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Health information technology and digital innovation for national learning health and care systems

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Health information technology can support the development of national learning health and care systems, which can be defined as health and care systems that continuously use data-enabled infrastructure to support policy and planning, public health, and personalisation of care. The COVID-19 pandemic has offered an opportunity to assess how well equipped the UK is to leverage health information technology and apply the principles of a national learning health and care system in response to a major public health shock. With the experience acquired during the pandemic, each country within the UK should now re-evaluate their digital health and care strategies. After leaving the EU, UK countries now need to decide to what extent they wish to engage with European efforts to promote interoperability between electronic health records. Major priorities for strengthening health information technology in the UK include achieving the optimal balance between top-down and bottom-up implementation, improving usability and interoperability, developing capacity for handling, processing, and analysing data, addressing privacy and security concerns, and encouraging digital inclusivity. Current and future opportunities include integrating electronic health records across health and care providers, investing in health data science research, generating real-world data, developing artificial intelligence and robotics, and facilitating public–private partnerships. Many ethical challenges and unintended consequences of implementation of health information technology exist. To address these, there is a need to develop regulatory frameworks for the development, management, and procurement of artificial intelligence and health information technology systems, create public–private partnerships, and ethically and safely apply artificial intelligence in the National Health Service.

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Introduction

Health information technology (HIT) needs to be seen as a means to an end and not an end in itself. It is not a panacea for the challenges facing the UK's health and care systems but, if thoughtfully developed, procured, and deployed, it can be used to support the wider goals of enhancing the quality, safety, and efficiency of health and care.[1] This development activity needs to be a combination of bottom-up innovation, addressing challenges facing patients and front-line health and care staff, and top-down strategies that are confined to areas where the government can add value by implementing common approaches across the entire health and care landscape.[2] Of even greater strategic importance than the deployment of HIT is that the data generated are used to inform and support health policy strategy and planning, enhance health and care delivery, and catalyse the emergence of patient-centred models of care.[3]

This Health Policy paper offers a timely, accessible, and up-to-date summary of policy developments, major priorities, and emerging opportunities through which HIT systems might provide the necessary infrastructure to enable the transition of the National Health System (NHS) and social care in each country of the UK into digitally enabled national learning health and care systems.[4] The COVID-19 pandemic has placed unprecedented pressure on health and care systems but, in some respects, has also accelerated the digital transformation of health and care services. This paper is published at a crucial time, when the NHS in each UK country is seeking to ensure this progress translates into long-term and sustainable change. We do not offer a comprehensive review of the sociopolitical aspects of the adoption and use of HIT,[5–7] and the political nature of the NHS and its history are discussed in the London School of Economics and Political Science (LSE)–*Lancet* Commission main report.[8] Instead, we discuss many practical aspects of HIT,

Key messages

- With the experiences acquired during the COVID-19 pandemic, each UK country needs to now re-evaluate their digital health and care strategies
- Each UK country should deliver on commitments to implement integrated electronic personal health records, with access for patients, carers, and health and care providers across multiple settings
- The usability and interoperability of health information technology (HIT) systems should be improved to mitigate against the unintended consequences of HIT such as medical errors and professional burnout
- Security and privacy concerns need to be addressed by improving cyber security and data governance to maintain public trust in how data are held, shared, and used; this priority needs to be balanced against the public benefit gained from rapid access to data to inform the policy response to major public health shocks such as the COVID-19 pandemic
- Easy-to-use platforms should be developed and capacity built among individuals and communities at risk of digital exclusion to ensure HIT does not widen inequalities
- Routinely collected data, such as genetic, omic, demographic, health and care, administrative, and social media data, should be collated into integrated datasets to support policy and planning, service delivery, and the precision medicine and public health agendas
- Investment is needed in HIT leadership, training and development of the existing workforce, and the creation of new roles such as data scientists and clinical informaticists
- Artificial intelligence and robotics have the potential to improve the efficiency and quality of health and care delivery but should be understood as complementary to pre-existing roles and a mechanism to reduce the burden on staff

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such as improving usability and interoperability, handling, processing, and analysing data, and addressing privacy and security concerns. Although we predominantly focus on the UK, we believe our analysis will be of interest to international policy makers who might seek to gain insights from the relative successes and failures of the UK approach to strengthening HIT and apply these insights to their own country context. This paper will also be of interest for health-care professionals and patients, many of whom advocate for improved access to an interoperable and usable electronic health record (EHR) as a key enabler to improving patient experiences and quality of care.

The concept of a learning health system can be understood as the use of data-enabled infrastructure to support policy and planning, public health, and personalisation of care.[9,10] This system involves a continuous cyclical process, whereby data are converted to knowledge, knowledge is translated into practice, and changes in practice generate more data.[11] HIT is a key enabler of a learning health system, by contributing to the generation, integration, processing, and interpretation of data generated from multiple sources, including EHRs, the government, disease surveillance, patients, and clinical research, which can support health and care policy and planning. Throughout this paper, we use EHRs to refer to any type of software that captures and electronically stores patient information; electronic personal health records (PHRs) refer to EHRs that are accessible to patients. We begin by discussing how the UK has leveraged HIT in response to the COVID-19 pandemic and then focus on the major priorities and opportunities to strengthen HIT across the UK.

Leveraging HIT in response to the COVID-19 pandemic

During the pandemic, the UK has had mixed success in repurposing and developing existing HIT—for example, for the rapid increase in remote consultations to minimise transmission of infection, in efforts to develop mobile applications to monitor the spread of disease, and in the development of shielded patient lists to issue guidance to vulnerable populations. We discuss these developments while also acknowledging barriers that restricted the ability of the UK to maximise the use of HIT for policy and planning, public health, and personalisation of care.

