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Preparing the NHS for the AI Era: A Digital Health Record for Every Citizen



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Our <u>Future of Britain</u> initiative sets out a policy agenda for governing in the age of Al. This series focuses on how to deliver radical-yet-practical solutions for this new era of invention and innovation – concrete plans to reimagine the state for the 21st century, with technology as the driving force.



Executive Summary

The UK has a new government with a strong mandate for reform of the NHS. When Secretary of State for Health & Social Care Wes Streeting spoke at the Tony Blair Institute's Future of Britain Conference shortly after the election, he set out his ambitions for that reform. He described the "three big shifts" required to put the NHS back on track:

- A shift from treatment to prevention.
- A shift from hospitals to primary and community care.
- A shift from analogue to digital, with a focus on innovation.

He also described his ambition for the Department of Health & Social Care to become not just a department of public service but one of economic growth, improving the health of citizens so that they are better able to live longer, healthier, more productive lives. This approach would also spur collaboration between life sciences and technology companies to develop new innovations in the UK.

Data underpin the government's ability to achieve those three big shifts. Earlier this year, TBI published <u>A New National Purpose: Harnessing Data for Health</u>; in it we advocated for a National Data Trust in the UK to support R&D and drive

economic growth. Here we propose a digital health record (DHR) to drive improvements to health and care, and ensure that the NHS is ready for the artificial-intelligence era.

Each person's DHR would be the "single source of truth" for their health and care data – data that currently sit in silos across hospitals, GP practices, pharmacies and phones. It would be the fundamental building block of all modern health systems and open up a whole new way of generating health and delivering health care in the future.

The DHR will have most impact in primary care. Inpatient hospital visits are episodic, with clinical teams able to access relevant personal health data through the hospital record. It is out of hospital where the impact of an integrated, digital, longitudinal health record will be felt. The Fuller Stocktake report¹ describes the three core functions of primary care – access, continuity and prevention – all of which will benefit from a DHR, especially with the advent of AI.

- Access: For patients with an acute care need (such as a fever, a cough or pain), access to a DHR would support services such as 111 to make sure they were seen by the right person, at the right time and in the right place – and that their complete medical record was on hand when they were seen.
- Continuity: With a DHR, patients with a long-term condition could be empowered to take greater control of their health through apps and digital therapeutics. It would also facilitate care closer to home, with all members of a neighbourhood team able to work with up-to-date information so that care would be safer and more effective.
- **Prevention:** A DHR could deliver precision public health, offering tailored advice, investigations and early treatment based on individual risk of ill health.

A DHR would also help the NHS prepare for the AI era. Health data are what AI is trained and deployed on – and, increasingly, data are used to regulate AI. A DHR would support the development, adoption and spread of AI technologies in the NHS, supporting the drive to increase productivity.

A DHR for every citizen would also allow the UK to roll out TBI's proposed prevention service, detailed in <u>Moving From Cure to Prevention Could Save the</u> <u>NHS Billions: A Plan to Protect Britain</u>. Recent macroeconomic analysis commissioned by TBI on the value of prevention described how a 20 per cent

reduction in the incidence of six long-term conditions could provide a permanent uplift of 0.74 per cent to the UK's GDP within five years (see *Prosperity Through Health: The Macroeconomic Case for Investing in Preventative Health Care in the UK*).

Investment in the country's digital and data infrastructure may seem like a second-order consideration at a time when elective waiting lists stand at more than 7 million² and there are an estimated 250 people dying prematurely in A&E every week³ – but without it, long waits and care failures will continue. There is strong public support for a DHR, with 89 per cent of patients in favour of having greater access to their medical records, and 81 per cent in favour of something akin to a digital health passport.

Professor the Lord Darzi is undertaking a review of the state of the NHS with a view to reform, making it safer, more effective and more sustainable in the future.⁴ The digital infrastructure and data underpinning the service – including a DHR for every citizen – must be part of that reform.

The Case for a Digital Health Record

Professor the Lord Darzi's audit is expected to reveal an NHS in urgent need of reform: long waits and poor outcomes, crumbling infrastructure and outdated IT, burnt-out and striking staff, and record low rates of public satisfaction.

The temptation is to ask for more money, but the NHS has never had more money and staff than it does now (not including the Covid years, when extra funding and staff were required for the vaccine programme, PPE, and test and trace).⁵ Its budget for the whole of the UK in 2022–23 was £225 billion⁶ and spending on the NHS now accounts for about 43 per cent of day-to-day spending in government departmental budgets.⁷ In fact, NHS spend has outpaced GDP growth for some time, crowding out spending in other sectors and steadily adding to national debt.⁸

It is clear that this situation is unsustainable and, upon taking office, Secretary of State for Health & Social Care Wes Streeting was quick to signal that he would put to an end to the "begging-bowl culture" of looking to government for handouts every winter. Productivity, then, will be a key theme of the proposed ten-year plan for the NHS. A recent report by the National Audit Office revealed that the health service now gets 45 per cent more money than it did a decade ago but is only doing 35 per cent more work.⁹ A failure to invest in capital infrastructure – both physical and digital – was cited as a major causal factor.

The other priority must be prevention. About 40 per cent of the NHS budget is now spent on the treatment of preventable illnesses¹⁰ and by the end of this parliament, sickness benefits are expected to cost the taxpayer an additional £64 billion a year.¹¹ There is, however, hope on both fronts. Advances in biotech, pharma, data, digital and artificial intelligence could deliver the gear change in both productivity and prevention that is needed. For example:

 In pharma and biotech the potential of GLP-1 agonist-type drugs is only just being uncovered. They appear to not only suppress appetite but also cravings; independently of weight loss, they also seem to reduce the incidence of heart attacks and strokes.¹² Al is helping to design novel antimicrobials,¹³ while new multi-cancer early-detection blood tests look set to transform screening and early diagnosis.¹⁴

- Data and AI are being trialled by the NHS in the UK and in other countries at every level of the health system, to guide decision-making and improve operational efficiency. At a national level, AI is being tested to guide health policy,¹⁵ regionally to coordinate care, in hospitals to improve operational efficiency, in primary care to support clinical decision-making and in backoffice departments to deliver administrative functions.
- Digital technologies are supporting patients and staff, with digital therapeutics empowering patients to take greater control of their own health and remote monitoring empowering clinicians to care for patients in the community.

In the AI era, it is simply not enough for health systems to amass as many AI technologies as possible into their current business models. They need to appreciate just how different the AI era will be and how fundamentally different they will need to look to survive – and that includes the NHS.

