir developed tools – built with the NHS and assured by the NHS, but built and owned by Palantir.

Cancer360 is being mandated by NHSE for some cancer hospitals, and is being made available to all of them. If Palantir wants to resell those tools to other customers for their own data, that is how Palantir recoup their own investments. If the NHS were to move away from Palantir's Foundry, Palantir would decide whether they wished to support Cancer360 on any other company's platform (which they would reasonably be reluctant to do).

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In this section and the next comes a lot of latitude for Palantir and the NHS to do whatever it is that is short term opportunistic for the NHS and long term opportunistic for Palantir without public scrutiny on either. We understand this is routine, and while it is *potentially* a breach of one interpretation of the contract, it is likely that NHSE has signed it off for NHSE's benefit, knowing NHSE will shortly be abolished leaving a mess for DHSC.

The gag clause and other word games with the contracts

Palantir allows customers to place a publicity ban on Palantir's work, and NHS England has instituted such a ban. If Palantir wishes to talk about their NHS England work publicly, Palantir must request and then receive permission to do so from NHS England – and that permission is almost never granted. NHS England knows that the list of institutions using it is toxic, and so it does not publish the list (NHSE says it does, but the list is empty).

The gag clause prevents patients from knowing what Palantir do with patient data**.** Palantir can only talk about work it has *not* done for NHS England – this talk by Palantir at the Institute for Government was about their work on what became Cancer360 and was not under the FDP umbrella and not subject to the NHSE gag rule, because it was contracted directly with an individual Trust, meaning Palantir and the Trust could talk about it publicly without restriction from NHS England.

The one attempt by Palantir (US HQ) to do unauthorised communications in favour of Palantir went badly (which, to NHSE, is justification for the gag rule). There was supposedly an NHS England investigation that was little more than a slap on the wrist and a worldwide reminder that NHSE has Alex Karp and below in a gag on their NHSE work, which suits Palantir just fine.

Palantir staff working for Palantir from inside the NHS

Palantir draws huge benefit from its work with the NHS but the deal favours the commercial supplier at the expense of the tax payer, the NHS, and the patient.

When Palantir "forward deployed engineers" (the Palantir name for consultants who are embedded at the customer site passing observations back to Palantir) notice that something is necessary, they can improve the product. When they see this across customers, they are encouraged to reproduce generic products – the platform is designed and primed for reuse.

Anything Palantir staff think of during their work inside the NHS is contributed back into the NHS tools first (or found not irrelevant to the NHS), is tested by the NHS and subject to NHS assurance and testing processes, but since those tools are owned by Palantir, once they have been built by Palantir for the NHS, Palantir can resell them to others (without additional benefit to the NHS).

Cancer360 wan't built by NHSE for FDP but built by Palantir for Foundry (it was built with individual Trusts, and likely with the knowledge and support of some parts of NHSE) – the code is Palantir owned. Palantir can resell it to other customers, as they can their other developed products including algorithms and discoveries from data mining.

Ownership (Palantir)

The Department has told Parliament "All products, outputs, and intermediate artefacts generated within the Federated Data Platform, *funded by the National Health Service… are the intellectual property of the NHS*, and Palantir is not permitted to utilise these for their own purposes". Which is entirely correct and narrowly written – where the work was not entirely funded by the NHS, that statement does not apply.

It is notable that staff move routinely between Palantir teams in different countries – a tour of duty for project(s) in the London office before taking what they have learnt back to their home markets. When NHS England states "It is a contractual requirement that personal data stored in the FDP and NHS PET cannot be accessed by its [Palantir's] own personnel or contractors from outside the United Kingdom" – it is unknown whether each of NHS England, DHSC, and Palantir would consider a Palantir engineer sitting in their US HQ using a VPN to connect into to the Palantir London office as satisfying that stated requirement and whether their citizenship would matter.

Reuse (Palantir)

So anything the NHS uses to find those who are at increased risk of various conditions, or where health data is predictive of something politically interesting, that knowledge can be reused by the "embedded" Palantir engineers on their next project, it can be fed back to Palantir for "product enhancement" and it can be resold by Palantir to other Palantir customers if Palantir own that part of the IP (which they usually do). They can't reuse the data, but they don't have to – as with tiktok and instagram, the money is in the algorithms and implementations.

Palantir's UK CEO's oral evidence to the Science, Innovation and Technology Committee showed (Q125) that tools built for the NHS have the capacity to be "drag and drop" onto other Palantir products which use the same data structures, including their US "ImmigrationOS" platform (just another name for the same Palantir product that the NHS calls FDP) – and tools built for the US will be applicable to the NHS if the NHS wants them – the data controller being the politician who is Secretary of State at the time. For their military customers, Palantir calls this "the digital kill chain" as experienced by civilians of any religion or none in Gaza (or from other suppliers by civilians in Ukraine or, in future, Taiwan).

The NHS number is coming to Schools

Government policy is to introduce a "consistent identifier" for children which is in practice the NHS number, which will facilitate linkage between health and school records for health prevention or other interests of national government (including anything termed "research", whether or not it is in the *child's* interest). There is no opt out or way for parents to object to what the Government of the day decides is a legitimate project as there are no statutory safeguards on uses beyond the legal minimums which are routinely evaded.

Data already held by DfE means data matching can be retroactively applied to those who have school records from any point in the late 1990s. The NHS number applies to a person from birth to post-mortem, and so is not a “child” identifier in any way, it is a life long identifier which schools and government will keep forever.

Data linkage plans will mean school and patient records can be linked to subsequent criminal and victim records. The lack of an explicit legislative basis for linkage creates unclear consequences for obligations on the state to disclose information about victims in criminal cases where the state is involved.

Context of Ubiquitous Audio Recording and Transcription

The proposals for “neighbourhood health centres” involve all consultations in neighbourhood health centres being recorded, transcribed, and summarised by AIs. Reliability concerns will mean that the transcript then the audio will be retained, which will radically change expectations of patients when talking “privately” to their doctors.

Anything said once, any question asked, will be stored forever and indexed by AIs. These records will be under the same data controllership as the Single Patient Record, which is to say they will be owned by the Secretary of State, and will be used for any purpose he sees fit, including performance management of consultations and treatments.

The culture of the current government is to replace (expensive) humans with (currently cheap) AIs and algorithms, and assume nothing will ever go wrong. Endless cost cutting and technical utopianism will result in future administrations replacing expensive humans making decisions with cheaper algorithms (which will eventually become more expensive algorithms). Religious institutions have a long history of introspection, and as Madhu notes at the end of her book, that’s really rather helpful right now, and generally lacking in some.

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