NATIONAL

Paper records hamper dream of a digital NHS

Warehouses of written files, myriad IT systems and threaten Labour's plan to modernise health service

LAURA HUGHES, LUCY RODGERS, SAM JOINER, CAROLINE NEVITT AND EMMA LEWIS

The world's largest publicly funded health service is buckling. A rapidly ageing population and growing numbers of patients with chronic illnesses are placing ever greater demands on an already overstretched NHS system.

This has led to record low levels of public satisfaction, with just 21 per cent of respondents saying they were happy with NHS services last year, according to the long-running British Social Attitudes survey in April.

The UK government's promised 10-year health plan aims to fix the crisis, with ministers arguing that the answer lies in better use of technology and data.

Health secretary Wes Streeting has made transitioning the NHS from "analogue to digital" one of three "big shifts" he says the service must undergo in how it delivers care.

Part of the plan involves creating a single patient record, or patient passport, which would hold each NHS user's data from across GP surgeries, hospitals and other care settings.

But this will require ministers and healthcare leaders in England to tackle dozens of different IT systems and inconsistent data-sharing practices across a tangled web of service providers. The current system is labyrinthine and contains a number of patient data dead ends, as the schematic diagram shows, right.

Prime Minister Sir Keir Starmer's government says "unleashing the power" of the health service's data would improve information-sharing across the NHS in England, while a single patient record would allow the public to access health information all in one place.

Plans for the record are expected to be set out as part of the 10-year health plan in June.

Officials believe a more centralised system would improve the use of data and increase transparency. They are also looking at pricing the patient data held by the NHS and streamlining its sale to companies and researchers.

New laws will make NHS patient health records available across all NHS trusts, GP surgeries and ambulance services in England, while notoriously inoperable systems will be able to share data more easily. The Department of Health and Social Care says this quicker access to patient data will save health service staff an estimated 140,000 hours every year.

The government has so far not confirmed what will happen to historic records, or who will upload handwritten notes into any new system. Hospital leaders on the ground are also sceptical about the plans.

Questions had yet to be answered about "how you safely bring existing disparate records together", especially those not recorded on any system, said one chief digital information officer at a hospital trust in England.

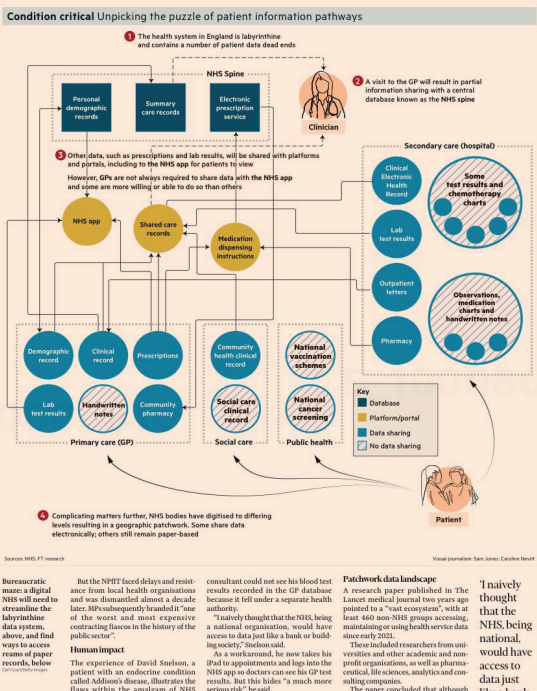
"We have literal warehouses filled with paper handwritten patient records," they added. "It sounds like a brilliant idea and would of course make our lives easier, but how you actually deliver something like this on top of the infrastructure we already have is going to be an enormous challenge."

The creation of a single patient record is distinct from work under way to roll out the Federated Data Platform, for which US data analytics group Palantir has secured a £330mn NHS England contract. The FDP brings together data from different systems on the availability of beds and medical supplies to the size of waiting lists, in order to help improve efficiency across NHS trusts.

"While a small amount of information may be used for both purposes, they are solving fundamentally different problems," the digital information officer said.

The ambition to create a more unified health record is not new. In 2002, then Labour prime minister Sir Tony Blair launched a £12bn National Programme for IT, or NPfIT.