To protect patients and prevent the transmission of SARS-CoV-2, access to primary care services across the UK rapidly transformed to a system whereby patients were triaged by telephone or a structured online form to receive either a video, telephone, or face-to-face consultation. In a matter of weeks, this transition successfully fulfilled a long-term goal of NHS England to provide a so-called digital-first offer for primary care services.[12] Data reported by NHS England indicated that, during the height of the pandemic, around 85% of consultations were done remotely and 95% of general practitioner (GP) practices had successfully implemented video consultation capability.[13] Similar to primary care, many secondary care providers scaled up their capability to provide telephone and video teleconsultations.[14] The effects of these striking transformations in patient access, experience, and outcomes are yet to be fully evaluated. The pre-existing evidence to support the use of video and telephone consultations is mixed. There are potential advantages as some patients might prefer to access health-care services in this manner,[15] but other studies suggest that telephone and video consultations are only suitable for some presentations and might not necessarily save costs.[16,17] Although comprehensive guidelines specific to COVID-19 were made available,[18] the scarcity of available and appropriate audiovisual infrastructure and software, and corresponding training,[19] required the NHS to recommend the use of any proprietary software that health-care providers were comfortable with,[20] rather than a consistent and verifiably secure service.

Like many other countries, the UK emphasised the potential of mobile applications to supplement efforts to monitor the spread of SARS-CoV-2, facilitate contact tracing, and issue self-isolation recommendations.[21] The UK had early success with the launch of the COVID-19 Symptom Study application, which was also launched in the USA. In the first month, 2·5 million UK individuals completed the surveys, which facilitated the early detection of previously unknown symptoms, such as a loss of taste and smell.[22,23] This information was quickly relayed to the public, encouraging individuals with such symptoms to self-isolate.[24] The UK has had less success in developing a mobile application for the purposes of automated contract tracing. The NHS spent many months developing an in-house mobile application that, after being trialled on the Isle of Wight, had several flaws, such as inadequate ability to detect iPhones, poor interoperability, and incorrect notifications.[25] Concerns were also raised about privacy safeguards, as the UK Government intended to retain information within a central database.[26] Ultimately, the UK Government abandoned its attempts to develop its own mobile application in mid-June, 2020, in favour of a decentralised approach developed by Google and Apple.[27]

Despite having many extensive health-care datasets across primary and secondary care, the UK has struggled to maximise the use of these assets to improve policy and planning. To protect the most vulnerable during the pandemic, each UK country drew up shielded patient lists to contact individuals to recommend complete shielding.[28] Criteria agreed upon by expert opinion from the four UK Chief Medical Officers were used to develop algorithms that identified individuals using datasets collated from hospital admissions, primary care EHRs, and prescription records.[29] These criteria notably omitted people older than 70 years, despite increasing age arguably being the most important predictor of increased

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mortality.[30] Other absent conditions, such as use of renal dialysis, have been subsequently added.[31] Many datasets included out-of-date information and thus excluded the most recently diagnosed individuals or did not include crucial information, such as on patients receiving chemotherapy for cancer.[32] The reliability of these datasets have been hampered by ongoing challenges in getting data to flow in real time, despite several stalled projects that aimed to address these issues after the 2009 influenza pandemic being re-initiated at the start of the COVID-19 pandemic.[33,34] Specialist medical societies, such as the British Society for Rheumatology, were recruited to assist in finding and contacting further individuals.[35] GPs and hospital consultants were also required to manually verify patient lists, which frequently required amendments.[36] By the nature of this process, many individuals who should have been notified were not and vice versa. Adding to the confusion, some individuals who had been initially flagged as vulnerable were later told they were no longer on the shielded patient lists,[37] excluding them from some benefits such as government food parcels. Work is currently underway to develop a data-driven, evidence-based algorithm to identify individuals at greatest risk of COVID-19 morbidity and mortality.[38]

Major priorities for UK HIT

In the years before the COVID-19 pandemic, all four UK countries published strategies that committed to strengthen the implementation of HIT. In 2015, Wales published Informed Health and Care—A Digital Health and Social Care Strategy for Wales.[39] Wales is positioned to become the first UK country to offer a patient-controlled PHR to all citizens, using a privately developed platform known as Patient Knows Best. This platform began in 2017 with access provided to all patients aged 16–24 years with diabetes.[40] In 2016, Northern Ireland published eHealth and Care Strategy[41] and is investing in a single digital health record known as ENCOMPASS, which is expected to be fully implemented by 2025.[42] In 2018, Scotland published Scotland's Digital Health and Care Strategy: Enabling, Connecting and Empowering[43] and announced its plan to consolidate its IT systems into a national platform.[44] In England, the Department of Health & Social Care (DHSC) published The Future of Healthcare: Our Vision for Digital, Data and Technology in Health and Care, followed by NHS England publishing the NHS Long-Term Plan in 2019,[45] which included a series of commitments that together outline a pathway to digitally enabled care. The specific commitments contained within each strategy and an overview of the digital health and care landscape across the UK can be found in panel 1. There is consensus among these strategies that UK health and care systems should work towards delivering an electronic PHR accessible for patients across multiple health and care settings. Other common priorities emphasised within these strategies include investing in HIT infrastructure, workforce development to ensure staff have the right skills to collect, process, and analyse data for policy and planning, strong leadership to foster an open culture for innovation, and improved governance to ensure agreed standards are met. In England, NHSX has been newly established to deliver these commitments and oversee several programme teams, previously under the remit of NHS England and the DHSC, focusing on areas such as artificial intelligence (AI), cyber security, and data transformation and policy.[47]

With the experience acquired during the COVID-19 pandemic, each UK country should now re-evaluate their digital health and care strategies. We argue there are various priorities common to all UK countries that need to be addressed, including achieving the optimal balance between top-down and bottom-up implementation, improving usability and interoperability, handling, processing and analysing data, addressing privacy and security concerns, and encouraging digital inclusivity. These priorities have also been raised in several other prominent reports on HIT.[48–51]