DHRs will be key to unlocking the benefits of these new technologies and establishing new models of care. They are fast becoming the foundational building blocks of modern health systems, with countries across the world investing in this critical piece of digital and data infrastructure. Estonia, for example, earmarked 1 per cent of its GDP to fundamentally reform its health-data infrastructure; now 98 per cent of citizens have a digital ID and everyone has a DHR – and 20 per cent have had their genome mapped and linked to their DHR.¹⁶

The structure and function of DHRs vary but they tend to have some key structures in common:

FIGURE 1

The structure and function of a digital health record



- 1. **Data core:** Cloud infrastructure that links personal health data about an individual from multiple providers in one place.
- 2. **Applications layer**: Interface between the data core and the wider world, where data are accessed by users.
- 3. **Patient portal:** Secure website or app through which patients can view their data, share them with third parties and process them using inbuilt algorithms. Patients may also be able to upload content such as photos, forms and wearables data.
- 4. **Provider portal:** Secure website, app or provider-management system through which providers can view the DHR, upload content (such as diagnoses and treatments) and process it using inbuilt algorithms to support clinical decision-making. It can also be used to audit provider

quality and performance against benchmarks and standards.

5. **Insurer portal:** Secure portal through which insurers can access anonymised and aggregated data about the risk profile of the population.

These features generate some unique functions that help prepare health systems for the opportunities and challenges that will be faced in the AI era.

1. DATA CORE

The data core is the heart of a DHR, essentially uniting information *about* the citizen, *around* the citizen.

This will become increasingly important in the AI era. AI is already eroding the asymmetry of information that underpins the clinician-patient relationship. In future, AI will make medical advice more widely, cheaply and quickly available, making it far less likely that any one provider (even the NHS) will be able to hold all relevant data about one patient.

In reality this only exacerbates an existing trend for people to seek advice and treatment outside the NHS. In 2023 nearly 45 per cent of young people who saw a GP used a private service¹⁷ and more patients than ever signed up for private medical insurance.¹⁸ DHRs bring those records together and include information from: public and private providers of care; primary and secondary providers of care; investigation and diagnostic services; and wearable monitoring devices.

Another key feature of the data core is its capacity to train clinical AI models. India's Apollo Hospitals group, for example, has created its own clinical intelligence engine (CIE): a clinical decision-support tool trained on personal health data from its millions of patients, the insights of its many clinicians and peer-reviewed journals.¹⁹ The CIE now has more than 1,300 conditions and 800 symptoms in its vocabulary, and it is available to all 4,000 Apollo doctors through a clinician portal and to all customers through a smartphone app.

The structure of the data core determines the extent of its functions. In a centralised model, all data are stored centrally in the cloud. Data are uploaded, standardised, labelled and stored in a structured database, with each citizen having their own "bubble" of dedicated, linked storage. In a federated model, the data remain stored at source but are called up as and when required to support decision-making. A hybrid model can do both, storing a core set of

information centrally but having links back to local data-storage systems to draw on as required.

There are two key benefits to having at least some data stored centrally. The first is that it speeds up processing times for the most common analyses of the data in a DHR; the second is that this kind of centralised structure is required for the training, deployment and regulation of AI models. This latter benefit is important if the UK is to consider developing some sort of large language model (LLM) to support clinical decision-making for citizens and clinical staff.

With hybrid DHRs there is also a decision to make about the amount and type of data that are stored centrally, and what can be called up as and when required. In the US a state body, the Office for the National Coordinator of Health Information Technology, determines that core dataset, which is called the United States Core Data for Interoperability (USCDI). This dataset is flexible, changing over time via a predictable, transparent and collaborative public process.²⁰ In the future one could imagine citizens having the option to upload genomic data, wearables data (such as heart rate and respiratory rate), microbiome data and real-time environmental data (such as ambient pollution levels in their postcode). Social determinants of health such as housing quality and employment status would also be an option.

2. APPLICATIONS LAYER

The applications layer is the interface between the DHR and those requiring access to the data within; application programming interfaces (APIs) are the gates through which that information flows. Each API has unique specifications that define the users that can access the information, what information that user is entitled to see and whether the citizen has consented to share the information with that user. APIs can also ingress information into the DHR, such as a new diagnosis from the hospital.

Information about an individual or a group of individuals can be shared, and those data may be personally identifiable or they may be anonymised. The three most common users requesting access to the information are the patient, the provider (an individual clinician or a wider organisation) and the insurer, although in some cases (with patient consent) DHRs can facilitate the sharing of information with academic bodies or commercial life-sciences companies for the purpose of research. Siemens Healthineers is an example of a company that provide this DHR function, linking personal health data for patients, providers and insurers across Europe and Latin America.

As with the data core, the structure of the applications layer determines its functionality. Having open APIs and complying with internationally recognised standards for data interoperability – fast health-care interoperability resources (FHIR) standards, for example – make DHRs optimally interoperable, which is key if they are to fulfil their potential.

Interoperability allows for choice, and choice can help with the capacity, innovation and agility of health systems, spurring entirely new models of care.

First, capacity. An interoperable DHR – independent of a GP or local hospital – immediately expands capacity, allowing citizens to consult a much wider range of providers while preserving both clinical safety and continuity of care. A DHR could expand primary-care capacity in the UK, for example, by facilitating wider expansion of the Pharmacy First scheme, drawing on the skills and capacity in community pharmacies to deliver more screening, vaccination, chronic-condition management and acute care. An interoperable DHR also enables patients to navigate entirely new digital pathways of care.

Increased choice of provider can also be a powerful driver of innovation adoption in primary care. This might be technical innovation (such as a new stethoscope that detects heart failure) or care-model innovation (such as virtual wards or home-treatment services). This is important. The old model of general practice (ten minutes for one problem, by the time you are already sick) still prevails in most practices – and hasn't changed since the inception of the NHS in 1948. Harbr is an example of a primary-care accelerator in the UK doing great work to scale innovation start-ups in general practice, but an element of competition and contestability can help too.

Competition and contestability are sometimes said to be at odds with integration, but global evidence shows that integrated care systems thrive in a competitive market. Montefiore, Kaiser Permanente and Geisinger are all highly innovative, accountable care organisations in the US, providing integrated care for whole populations of patients. These organisations are in competition with each other for custom, which provides at least some of the financial incentive to innovate.

The same is true in Israel, which has a publicly funded health system. There,

four health-maintenance organisations (HMOs) compete to provide citizens with a "basket of goods" set by the Ministry of Health, to which all citizens are entitled. At least two of them, Clalit and Maccabi, continuously push boundaries in their innovative approach to care delivery; as such, it's no coincidence that health outcomes in Israel far exceed those in the UK.

Even in Spain, where health-care provider Ribera Salud runs an integrated health system on behalf of the government for Valencia's citizens, there is contestability: if health outcomes and performance objectives are not met in the course of the five-year contract, the provider can be replaced.

In each of these examples, the systems in question have created an environment where mobility of custom propels innovation throughout those systems. Providers are encouraged to "pull" innovation towards them, rather than someone else pushing it onto providers that are sceptical of change and resistant to externally developed solutions.

The choice and mobility that an interoperable DHR confers will also be critical to the agility of health systems in the AI era, providing the flexibility for them to evolve and adapt as new treatments, technologies and models of care are developed. The nature of AI as a general-purpose technology, pervasive across all sectors and disciplines, will lead to an acceleration in the pace of innovation. Without choice and movement, health systems will become fossilised in old models of care.

