

# A digital NHS?

## An introduction to the digital agenda and plans for implementation

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# Key messages

- Digital technology has the potential to transform the way patients engage with services, improve the efficiency and co-ordination of care, and support people to manage their health and wellbeing.
- Previous efforts to digitise health care have resulted in considerable progress being made in primary care, while secondary care lags significantly behind.
- The government and national NHS leaders have set out a high-level vision and goals for digitising the NHS. However, there is a risk that expectations have been set too high and there has been a lack of clarity about the funding available to support this work.
- In view of this, we welcome the more realistic deadlines called for in the Wachter review. We also welcome the Wachter review's conclusion that current funding would be insufficient to achieve the goals set for 2020.
- This agenda has been subject to a confusing array of announcements, initiatives and plans. Shifting priorities and slipping timescales pose a risk to credibility and commitment on the ground.
- Ministers and national leaders must now set out a definitive plan which clarifies priorities and sets credible timescales, generates commitment and momentum, and is achievable given the huge financial and operational pressures facing the NHS. This requires urgent clarification about when funding already announced will be available and how this can be accessed. Holding back investment until the end of the parliament, as appears to be planned, will impact on the ability of local areas to make significant progress.
- Progress in this area requires much more focus on engaging and upskilling the people (at all levels in the NHS) who are expected to use it. The importance of engaging clinicians, in particular, and conveying the benefits associated with digitisation should not be underestimated.
- Data sharing is essential for conducting research and improving patient care. The recent Caldicott and Care Quality Commission reviews present an opportunity to address legitimate public concerns about data sharing in the NHS. However, it is also critical that information governance is not a barrier to progress.

# Introduction

The report by Professor Robert Wachter and the National Advisory Group on Health Information Technology (2016) is the most recent in a series of reviews and initiatives seeking to support the NHS's efforts to digitise. Together with ambitions set out in the *NHS five year forward view* ([NHS England et al 2014](#)) and supporting strategies, this represents a sustained push from the centre to deliver a step change in how the NHS uses digital technology.

This briefing seeks to make sense of the national policy agenda in this area, providing a context for leaders developing local plans and a broad assessment of progress thus far. It includes an analysis of the remaining barriers to progress as well as the opportunities for overcoming them. It draws on key policy documents, a literature review and quantitative data published by the relevant national bodies.

# Where have we come from?

Digitisation in health care is not new, with computers first being used for administrative, financial and research purposes in the 1960s, and Department of Health reviews dating back to the 1970s ([Alderson 1976](#)). The first national information technology (IT) strategy for the NHS came in 1992 (NHS Management Executive 1992). Subsequent strategies in 1998 and 2002 led to the creation of the National Programme for IT (NPFIT), later called Connecting for Health, which aimed to create a single electronic care record for patients, connect primary and secondary care IT systems, and provide a single IT platform for health professionals.

This multi-billion-pound programme of investment dominated the digital agenda under the Labour government. Running from 2002 to 2011, it failed to achieve its main objectives – including establishing an integrated electronic health record system across secondary care – although it did establish some important national digital infrastructure and services ([National Audit Office 2013](#)). Overly centralised decision-making, combined with a lack of local engagement, meant that users' needs were poorly understood and providers were directed to implement at pace systems they had little say over ([National Advisory Group on Health Information Technology in England 2016](#)). In contrast, digitisation in general practice has been much more widespread, with almost all GPs using electronic health records and computers in their interactions with patients; something described in the Wachter review ([2016](#)).

By the time Jeremy Hunt took up his post as Secretary of State for Health in 2012, NPFIT was all but wound down, though some contracts will continue into the 2020s. In 2013, he challenged the NHS to 'go paperless' by 2018 ([Hunt 2013](#)). This ambition was expanded on in the *NHS five year forward view* ([NHS England et al 2014](#)) and subsequently extended to 2020. The National Information Board was set up to lead this strand of work and to support the health and care system to deliver the digital transformation set out in the Forward View.