Balancing top-down and bottom-up implementation

The NHS Long-Term Plan includes the commitment that all providers will achieve a core level of digitisation over the next 5 years, implemented to nationally agreed standards to enable integration with a local health and care record. This integration will be supported by robust, modern IT infrastructure services for hosting, storage, networks, and cyber security.[45] However, many will be wary that too much top-down implementation, as was the case with the National Programme for IT (appendix p 2),[26] will fail to engage with the needs of local health-care providers and therefore result in an unfeasible agenda that expects too much too quickly. Many stakeholders underestimate the challenges of developing and implementing high-quality, large-scale HIT systems. Effective implementation requires a process of mutual adoption, typically at the local or organisational level, by which technology and work processes become aligned.[6] System-level change also requires being responsive to the perspective and needs of multiple stakeholders and the political, regulatory, and sociocultural context of health systems.[52] HIT systems should be understood as complex interventions that need to be managed adaptively to accommodate local contexts.[53] The middle-out approach to implementation, which attempts to balance top-down and bottom-up implementation, might be one solution.[54] It acknowledges that governments and providers have different starting points, goals, and resources. At the earlier stages of development, governments predominantly focus on helping fund local innovation, rather than setting mandates. Once existing systems are in place, there is a role for governments to set standards and introduce incentives to providers to acquire

See Online for appendix

Panel 1: Overview of commitments within UK health and care digital strategies

NHS England Long-Term Plan (2019)[45]
- From 2019, all new systems purchased will have to comply with agreed standards, as set out in *The Future of Healthcare*[46]
- By 2021, there will have to be 100% compliance with new mandated cybersecurity standards
- By 2023, a Child Protection Information system including access for general practitioners (GPs) will be implemented
- By 2023, diagnostic imaging networks will enable the rapid transfer of clinical images between health-care providers
- By 2024, the functionality of Summary Care Records will be moved to a Local Health and Care Record, which will allow reminders and alerts to be sent directly to the patient
- By 2024, all women will be able to access their maternity record digitally
- By 2024, every patient will be able to access a GP digitally, and, where appropriate, opt for a virtual outpatient appointment
- By 2024, all providers across acute, community, and mental health settings will be expected to advance to a core level of digitisation to nationally agreed standards

UK Department of Health & Social Care's The Future of Healthcare: Our Vision for Digital, Data and Technology in Health and Care (2018)[46]

Infrastructure
- Put in place the right infrastructure so hospitals, GPs, pharmacies, and community and social care providers can join up care and patients do not have to repeat their medical history or care needs; systems will be able to talk to each other safely and securely, using open standards for data and interoperability, and will be open with people about how their information is used to increase confidence in the legality, safety, and security of the system
- Buy the best technology to ensure staff who work in the health and care system have the technology to help them do their jobs effectively and the National Health System (NHS), social care organisations, and taxpayers get the best value for money

Digital services
- Ensure that digital services meet people's needs—understand who the users of a system, website, or service are, what they need to do, the problems or frustrations they experience, and what they need from a system, website, or service to achieve their goal

Innovation
- Enable health technology and innovation so the cutting-edge technology developed by our thriving health-technology economy can be more easily developed and used across the health and social care system; NHS and social care can benefit from world-leading innovation and research

Skills and culture
- Develop the right skills and capabilities to support staff and enable leaders to aim for the best outcomes; the right skills are not only digital skills but also the leadership and change-management skills needed to iterate and improve processes
- Build an open culture, working with innovators, academics, industry, staff, and the people who use health and care services to deliver better outcomes for everyone, welcoming feedback and seeking constant improvement

Scotland's Digital Health and Care Strategy: Enabling, Connecting and Empowering (2018)[43]
- By July, 2018, we will establish a national decision making board made up of executive representatives of the Scottish Government, local government, and the NHS, with additional support and advice from industry, academia, and non-governmental organisations
- By 2020, we will have in place clear arrangements to deliver a simplified and consistent national approach for information assurance that will take into account the different needs of users and citizens, and provide clarity around information sharing across health and care
- By the end of 2018, we will have in place a clear national approach to supporting local co-designed service transformation with clearly identified leads
- By September, 2018, NHS Education for Scotland, the Local Government Digital Office (working with COSLA and Health and Social Care Partnerships), and the Scottish Social Services Council will have in place a clear approach to developing the modern workforce and the necessary leadership to drive change
- We will begin work to deliver a Scottish health and care national digital platform, through which relevant real-time data and information from health and care records, and the tools and services they use, are available to those who need it, when they need it, wherever they are, in a secure and safe way
- We will work with eHealth and clinical leads, NHS National Services Scotland, and the Local Government Digital Office (working with COSLA and Health and Social Care Partnerships) to plan and manage the transition process, and will review through our new governance existing projects and investment to ensure best value and alignment to our future direction

eHealth and Care Strategy for Northern Ireland (2016)[41]
- Supporting people: provide eHealth services supporting electronic access for everyone; this will include electronic information services, electronic records access, online support and care services, appointment booking, and remote care

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(Panel 1 continued from previous page)

- Sharing information: give care professionals appropriate access to information to improve the speed and quality of their care decisions
- Using information and analytics: develop ways of transforming data and information into knowledge (informatics) that supports care, from being able to suggest personalised preventive care through to supporting population-level health and care planning
- Fostering innovation: work with businesses, colleges, and universities, community and voluntary organisations, other government departments, and international partners to develop uses of eHealth to help improve health and wellbeing, prosperity, and job creation
- Modernising our eHealth infrastructure: maintain a modern, reliable eHealth infrastructure, including investment in supporting, modernising, and replacing key systems, networks, and hardware as needed
- Ensuring good governance: make thinking about eHealth central to planning any changes to health and care services; this is to ensure we are making the most of technical opportunities and the potential for better information flows to support improvements