Many private medical insurers have started to recognise this and prepare. AXA, for instance, uses health-technology platform Healthanea to provide a DHR functionality, mapping typical care pathways and modelling how they change in response to new technologies and care models. This means that AXA can keep up, working with innovative providers to make new care pathways standard practice. Healthanea is piloting this technology in Sweden, which is another country with a national health service, predominantly taxbased financing and public provision. Like the UK, it also has a capitated health-payment model.

In the US, this interoperability has been mandated in law as a result of the 21st Century Cures Act. Passed in 2018, it compels the creators of all electronic health records (EHRs) to have open APIs, making the data readily available to all those with the right to access it. This also ensures that the data are presented to users in an agreed and standardised format (so, for example, a hypertension diagnosis in one system is a hypertension diagnosis in another). In reality, this legislation can be difficult to enforce and in the UK, there are examples of interoperability working without legislation; Cheshire and Merseyside integrated care system (ICS) is one example.

3. PATIENT PORTAL

Patient portals are not technically part of the DHR – they are add-ons – but they vastly improve functionality and create a whole new use case: self-care. The health-care industry is decades behind industries such as retail and banking that made this switch years ago, putting control and responsibility into the hands of consumers so that they can make autonomous decisions.

In the age of AI, this autonomy becomes even more powerful. Citizens are about to be confronted with a range of industry-grade, consumer-facing apps that could help them manage their own heath. Patient portals can act like a digital marketplace for those apps, with the option for citizens to share their DHR to improve the accuracy and personalisation of the advice. The NHS App is an example of a patient portal that could potentially do this. The AI-enabled digital physiotherapy app Flok Health, for example, was recently approved by the NHS for the self-management of lower back pain, but currently has to be accessed outside the NHS App.

Patient portals don't have to be owned by or accessed through "official" health systems, however; in the US, for example, the 21st Century Cures Act enables people to download their health records from any provider and add them to the Health Wallet app on their smartphones. From there they can download third-party apps, share their health data (with consent) and get access to personalised Al-powered insights.

Through Apollo's patient portal (the Apollo ProHealth app), patients can use the CIE to support them in preventing ill health, accessing timely advice and treatment when they do get ill and managing longer-term conditions when illness persists. The app gives patients access to a chatbot-based symptomchecker (CSC), tailored advice on how to manage chronic long-term illnesses such as diabetes, and a personalised health-risk assessment and treatment plan.²¹ Each of these functions uses a combination of the patient's own health data and the analytics capability of the CIE to give bespoke advice.

Apollo's AI cardiovascular-disease tool uses recorded medical data combined

with reported lifestyle factors and wearables data to provide each patient with a personalised risk score and prevention plan. This risk-prediction algorithm is constantly updated based on the feedback it gets from patients; the platform also allows clinicians to track progress and compliance with the treatment plan, and identify where intervention may be required.²²

Similarly, Greater Manchester uses the GM Care Record and patient portal My GM Care to develop care plans and share them between health and social care. Patients can also contribute to those plans by adding information such as blood pressure, weight and mood.

4. PROVIDER PORTAL

Provider portals are an interface through which health-care providers (and, in particular, clinical staff) are able to view, edit and process the DHR. Depending on the tech stack, provider portals can enable collaboration between multidisciplinary teams, new models of care closer to home and the performance management of clinicians. In the AI era, they also enable personalised treatment for each patient, based on individual characteristics and risks of ill health.

In Israel, HMO Clalit achieves this using its Proactive-Preventive Interventions platform.²³ This clinical-analytics platform analyses each patient's personal health data and ranks their management against gold-standard guidelines – and their outcomes against typical benchmarks. It thereby delivers real-time updates on who is at risk and what to do about it, allowing for tailored advice and treatment options. Meanwhile, Mayo Clinic uses a common care record to coordinate home-care services for patients with medical complexity. Multiple community-care teams report into a 24/7 command centre with medical-speciality oversight.²⁴

A DHR with a shared provider portal will be critical to underpinning Dr Claire Fuller's vision for neighbourhood teams (as set out in the Fuller Stocktake report²⁵), as well as the shift towards community-care models such as virtual wards. The NHS's Shared Care Record programme has delivered provider portals for the majority of ICSs, but more transformation work would be required to get them embedded into GP workflows and ICS care pathways.

5. INSURER PORTAL

Insurer portals are not technically part of a DHR, though given it is often insurers providing a DHR function in other countries, they commonly feature. These portals allow insurers to understand the risk of each of their customers. This allows them to set premiums and copays, define the services that each customer is eligible for, balance their assets and liabilities, and make sure they at least break even (or, ideally, make a profit).

The NHS often isn't thought of as an insurer, but it should be; it's the NHS's insurer function that allows UK citizens to pay according to their means, take according to their need and receive their services free at the point of use. At present, however, the NHS is unable to perform its insurer function effectively. It lacks the data to understand the risk profile of its population and it lacks the mechanism to ensure that risk profiles guide decisions about entitlements and allocation of spending – namely, the services that all UK citizens are entitled to and therefore can expect the NHS to deliver.

Ultimately, what the lack of this mechanism leads to is long waits across the system, whether that's waiting for a GP appointment, waiting for an ambulance, waiting for an elective operation or waiting to be seen in A&E. It also leads to widespread disappointment. Failing to meet people's expectations of the health service, especially when the tax burden is so high, could lead to people questioning exactly what it is they are paying for and whether it's worth it – and that attitude is insidious. It undermines faith in the principles of the NHS, just at a time when we need a nationalised health insurance system the most: the AI era.

With the advent of AI, the world is entering an era where, almost from the moment someone is born, it will be possible to determine (with some degree of accuracy) what they are going to die of and when. In a competitive health-insurance market, that could make a lot of people instantly uninsurable. Only government, with its unique capacity to pool risk across the whole population, can provide the level of protection required, protecting its citizens from catastrophic health-care costs.

Establishing a Digital Health Record for Every Citizen

Before describing the practical steps that the government should take to establish a DHR, it is worth setting out a picture of the landscape that currently exists for integrated care records in the UK, and some of the issues that there have been with progressing that into a national record for every citizen.

CURRENT LANDSCAPE FOR PERSONAL HEALTH DATA IN ENGLAND

Endeavours to integrate personal health data into a DHR in the UK have been fraught with difficulty; multiple attempts have been suspended or cancelled due to concerns about transparency, patient consent and data security.

As a result, the UK has been left with a mixture of integrated health datasets: some very narrow, nationally integrated datasets such as the Summary Care Record (SCR), and many much broader local ones. National datasets tend to include the kind of information required in an emergency: basics such as past medical history, allergies and current medications. Local datasets are usually used to coordinate care around complex patients and have input from many providers.

The SCR is an example of a narrow, national database with basic data. It draws on the GP record and is most commonly used in A&E, by pharmacies and by other authorised providers outside of general practice. Private providers are not able to access it and it does not have a direct link back to the GPs' provider portal, nor into a patient portal such as the NHS App. Patients are unable to view it and clinicians are unable to make changes to it – and it is updated only when the GP record is updated.