# What are the potential benefits of digitisation?

It is often remarked that technological change has been much slower in health care than in other sectors such as banking and retailing, where technology has wrought significant changes in the relationship between service providers and their customers. This may be a reasonable analogy for online transactions (for example, ordering a prescription or making an appointment is similar to arranging a bank transfer or buying a train ticket). Being able to do these things online would be more convenient for many people, although on its own would hardly amount to a transformation in patients' experience of health care.

However, technology has the potential to bring about a more fundamental change in the relationship between patients and health professionals. Greater adoption of technology and using it more effectively present opportunities to drive improvements in quality, efficiency and population health ([Imison et al 2016](#)) and revolutionise patient and user experience ([Ham et al 2012](#)) in a number of ways.

- It could help put people in control to take a more active role in their own health and care (Klasnja and Pratt 2012) by providing access to relevant, high-quality information and facilitating peer support online ([Gretton and Honeyman 2016](#)).
- It can support improvements in the safety and quality of care – for example, by reducing the risk of mis-identification and other avoidable errors ([NHS Connecting for Health and NHS National Patient Safety Agency 2009](#)).
- For clinicians, it may mean less time and effort in accessing information about patients; remote monitoring can help clinicians better understand the progress patients are making and ultimately help to deliver better health outcomes.
- It can facilitate advances in medical practice – for example, through the use of advanced analytic techniques, such as machine learning, to support clinical decisions and supporting personalised treatments based on analyses of people's genomes ([Gretton and Honeyman 2016](#)).

- Data captured by digital technologies could improve service planning, help align capacity more closely with demand ([Imison et al 2016](#)) and enable new service configurations – for example, GP federations where practices co-ordinate and facilitate patient access through online hubs ([Castle-Clarke et al 2016](#)).
- IT, data systems and information sharing are critical to delivering integrated care and can help to co-ordinate care delivered by professionals across different organisations and even across patients' wider support networks.
- It can help deliver efficiency improvements. McKinsey estimated that modern health systems can save between 7 per cent and 11.5 per cent of their health expenditure ([London and Dash 2016](#)), while a study commissioned by NHS England estimated annual savings of £10 billion or more would come after commensurate investment in this agenda (Dunhill 2015). However, the calculations behind this have not been published, leading many to question whether it is a realistic estimate.

# What is the national vision and how much progress has been made towards it?

The Forward View built on Jeremy Hunt's challenge to the NHS to 'go paperless', outlining ambitions to 'exploit the information revolution' to help close the three gaps identified (care and quality, funding and efficiency, health and wellbeing). It promised to take a different, more even approach to policy, in contrast to the recent oscillation between two poles. 'Letting a thousand flowers bloom', as the Forward View described much of the NHS's approach to digital technology in recent years, has resulted in fragmentation and systems that do not work together, while over-centralisation has led to systems that do not meet local need. In future, national bodies are to focus on providing the 'electronic glue' and national standards for interoperability to enable different parts of the system to work together, while allowing local partners to make decisions on what they need in their area.

The National Information Board report, *Personalised health and care 2020* (PHC2020), set out core priorities and a framework for action for delivering the Forward View's vision (National Information Board 2014). Local implementation was to the fore, to be driven by 'local digital roadmaps'. Led by clinical commissioning groups (CCGs), these roadmaps set out a five-year vision for how local areas – having come together to form 89 'footprints' across England – aim to improve digital technology, strategy and organisational leadership (referred to collectively as 'digital maturity') and deliver the paperless vision by 2020. Local digital roadmaps were submitted in June 2016 and will now be aligned with the 44 sustainability and transformation plans (STPs) currently being finalised (see [The King's Fund 2016b](#)).

In early 2016, Jeremy Hunt announced that more than £4 billion had been set aside for digital and technology projects in the NHS over the course of this parliament, including £1.8 billion to meet the 'paperless at the point of care' ambition.

