The Institution of Engineering and Technology

The digital advantage

Realising the benefits of interoperability for health and social care in England.

theiet.org/healthcare

Contents

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Please note that the views expressed in this publication are not necessarily those of the IET.

The guide only intends to identify the relevant issues and to inform a public policy debate around the topic, rather than to provide a definitive solution.

The IET Healthcare Panel would welcome any comments you may have on the contents of this guide, and your ideas for future publications. Please get in touch by emailing **sep@theiet.org.**

The Institution of Engineering and Technology

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Opening remarks

Dr Lisa Cameron, Chair for the All-Party Parliamentary Group on Health.

As chair of the All-Party Parliamentary Group (APPG) on Health, I welcome this new report, compiled by the Institution of Engineering and Technology (IET). The report sets out the IET's position on digital transformation of the National Health Service (NHS) and social care across England.

The interoperability of medical records in the NHS is a very daunting task. Obstacles arise including the sharing of highly sensitive personal health information. Shared health record systems have to conform to the UK's strong legal protections for patient confidentiality and link up technologies developed within a complex network of organisational silos. The sheer size of the NHS makes the transmissibility of data among NHS systems a very difficult challenge. The Covid-19 pandemic has brought these issues to light due to increased hospitalisations across the United Kingdom. Failing to address this dilemma will result in even more delays in the NHS, something we cannot afford.

The IET report has highlighted good progress made to address the interoperability issues. They have noted that integrated patient health records are being piloted across five Local Health and Care Record Exemplars, which together cover 41.9% of England's population. Furthermore, advice issued by the National Data Guardian has been given legal weight. The Professional Record Standards Body has devised specialised content standards for patient records in 22 clinical contexts. New training programmes have been launched for health informatics professionals. NHS Digital has released for consultation a draft NHS Digital, Data and Technology Standards Framework, which sets out proposed mandatory data standards for interoperability. Continued progress is an absolute necessity if the NHS is to be able to maintain sufficient data sharing, especially during the pandemic.

I would like to sincerely thank the IET and all contributors for constructing this report. The organisation highlights four key elements of a framework for interoperability. These are robust protection for patient confidentiality; national data and content standards; localised delivery of integrated patient records; and development of the health informatics profession. I am in complete agreement with the IET's recommendations. Their belief is that the time for a new initiative to join up the pieces with an overarching national structure is fast approaching. A careful post-pandemic review and stock-taking process should now begin, followed by an implementation plan for achieving full interoperability and legislation to mandate open data standards.

About this report

This Institution of Engineering and Technology (IET) report sets out our position on the digital transformation of the National Health Service (NHS) and social care across England. While the NHS has faced and met the greatest challenge of its 73-year history in the Covid-19 pandemic, preparatory work has continued towards the long-term goal of ensuring widespread interoperability across the sector.

For as long as healthcare providers have used multiple IT systems, the NHS has struggled with interoperability. The problem grows exponentially as the number of systems supporting administrative and clinical processes within a healthcare provider increases and it gets even bigger when these providers are required to share information. Yet achieving interoperability is becoming ever more critical as we move towards statutory integrated care systems, through proposed legislation that has been drafted by the Government.[1] While we have achieved significant success in a few narrowly defined areas, resolving the majority of interoperability challenges continues to elude us – as it has for over 30 years.

This report aims to define and summarise the difficulties inherent in achieving interoperability and analyse accomplishments to date through a series of case studies. The next set of interoperability challenges that need to be overcome and the steps that should be taken to get there - backed up by evidence of what works - are also identified. This report has been written for all stakeholders across academia, industry, the health service and government, who are interested in achieving the benefits of healthcare interoperability.

The author of the report is Liz Heron. It was reviewed by the members of our Healthcare Sector and input was provided by the participants of our policy roundtable on the future of interoperability in our healthcare systems:

Mike Andersson - Healthcare Informatics and Information Governance Specialist
Mark Avery - Director of Health Informatics, Eastern Academic Health Science Network (AHSN) and Cambridge University Health Partners
Dr Peter Bannister - Vice President Life Sciences, Ada Health and Executive Chair, The IET Healthcare Sector
Dr Nilesh Bharakhada - Clinical Director, PRSB
Irina Bolychevsky - Director of Standards and Interoperability, NHSX
Dr Lisa Cameron MP - Chair, All-Party Parliamentary Health Group
Andrew Davies - Digital Health Lead, Association of British HealthTech Industries
Tony Davis - Director of Innovation and Commercial, West Midlands AHSN
Chris Geary - Innovation Lead, Digital Health, Innovate UK
Dr Guy Gross - Chief Operating Officer, Teladoc Health
Stuart Harrison - Co-founder and CEO, ETHOS
Nicola Haywood-Alexander - Chief Information Officer, Lincolnshire NHS
Ross Lydall (Chair) - Health Editor, the Evening Standard
David Maguire - Senior Analyst, The King's Fund
Benita Mehra - Member, The IET Healthcare Advisory Board
Nury Moreira - Healthcare Lead, The IET
Helen Oliver - Chief Operating Officer, Eastern AHSN
Nick de Pennington - CEO and Founder, Ufonia, and Innovation Lead, Oxford University Hospitals
Sophie Taysom - Director, Keyah Consulting
Sarah Wilkinson - Chief Executive Officer, NHS Digital (2017-2021)

[1] Integration and innovation: working together to improve health and social care for all - GOV.UK (www.gov.uk).

Recommendations

England's health and social care sector has made steady progress in developing secure e-health records over recent years and is now poised to begin the wider roll-out of shared patient record systems. We have outlined five key recommendations for a new, national initiative to ensure that citizens reap the benefits of digital transformation.

Recommendations:

1. **Introduce legislation to underwrite agreed national data standards and mandate NHS organisations and social care bodies to use them for patient records.**
   Legislative authority will provide trusts with certainty, unleash collaboration, and add impetus to the nationwide roll-out of integrated patient records.

2. **Extend the 2024 deadline for NHS trusts to achieve a "core level of digitisation" to take account of the impact of Covid-19.**
   While some Local Health and Care Record Exemplars (LHCRE) continued to make notable progress in 2020, the pandemic inevitably slowed work on e-health records and plans should take it into account.

3. **Publish a technology implementation plan for health and care that sets a budget with clear milestones and measurable actions for achieving full interoperability.**
   It should take account of cost-benefit assessments of patient record systems, while the contributions required from government and other parties should be clearly defined.