Another example of a narrow but nationally available solution is the NHS App. At present it can display basic information from the GP record and pathology results; soon it will display information from secondary providers too. It is only available for patients to view (they are unable to share the data with third parties) and at present there is limited functionality in terms of analytics: identifying when patients are due a checkup or screening. One major problem that the NHS App has is that only about 80 per cent of patients are able to view their GP record through it.²⁶ The reason for this is that many GPs, as sole data controllers of their patients' health information under GDPR legislation, are understandably reticent to share it for fear of data breach and litigation. This highlights another key problem with data integration in the UK: while open APIs and interoperability standards are almost universally stipulated as part of NHS supplier contracts, they are rarely enforced because the UK lacks the legislative framework to compel vendors to comply (and sometimes because the NHS offers inadequate terms in their procurement contracts for suppliers to comply).

An example of a comprehensive, regional offering in the UK is the Combined Intelligence in Population Health Action (CIPHA) programme, which is based on the Graphnet record-sharing platform. This programme combines datasets across populations of between 1 and 5 million, drawing on data from mentalhealth, primary-, secondary- and community-care settings, and includes local authority social-care data and additional datasets from the likes of housing, 111 and 999 services.

Led by Frimley Health and Care ICS, and Cheshire and Merseyside ICS, 11 ICSs covering 17 million patients operate the system and work together. CIPHA uses the data, analytics and associated tools to provide insights for service transformation in areas such as the management of patients with long-term conditions (LTCs), support for patients in care homes, prevention programmes (covering the likes of strokes, fuel poverty and diabetes) and the management of waiting lists. With its rich dataset, CIPHA is able to provide those ICSs with a comprehensive understanding of the risk profile of their populations, which enables them to plan services accordingly. CIPHA includes patient access in some ICSs, including the ability to upload home-monitored data such as blood pressure and weight, as well as ECGs. In some cases it also feeds patient-level insights back to clinicians in primary care.

Patients Know Best (PKB) is another example of a more comprehensive and regional solution.²⁷ Designed to unite all data into a lifetime record that is owned by the citizen, PKB has about 18 million registered patients to date. It currently supports 19 ICSs in collating, linking and processing the mainly primary- and secondary-care records of local residents. The records are hosted and processed on the cloud and communicated back to both patients and GPs, with actionable insights through PKB's patient portal and clinician

portal, as well as the national NHS App. Patients can authorise third parties to access their record using open APIs with FHIR²⁸ and OAuth standards.²⁹

There are also some commercial, patient-facing DHRs on the UK market; while their use is fairly limited at present, there is potential to scale. An example is Apple, which has agreements with two NHS trusts (Milton Keynes University Hospital and Oxford University Hospitals) to allow patients to download and view their hospital care records through the Health app on their smartphones, though this is a viewing function only and data cannot be exported or processed.³⁰

There are two other key integrated health-data solutions: secure data environments (SDEs) and the Federated Data Platform (FDP).³¹ SDEs are data platforms used to provide authorised researchers with secure access to integrated NHS data for R&D purposes. They do not have a remit for use as a DHR but have the geographical footprint to act as one.

The FDP is a group of 12 regional data platforms all joined up to one national data platform, designed to "bring together operational data – currently stored in separate systems – to support staff to access the information they need in one safe and secure environment".³² It draws on secondary-care data and has two target audiences: NHS trusts and integrated care boards (ICB)s. It helps trusts with elective recovery and supply-chain management; it helps ICBs with population health management (PHM) such as planning services, and care coordination such as supporting hospital discharges. There is also a use case to ensure fair and equal access to vaccination and immunisation.

Use cases for the FDP are strictly defined: they do not include use of the platform as a DHR and neither are there any plans to develop its analytics capacity to process individual health data in this way. There are no plans to communicate actionable insights back to the patient, GP or relevant care team, nor has it been designed as a tool for monitoring primary-care performance, driving payment reforms or auditing patient management against gold-standard protocols.

The FDP is an NHS product, so it is not designed to ingress data from privatesector providers or wearables, nor interact with any personal applications, and there are also specific concerns about the potential for the NHS to be locked into a single vendor for the analytics functions. In addition, progress on the FDP has been slow and there has been a reticence within trusts and ICSs to adopt it if they have systems in place that already function for them.

PRACTICAL STEPS THE GOVERNMENT SHOULD TAKE TO ESTABLISH A DIGITAL HEALTH RECORD FOR ALL CITIZENS IN THE UK

Commit to a Digital Health Record for Every Citizen Within One Term

The government should commit to creating a DHR for every citizen. This would become the single source of truth for every citizen's personal health data, replacing the GP record as the integrator of health information. The DHR should be able to ingress personal health data from all NHS providers of care (primary, secondary and community), as well as private- and third-sector organisations, and wearable devices. The DHR should be hosted on cloud infrastructure in a hybrid model, with some data held centrally and other components federated.

Recommendation: The government should commit to creating a DHR for every citizen within one term of government.

Establish a Unit Within DHSC to Deliver the Digital Health Record

The DHR should be a non-proprietary resource conferred on citizens by the Department of Health & Social Care (DHSC), rather than a private entity or the NHS. Its purpose should be to safely collect and store the personal health data of every citizen, with citizens in turn able to share that data with chosen third parties if desired. This investment should not preclude IT budgets elsewhere, which should be ringfenced and protected.

We propose that the government establish a dedicated unit within the DHSC to deliver this new resource. This department should report to the health secretary and aim to have a working minimum viable product for the DHR within two years, and a comprehensive record within five years (one parliamentary term). Governance of the DHR's design and build should include representation from clinicians (especially GPs) and patients.

Recommendation: The government should establish a dedicated unit within the DHSC to deliver a DHR, reporting to the health secretary.

Legislate for Joint Data Controllership

The government should legislate to make the health secretary a joint data controller with GPs. This will be essential for the functioning of the DHR, is similar to the arrangement agreed in Scotland and was proposed in our recent paper, <u>A New National Purpose: Harnessing Data for Health</u>.

Recommendation: The government should legislate to make the health secretary a joint data controller with GPs.

Legislate for Interoperability

The government should legislate to compel all vendors of EHRs to comply with internationally recognised FHIR resources³³ – to provide a framework for exchanging electronic health information consistently and securely across different health-care systems and applications – and have open APIs.

As previous attempts to enforce interoperability through contracts with providers has failed, government should pass legislation similar to the 21st Century Cures Act³⁴ in the US, compelling all EHRs to have open APIs with health information supplied in a standardised, readable format. This should apply to both NHS and private providers, as well as primary and secondary care. Mandated changes to interoperability would need to be adequately funded however, as these changes take considerable time, effort and money.

This legislation should also define the minimum dataset required for ingression in this format, similar to the USCDI, and compliance should be enforced retrospectively to allow all existing data to be ingressed to the new record.

Recommendation: The government should legislate to compel all vendors of EHRs to comply with internationally recognised interoperability standards, and have open APIs.