Most recently, the Wachter review made a series of recommendations to the Department of Health and NHS England on their efforts to digitise secondary care. These included:

- the appointment of a national Chief Clinical Information Officer (CCIO) to oversee NHS clinical digitisation efforts
- CCIOs in every trust to lead the development of clinical information systems, supported by a new cadre of trained, professional clinician-informaticians
- additional funding and a phased approach to implementation with a revised target for all trusts to reach 'digital maturity' by 2023
- ensuring that interoperability is a core goal and feature of a digitised NHS
- a national engagement strategy, robust independent evaluation and establishment of digital learning networks to support implementation.

The Department of Health has not formally responded to the report so it is not yet clear how much of it will be adopted as policy. However, the Secretary of State and NHS England have responded positively and some recommendations are already being implemented, so it is clear that the report will have a significant impact on the approach taken to digitisation across the NHS.

This next section of this briefing looks in more detail at the key commitments made prior to Wachter, and what we know about progress so far, grouped under three broad themes:

- interoperable electronic health records
- patient-focused digital technology
- 'secondary uses' of data, transparency and consent.



## Interoperable electronic health records

The main commitments of the Forward View and PHC2020 in this area are as follows:

- by 2018, clinicians in primary care, urgent and emergency care, and other settings will have gone 'paperless' - ie, will be using digital patient records only.
- a set of national standards and interoperability requirements will be agreed in 2015 and rolled out across the system by 2020
- by 2020, digital care records will be interoperable and in real time.

The Wachter review suggests a phased approach to digitisation in acute hospitals and proposes a new target for all trusts to achieve 'digital maturity' by 2023.

Electronic health records are digital records of a patient's health and care (*see box*). Provided that certain conditions (mainly related to interoperability) are met, using digital health records should allow the whole record (or relevant information from it) to be shared quickly, securely and in a standard way between health professionals to support patient care, forming an 'integrated' electronic health record. The complex mix of systems and practices in the NHS at present means that this is not happening as often as it could. It is this vision that local commissioners and providers are being asked to achieve. This goal is also a fundamental building block for much of the rest of the strategy to harness digital technology, as the health record can be a rich source of useful information for many different purposes.

## Health records explained

A health record is a set of information about a person's contact with a health care provider. Health records currently come in a range of formats (paper and electronic) and are stored using a range of systems. They include various pieces of information (eg, current treatments, test results, clinical notes, care plans, correspondence between professionals).

Traditionally, in England, the most comprehensive records are those created and held by general practitioners (GPs). When clinicians in other parts of the system need a patient's record (or part of it), they can request it. This information has typically been shared by letter, email, fax or phone. Hospital doctors treating patients who are admitted urgently will often not have access to an up-to-date record, relying on the hospital's latest record for the patient (if one exists) until the record arrives from primary care. Paramedics often do not have access to any NHS information about patients when attending emergencies.

The Summary Care Record, a national service provided by NHS Digital, gives basic information (allergies and ongoing medication) to those with systems that can access it.

When clinicians interact with patients in settings outside primary care, they will create their own set of records covering that interaction - often on multiple systems, depending on the specialty. A summary of this information is fed back to GPs, typically in the form of a letter from the person responsible for care. GPs then update their records accordingly.