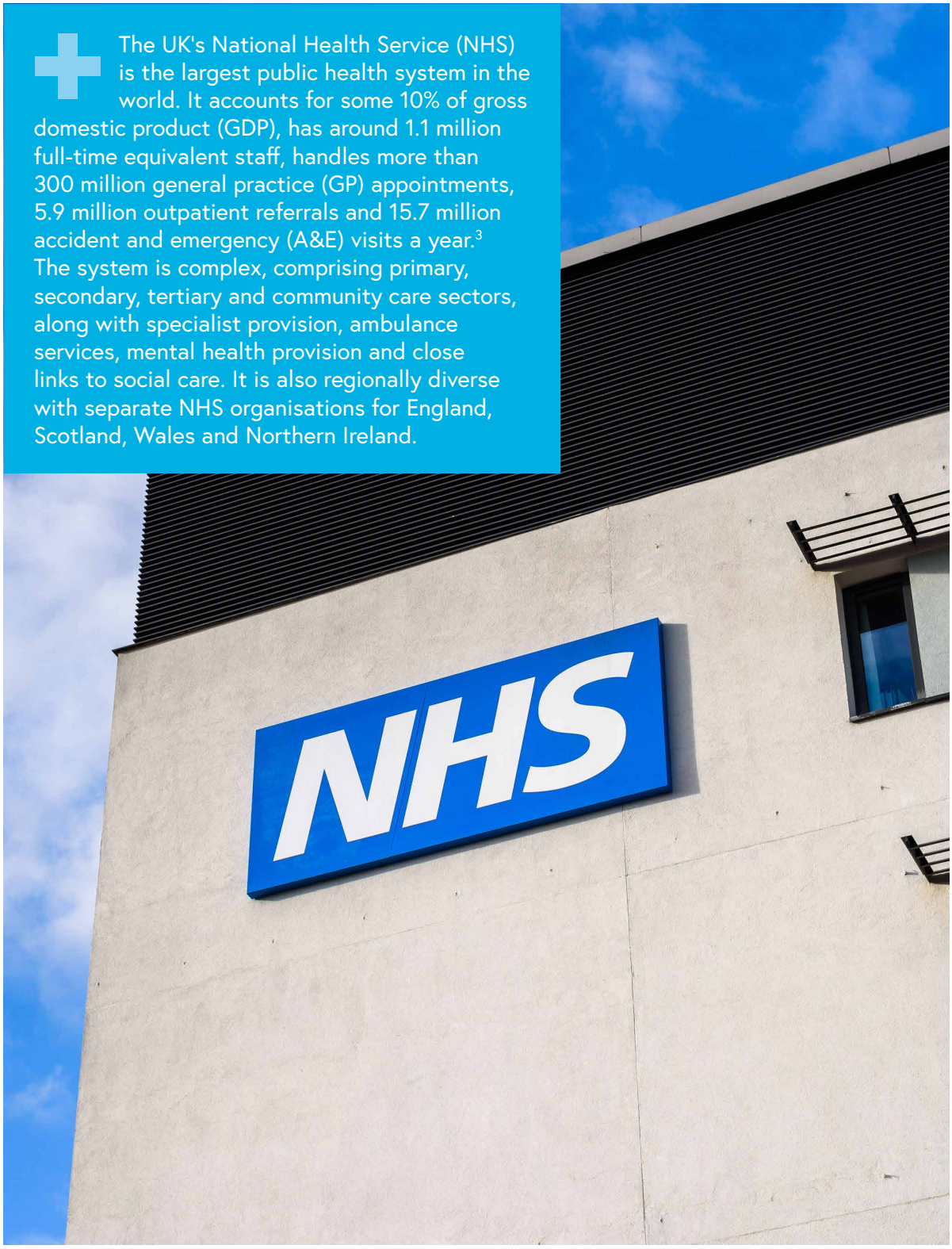
4. **Provide seed funding for accelerated trials of the Trusted Research Environment model to address questions such as how to accredit participating researchers.**
   The model devised by Health Data Research UK promises to provide a secure national ecosystem for using health datasets to research vital new treatments.

5. **Commission a data security team to help NHS trusts meet the Cyber Essentials Plus standard introduced after the 2017 WannaCry ransomware attack.**
   Robust cyber security is vital to maintaining trust in e-health records. Only one of England's 236 NHS trusts met the standard fully in 2020, while 32 had not completed the assessment.[2]

[2] Digital transformation in the NHS - National Audit Office (NAO) Report.

Introduction

The UK's National Health Service (NHS) is the largest public health system in the world. It accounts for some 10% of gross domestic product (GDP), has around 1.1 million full-time equivalent staff, handles more than 300 million general practice (GP) appointments, 5.9 million outpatient referrals and 15.7 million accident and emergency (A&E) visits a year.[3] The system is complex, comprising primary, secondary, tertiary and community care sectors, along with specialist provision, ambulance services, mental health provision and close links to social care. It is also regionally diverse with separate NHS organisations for England, Scotland, Wales and Northern Ireland.



[3] Key facts and figures about the NHS | The King's Fund (kingsfund.org.uk).

A unique opportunity

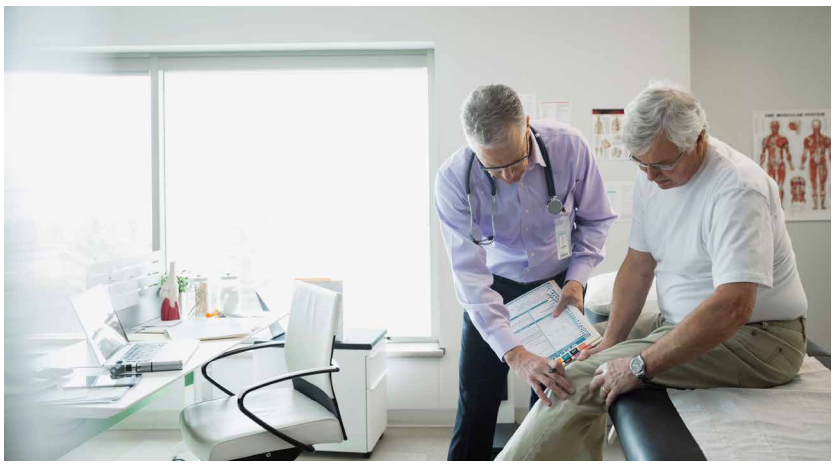
The potential benefits of introducing state-of-the-art digital connectivity to the NHS are many. Secure access to electronic patient health records by clinicians across GP surgeries, hospitals, ambulances and social care promises to improve the coordination of services, resulting in higher standards and fewer delays. Electronic health records can give patients access to their own health information and thus help them to take part in managing their long-term health. The anonymised data pools generated by a digitally connected NHS could provide a powerful resource for planning and research and drive an eco-system of health apps offering innovative digital services. Once established, digital connectivity should also boost the efficiency of NHS units, enabling staff to spend more time on front-line care.

The digital challenge

While the advantages of digital transformation may be as clear in healthcare as in sectors such as retail, banking and travel that have moved swiftly to online delivery models, the sheer complexity and size of the NHS and the sensitive nature of personal health information have slowed adoption. For primary care, the process began in 1982, when the Micros for GPs programme was launched, and the roll-out proceeded steadily, with nearly all general practitioners (GPs) using computerised patient records by 2002.[4]

However, two attempts at digitising secondary care have run into severe difficulties and have been abandoned. The first was the National Programme for IT (NPfIT), which was launched in 2002 and cancelled in 2010,[5] after it ran billions of pounds over budget and four years over schedule.[6] NPfIT, which aimed to create a single electronic care record system for patients, was described by the Public Accounts Committee as one of the "worst and most expensive contracting fiascos in the history of the public sector".[7] The NHS Connecting for Health agency, which ran the programme, was disbanded in 2013. Nevertheless, the NPfIT did succeed in setting up a national infrastructure for care records in the NHS called the Spine, which was transferred to the Health and Social Care Information Centre (HSCIC).

The second initiative, care.data, was launched by the HSCIC in 2013. It aimed to extract data from GP surgeries into a central database for use in a pseudonymised form by healthcare planners, managers and researchers. A leaflet was sent to every patient in England informing them that their health information would be uploaded to the central database unless they declined to take part by contacting their GP practice.[8] A review conducted for the Cabinet Office found that the programme had "major issues" that included budget, schedule and project definition.[9] It was finally abandoned in 2016, after being paused over unresolved confidentiality concerns,[10] and HSCIC was renamed NHS Digital.