Informed Health and Care—A Digital Health and Social Care Strategy for Wales (2015)[39]

Priorities for early action

- In 2016, we will establish a programme board with a clear remit to develop the route map to better exploit national and operational data sources and maximise data-analysis skills and services available across health and social care
- In 2016, we will develop a strategy for a digital health collaboration network or ecosystem, which will support skills development, promote access to core systems for partners, and set out a clear deployment pathway for new products
- In 2016, we will publish a set of technical standards and a software development toolkit to open up the national platform, support training, and allow an accredited network of partners to develop applications and solutions; a strategy for new applications will be produced to ensure they can be delivered and deployed quickly
- In 2016, we will produce a technical strategy that will modernise and standardise the infrastructure across health and social care in Wales—to support collaborative working with other public sector bodies and enable open networks and services; it will include the introduction of single sign-on for staff working in clinical environments who rely on multiple systems to carry out their duties, enabling them to use their own devices, where appropriate, and support mobile working; we will also explore the opportunities of cloud computing to support more efficient and cost-effective digital services

Expectations for NHS organisations and local authorities

- Embrace the vision, ambitions, and opportunities set out in this strategy; use the local and national planning processes and partnership arrangements that already exist to develop joint delivery plans
- Engage with all stakeholders, particularly local people, service users, and staff, to understand requirements and needs for information and digital solutions
- Develop 3-year, rolling local digital health and social care (DHSC) delivery plans to underpin service change and new workforce models to transform local services
- Agree and align the delivery of local DHSC plans with the national delivery plan developed collectively and in collaboration with NHS Wales Informatics Service
- Ensure the DHSC delivery plans, locally and nationally; address the priorities for early actions identified in this strategy

Welsh Government objectives

- Revise the national planning guidance to reflect the requirements for local and national DHSC delivery plans aligned to the All Wales Capital Health Programme
- Ensure that prudent health-care principles are embedded in the delivery approach to digital health and care across the whole system
- Continue to work proactively with UK and international standards bodies and review governance and infrastructure arrangements for adopting national standards in Wales
- Continue to build partnerships and harness opportunities from close working with European health and social care systems, including greater involvement and use of research and innovation funding programmes
- Work with the NHS, local government, and other partners to develop a strategy for a digital health ecosystem in Wales

functionally and technically compliant HIT systems, allowing providers to gradually converge upon similar standards, while not setting unrealistic or harmful deadlines that might ultimately hinder adoption. A greater degree of bottom-up implementation can also facilitate valuable opportunities for involvement of patients and health-care professionals in HIT development, which is key to addressing usability issues, being responsive to concerns regarding data privacy and security, and incorporating patient-generated data into electronic PHRs.[55]

Usability and interoperability of HIT systems

All UK countries have highlighted improving usability and interoperability of HIT systems as a priority.[39,41,43,46] Usability can be understood as the extent to which technology can be used efficiently, effectively, and satisfactorily on the basis of system design.[56] Poor usability can contribute to errors in the process of entering and retrieving information and errors in the communication and coordination process,[57] while also jeopardising patient safety and creating substantial psychological stress for users.[58] Poorly designed systems also contribute to professional burnout and low morale of staff.[59] To improve the design of HIT systems, there needs to be greater engagement from HIT vendors to understand health-care professional and patient needs and ensure basic usability issues are met.[60,61] HIT vendors, health-care professionals, and patients can work together to iteratively deploy HIT systems to enhance care delivery and overcome usability challenges such as difficult-to-interpret visual displays, poor system feedback and responsiveness to end-users, and data entry issues.[62] Iterative deployment, including the thorough and systematic application of usability testing to inform system design and evaluation, has been shown to be a cost-effective method of rectifying many usability issues.[63]

Interoperability, a key facilitator to improving usability of HIT systems, can be defined as the ability of two or more systems or components to exchange information and to use the information that has been exchanged.[64] There are two aspects: technical interoperability (ie, the process of moving data between two or more systems) and semantic interoperability (ie, the process of ensuring that each system can understand and use the information received from the other).[64] Achieving interoperability within complex health-care organisations doing very different functions simultaneously is challenging. Currently, within individual hospitals for example, there might be numerous products deployed with most lacking both technical and semantic interoperability. This state has many implications for patient safety and infection control by creating barriers, for example, for the early detection of nosocomial infections[65]—an important issue during the COVID-19 pandemic. Health-care professionals are typically expected to use many different products, thereby contributing to transcription errors because of the need to collect and report more information.[66,67] This expectation is driven in part by contracts often not specifying the necessary standards required to facilitate interoperability between different products.[48,68] However, efforts to address this problem are underway. In 2015, the UK's National Information Board produced an interoperability strategy accompanied by an interoperability handbook.[69] The strategy consisted of a series of building blocks to improve interoperability, such as establishing regional interoperability communities tasked with developing local digital roadmaps,[70] enabling open interfaces (through open application programming interfaces [APIs]) between integrated EHRs,[71] and prioritising the uptake of uniform digital standards as ratified by NHS England (eg, the use of Systematized Nomenclature of Medicine Clinical Terms by all health-care professionals entering data into EHRs).[72] Prioritising uniform digital standards is an important step to producing comparable health data not just within the UK but also internationally, thereby facilitating cross-country learning and research opportunities. NHS England has now included interoperability standards within the NHS standard contract[73] and, since 2018, all health-care providers are expected to ensure their HIT systems provide open interfaces in accordance with NHS England's open API policy.