### Other sources:

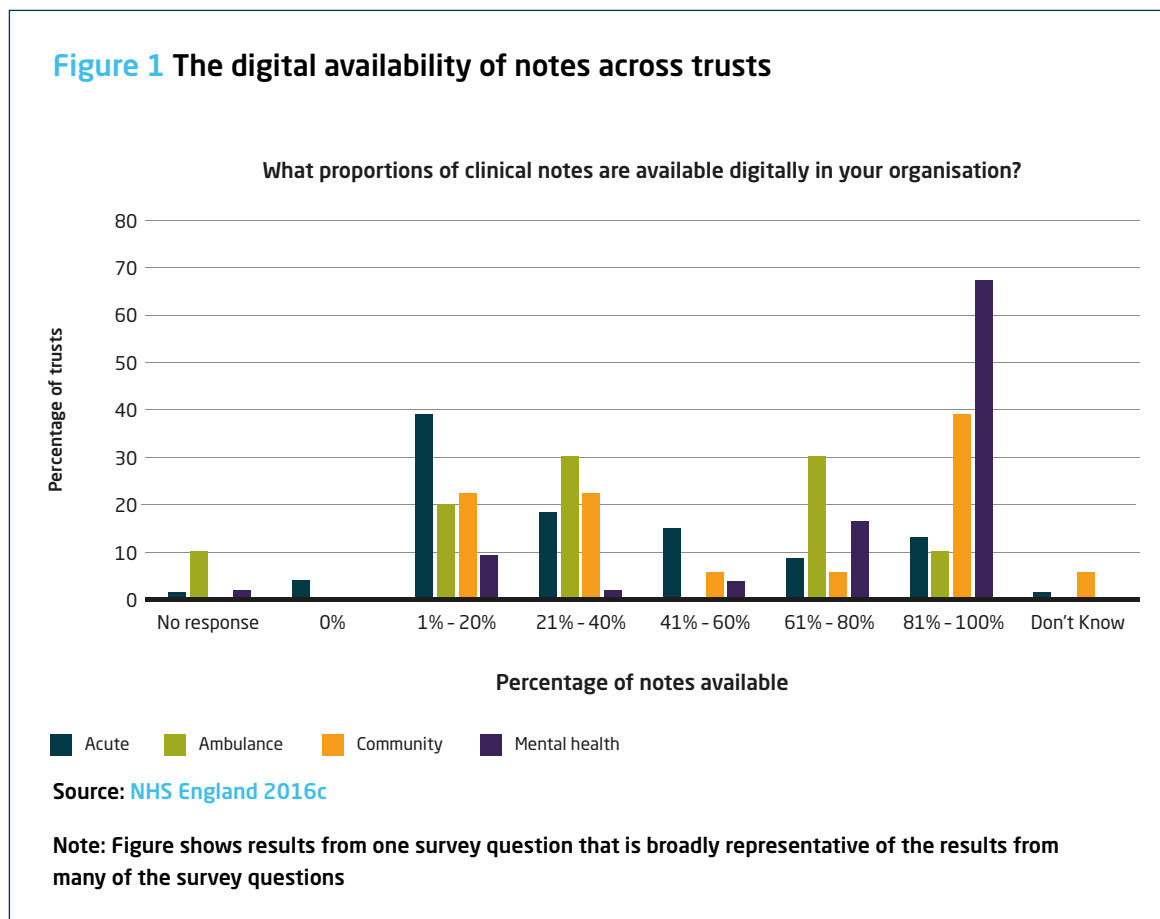
For more information see: NHS Choices, '[Your health and care records](#)'

Parliamentary Office of Science and Technology note, '[Electronic health records](#)'

In primary care, the vast majority of practices have some form of electronic health record system ([The Commonwealth Fund 2015](#)). This widespread adoption has been driven by the fact that, since 2007, most primary care IT systems in England (75 per cent) have been centrally funded, with commissioners choosing an approved system on behalf of their local GP practices via the GP Systems of Choice (GPSoC) framework. This approach has led to market consolidation ([Hampson et al 2015](#)), with EMIS Health and TPP systems covering about 90 per cent of patients in England ([Health and Social Care Information Centre 2016b](#)).

Beyond primary care, digital systems are more diverse and fragmented. In late 2015, all 239 NHS trusts and foundation trusts self-assessed their existing digital capabilities (*see* Figure 1). This process revealed that:

- information in acute trusts is less digitised and less structured and they are less able to share information digitally
- a similar but slightly improved picture exists among community trusts
- mental health trusts seem further ahead, with most reporting near-full digitisation of clinical information and a greater capacity to share information.



The same assessment exercise is now available (but not mandatory) for social care providers. No results have been published as yet.