[4] Why general practitioners use computers and hospital doctors do not — Part 1: incentives (nih.gov).
[5] UK gov finally pulls plug on National Programme for IT | The Register.
[6] NAO report (HC 1173 2005-2006): The National Programme for IT in the NHS; A National Programme for IT in the NHS: A Case History (cam.ac.uk).
[7] NHS IT system one of 'worst fiascos ever', say MPs - BBC News.
[8] NHS England - Better Information Means Better Care: NHS contacts all English households from today.
[9] NHS patient data plans unachievable, review finds | Health policy | The Guardian.
[10] NHS to scrap single database of patients' medical details | Data protection | The Guardian.

Learning from experience

The failure of these initiatives provided a learning experience for the then Department of Health and the NHS leadership that prompted a more considered and inclusive approach. A new National Information Board (NIB) was set up in March 2014 – with members drawn from across health and social care organisations – to develop strategic priorities for data and technology in the sector and a joined-up approach to implementation.[11] In November 2014, the NIB published its proposals in the white paper Personalised Health and Care 2020.[12] Instead of a national plan, it put forward a "framework for action" that aimed to support frontline staff, patients and citizens to take better advantage of digital opportunities for improving health and care services. The report aligned with the NHS Five Year Forward View, which was released the previous month, and coincided with the establishment of a new National Data Guardian to serve as an independent champion for the confidentiality of sensitive personal health information.

The following year, the National Advisory Group on Health IT was set up to develop guidance on how to digitise the secondary care system. The group drew seven of its 17 members, including chairman Professor Robert M Wachter, from the United States, a global leader in the digital transformation of health services. The recommendations of the Wachter report, which was published in August 2016,[13] has become the template for the digitisation of the secondary care sector in England. It advocates a balanced and phased approach to implementation that guarantees widespread interoperability across the system. Other key features include combining strategic use of national incentives with an emphasis on local and regional control, developing a professional workforce of clinician-informaticists, and appointing a national Chief Clinical Information Officer (CCIO).

Momentum gathers

Within 18 months, pieces of the new approach were beginning to fall into place. In February 2018, Dr Simon Eccles was appointed as England's first national CCIO.[14] In March 2018, the Professional Record Standards Body (PRSB) published a draft Digital Care and Support Plan that is intended to serve as a national standard for transferring information between providers about patients with long-term conditions or complex needs.[15] The PRSB went on to produce similar standards for use in a wide range of other healthcare contexts. By June 2018, five NHS regions had been selected to become Local Health and Care Record Exemplars (LHCRE) that were each awarded £7.5 million to pilot the use of electronic health and care records across their services. The LHCREs' primary brief was to improve and

[11] About us - National Information Board - GOV.UK.
[12] Personalised health and care 2020 - GOV.UK.
[13] Make IT Work: Using information technology to improve the NHS - GOV.UK.
[14] NHS England - Emergency medicine consultant unveiled as new Chief Clinical Information Officer for Health and Care.
[15] Digital care and support plan standard final report.pdf (theprsb.org).

coordinate care for individual patients, but they were also asked to look at how the records could be used for health research and planning.

Further initiatives came thick and fast. In September 2018, the first students were admitted to a new diploma programme for aspiring CCIOs and Chief Information Officers. It was commissioned by the fledgling NHS Digital Academy, which has been charged with providing training for a new generation of digital health leaders.[16] In December 2018, the National Data Guardian was granted power – through new legislation - to issue official guidance on the way health and adult social care data is processed in England, strengthening the protection of patient confidentiality.[17] Then a unit called NHSX was set up within the Department of Health and Social Care (DHSC) to develop national policy and best practices – with an emphasis on user experience for digital technology in health services.[18] Meanwhile, NHS Digital was working steadily to coordinate the diverse local and national efforts and to devise optimum technical solutions and specifications for the system in partnership with stakeholders. By January 2020, it had released the NHS Digital, Data and Technology Standards Framework.

This lays out new data, interoperability and design standards for the NHS that are expected to provide the lynchpin of the emerging national electronic health records system.[19]

Template for a healthcare IT ecosystem

"The system, standards and interfaces should enable a mixed ecosystem of IT system providers to flourish, with the goal of promoting innovation and avoiding having any one vendor dominate the market. Widespread interoperability will require the development and enforcement of standards, along with penalties for suppliers, trusts, GPs and others who stand in the way of appropriate data sharing."

The Wachter report, Making IT Work[20], published by the National Advisory Group on Health IT.

16 NHS Digital Academy | Health Education England (hee.nhs.uk).
17 About us - National Data Guardian - GOV.UK.
18 NHSX: new joint organisation for digital, data and technology - GOV.UK.
19 BETA - NHS digital, data and technology standards framework - NHS Digital.
20 Making IT work; Using information technology to improve the NHS - GOV.UK.

What is interoperability?

Interoperability is one of the most central concepts and common buzzwords involved in information technology (IT) and systems engineering today. But what does the term exactly mean?

Take a USB storage device such as a memory stick and plug it into your laptop's USB port. The computer will recognise the device and open a window providing access to the information that is stored on the stick, which can be freely copied, stored, and sent to a printer. This barrier-free exchange of information is possible because the USB device was designed in accordance with interoperability standards.

Interoperability is fundamental to the tech industry, where devices and components that are technically diverse and made by different organisations need to interact with each other to provide services to users. There are two types of technical interoperability: syntactic and semantic.

Syntactic interoperability involves two or more systems that use different standards but can communicate with each other because they use common data formats and communication protocols, such as XML or JSON.

Semantic interoperability is the ability of different computer systems to interpret the information they exchange in an accurate and meaningful way. To achieve semantic interoperability, the systems must deploy a common reference model, which defines the content of their information exchange requests in an unambiguous way. This enables them to automatically interpret the information they exchange and produce meaningful and accurate results for users of both systems.[21]

Interoperability relies on open standards that are developed by groups of manufacturers, academics and other stakeholders who jointly devise a common protocol, endorse it as a common standard and release it to the public. It then becomes an open standard that is typically available free of charge or at a nominal cost to any company or individual that wants to make a product based on the protocol. Customers are thus able to choose between different products that serve the same purpose while competing in terms of performance and price. This is known as true or ab initio interoperability.

The World Wide Web is a prime example of true interoperability. It was designed by the World Wide Web Consortium (W3C), a group with members drawn from industry, academia and government, and led by British computer scientist Tim Berners-Lee.[22] Together they devised, agreed and applied common technology

[21] Interoperability - Wikipedia.
[22] Facts About W3C.

and open standards for their products, which broke down barriers in internet access. Today the web is the world's largest and most interoperable network, with a membership that includes everyone who has an email address or access to a browser.[23]