Conduct a Public-Engagement and Deliberation Exercise

The DHSC, with the NHS, should embark on a public-engagement and deliberation programme before and during the creation of the DHR, then invest in adequate communications when it is implemented. This may involve the public participating in procurement decisions and getting other opportunities to provide input regarding the process. Being able to demonstrate that the DHR has secure governance will help to build and maintain public trust.

Many of the ICSs with advanced data stores already have comprehensive communication plans in place, using adverts, mailshots, social media, and posters to communicate changes. Some ICSs like One London have done public consultation sessions and most Information Governance boards include patient representatives. There will be plenty of learning here to support the implementation of a DHR more widely.

Recommendation: The DHSC and NHS England should conduct a publicengagement and deliberation exercise about the DHR and then invest in adequate communications when it is implemented.

Commence a Rapid Design-and-Build Phase

The DHSC should commence a rapid design-and-build phase, starting with a critical evaluation of the options. How that is achieved, however, is open to debate. Below we consider four options, each with their own merits, though they vary in likely cost, speed, ease of implementation, ease of use and propensity for vendor lock-in.

Each will require testing, piloting and graded rollout, with both organisational design and change management in place to support the new system and ensure users are guided through the transition process.

The options considered are:

- 1. Build from scratch.
- 2. Build out from existing secondary-care infrastructure.
- 3. Build out from existing primary-care infrastructure.
- 4. Scale an existing digital health record.

Here we summarise some of the key pros and cons, before going into more detail on each approach.

1. BUILD FROM SCRATCH

Building a DHR from scratch would require the national procurement of both cloud infrastructure (data core) and software (applications layer), followed by a

process of integration, ensuring interoperability between instances, with key providers of information (such as GP practices) and with users of that information (such as patients).

Interoperability is key between any instances if a federated platform model is selected (so that DHRs in different parts of the country can talk to each other), and also between the data core and applications layer (so that the applications layer functions as a true marketplace).

However, there are plenty of examples of interoperability not been achieved, even with laws and contracts in place mandating it. This can occur when different suppliers are procured to operate different instances; interoperability stalls because there is no incentive for the instances to cooperate. This has led some health systems to procure instances from one supplier (despite effectively creating a monopoly for them), which is a consideration if the "build from scratch" option is selected.

Conversely, interoperability between the data core and the applications layer can be lost when both are provided by the *same* supplier. This is because, when one supplier holds the contract for both data core and analytics layer, there is an incentive to ensure that the applications layer is only really compatible with its own third-party apps (or third-party apps with which it has an affiliation). As such, the value of the applications layer as a true marketplace is lost.

A potential solution to this problem would be to procure the data core and analytics layer from separate suppliers, then put strict terms and conditions around whether the supplier of the data core could bid for application layer contracts. DHSC could also maintain strict control of the APIs and distribution of API keys, but to achieve this control it would need a governance board for the DHR with independent technical experts.

Building from scratch has one key advantage: it means being able to design a bespoke solution. However, it does not solve the problem of the outdated tech stack that exists in primary-care practice-management systems. This will have a huge impact on how impactful a DHR is in practice, as it is all very well offering data but it is the insights and actions that follow that will impact care and outcomes.

In addition to this, the initial costs of development, infrastructure and migration

are likely to be high for a build-from-scratch option, while large-scale IT projects often face delays and unforeseen challenges, impacting costs and the rollout schedule. Building from scratch would likely require external consultants with relevant technical expertise to oversee the design and build.

2. BUILD OUT FROM EXISTING SECONDARY-CARE INFRASTRUCTURE

DHSC could also consider using the existing FDP infrastructure, though this option would take some work. It would require the onboarding of primary-care records, which has been difficult historically because of the challenge of getting buy-in from GPs and the owners of practice-management systems. It would also add a use case to the FDP for direct patient care, which is a controversial option.

Even then, however, the FDP might not provide the outcomes desired of a DHR. The FDP is not a persistent data store: it is a federated model that draws on data as and when required, which puts a limit on the capacity of government to develop AI models trained on health data as other countries have done. A federated model can also slow the processing time of requests, and at present the FDP contract makes it difficult to separate out the provision of a data core and the applications layer.

The FDP has been slow to make progress, in part due to opposition from data-privacy groups and in part due to slow uptake from trusts and ICBs. This may change given the recent decision of NHS England to mandate sign-up, given that only around 50 per cent of trusts have signed up to the platform. Use of the FDP infrastructure would also mean the DHR was an NHS asset, rather than a national asset for citizens. That said, the FDP may be a good option as an insurer portal, providing collated, anonymised information for the DHSC on the risk profile of the population.

3. BUILD OUT FROM EXISTING PRIMARY-CARE INFRASTRUCTURE

An advantage of this option is that most people in the UK already have a primary-care record; at the moment it is the closest thing everyone has to an integrated longitudinal health record, and these records sit with one of only two major suppliers: EMIS and TPP/SystmOne. This could make it simpler and faster to create one single, joined-up national asset in the form of a DHR.

In addition, primary-care records are already connected to a patient portal

(the NHS App) and a provider portal (through the GP practice-management system) and one of the latter, EMIS, is in 90 per cent of pharmacies. Integration with an existing provider portal would be particularly useful for multidisciplinary teams. Neighbourhood teams will need a common platform with read/write access that allows for coordinated teamwork, even when individual clinicians might be working across different geographies and on different sites.

The difficulty with this option is that procuring one (or even two) of the suppliers to take on a contract for a national DHR creates a formalised monopoly or duopoly, which could lead to claims of anti-competitiveness (with potential for legal challenge) and vendor lock-in (with associated risks in terms of price and dependency, and the lack of a true marketplace in the applications layer).

One potential solution is to avoid the procurement route altogether and pursue a public-private partnership. In return for the national contract, either one or both systems would hand over the UK licence for their products to the DHSC – and with it the data core, analytics layer, clinician portal and right to develop the tech stack to the DHSC's own spec.

Dealing with one or two organisations would have the advantage of tightening the line of accountability for rollout. And while there would be vendor lock-in to these systems initially, the structure of the DHR could be developed in such a way as to ensure that the contract was completely contestable within five years.

This option would create a single national asset that was state owned and controlled from the start. Full integration with a provider portal could also eliminate the need for separate electronic-referral pathways.

4. SCALE AN EXISTING DIGITAL HEALTH RECORD

There are good reasons for considering this option. Several integrated-record solutions already exist in the UK – in fact it is estimated that about 50 per cent of the English population already has a local solution with most of the data required for a DHR. The most advanced are probably the Shared Care Records in Manchester and London.

The CIPHA programme, based on Graphnet and operating in 11 ICSs including

Manchester, covers 17 million patients; One London, operated by Oracle Cerner, integrates primary- and secondary-care records for 9 million people in the capital. PKB is another solution provider, with 18 million patients on its books.

Building out the DHR from existing Shared Care Records in Manchester, London, Frimley and elsewhere would require a combination of the following steps:

- Adding functionality to the existing solutions where they exist, deploying a standard API set to match the agreed DHR specifications.
- Building new instances in parts of the country where none exist currently.
- Ensuring that each of the instances are interoperable with each other.