For more on the **Clinical Practice Research Datalink** see https://www.cprd.com/

Handling, processing, and analysing data

As the UK's health and care digital capabilities improve, vast quantities of data are being generated that offer opportunities to continuously monitor, analyse, and improve quality of care. The evolving data ecosystem includes a wide range of data on an individual's environment, lifestyle, and socioeconomic status,[74] as well as patient-generated data from wearables, sensors, applications, and social media. However, integrating many types of patient-generated data within EHRs is challenging because of technology-related factors, such as poor interoperability and data overload.[75] Creating regulatory environments and incentives that promote data integration and developing data governance and ethical frameworks that allow data sharing are key to addressing these issues.[75]

The UK's health and care data landscape is complex, with data collected by many national and local organisations, each with its own scope, capacity, and capability to process and analyse the information. Standardised data collection does not exist across all four UK countries, which, in some cases, restricts possibilities for cross-country comparison and learning. Linkage between datasets and the mapping of patient pathways as a result remains difficult. Datasets such as Hospital Episode Statistics[76] and the Clinical Practice Research Datalink are predominantly used for research purposes and not for routine quality improvement by health-care professionals working in clinical settings. High access fees and lengthy application processes continue to restrict opportunities for analysis. Even for publicly available health-care data, issues such as datasets repeatedly changing location or longitudinal datasets changing their structure without warning also hinder potential for analysis.[77] To capitalise on these existing datasets, the NHS needs a supply of data scientists and clinical informaticists to work with front-line health-care professionals and patients. Currently, there are few well-placed teams in clinical settings to handle, process, visualise, and interpret data into actionable analytics,[78] which restricts opportunities to routinely use data to improve the quality, safety, and efficiency of health and care. To address this gap, there is a need for Health Education England and counterparts in other UK countries to invest in data science and quality improvement training for the existing workforce, introduce mandatory health informatics training for health-care students, and incorporate new roles such as data scientists and clinical informaticists into workforce planning efforts.[79]

Addressing security and privacy concerns

As momentum towards embracing HIT builds, an array of security and privacy concerns need to be addressed.

Health-care organisations are far behind other industries in their ability to handle cyber-attacks.[80] These organisations might use outdated hardware and software, and staff too often use default passwords.[81] The catastrophic impact of security and privacy breaches was seen in the WannaCry ransomware episode.[82] In 2017, around 30% of hospital trusts and 10% of GP practices across England were affected as cryptoworms targeted machines running outdated Windows software, blocking access to essential NHS operating systems.[83] Beyond unanticipated attacks, there is also potential for internal mismanagement of patient data due to errors or uncertainty of how the NHS should share patient data with outside groups. In 2018, NHS Digital shared the data of 150 000 patients for research purposes, whose opt-out choices were not respected because of a coding error.[84] Discussions on the boundaries of how and by whom such data are used and shared are essential and should involve all relevant stakeholders, including patients, health-care professionals, and policy makers. Health and care organisations should also introduce secure mechanisms and policies for patients wishing to access their own data, a legislative requirement in its own right.[85] In the USA, for example, the Blue Button initiative offers patients a secure mechanism to access and share their health records with alternative health-care providers.[86] To maintain public trust in how data are held, shared, and used, health-care organisations need to have and abide by clear data and cyber security standards, such as regularly upgrading software, procedures for handling a data breach, the use of virtual local area networks and secure cloud-based computing, and training users not to open suspicious emails.[80,87]

While data protection regulations are an essential mechanism to ensure health-care organisations safeguard the security and confidentiality of identifiable information, the COVID-19 pandemic has exposed the limitations of current data protection regulations in delaying timely access to data to inform policy making.[88] In response, the UK Secretary of State for Health and Social Care suspended the need for approval for some aspects of the Health Service Control of Patient Information Regulations 2002 for COVID-19-related research,[89] as public benefit from this research was assumed. This change has facilitated quicker access to data on a scale never seen before and the rapid proliferation of research to inform the policy response to the pandemic. To ensure progress is not lost after the pandemic, there is a need to streamline data approval processes across organisations, including demonstration of public benefit.[88] Where possible, data protection regulation could also be simplified. Steps have already been taken in this direction, with the UK Government passing legislation to amend the Data Protection Act 2018 to merge it with the requirements of the General Data Protection Regulation in anticipation of the UK leaving the EU.[90]

Encouraging digital inclusivity

Health and care providers should ensure that digitisation does not inadvertently exclude or cause greater health inequities, which is especially important in relation to the acceleration in the use of remote consultations during the COVID-19 pandemic. People with disabilities and older people, who might have lower levels of digital literacy, are particularly at risk of digital exclusion. For example, although the number of adult internet non-users has been declining every year, the proportion of adults with disabilities in this category remains much higher than that of adults without disabilities (figure). Moreover, less than half of people older than 75 years report using the internet in the past three months,[91] although the gap between older and younger populations is narrowing.

Digital inclusion attempts to mitigate against this risk[92] by ensuring that vulnerable and disadvantaged populations are not excluded from the benefits of advancements in digital technology. This objective entails an equal emphasis on making software easy to use and building capacity among individuals and communities so that they are able to use and benefit from the internet and digital innovations such as PHRs. To achieve these goals, cooperation between the public, voluntary, and private sectors is required. One such example is a partnership between the Good Health Foundation and NHS England, which focused on so-called hard-to-reach communities and on training over 220 000 people to use online resources to contact GPs, manage medical conditions, and choose services.[93,94] In Wales, a dedicated national digital inclusion programme, Digital Communities Wales, has been launched.[95] This programme includes many positive examples of digital inclusion such as the Digital Heroes initiative in partnership with the Welsh Joint Education Committee that creates opportunities for young people to befriend older people and introduce them to a new digital technology. In Wales, 1250 young people are now trained as Digital Heroes and have volunteered in hospitals, care homes, and libraries.