Condition critical Unpicking the puzzle of patient information pathways



Sources: NHS, FT research

Visual journalism: Sam Joiner, Caroline Nevitt

Bureaucratic maze: a digital NHS will need to streamline the labyrinthine data system, above, and find ways to access reams of paper records, below Carl Court/Getty Images

But the NPfIT faced delays and resistance from local health organisations and was dismantled almost a decade later. MPs subsequently branded it "one of the worst and most expensive contracting fiascos in the history of the public sector".

Human impact

The experience of David Snelson, a patient with an endocrine condition called Addison's disease, illustrates the flaws within the amalgam of NHS systems.

His complex condition requires monitoring every six months through blood tests by his GP, as well as an annual review by an endocrinology hospital consultant.

Although he lives in Hampshire, Snelson chose to see a consultant over the county border in Guildford, Surrey, because of a recommendation. But he was "astonished" to discover his consultant could not see his blood test results recorded in the GP database because it fell under a separate health authority.

"I naively thought that the NHS, being a national organisation, would have access to data just like a bank or building society," Snelson said.

As a workaround, he now takes his iPad to appointments and logs into the NHS app so doctors can see his GP test results. But this hides "a much more serious risk", he said.

People with Addison's can suffer from an adrenal crisis, rendering them unconscious and in need of an injection of hydrocortisone.

"If found unconscious and in an ambulance or A&E, it is highly unlikely, even if I have been identified, that the people treating me will be able to see my record and deduce the reason for my coma and the treatment needed," Snelson added.

UseMyData, a group that campaigns for better data usage in the NHS, said overhauling systems would be "difficult" but "welcomed the government's determination to tackle this".

Jeremy Hunt, former Conservative health secretary and chancellor, told the Financial Times: "A single patient record can save people's lives.

"The key thing is not to go down the rabbit hole of saying we need a single national database, which has 50mn electronic records on it, because you have all these security issues," he added. "My feeling is that we are actually making very good progress and I am reasonably positive we will get there."

Patchwork data landscape

A research paper published in The Lancet medical journal two years ago pointed to a "vast ecosystem", with at least 460 non-NHS groups accessing, maintaining or using health service data since early 2021.

These included researchers from universities and other academic and non-profit organisations, as well as pharmaceutical, life sciences, analytics and consulting companies.

The paper concluded that although the NHS collected data centrally, systems for storing and managing it had evolved locally, resulting in a fragmented landscape, with little understanding of which databases or users existed.

This is largely the product of technology procurement being delegated to local levels and data controller responsibilities falling to nearly 7,000 individual providers, which make independent decisions on how data is used.

Last year, a government-commissioned study by surgeon and former health minister Lord Ara Darzi found the "extraordinary richness" of NHS data sets was largely unrecognised by clinical care, service planning or research.

Officials are now modelling pricing structures as part of proposals to create a "national health data service", which is likely to form a part of the government's 10-year plan. Streeting said in October that data was "the future of the NHS" and the UK "could lead the world in medical research".

Ministers have also outlined plans to give researchers and artificial intelligence companies access to public data sets, including anonymised NHS patient information, in an effort to make Britain an attractive place for businesses and to improve productivity.

Accountancy firm EY has previously estimated that an NHS patient record data set could be worth about £5bn a year to a commercial provider. Starmer has said this NHS data would be made available to "support AI research and innovation", as ministers lean heavily on the promise of the technology to boost both productivity and public services.

But privacy campaigners have warned that one single database, even if anonymised, would be more vulnerable to hackers and cyber attacks.

While a single data set "on paper could be great for patient care", it would also be "a gift for cyber criminals and adversarial nation states who want to disrupt critical infrastructure", said Saif Abed, a former NHS doctor and expert in cyber security and public health.

Without significant safeguards, an integrated system would mean cyber crime groups would need only "a single point of entry to launch an attack", he added.

Privacy campaigners also have concerns about patient data being accessed by anyone working in the NHS, as well as potential risks from it being sold to pharmaceutical or tech companies.

Sam Smith, spokesperson for advocacy group medConfidential, said the offer being made to the public was "that if you want good care then the Department of Health must be able to sell your records. It's your data or your life."

But Ciaran Martin, former chief executive of the National Cyber Security Centre, a branch of signals intelligence agency GCHQ, said there were ways of "significantly reducing the risk" associated with one new information system and that solution would have advantages over incompatible systems that were "too out of date to run safely".