Ultimately, the structure would look like 15 to 20 instances (data warehouses) across the country, each covering a population of between 1 and 5 million. These instances would ingress information from a range of health-care providers, then cleanse it, link it and store it before offering it to third-party applications when required for viewing or insight generation. Local instances could then be linked to one large national platform that would be able to connect data about individual patients across the country, making it a truly national service.

National specification standards for each instance could ensure that each of the instances performed the functionality of a DHR, despite being delivered by different suppliers. For instance, a common set of APIs would be specified (the UK core standard developed by NHS England and owned by HL7UK would be an obvious place to start), meaning data could be held or organised differently in each local data store but still be served up using a common format, irrespective of the data store in use. This would have to be financed, of course. Interoperability standards take time, effort and money to apply and have been historically underfunded in procurement contracts; suppliers have even been put out of business when these stipulations have been retrospectively applied. These standards would also need to be UK specific, as off-the-shelf US interoperability standards are not directly applicable to UK systems.

The advantage of this solution is that it builds on existing infrastructure, with existing information-governance solutions, existing relationships with clinicians and system leaders, and existing connections to providers of care (such as hospital EHRs).

That said, the coordinated effort required to mobilise a national project with multiple suppliers, all integrating with multiple providers, could prove challenging to progress at pace within one term of government. Differing approaches to data architecture across regions could also create inconsistencies that make national initiatives (such as public health or Office for Life Sciences strategy pieces) much harder to deliver – unless APIs are standardised. It also means that data control remains at a regional level, potentially hindering national initiatives.

Recommendation: The DHSC should start a rapid design-and-build phase of the DHR based on an evaluation of the options outlined above: build from scratch; build out from existing secondary-care infrastructure; build out from existing primary-care infrastructure; or scale an existing digital health record.

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Realising the Value of a Digital Health Record

A DHR could transform the way we generate health and consume health care in the AI era, delivering all three of the big shifts identified by the health secretary in July 2024. But while a DHR is necessary, it is not sufficient. A proactive, digital-first, tech-enabled and community-based health service will require parallel efforts to support the ambitions of the DHR and help it achieve its potential.

SHIFT ONE: FROM TREATMENT TO PREVENTION

A DHR really could allow for a pivot to a more proactive, prevention-focused service. This is because one of the unique features of AI is its ability to help with the understanding of risk. Understanding risk means being able to predict events – and predicting events means being able to prevent them. When applied to the personal health information in a DHR, AI could generate a detailed and personal understanding of health risk for each citizen – and even a mitigation plan.

For instance, AI in conjunction with a DHR could identify people at increased risk of cancer and suggest earlier or more frequent screening programmes. It could detect trends in blood tests that suggest control of their long-term condition is deteriorating and prompt a change in management. It could detect risk factors for frailty that prompt a review, avoiding a fall and subsequent hospital admission. It could also identify people who are eligible for new prevention drugs and prompt a consultation.

Identifying those at risk and intervening early could be a game-changer for patients and the NHS – but as well as analytics, primary care will need more capacity and funding. While a comprehensive approach to prevention is described in our paper <u>Fit for the Future: How a Healthy Population Will Unlock</u> <u>a Stronger Britain</u>, here we describe the policy considerations that would make a DHR successful in supporting that mission.

Invest in an AI-Powered Health-Analytics Platform

The NHS should invest in the development of a national AI-powered healthanalytics platform to drive clinical decision-making for patients and clinicians in the UK. It should be trained on the anonymised contents of the DHR, as well as peer-reviewed journals and clinical insight from practitioners. It should be a self-learning system that regularly updates its algorithms based on real-world evidence and should have strong governance with representation from government, academia, the health profession and citizens to protect against bias, hallucinations, privacy and cybersecurity issues.

Over time the platform would become a personal digital health assistant or "Al doctor", interacting with citizens through an LLM. Citizens could then consult this Al doctor to help maintain their health (through personalised prevention plans and bespoke health coaching), for advice when they are unwell (through personalised symptom checks, self-care, triage and navigation advice) and to help them manage LTCs.

The AI doctor could also be deployed to support clinicians. It could be incorporated in the triage and navigation functions of 111, as well as in GP management systems. The latter would drive clinical decision-making and population health management, and in the future could support more accurate and personalised decision-making about treatment.

The group responsible for establishing this analytics platform should be crossgovernmental and include NHS England, the DHSC, Genomics England and the Royal College of General Practitioners. Together with industry experts, this group could develop the platform and then think about exporting the tool for use by health systems globally.

Recommendation: The government should commit to establishing a national Al-powered health-analytics platform.

Rapidly Expand Capacity for Prevention Activities in Primary Care

Primary care will also need to address its capacity issues if it is to act on risk and deliver targeted prevention. The "8am rush" and weeks-long delays for a GP appointment are familiar to many, making it difficult to add to the responsibilities of general practice. There are 4 million people in the UK eligible for treatment with a GLP-1 analogue for obesity, for instance, but only 35,000 weight-management spaces.³⁵ It is simply not feasible to expect this drug to be rolled out routinely for weight management in general practice.

In 2023, TBI proposed a new prevention service in the paper <u>Moving From</u> <u>Cure to Prevention Could Save the NHS Billions: A Plan to Protect Britain</u>. Instead of relying on existing general-practice infrastructure, this service would make greater use of the skills and capacity that sit in community pharmacy, meeting people where they are: online, at home and in the high street.

A more detailed description of the service is set out in <u>The Economic Case for</u> <u>Protect Britain, a Preventative Health Care Delivery Programme.</u> Crucially, this kind of service is only possible with a DHR, which would integrate personal health information across both services and ensure a safe and coordinated approach to prevention.

Recommendation: Launch Protect Britain, a preventative vaccine and therapeutics programme reporting into the health secretary.

Prioritise Prevention Spending

At our 2024 Future of Britain Conference we presented findings from our paper, <u>Prosperity Through Health: The Macroeconomic Case for Investing in</u> <u>Preventative Health Care in the UK</u>. This research, conducted by economist Andrew Scott from the London Business School, shows the direct link between prevention and economic growth, quantifies the size of the impact and shows that it is not necessary to wait a generation to see the benefits. It estimates that a 20 per cent reduction in the incidence of six major LTCs would increase GDP by 0.74 per cent within five years and 0.98 per cent within ten, thanks to people living longer, healthier and more productive working lives.

There is a clear case, benefiting both the economy and public health, for investing in prevention – but prevention budgets are too often cut. The public-health spending grant, for example, has been cut by 26 per cent per person in real terms since 2015–16.³⁶ We propose a new function carried out jointly between the DHSC and the Treasury, looking at the impact of targeted prevention spending on national income before determining spending budgets for the NHS.

Recommendation: The DHSC should have access to anonymised insights from the DHR through an insurer portal, to understand the risk profile of the population. This will help it to inform the allocation of spending across demographic groups and time horizons.

Recommendation: The government should establish a national health accounting mechanism between the DHSC and the Treasury to determine prevention spending. Health should be tracked as a national asset.