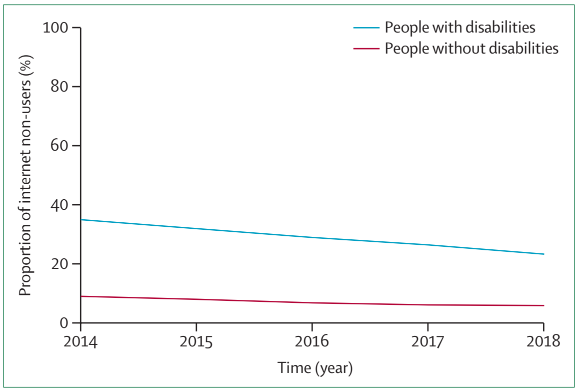

***Figure*: Percentage of adults with disabilities and without disabilities who are internet non-users over time in the UK, 2014–18**
Source: UK Office for National Statistics.[91]

Major opportunities for UK HIT

Despite the need to overcome some challenges, the four countries of the UK are well positioned to strengthen HIT capacity and capabilities. As fairly centralised and publicly funded systems, the UK benefits from health and care organisations with similar organisational structures and institutional behaviours. This arrangement offers opportunities to coordinate large-scale research projects, such as the Randomised Evaluation of COVID-19 Therapy (RECOVERY) multiarm trial that has generated valuable evidence of the effectiveness of alternative treatments for COVID-19, involving over 11000 patients in 176 NHS hospitals situated across all UK countries.[96] Strong leadership combined with strategic vision and sustainable investment can contribute to health and care providers converging upon a consistent standard of digitisation. Moreover, the UK has a strong primary care system, with GPs well positioned as care coordinators benefiting from access to a mature EHR infrastructure, which could form the basis for an integrated PHR. To achieve these goals, government mandates, legislation, and standards are useful levers. More can be done to capitalise on data from EHRs and real-world data for research purposes and to evaluate the effectiveness of novel health technologies. As rapid developments in AI and robotics continue to emerge, the imperative to maximise the use of data from EHRs will increase.[97] However, to develop these new technologies, public–private partnerships will need to be facilitated and expected terms and conditions drawn out. The COVID-19 pandemic has shown that large-scale changes are possible in a fairly short timeframe. It is important that the increased willingness to innovate and implement HIT solutions to health-care challenges fostered during the COVID-19 pandemic is built upon.

Fostering a generation of HIT leaders

Strong leadership at both national and local levels is needed to oversee and manage HIT implementation and infrastructure. To deliver a generation of HIT leaders capable of this task and equipped with the necessary skills to analyse and interpret data, digital leadership programmes are being made available across the UK. The role of Chief Clinical Information Officer (CCIO) for England has been established,[98] and similarly NHS Scotland will be appointing a CCIO and senior leadership team. NHS England has launched the Global Digital Exemplar and Fast Follower programmes, as well as the NHS Digital Academy.[99] The NHS Digital Academy is helping to build leadership capacity in HIT through a 1-year blended diploma-level training programme. NHS Scotland, NHS Wales, and Health and Social Care services in Northern Ireland are now also participating in this capacity development initiative.[43] The UK Faculty of Clinical Informatics has been established and will support the development of clinical leadership capacity.[100] Additionally, NHS National Directors set up the Federation for Informatics Professionals in Health and Social Care, which brings together individuals and organisations to form an informatics community.[101]

Integrating HIT systems

The current direction of travel for the NHS across all four UK countries is for integrated health and care services.[45] A key enabler to delivering integrated care will be an integrated electronic PHR, accessible to patients across all health and care providers. As priorities align between these organisations, the imperative to invest in joint HIT infrastructure will increase. Patient care and treatment pathways can be linked through existing unique patient identifiers, thereby allowing disparate data from across health and care to be linked into integrated PHRs and EHRs. Within such a system, the expectation would be that data follow patients as they navigate between health and care providers. There are already various nationally and locally driven schemes that have shown some preliminary success in achieving these goals (panel 2). These programmes reveal the potential of HIT to support integrated health and care delivery and to do pivotal and innovative research.

These examples are useful to show how HIT systems can be integrated in isolated populations. However, to ensure consistent implementation across the UK, reinforcing techniques such as government mandates, standards, and regulation might be required. In the USA, the Centers for Medicare & Medicaid Services' Interoperability and Patient Access Proposed Rule includes proposals that insurers must make EHRs available through APIs so that data can flow seamlessly with the individual as they change providers, plans, and insurers, and that innovation can be encouraged.[108] The US Office of the National Coordinator for Health Information Technology has also produced a shared nationwide interoperability roadmap, which emphasises the need to improve technical standards and implementation guidance. It also aligns federal and state payment policies, and privacy and security requirements to ensure interoperability.[109] In Europe, the European Commission has committed to removing barriers to "fully mature and interoperable eHealth systems in Europe"[110] and approved a recommendation for a European EHR exchange format.[111] After leaving the EU, the UK now needs to decide whether it wishes to join this initiative as substantial migration between the UK and EU countries will inevitably continue. There are currently over a million UK citizens living in EU countries, with the highest numbers in Spain, France, and Ireland, and many older individuals who choose to retire in these countries would benefit from health-care professionals being able to access their EHRs.[112] To identify legal barriers to sharing EHRs across borders, an overview of national laws in Europe revealed that, although some countries do have a specific legal framework for shared EHR systems, the UK has only a few legal provisions relevant to EHRs.[113] The scope of most legal provisions in the UK relates to medical records more generally, such as the Caldicott Principles on information governance and the Data Protection Act 1998, which outlines patients' rights to view their own records.[114]