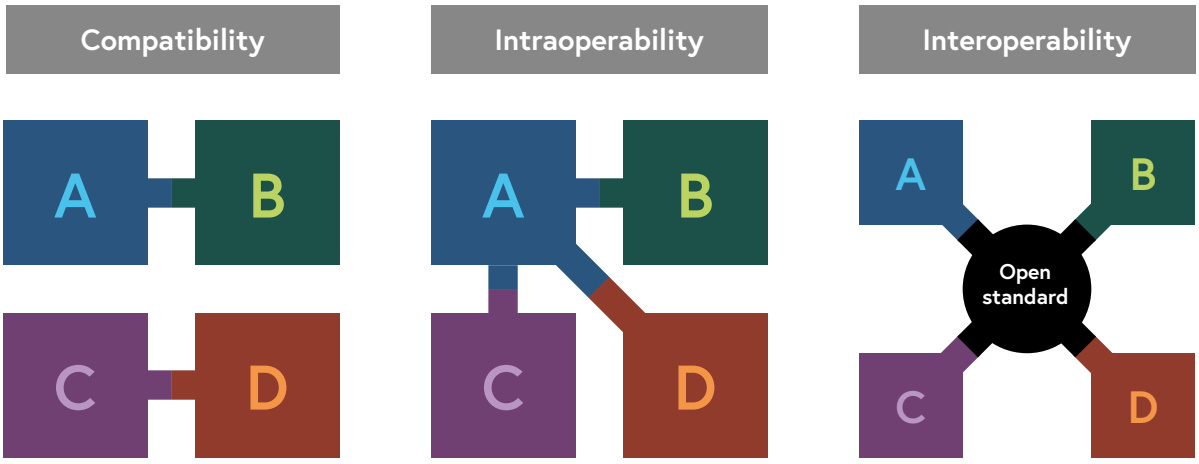
Where one vendor has achieved market dominance with a product that has its own standards, suppliers of other related products may seek to align with the proprietorial standards. This can be done by requesting permission from the vendor or through reverse engineering. This is referred to as post facto interoperability or intraoperability.[24] However, standards are usually not fully open in this scenario, while the vendor of the original product may find ways to hamper free competition. Where a particular product has a complete monopoly in a market, other suppliers of related products are obliged to meet the vendor's standards through compatibility – not interoperability. As the number, size and range of industries and organisations seeking to benefit from the digital revolution has grown, interoperability has also acquired a broader definition that takes account of social, political and organisational factors involved in the exchange of information between systems. In this wider sense, systems with elements that are technically diverse and managed by different organisations show interoperability when they provide coherent services for users.

Interoperability: a definition

"Interoperability is a characteristic of a product or system, whose interfaces are completely understood, to work with other products or systems, present or future, in either implementation or access, without any restrictions."[25]

French speaking Libre Software Users' Association interoperability working group.

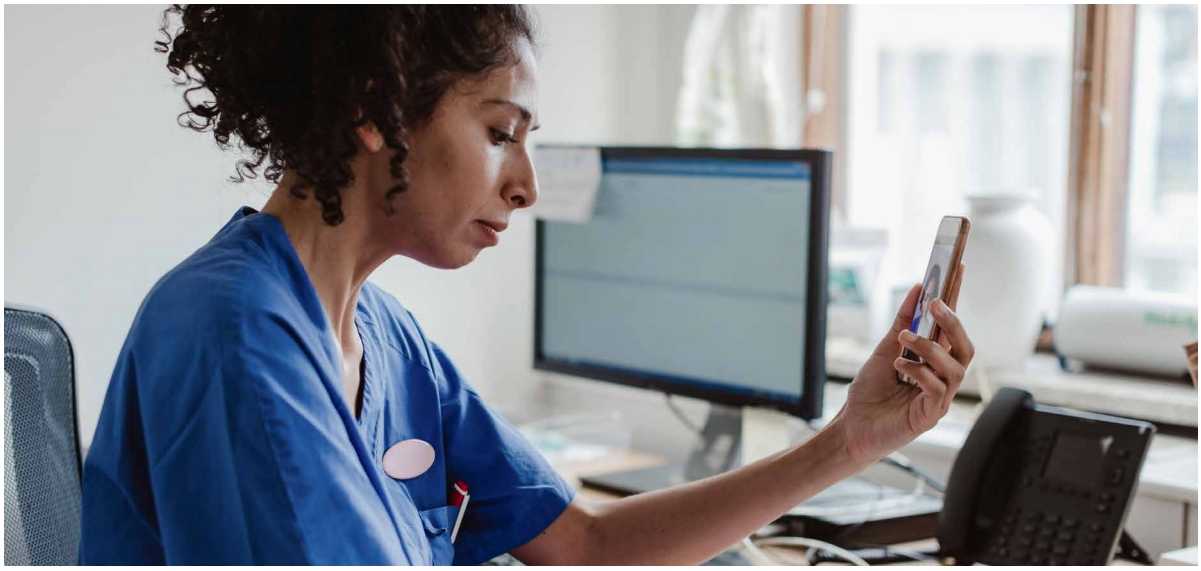
Degree of operability



Source: Association Francophone des Utilisateurs de Logiciels Libres (AFUL)
French-speaking Libre Software Users' Association interoperability working group.[26]

[23] What is Interoperability? – NCOIC.
[24] Bob Sutor: Open Blog | Interoperability vs. intraoperability: your open choice (archive.org).
[25] French speaking Libre Software Association interoperability working group; Interoperability - Wikipedia.
[26] Interoperability - Designing Buildings Wiki.

The barriers to interoperability



Confidentiality and the issue of consent

The requirements facing developers of IT systems for the NHS are more demanding than those for sectors such as banking, retail and travel. First, there is the issue of patient data, which is treated as sensitive personal information requiring higher levels of protection under the Data Protection Act 2018 and is subject to a raft of other legal restrictions.[27] The act also makes provision for the NHS to use such information on public interest grounds, which effectively means that patients cannot prevent clinicians from accessing their data for the purpose of providing direct care. However, this exemption does not apply to secondary uses of confidential patient data, such as healthcare planning and health research, which are crucial for enhancing services. This leads to the controversial issue of consent that has dogged previous efforts to create a national electronic health record system. Patient data is typically anonymised to generate health statistics for secondary use, but the law remains complex in this area. Systems also have to be designed and managed in line with the seven ethical Caldicott Principles in the NHS confidentiality code of practice[28] and take account of a national "data opt-out" that was introduced in 2018 for patients who only want their health information used for direct care.[29]

A lack of agreed standards

National standards need to be agreed upon for both the technical platform and the clinical content of electronic health records before systems can achieve interoperability across all parts of the NHS. This is a collaborative process that involves policymakers, NHS leaders, clinicians, tech companies and users. It is led by the Government, which ultimately adopts the standards and makes them mandatory to ensure consistent application across the health service. Systems must be developed, implemented, fine-tuned and evaluated, while updating standards in line with technological advances is an ongoing task. The process is a long-term effort that requires planning, organisational capacity, resources, commitment and clear direction to achieve the benefits that widespread interoperability can bring. The initial choice of technical standards is crucial, while consistent standards for clinical content in the NHS context must be developed. The Wachter report stressed that "interoperability should be built in from the start" and warned against "going too quickly" in the attempt to digitise the NHS. The report pointed to the "productivity paradox" of IT, whereby short-term return on investment is more likely to come from safety and quality, while cost savings may take 10 years or more to emerge.[30]

[27] Guide to the General Data Protection Regulation - GOV.UK (www.gov.uk).
[28] Confidentiality: NHS Code of Practice - GOV.UK (www.gov.uk).
[29] National data opt-out - NHS Digital.
[30] Using information technology to improve the NHS - GOV.UK.