As already noted, local digital roadmaps are the main mechanism for supporting and driving the adoption of digital records and information sharing ([National Information Board 2016](#)). These roadmaps describe how local areas will put in

place 10 ‘universal capabilities’ by 2018, including information sharing across general practice, secondary care and social care, and patient access to records and transactions. Existing projects around integrating information will now become major parts of the roadmap. Local progress will be measured through the CCG Improvement and Assessment Framework and similar frameworks for providers ([NHS England 2016b](#); [National Information Board 2016](#)).

To support hospitals to progress, 12 of the most digitally advanced acute trusts were recently selected as new ‘global digital exemplars’, each receiving up to £10 million from NHS England and partnering with international organisations to develop good practice and ‘deliver pioneering approaches to digital services’ ([NHS England 2016a](#)). A further 20 trusts will become national exemplars, receiving up to £5 million each as well as support from a new NHS digital academy.

Some funding and support is available for primary care too; GPSoC monies allocated to CCGs have increased this year and other measures are promised in the General Practice Forward View ([NHS England 2016d](#)). The Estates and Technology Transformation Fund (formerly the Primary Care Transformation Fund), providing £900 million over five years, explicitly invites applications from practices through their CCG for capital funding to improve technology, alongside applications for estates funding.

A crucial part of the digital vision is ensuring that records are fully interoperable (*see box*).

### **Interoperability explained**

Interoperability is the ability of different health information systems and software applications – both within and across organisational boundaries – to ‘talk to each other’ and share information.

There are different kinds of interoperability and, for this reason, calls for interoperability in health care should be understood as much more than simple exchanges of data. The systems involved need to be able to share information in such a way that other systems can make good use of it, in standard structured forms. This poses technical challenges to system developers who have to agree to adopt consistent standards to enable meaningful information sharing to happen.

NHS England's interoperability strategy reflects its desire to provide the 'digital glue' to bind local systems together. As well as having NHS Digital continue to provide and expand national infrastructure with a new patient record locator service and the existing Summary Care Record service, the strategy commits to:

- declaring a set of national standards for storing data and exchanging it between providers that will, in future, form a 'licence to operate' for digital suppliers
- defining a set of open interfaces – known as open APIs<sup>1</sup> – that suppliers of patient record systems will be required to provide to others in the health system ([NHS England et al 2015](#)).

The first set of national standards was published in 2015 ([NHS England 2015](#)). Adoption of these standards was included in the baseline self-assessment that trusts carried out in 2015 ([NHS England 2016c](#)). The baselines show that the adoption of the NHS number is now relatively extensive, having been mandated by the Health and Social Care (Safety and Quality) Act 2015. Nearly all trusts (with the exception of ambulance trusts) reported between 90 and 100 per cent usage of the number as the primary identifier for patients when information is shared with other providers. Additional standards for consistent clinical terminology and describing medicines and devices are still used by a minority of providers. Most ambitiously, a standard structure for all medical records agreed by the Health and Social Care Information Centre and the Academy of Medical Royal Colleges ([2015](#)) is mandated for all digital transfers of care – this is something most trusts are using some of the time but it is a long way from being universally adopted even in those trusts. There is no data yet on adoption of standards relevant to social care among providers in that sector.

Regarding open APIs, NHS Digital has established a programme within primary care called GP Connect. This will define a set of open APIs that GP suppliers must provide. The first iteration covers record viewing, appointment booking and task management, and is scheduled to go live in January 2017. We are not aware of a similar programme for the roll-out of open APIs in secondary care that could support clinician-facing apps, despite most clinicians already being equipped with the technology and skills to take advantage of such apps ([Mobasheri et al 2015](#)).

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<sup>1</sup> An API (Application Programming Interface) is a set of routine rules and procedures that govern how one piece of software can interact with another (eg, how an app can access the data held in a GP's IT system). Open APIs make these rules and procedures publicly available.

Additional support for delivery of the interoperability strategy includes a community of interest (Code4Health) to share wider learning on interoperability.