Artificial intelligence era

The urgency of resolving these questions is not lost on policymakers.

Government officials said they were still in the early stages of scoping out how single patient records would integrate with existing NHS technology. One option being discussed is to create patient passports for a pilot group, before they are rolled out across the health service.

Officials also said the single patient record was not intended to replace existing electronic systems used by healthcare professionals, but instead to provide a way of synchronising information so that all data systems were accurate and up to date.

Charlotte Refsum, director of health policy at The Royal Marsden Institute for Global Change, said: "The traditional argument is that having all your data in one place makes it easier for a doctor to provide care, but I think there is an added imperative in the AI era."

She added: "The reason a unity of records is important is that AI is eroding the asymmetry of information that exists between doctors and patients . . . you need somewhere to hold all that information in one place, for the first time AI is allowing us to move from an era of 'see and treat' to 'predict and provide'."

With the stakeholder engagement process still under way, officials were unable to say who would operate the new system, when it would launch or how it would be rolled out.

For Snelson, who has had leukaemia for about 15 years alongside Addison's disease, it is about more than a simpler way of accessing the NHS. He wants his medical data to be used for research.

"My leukaemia has started to get better of its own accord without treatment," he said, adding that researchers would never find his full health record since it was spread between three hospitals and two GP surgeries.

"Only I have it all on an Excel spreadsheet."

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> 'I naively thought that the NHS, being national, would have access to data just like a bank or building society'
>
> David Snelson, patient

Contamination fears

Review to look at health risk from lead mines

LAURA HUGHES

Ministers have launched a third review into the risks posed to human health by abandoned metals mines in England and Wales after a Financial Times investigation.

Nottingham university is probing "the health impacts and risks to humans, wildlife and the environment due to heavy metals discharged from abandoned metal mines to ground and surface waters and local soil environment", under a contract awarded by the government.

The UK has 6,630 disused industrial lead mines — with more than half in England alone — that continue to disperse the metal into the environment. Lead can accumulate in waterways and soil before being consumed by animals and entering the food chain.

Consumed by humans, the metal has a devastating impact on almost every organ in the body, with any level of exposure capable of having a harmful effect.

The Department for Environment, Food and Rural Affairs, which commissioned the review last year, declined to comment. But government officials said the review was looking into existing evidence and data around the effects and risks on animals and humans from land and water contaminated by metals. The review, which is to cost £114,250, follows separate investigations by England's environmental watchdog and food standards regulator. The findings are due to be published in October, the officials added.

The academics leading the report previously worked on a study funded by the Welsh government, which identified potentially harmful levels of lead in eggs produced on two small farms downstream from abandoned lead mines in west Wales.

A young child eating one or two of the eggs a day "could become cognitively impaired", according to their research.

Transport

London's congestion charge set to rise by 20%

ROBERT WRIGHT

London's transport authority has proposed a 20 per cent increase in the congestion charge and ending residents' discount for non-electric vehicles, in changes the body said would maintain the fee's effectiveness.

Under the proposals, which are subject to public consultation, the standard congestion charge would rise from January 2 next year to £18 per day, from £15 currently.

The plans would also eliminate a 90 per cent discount for drivers who live in the congestion charge zone, in central London, unless they have a pure EV.

The announcement comes as Transport for London continues efforts to restore its finances, which were battered during the coronavirus pandemic. A person close to TfL said the changes were expected to generate an additional £30mn in revenue during 2026.

TfL required several short-term bailouts from the previous Conservative government and has demanded that chancellor Rachel Reeves implement a new, long-term funding deal for the organisation in June's spending review.

The congestion charge, levied on vehicles entering central London between 7am and 6pm Monday to Friday and between noon and 6pm at weekends, was controversial when it started in 2005 but has since become largely accepted. The charge was last raised in 2020.

Among the proposed changes is a shift in the focus of the cleaner vehicle discount, which exempts all EVs.

From January 2, the discount would be limited to 50 per cent for electric vans and heavy goods vehicles and 25 per cent for electric cars. It would be further reduced from 2030 to 25 per cent for vans and 12.5 per cent for cars.

The move to charge EVs in proportion to growth in the number entering London, which has undermined the charge's effectiveness in combating congestion.