A complex and decentralised health system

The complex structure of the NHS in England, with its multiple, interlocking organisations and services, has slowed the roll-out of electronic health records. Systems developed within organisational silos have been designed around the needs of the organisation rather than the patient – and with different specifications to those in other NHS services.[31] Most social care providers have adopted computerised record systems, yet cannot share information from them with other care professionals. Nor can data from many hospital information systems be accessed by care providers. While nearly all GP practices have digital clinical record systems, many are outdated and most remain inaccessible to patients. In 2019, the Royal College of General Practitioners (RCGP) issued a "tech manifesto" calling for all GP practices to have fully interoperable IT systems, access to secure high-speed broadband and a single, shared electronic patient record.[32] The three biggest challenges to digitisation identified in a survey of 1,500 health professionals conducted by consultancy network Deloitte,[33] were the cost of technology (backed by 55% of respondents), finding the right technologies (backed by 11%), and the complexity of technology (backed by 10%), while 61% felt "not at all" or only "a little" informed about their organisation's digital strategy.

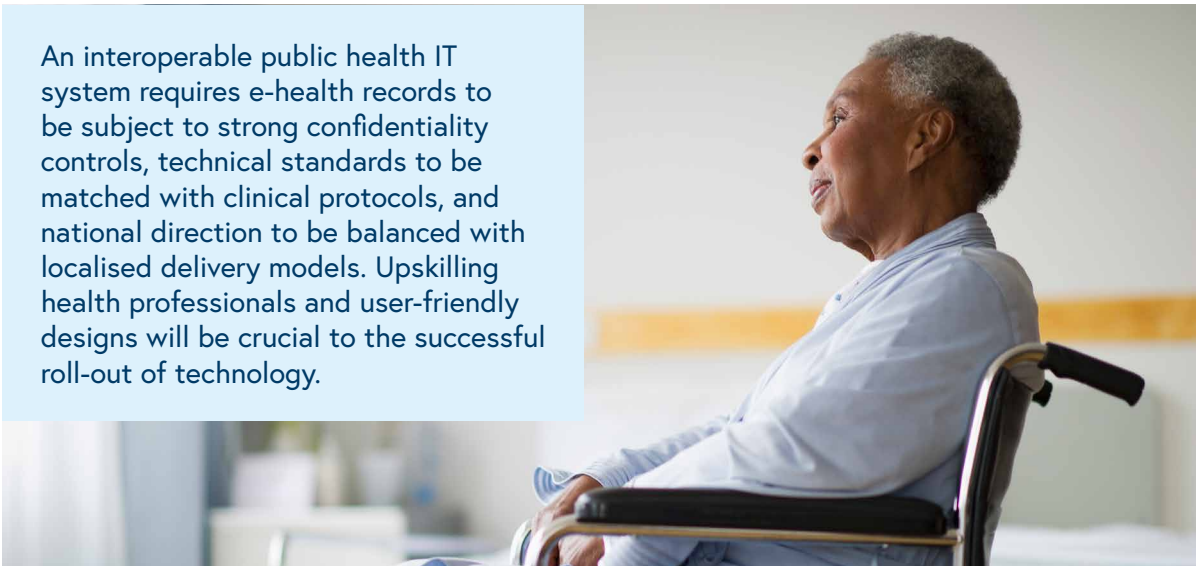
A shortage of technical knowhow and skills

All NHS trusts in England were required to undergo a validated assessment of their digital maturity by the National Information Board (NIB) in 2016 and 2018.[34] The exercises were designed to measure trusts' strengths and weaknesses in utilising digital technology to achieve a health and care service that is paper-free at the point of care. Each trust was assessed across three main themes: readiness, capabilities and infrastructure. In 2018, England's NHS trusts achieved an average digital maturity score of 66 but there was a wide variation between them, with the most mature achieving 93 and the least mature scoring just 18.[35] Trusts with higher scores in 2016 were invited to become Global Digital Exemplars (GDEs), which were given extra funding to lead digitisation efforts. However, while scores on all three themes improved from 2016-2018 for trusts across England, the "digital gap" between GDEs and other trusts widened in the North, Midlands and East, and South East regions. An acute lack of Chief Clinical Information Officers and clinician-informatics professionals and the need to develop a workforce to engage healthcare professionals and patients more widely in digitisation were key findings of the Wachter report.[36]

[31] Personalised health and care 2020 - GOV.UK.
[32] College calls on Health Secretary to make NHS a world leader in tech by getting the basics right first (rcgp.org.uk).
[33] Closing the digital gap: Shaping the future of UK healthcare - Thoughts from the Centre | Deloitte UK.
[34] NHS England » Digital Maturity Assessment.
[35] Deloitte UK life sciences healthcare closing the digital gap.
[36] Using information technology to improve the NHS - GOV.UK.

A framework for digital transition

An interoperable public health IT system requires e-health records to be subject to strong confidentiality controls, technical standards to be matched with clinical protocols, and national direction to be balanced with localised delivery models. Upskilling health professionals and user-friendly designs will be crucial to the successful roll-out of technology.



Robust protection for patient confidentiality

The framework for digital transformation of the NHS requires e-health record systems to satisfy the UK's strong legal protections for patient confidentiality. These include 10 data security standards put forward by the National Data Guardian that form the basis of an online Data Security and Protection Toolkit.[37] The standards lay out stringent requirements for all people, processes and technology involved in handling confidential health information to prevent cyber-attacks and other data security breaches. All IT system suppliers and contractors with access to NHS patient data systems are required to use the toolkit to assess their compliance with the standards and publish the results. The framework stipulates that patient records should use the NHS Number - a unique identifier given to all NHS patients in England – wherever possible. It also requires that all access to NHS systems is provided through an approved authentication system to prevent unauthorised access. For patients, this is the NHS Login and for staff, it is the NHS Identity platform.

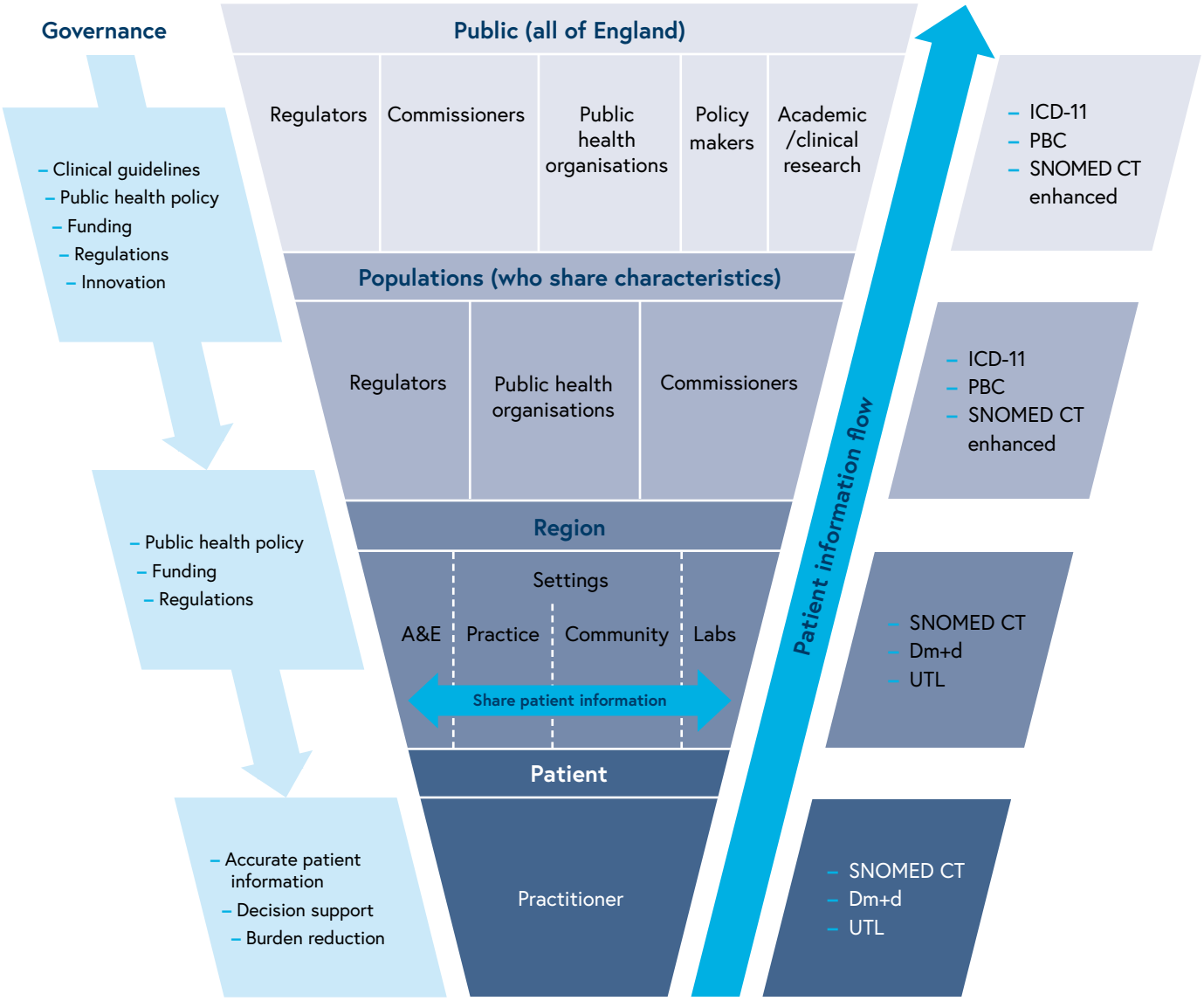
National standards for both data and content