SHIFT 2: FROM HOSPITAL TO THE COMMUNITY

A DHR will be critical to delivering the shift away from hospital-focused medicine to community-based care. That vision was set out in the Fuller Stocktake report³⁷ and makes the case for a more tailored primary-care offer depending on each person's risk and need. There are different ways of segmenting and stratifying populations, but for illustrative purposes, we can think of four broad groups, listed below. A DHR would help achieve a more effective, convenient and valuable model of care for each.

Patients with Complex Medical and Social-Care Needs

This group represents about 5 per cent of the population but is thought to account for about 50 per cent of NHS expenditure.³⁸ A common reason for the high expenditure is that this group relies on a wide range of health and social-care services – such as GPs, secondary-care specialists, social workers, mental-health practitioners and district nurses – to coordinate their care. When this care fails it leads to poorly managed conditions and frequent admissions to hospital (frailty is a common example).

The value of a DHR in this instance is twofold. First, it provides a single version of the truth for caregivers, facilitating team-based care even when team members are not co-sited with each other and delivering on the vision of neighbourhood teams, as set out in Fuller's vision. Second, analytics applied to DHR data can track risk over time, picking up on early signs of deterioration so that interventions are timely and preventative.

Patients With Long-Term Conditions

This group of patients may have one or two LTCs that they could take far greater control of with the right support, using digital therapeutics, peer

support and regular remote advice from specialists. One benefit of a DHR for this group would be the ability to navigate entirely new digital pathways of care online and to self-care more effectively. In South Korea, for example, Kakao Healthcare has partnered with Novo Nordisk to provide diabetes care using a digital diabetes-management service,³⁹ and care pathways are continuously updated in line with best practice. In the UK, Frimley Health and Care ICS has used data to identify and enrol more than 10,000 high-risk patients onto a remote-monitoring programme. Early-outcome data has shown a 38.6 per cent reduction in A&E attendances, 53.7 per cent reduction in admissions and 26.7 per cent reduction in outpatient appointments for those on the programme.

The DHR could transform the outpatient model. Rather than patients attending in person, continuous monitoring of physiology (through the integration of tools such as blood-glucose monitors, as well as self-reporting) could enable GP teams and specialists to access real-time patient records, monitor risk and only see patients when clinically necessary. Meanwhile, greater "patient activation" (the ability to better manage one's own care) could benefit the system as well as patients: those with the lowest level of activation cost an average of 8 per cent to 21 per cent more than those with the highest.⁴⁰

Patients Requiring Temporal Continuity

Even citizens who are generally well go through times when continuity is preferable: pregnancy, situations that require palliative care or investigations of unexplained symptoms are examples. In those circumstances, a DHR would allow patients to choose from a greater range of services – even private-sector services if they preferred – while preserving a digital continuity with their GP and the NHS.

This could be important if, for instance, a patient contracted a private provider for palliative care services but then required urgent advice and treatment from 111 or 999 overnight. Those NHS professionals would have access to a full, upto-date record of that patient's condition and medications. Use of private services in this way could even be achieved at no cost to the patient, if those providers were recognised by the NHS and a tariff agreed. Combined with nationally agreed and transparent care pathways, the DHR would allow patients to propel themselves through the referral, investigation and consultation process without constant back and forth with their GP.

Patients Who Are Generally Well but Have an Acute Same-Day Care Need

A DHR coupled with Al would mean patients could be more effectively navigated to the right service first time. This would reduce the inefficiencies inherent in patients attending a high-resource setting unnecessarily, or bouncing between low-resource settings that don't meet their needs. A DHR could also transform the experience of triage and navigation for patients, facilitating a truly omni-channel communication that would see patients move seamlessly between online, in-person, text, email and phone contact, all without losing the thread of a conversation or repeating information. It can also broaden the range of providers that patients can access when they are unwell, as their medical history comes with them.

It is clear from these four examples that more tailored primary-care services are possible with a DHR, but more tailored primary care also requires diversity in the primary-care offer – and this requires scale. Below we suggest measures that could help achieve that diversity.

Commission Primary Care at Greater Scale

Primary care has been moving steadily towards a more diverse and tailored offer for some time. The traditional model of ten minutes with a doctor to discuss one problem by the time you're already sick persists in some places, but increasingly practices are adopting a PHM approach. This means applying advanced analytics to locally integrated datasets to risk stratify and segment their populations; it also means they can design care around cohorts of patients with similar needs.

Commissioning primary care at greater scale would propel this trend. Currently, primary-care networks look after populations of between 30,000 and 50,000, but some federations look after far greater numbers of patients and can offer more tailored services, with integrated outpatient, diagnostic and access hubs built in.

It is outside the scope of this paper to advise on the specifics of primary-care delivery – the primary-care organisations themselves are in a far better position to design what works for their populations – but a value-based contracting mechanism could help. We recommend that NHS England

considers a new contracting mechanism for primary care that is outcomesbased, commissions for scale (populations of 250,000 patients) and has a gain-share component. This would see groups of practices benefiting financially from better outcomes and lower rates of hospital admissions; it would also facilitate the movement of funds from secondary to primary care over time.

The new contract would not be mandatory and could run in parallel with the standard General Medical Services contract.⁴¹ However, practices could be incentivised to take these contracts if they offered other benefits such as longer terms (three years, for example), lump-sum payments (for the likes of digital and physical infrastructure development) or free services (such as practice-management software or other back-office functions). These should be offered on condition of meeting outcomes-based targets. In time the primary-care landscape would change to one with far fewer groups of primary-care practices – and meaningful choice for patients over which group they register with.

In developing this new contract, however, we recommend that NHS England avoids commissioning based on geographical area, and instead focuses on combined list size. The reason for this is that commissioning based on geographical area precludes patients from having meaningful choice over their primary-care supplier, and it limits the ability of NHS England to enforce meaningful sanctions on practices that don't meet their targets. NHS England could even end up financially liable for groups of practices that go into deficit if there are no alternative providers in the locality.

Recommendation: NHS England should consider developing a new primarycare contract for groups of practices with a combined list size of around 250,000.

Develop an Effective Provider Portal in Primary Care

The provider portal, through which primary-care teams can view and edit the DHR, will be critical to delivering primary care at scale. It can also be used to apply a range of analytics and algorithms in order to conduct functions such as the auditing of clinical management against best practice, the performance management of clinicians based on patient outcomes and the execution of value-based contracts.

At present the NHS has very little control over the patient portals used in primary care, as each GP practice commissions its own practice-management system independently. This has created issues in the past because the tech stack has not been readily adapted by the two dominant vendors in the market: EMIS and SystmOne. GPs lack the contractual levers to demand change, so added functionality frequently relies on workaround apps. This means that user experience is rarely prioritised and has led to a proliferation of add-on technologies, all with separate interfaces that rarely integrate with each other.

To gain greater control of the provider portal, the DHSC could consider two options in building the DHR: procure an entirely new practice-management system for general practice or work with an existing one to build out the tech stack.