Investing in health data science research and the generation of real-world data

The UK already benefits from substantial investment in data science research,[115] which can be used to strengthen the implementation of HIT systems. Pre-existing investments in UK data science research should be mapped, synergies identified, and priorities aligned, so investments are targeted to the areas of the highest need. Pre-existing examples of large UK datasets are regularly used for research purposes, such as Clinical Practice Research Datalink, The Health Improvement Network, Hospital Episode Statistics, the National Cancer Registration and Analysis Service, and the Systematic Anti-Cancer Therapy Dataset. Health Data Research UK, through its Innovation Gateway, is one organisation that works towards maximising the social value of these datasets, by uniting health data assets across the UK and making these available to researchers. As EHRs develop and generate more data that can be collated into integrated datasets, the UK population could be turned into a prospective, multidimensional, deeply characterised cohort, incorporating, for example, genetic, omic, demographic, health and care, administrative, and social media data, which can be used to support policy and planning, service delivery, and the precision medicine and public health agendas. Within a defined population, this use of data is already happening. UK Biobank, a prospective study of over 500 000 people who have undergone physical measures, provided blood, urine, and saliva samples for analysis, and given detailed information about their health and behaviour, is in the process of linking to datasets formed from data within EHRs. This combined dataset, along with other data assets such as disease registries and EHR datasets, can facilitate pragmatic randomised controlled trials, which are increasingly being seen as a way to make routine, less expensive, and more efficient clinical studies possible.[116] Promising examples already exist in the UK, such as the Salford Lung Study,[107] the ORION-4 trial (NCT03705234), the Lowering Events in Non-Proliferative Retinopathy (LENS) trial (NCT03439345), and the RECOVERY trial.[96] However, there is a need to outline standards for the harmonisation of different datasets and to develop the capacity and capability in the clinical workforce to ensure routine collection of high-quality real-world data.[117] To achieve these goals, sustainable investment is needed for the development and maintenance of the necessary infrastructure in clinical settings for real-world studies, and the training of clinical staff.

***Panel 2*: Selected examples of integrated health information technology systems across the UK**

Patient Knows Best

In Wales and in some parts of England, a system based on patient-facing information portals has been developed, known as Patients Knows Best.[102] This web-based system pulls together records from hospitals, general practitioners, mental health practitioners, community services, and social care (alongside data from wearable devices), and provides the combined record to the patient. The patient can see who has viewed and contributed to their records and can share either particular components or the entire record to a clinician or family carer. The data are stored securely on a cloud and can be accessed anywhere.

Northern Ireland Electronic Care Record

The Northern Ireland Electronic Care Record[103] is an integrated electronic care record covering a population of 1·8 million and provides all health-care professionals across secondary, primary, and social care with a single view of key patient information, with features such as facilitating referrals between primary and secondary care, a regional mortality and morbidity system, and a single diabetes pathway that enables multidisciplinary and collaborative recording of encounters and treatments.

East London Patient Record and Discovery Programme

The East London Patient Record involves data sharing between general practitioners, secondary care, and clinical commissioning groups in real time, covering a population of almost 1·5 million. Alongside this data-sharing system, the Discovery Programme brings together this data in a linked dataset designed to predict, anticipate, and inform individual health needs; expand upon existing primary care informatics-driven population health programmes; provide real-time reporting on programmes by providers supporting clinical improvement; and use data by third parties such as commissioners, public health professionals, and academics to support research, development, and planning.[104,105]

Salford Integrated Record (SIR) and Lung Study

The SIR, established in 2001, connects Salford Royal Hospital with surrounding primary care practices.[106] The Salford Lung Study, funded by GlaxoSmithKline, used data from the SIR and community pharmacies for a digitally enhanced pragmatic randomised controlled trial called the Salford Lung study, which assessed the effectiveness of a new dry-powder inhaler versus standard therapy for chronic obstructive pulmonary disease and asthma.[107]

Connecting Care

In Bristol, Connecting Care, a locally led partnership between Bristol, North Somerset, and South Gloucestershire Clinical Commissioning Group, and several local authorities and hospital trusts have worked together to provide a summary care record that provides information about contacts with out-of-hours services, hospitals, primary care, social care, and mental health, including safeguarding flags and alerts.

Developments in AI and robotics

There have been major developments in the ability to process (eg, with parallel computing), securely handle (eg, with encryption and safe havens), and interrogate or mine health data (eg, with machine learning and natural language processing).[97,118] The resulting momentum has led to the convergence of these developments in the fields of AI and robotics. Multiple sources of data, such as high-frequency signals (eg, monitored vital signs), laboratory or imaging test results, genetic information, clinical notes, and longitudinal records, are increasingly being used to develop algorithms.[119] However, challenges such as incomplete or missing data, data heterogeneity, and bias

For more on **Health Data Research UK** see https://www.hdruk.ac.uk/

For more on the **UK Biobank** see https://www.ukbiobank.ac.uk/

For more on the **Connecting Care partnership** see https://www.connectingcarebnssg.co.uk mean that much of these data remain underutilised.[119] In the future, so-called omic assessments, which will provide data regarding an individual's genome, proteome, metabolome, and microbiome, might be used to improve medical treatment and personalise preventive strategies.[120] To date, the applications of AI in the NHS remain sparse.[121] Although there is growing enthusiasm to expand the role of AI in health care, many ethical complexities exist related to so-called black-box algorithms, patient safety, informed consent, and privacy and confidentiality.[51] The potential risk regarding patient safety has been highlighted by a high-profile breast screening incident in England in 2018, in which errors contained within algorithms resulted in over 120 000 women not being invited to their final screen.[122] Considerable uncertainty associated with the effectiveness of many AI-based technologies also exists and, although the National Institute for Health and Care Excellence has published evidence standards, there is currently no mandatory requirement to evaluate the effectiveness of novel digital health technologies.[123] Moving forward, the development of regulatory frameworks for the procurement of AI and HIT systems, the ethical and safe application of AI in the NHS, testing bias in AI systems, and terms and conditions for partnerships with industry might help navigate some of these challenges.[121] In England, NHSX, in collaboration with the Accelerated Access Collaborative, has established the NHS AI Lab and committed £250 million of funding to work towards addressing these challenges.[124]