A consistent set of open-access technical standards is critical to the development of transferable electronic healthcare records. NHS Digital has adopted the international standard Fast Healthcare Interoperability Resources (FHIR) and used it to co-produce Application Programming Interfaces (APIs) with the collaborative health IT group INTEROPen.[38] Together, they have devised two FHIR APIs for England's healthcare system, CareConnect and Transfers of Care. They enable the transfer of agreed clinical information between different settings. NHS Digital, which aims for semantic interoperability across the NHS, is leading the development of systems for safely transferring health records using the two APIs in collaboration with healthcare providers, system vendors, and the Professional Record Standards Body (PRSB). This involves matching the NHS Clinical Information Standards for data with content-based standards that specify the type of information about patients and their treatment to be shared. NHS Digital expects Local Health and Care Record Exemplars (LHCRE) to use the FHIR APIs when developing e-health records and all NHS services to support them. The PRSB has developed 22 standards for the content of e-health records in contexts ranging from hospital referrals to maternity services.[39] The standards are freely available on the PRSB website.

[37] BETA - NHS digital, data and technology standards framework - NHS Digital.
[38] BETA - NHS digital, data and technology standards framework - NHS Digital.
[39] Standards – PRSB (theprsb.org).

Patient information flow in the health and care system

The evolving national health information system will use a curated set of NHS Clinical Information Standards that is being developed by NHS Digital.[40]



Source: NHS Digital.[41]

Key:
SNOMED_CT is the NHS standard for clinical data records.[42] It includes nearly a million clinical terms covering all aspects of medicine.
ICD is the NHS standard for diagnosis-based statistical analysis of hospitals. ICD-10, 5th edition, is the current version but NHS Digital plans to replace it with ICD-11.
UTL is the NHS standard for describing clinical tests and their results. A simple reference set was published in June 2019 for trial use and content is being added to it.[43]
Dm+d is the NHS standard for describing medicines and medical devices. It covers many medicines and devices.
OPCS is the NHS standard for procedure-based statistical analysis of hospitals. The current version is OPCS-4.8. NHS Digital plans to replace it with a new standard.
PBC is the standard used for analysis of NHS expenditure.[44] It enables NHS spending to be mapped against 23 types of disease, such as cancer or blood disorders.

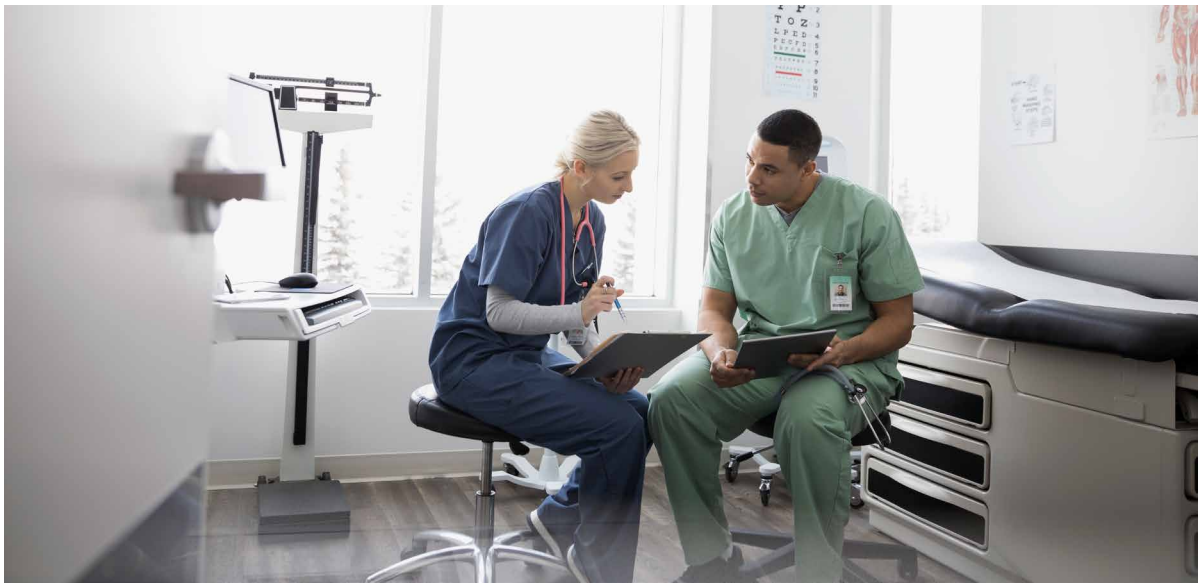
40 BETA - Clinical Information Standards - NHS Digital.
41 BETA - Clinical Information Standards - NHS Digital.
42 BETA - NHS digital, data and technology standards framework - NHS Digital.
43 Unified Test List result observables simple reference set (foundation metadata concept) (digital.nhs.uk).
44 Programme budget categories (PBC) | NHSBSA.

Regional pilot programmes to lead delivery

The five Local Health and Care Record Exemplars (LHCRE) that were set up in 2018 are leading the roll-out of shared health records to improve and coordinate patient care.[45] They are collaborating with NHS Digital and NHSX to develop local solutions using national FHIR APIs and content standards. The five LHCRE are Greater Manchester, Yorkshire and Humber, One London, Thames Valley and Surrey, and Wessex. Each includes several counties, districts or boroughs and together they cover 41.9% of England's population. The localised approach to implementation means that diverse models can be developed to match different circumstances. In Greater Manchester, for example, a single instance of a shared care record is combined with a standardised and consolidated care record data layer.[46] Yorkshire and Humber LHCRE uses a federated model to access data, which then forms a standardised and consolidated data layer for individual care and population health. Wessex has linked two shared care records to create a standardised and consolidated care record data layer. Once the new systems are working smoothly, the LHCRE will share their respective models and experience with other regions.