Recommendation: To drive the successful implementation of the DHR in primary care, NHS England should either procure a new practice-management system for general practice, acquire the UK licence for one of the major practice-management systems already in existence or support the rollout of existing workaround solutions for a functioning clinician portal. NHS England could then work with that practice-management system to build out the tech stack necessary for modern general practice.

Publish Care Pathways and Broaden the Range of First-Contact Providers

In order to diversify the primary-care offer for patients, NHS England should draft national pathways for common conditions and make these transparent to patients through the NHS App. This would allow a patient, empowered by their DHR, to progress along a care pathway with a meaningful choice of providers for different steps on their journey. For example, if a patient needed a blood test they could choose to have that done in a pharmacy, at hospital, at a GP surgery or at home (with equipment delivered through the post), depending on waiting times, preference and convenience; the same would be true for other primary-care services such as imaging and LTC management. Innovative ICSs could even make local adjustments to these care pathways, to drive innovation locally and online.

To progress along a care pathway, moving seamlessly between NHS and non-

NHS care providers, agreed national tariff arrangements would be required to ensure that patients could rely on the NHS to cover the cost.

Recommendation: Through the NHS App, NHS England should make transparent care pathways for common conditions.

Recommendation: NHS England should agree national tariff arrangements with non-NHS providers of health and care services, which patients could access with their DHR. For patients with longer-term care needs, a DHR supports the stratification and segmentation of patients into cohorts with similar needs.

Integrate the DHR and AI into the Triage and Navigation Process

Patients with an acute care need that they are unable to manage themselves may need support in navigating what is a confusing health-care landscape. It may not be immediately obvious to that patient whether a GP, pharmacy, urgent-care centre, minor-injury unit, A&E department, emergency advice line or walk-in centre is the right place to attend with their problem.

It is easy to see why many default to the highest resource setting where the barriers to entry are low (no booking required) and all potential diagnostics and specialist advice are on site if required. Existing triage and navigation services in GP reception and 111 do their best, but without access to prior risk stratification and clinical-decision support, the impact is limited.

In other parts of the world, CSC apps can offer asynchronous advice, sometimes over WhatsApp. But if they reach the end of their competence, or need a human-in-the-loop to take accountability for the advice, the apps are able to facilitate direct access to the most appropriate doctor – complete with a summary and proposed care plan. Abi Global Health provides just such a service for patients across the world, with health insurers AXA, Zurich and Allianz.⁴²

Access to a citizen's DHR, no matter where they are or who they are seeing, could vastly improve the safety and effectiveness of first-contact care. In Estonia, the e-Health record is a nationwide system that integrates data from the country's health-care providers to create a common record that patients can access, functioning like the proposed PHA. All patients have this record

and it provides access to all licensed medical practitioners in Estonia.⁴³

Recommendation: NHS England should work to integrate the DHR and the national AI-powered health platform into NHS 111 services. This should then be used with an LLM as a CSC, to power triage and navigation within the NHS 111 service.

SHIFT 3: FROM ANALOGUE TO DIGITAL

A DHR will be critical to helping patients navigate new digital pathways of care. This will not just be through new patient-facing apps but also the ability to access a whole world of online services: a digital health service. At present there is limited regulation and understanding of how to use these applications and services, so we suggest the following.

Build Out the NHS App as a Patient Portal

With 33.1 million logins in June 2024 and an active user base of about 10 million, the NHS App is well known and well trusted. It already has good functionality as a "digital front door", used most frequently by users to view their health records (20.5 million views in June 2024), request repeat prescriptions (3.3 million requests in June 2024) and book GP appointments,⁴⁴ with new functionality added regularly. Patients are increasingly able to track secondary-care referrals, see waiting times, check quality ratings and book their first appointment in secondary care.

In terms of the data that citizens can access and view, most (85 per cent) have access to their primary-care data, while some have access to screening, vaccination and test results; soon they will be able to upload wearables data and access secondary-care data. At present, however, there are no plans to put the information in longitudinal form.

NHS England has great ambitions for the app. However, the budget for its development is often compromised due to competing operational demands in the health service.

Recommendation: NHS England should increase and ringfence spending on development of the NHS App, dedicating funds from the productivity plan announced in the Spring Budget to fund it.

Create a Digital Care Hub Within the NHS App

The public already has access to a limited number of NHS-approved apps. However, the desire of citizens to have complete control over how they view, share and process personal health information will become more urgent as they gain access to high-grade consumer-facing Al through their smartphones.

The passing of interoperability legislation (as suggested earlier in this paper) would enable citizens to share data contained in their DHR with third-party apps to gain personal actionable insights – but not all apps accessed through the App Store (or equivalent) will be regulated.

Access to safe, regulated and NHS-approved apps should be provided in a Digital Care Hub within the NHS App itself. With consent from the individual, these apps could access relevant information from the DHR (such as bloodsugar readings) to help support citizens in managing their data. The apps would be able to provide some clinical advice but could also support behavioural change, as well as providing access to peer support and specialist advice.

For this reason, the NHS App must have the capacity for patients to upload information into the DHR themselves – things like blood-pressure readings, photographs and voice recordings – and, if they wish, download information to use in another app. The third-party app then needs the ability to ingress data back into the patient's DHR.

Applications should be procured centrally by NHS England and made available to citizens through the NHS App; they could be branded or white-labelled applications. The information conveyed back to the patient should be their responsibility to act upon, but should also be ingressed into the DHR and shared with their primary-care provider.

Lessons should be learnt from the NHS Apps Library, which was discontinued after many of the apps were found not to meet appropriate levels of clinical quality and data privacy, and often exceeded cost.⁴⁵ NHS England should work with the Medicines and Healthcare products Regulatory Agency (MHRA) and National Institute for Health and Care Excellence (NICE) to help curate this range of apps, ensuring that they are both safe and cost effective. The regulation of these apps should be expedited, not just in terms of safety and

effectiveness but also in terms of cybersecurity, as this can delay their implementation.

There should also be advance agreement about which organisation funds the apps: NHS England or each local ICS. Given its national role, we suggest that NHS England is best placed to fund them.

Recommendation: The NHS App should develop a Digital Care Hub with the capacity to draw on relevant personal health data within the DHR (where a citizen has explicitly consented to the process).

Recommendation: NHS England should work with MHRA and NICE to curate a range of safe, cost-effective digital therapeutic apps for a marketplace. NHS England should procure these apps on behalf of all citizens and install them in the NHS App as white-labelled applications.



Conclusion

The UK faces a choice: prepare the NHS for the AI era or prepare to lose the NHS.

Al can help drive the step-change in productivity that the NHS needs, and help it pivot from a reactive sickness service to a proactive health service. But this is only possible if the UK government recognises the fundamentally different era that the NHS needs to survive in for the next century – and if the NHS continues to meet people's expectations when it matters most.

A digital health record, put into the hands of patients as well as health professionals, is the obvious solution. Other countries are investing on behalf of their citizens; the UK should do the same. It will require investment and must be done in lockstep with citizens to gain their trust, preserving privacy, security and patient choice at all times. But it is eminently achievable within one term of government – and should be considered an urgent priority.

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- Tom Whicher, DrDoctor

Endnotes

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