For more on the **health-care platform of Apple** see see https://www.apple.com/uk/healthcare/

For more on the **health-care platform of Google** see https://health.google/

For more on the **health-care platform of Samsung** see www.samsung.com/uk/business/healthcare-solutions/

The Topol Review suggested how developments in AI and robotics might impact the NHS and its workforce.[49] The most immediate impact on the NHS is likely to be the replacement of manual (eg, catering, cleaning, portaging, drug stock control), reception, and technical roles (eg, image analysis and assessment, and dispensing of medications).[125,126] The use of robotics might also protect staff from potential exposure to SARS-CoV-2 by undertaking testing or cleaning high-risk areas after use by patients with COVID-19 symptoms.[127] Through advancements in machine-learning algorithms, the interpretation of imaging has progressed, and consequently so has the detection of various cancers and neurological illnesses, at equal detection accuracy rates to senior clinicians.[128] Techniques in natural language processing can be used to extract information from PHRs and EHRs that can be analysed for valuable insights into patient experiences and can improve the responsiveness of health-care services.[129] However, it is important to emphasise that AI should be understood as complementary to pre-existing roles and a mechanism to reduce the burden on staff. Clinicians, surgeons, dentists, nurses, and occupation therapists have been identified as jobs that are least likely to be automated in the future.[126] Humans are better placed to understand an individual's holistic needs and the complex sociocultural factors that underlie illnesses. AI algorithms struggle to appreciate the nuances of interpersonal interactions, which change depending on non-verbal communication, emotions, values, personal preferences, and social circumstances.[130] AI algorithms might also reinforce prejudices and bias by identifying patterns from existing behaviours.[131] Research from the USA exposed how a widely used algorithm was racially biased and responsible for reducing the availability of support to black patients with complex health needs.[132]

Facilitating public–private partnerships

As shown by the experience with developing a mobile application to support contact tracing of COVID-19 cases,[26] the NHS is likely to face challenges if it attempts to develop HIT capabilities and drive innovation in digital health technology such as AI and robotics in isolation. In the context of advanced analytical capabilities, there is now substantial expertise in the private sector, namely EHR vendors and the medical device and pharmaceutical industries, and comparatively less expertise in the NHS.[133] Therefore, it is not surprising that many developments in AI and robotics are the product of public–private partnerships. To encourage innovation, the UK Government and, where appropriate, the devolved governments need to further invest in developing public–private partnerships that can enhance care processes and stimulate research and innovation. Key multinational companies, such as Amazon,[134] Apple, Google, and Samsung, have or are poised to make major entries into health and care. However, there are several ethical issues to consider related to data governance, privacy and confidentiality, and informed consent.[135,136] Questionable instances regarding the handling of patient data have already taken place. For example, the transfer of 1·6 million patient records by the London's Royal Free Hospital to the Google subsidiary Deep Mind for the creation of a health-care app addressing the detection of acute kidney injury has been questioned.[137] Such a transfer of patient records to a private company was outside the remit of what a patient might foresee as reasonable usage of their data. Moving forward, there is a need for regulatory and ethical frameworks that define the expected terms and conditions of public–private partnerships in health and care based on the principles of accountability, consistency, engagement, reasonableness, reflexivity, transparency, and trustworthiness.[138] These frameworks will include drawing out specific agreements on what is considered reasonable use of data, potential commercialisation of data, and ownership of intellectual property or products.

Conclusion

In some respects, such as in the rapid uptake of remote consultations, the COVID-19 pandemic has accelerated the digitisation of the UK health and care systems. Other experiences, such as the development of mobile applications to support contact tracing and the creation of shielded patient lists, have shown how persistent barriers, such as poor interoperability, concerns about privacy, and difficulties to get data to flow in real time, have continued to restrict the ability of the UK to leverage HIT to support policy and planning. With the experience acquired during the COVID-19 pandemic, the next decade presents a major opportunity to strengthen the implementation of HIT systems to support the goals of improving the quality, safety, and efficiency of health and care. We have outlined various priorities that need to be addressed, including improving usability and interoperability of HIT systems, developing capacity for handling, processing, and analysing data, assuring the privacy and security of data, and encouraging digital inclusivity. However, the UK needs to learn from past mistakes and understand that HIT systems are complex interventions that need to adapt to local needs and contexts. This process will require striving for the optimal balance between bottom-up and top-down implementation, which, if successful, can lead to many potential benefits. As PHRs continue to develop, data routinely generated as by-products of care can be used to support health and care policy and planning. Integrating data in this way will allow UK health and care systems to move towards data-enabled learning health and care systems with the necessary seamless, longitudinal digital infrastructure and simultaneous availability of health data for all relevant stakeholders. Increasing availability of data can also contribute to developments in AI and robotics, and the real-world evaluation of novel health technologies. To avoid jeopardising progress, everyone involved needs to be responsive to the ethical challenges and unintended consequences of HIT.

Contributors

AS is the lead author, who drafted the paper. MA and SA edited the paper and managed the process of the working group. BC, BDF, MR, DT, HT, and EM all provided edits and comments to the paper throughout several iterations.

Declaration of interests

BC reports in-kind contributions to research projects from Roche Diagnostics and iRhythm, outside the submitted work. BDF reports grants from Cerner and personal fees from Pfizer, outside the submitted work. All other authors declare no competing interests.

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