Development of the health informatics profession

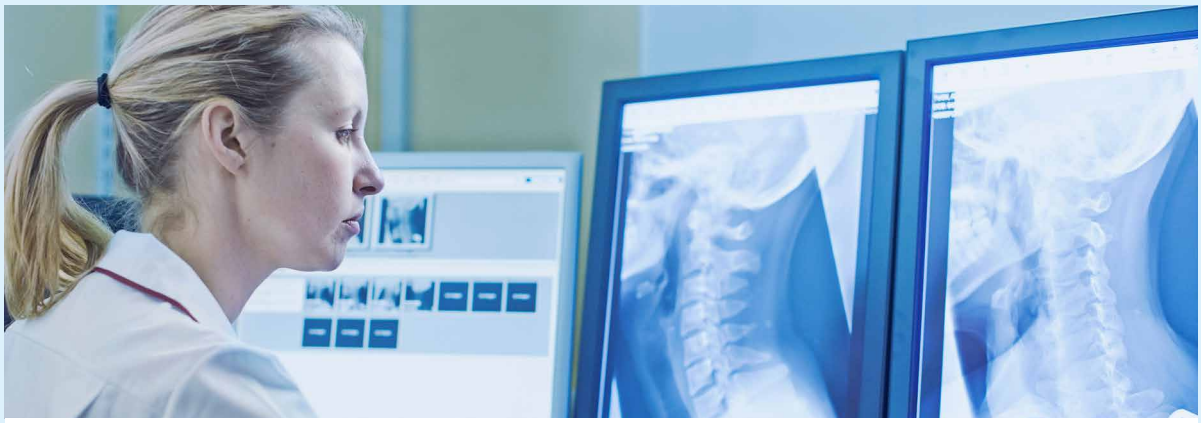
The digital challenges facing the NHS are leading to increased demand for skilled health informaticians. By 2030, the NHS will need to make up a shortfall of some 18,000 full-time-equivalent health informatics staff to meet projections of a "data-rich future", according to workforce modelling by Health Education England (HEE).[47] The growing demand is stimulating new initiatives across professional training, registration and recruitment. HEE set up the NHS Digital Academy to spearhead training of health informatics professionals.[48] Its flagship programme is a Postgraduate Diploma in Digital Health Leadership that is designed to train up a new cadre of Chief Clinical Information Officers for NHS trusts – a key recommendation of the Wachter report – and other digital change leaders. HEE also funds the NHS Graduate Digital, Data and Technology Scheme, which fast-tracks high quality graduates into hard-to-fill, vacant digital roles.[49] Non-profit organisation Health Data Research UK has set up parallel postgraduate programmes and research fellowships in health data science, including the HDR UK-Turing Wellcome PhD Programme.[50] Meanwhile, the Faculty of Clinical Informatics has drawn up six registration standards for health informatics professionals and is joining the Federation of Informatics Professionals to create a unified professional registration body for the field.[51]



[45] The future for patient data | Association of Medical Research Charities (amrc.org.uk).
[46] So, what is a Local Health and Care Record anyway? - NHS Digital.
[47] Digital and Informatics workforce planning and modelling | Health Education England (hee.nhs.uk).
[48] NHS Digital Academy - Digital Transformation (hee.nhs.uk).
[49] NHS Graduate Digital, Data and Technology Scheme — Graduates into Health.
[50] Careers in health data science - HDR UK.
[51] FEDIP workshop - Digital Health Rewired.

Case studies

Estonia builds national system with blockchain technology



A small country on the edge of Europe, Estonia has one of the most advanced e-health systems in the world. The Estonian National Health Information System (ENHIS) holds more than 40 million health documents and is used by 99% of all patients.

As well as an e-Health Record accessed through a Patient Portal, it boasts an e-Prescription system linked to every pharmacy and hospital in the country, and an e-Ambulance service that can locate phone requests for an ambulance within 30 seconds.[52]

The nationwide system provides real-time access to a patient's record for doctors across Estonia, enabling vital health information to be considered during emergency treatment, while test results and medical images can be viewed instantly. It also compiles health data for national statistics, which are used to measure health trends and plan provision.

Patients can view their own health records through the Patient Portal and submit statements of intention on a health matter, or appoint someone to represent them. They can also prevent medical professionals from accessing some or all of their health information.

The system, which was launched in 2008, uses an electronic ID-card for secure authentication, while all medical documents are digitally signed or stamped. Personal data is coded to separate it from medical data, and encryption is used to prevent confidentiality breaches by technical staff.[53]

Accountability and transparency are reinforced through a permanent, secure log of all actions and visits relating to a patient's record, along with continuous monitoring. Keyless Signature Infrastructure (KSI) blockchain technology that was developed in Estonia is used for protection against cyber threats.

"This system... not only improves the cost-effectiveness, sustainability and efficiency of the Estonian healthcare service but also facilitates the transition to preventative, rather than curative, medicine. [It] is underpinned by blockchain technology, a crucial pillar in ensuring the integrity and security of all patient data."[54]

Riina Sikkut, Minister of Health and Labour, Republic of Estonia

[52] e-Health Records — e-Estonia.
[53] Healthcare — e-Estonia.
[54] Learning from the Estonian e-health system (healtheuropa.eu).

Case studies

Digital care plan aims to support patient power

A proposed national standard for sharing the healthcare records of people with long-term conditions or complex needs aims to empower patients and boost their health prospects through better coordination and planning.

The standard was drawn up by the Professional Record Standards Body in collaboration with the North West London Clinical Commissioning Group (NWLCCG), NHS Digital and the Healthier London Partnership.[55]

The Digital Care and Support Plan provides a set of headings for use when sharing records across both the health system and social care sector. It also supports a personalised approach to healthcare in which patients set their own goals in discussion with medics and carers.

Patients describe themselves and their needs in an About Me section and proceed to set out - together with a health or care professional - their strengths, needs, concerns and health problems, goals, actions and activities, outcomes of such actions and planned review date.

The document, which provides details of the patient and all relevant health professionals, can also include a contingency plan outlining what should be done in the event of a crisis; and an additional supporting plan that meets data requirements for a particular condition. Entries by the patient, medics and carers are instantly shared, facilitating joined-up care.

The headings and content were developed following extensive consultation across relevant health and care sectors, including an online discussion forum, a webinar, a workshop and an online survey of 200 stakeholders. NHS Digital is preparing technical standards to match the plan, which will then be trialled across northwest London.

"Before we start to talk about... technical specifications, [there is a lot of work] that needs to happen upstream, in terms of getting the system to agree [on] a common understanding of what constitutes a professional standard. Prior to 2018, we didn't have a consensus across health and care as to what even constitutes a care plan."

Dr Nilesh Bharakhada, PRSB Clinical Director

[55] Standards – PRSB (theprsb.org).

Case studies

Bucks goes live on Connected Care e-health platform

The first patient records are being shared across a region of Southern England with 3.8 million residents after Buckinghamshire was connected to its e-health platform.

The Connected Care platform is being developed by Graphnet for Thames Valley and Surrey Care Records Partnership (TVSCRP) under a £12.5 million, seven-year contract.[56]

The region is one of five Local Health and Care Record Exemplars (LHCRE) that each won £7.5 million over two years from NHS England to spearhead the development of shared patient record systems. Its platform will join up local e-health record sets, which use diverse technical solutions, from six integrated care systems (ICSs).

Data from Buckinghamshire's My Care Record went live across the TVS region in November 2020, and Frimley and Berkshire West were connected to the platform in January 2021. This enables medics in the two Berkshire ICSs to access Buckinghamshire patient data.[57]

TVSCRP points out that 18% of all acute care in the region is provided outside the patient's local area and wider sharing of patient records will enable healthcare professionals to make better decisions about treatment.[58]

The pieces of the platform are being fitted together gradually as local systems are rolled out and readied for connection. The Oxfordshire Care Summary was launched within the county in April 2020 and the Surrey Care Record was introduced across Surrey Heartlands ICS in May 2020, despite the pressures on the NHS due to Covid-19.[59]

As well as GPs and hospitals, ICSs include ambulance services, local authorities, children's services and community mental health services. Connected Care will also be used for population health management.

[56] Standards – PRSB (theprsb.org).
[57] Thames Valley and Surrey LHCRE picks Graphnet for regional shared records (digitalhealth.net).
[58] Current Status (thamesvalleysurreycarerecords.net).
[59] Thames Valley and Surrey Care Records Partnership (thamesvalleysurreycarerecords.net).

Case studies

Flagship programme seeks digital changemakers

Applications opened in April 2021 for the Postgraduate Diploma in Digital Health Leadership after Imperial College London won the contract for the programme again.[60]

Health Education England (HEE) will provide 100 fully funded places on the flagship NHS Digital Academy programme. This prepares serving health informatics staff for the roles of Chief Clinical Information Officer, Chief Information Officer and related posts.

The programme, which is in its fourth year, will be delivered by Imperial College in partnership with the University of Edinburgh and Health Data Research UK, which is leading the development of a secure national research ecosystem based on health data.[61]

Successful applicants will begin their studies in September 2021 – as opposed to April for previous cohorts. The one-year, part-time programme will also be offered through a combination of online and face-to-face learning, after tuition moved entirely online due to Covid-19. Accreditation will be provided by the Federation of Informatics Professionals and the Faculty of Clinical Informatics.

A new NHS Digital Academy website[62] was launched in March 2021 to support applications to the £1.75 million programme, with drop-in webinars also planned. HEE aims to attract more applications from underrepresented groups including ethnic minorities and women.

It has also introduced a transparent recruitment process with published shortlisting criteria and scoring to support diversity and inclusion. To qualify for the programme, candidates must be working in a health service role, where they are required to drive and implement practical digital transformational change. They can be from a health or tech background.

HEE plans to reuse some content from the programme for open-access modules through platforms such as its e-Learning for Healthcare[63] site to cater for a wider range of NHS staff. Other plans to expand the NHS Digital Academy include dedicated courses for clinical or IT specialists.

60 Thames Valley and Surrey Care Records (thamesvalleysurreycarerecords.net).
61 Digital Health Leadership - Digital Transformation (hee.nhs.uk).
62 NHS Digital Academy - Digital Transformation (hee.nhs.uk).
63 Home - e-Learning for Healthcare (e-lfh.org.uk).

The next steps

The transformations and accomplishments outlined in this report have occurred over the course of several decades of change in government, industry, and the general public. Digital transformation must continue at pace in order to minimise environmental impact, increase social value, and provide our industry with a competitive edge.

So how do we engage with stakeholders to accelerate progress? Here are some measures for immediate implementation that would make a significant impact within the next five years.

1 Confidentiality

- Conduct a review of the use of blockchain, encryption and coding techniques for security and confidentiality in the Estonian National Health System and other global early adopters.
- Set up a forum for health informaticians and innovators working on the roll-out of integrated patient records to share technical solutions relating to confidentiality and consent.

2 Data standards

- Set an end date for the consultation on the draft NHS Digital, Data and Technology Standards Framework and publicise the exercise more widely.
- Clarify which aspects of the framework are already mandatory and publish the planned procedures and target dates for giving them legal status.

3 Implementation

- Conduct a post-Covid-19 review on integrated patient records in LHCRE to check progress and set realistic new targets that consider the pandemic.
- Carry out a cost-benefit review of the various approaches to integrating patient care among LHCRE to identify flexible and effective models.
- Launch a new round of digital maturity assessments across NHS trusts to capture current levels of digital readiness and identify potential "fast followers" of the LHCRE.

4 Professionalisation

- Mount a series of workshops for human resource leaders in NHS trusts using projections of future demand for clinical informatics staff from workforce planning exercises.
- Conduct information campaigns across universities on upcoming career and training opportunities for clinical informaticians.

5 Engagement

- Hold workshops for tech firms on how to meet the requirements of the Data Security and Protection Toolkit,[64] Digital Technology Assessment Criteria,[65] and NHS Standard Contract.[66]
- Commission surveys of NHS staff who are using integrated patient health records to identify any issues they may face, so appropriate support measures can be devised.
- Carry out a national survey of patients' digital access to their GP records to assess digital readiness across primary care.

[64] Data Security and Protection Toolkit (dsptoolkit.nhs.uk).
[65] Digital Technology Assessment Criteria (DTAC) - NHSX.
[66] NHS England - NHS Standard Contract.

Conclusion

While the NHS faced and overcame the greatest challenge in its 73-year history during the Covid-19 pandemic, much preparatory work remains to be done towards the long-term goal of achieving widespread interoperability across the sector. The road to establishing a national electronic health information system has been long and winding and there are numerous obstacles yet to overcome.

The NHS's sheer size and complexity, as well as the highly sensitive nature of personal health information, are major impediments to interoperability within this one-of-a-kind public health system. Shared health record systems must adhere to the strict legal protections for patient confidentiality in the United Kingdom and integrate technologies developed within a complex network of organisational silos. Other significant impediments have included a lack of health informatics expertise within the NHS and the requirement for national data standards to be developed, then agreed upon by a broad range of stakeholders, and finally adopted.

A new, more gradualist approach to addressing these challenges has gained traction over the last five years. Five Local Health and Care Record Exemplars (LHCRE) are piloting integrated patient health records. Together, they cover 41.9% of England's population. The National Data Guardian's advice has been given legal weight. The Professional Record Standards Body has developed specialised content standards for patient records in 22 different clinical settings. New training programmes for health informatics professionals have been launched. NHS Digital has published a draft NHS Digital, Data and Technology Standards Framework, which proposes mandatory data standards for interoperability.

A framework for interoperability should include four critical components: robust protection of patient confidentiality; national data and content standards; localised delivery of integrated patient records; and professional development for health informaticians. With critical building blocks in place across all four areas, we believe the time has come for a new initiative to connect the dots through an overarching national structure. A thorough post-pandemic review and inventory should now begin, followed by a strategy for achieving complete interoperability and legislation mandating open data standards.

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The Institution of Engineering and Technology

Contact information

London, UK
T +44 (0)20 7344 8460
E faradaycentre@ietvenues.co.uk

Stevenage, UK
T +44 (0)1438 313311
E postmaster@theiet.org

Beijing, China*
T +86 10 6566 4687
E china@theiet.org
W theiet.org.cn

Hong Kong SAR
T +852 2521 2140
E infoAP@theiet.org

Bangalore, India
T +91 80 4089 2222
E india@theiet.in
W theiet.in

New Jersey, USA
T +1 (732) 321 5575
E ietusa@theiet.org
W americas.theiet.org

@TheIET theiet.org

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