### **Recommendations from Wachter**

The Wachter report makes detailed recommendations about the implementation of electronic health records and digitisation in secondary care, stressing the need to engage clinicians. These recommendations include:

- a phased approach to digital implementation in acute trusts. The first phase would run from 2016 to 2019 for those ready to be or already digitised, combining national funding with local resources. Further central funding (on top of existing commitments) would then be required to support trusts in the second phase (2020–23). Beyond 2023, the report suggested no further government funding would be required as all trusts should have ‘achieved a high degree of digital maturity’ – any trusts failing to meet this would be judged by regulators as non-compliant on quality and safety grounds
- the timetable for interoperability should be modified while building on the local efforts to share data. Wachter recommends that ‘regional interoperability’ remain a priority for 2019 – suppliers and organisations in a local area can reach their own arrangements to ensure information flows reliably across settings. He recommends national interoperability should be timetabled for 2022, with penalties eventually imposed on those ‘suppliers, trusts, GPs and others who stand in the way of appropriate data sharing’. This extended timetable gives some important technical standards time to mature.

## Patient-focused digital technology

The main commitments in the Forward View and PHC2020 in this area are:

- to enable patients to have access to their health records, including:
  - accessing a summary of the record by March 2015
  - accessing the full record by 2016<sup>2</sup>
  - viewing information from all health and social care interactions by April 2018
  - adding comments and preferences to records by April 2018
- to make online access routinely available for booking GP appointments and repeat prescriptions
- to expand the set of NHS-accredited health apps for patient use
- to promote uptake of health innovations, including by creating new 'test bed' sites for innovators.

### Access to health records

Despite extensive roll-out of technology in general practice to give patients access to their records, public awareness and use of this feature is minimal. The best national data (from the national GP patient survey and data uploaded by GP practices) confirms this.

- **Capability** – Technology is in place in nearly all practices (covering 92.1 per cent of patients) to enable patients to access 'detailed, coded' (ie, full) records online ([Health and Social Care Information Centre 2016b](#)).
- **Awareness** – Only 5.2 per cent of GP patients report being aware that their practice offers the ability to access records online.
- **Usage** – Only 0.9 per cent of GP patients report having used this feature ([NHS England and Ipsos MORI 2016](#)).

The technology to enable patients to view information from their interactions with other parts of the health service is only just being rolled out, having started from a very low base. By March 2016, practices covering 35.8 per cent of patients had the functionality to show people test results online from their interactions with services beyond primary care, while 54.7 per cent had the functionality in place to issue

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<sup>2</sup> This commitment was made in a speech by the Secretary of State ([Hunt 2015a](#))

letters (eg, referral letters) ([Health and Social Care Information Centre 2016b](#)). Having initially concentrated on building system capability, the focus of NHS England's Patient Online programme will now be on promoting awareness and supporting patients to make use of these new functionalities.

To our knowledge, there is no data available to track progress on the target that patients should be able to comment on or add to their records.

In July 2015, the Secretary of State for Health invited the former government digital champion Baroness Martha Lane Fox to examine how the NHS could boost adoption of digital technology among patients. Lane Fox's report recognised the gap between the technical capability being in place and the low use of services. Its main recommendation was to introduce targets to increase patient usage of online services – including access to online records but also online appointment booking and repeat prescriptions (*see below*) – initially set at 10 per cent of registered patients by March 2017. This was subsequently adopted by the British Medical Association (BMA) and NHS England as a 'non-contractual arrangement' in negotiations for the 2016/17 GP contract ([NHS Employers et al 2016](#)). Lane Fox suggested that the target be extended annually by a further 10 per cent.

### Online transactions

In 2015, the National Information Board published plans for a single point of access (likely to be through the NHS.UK website) for all transaction services, including the appointment and prescription services set out below ([National Information Board 2015](#)). This will incorporate the popular NHS Choices website, which has more than 23 million visitors annually ([Coulter and Mearns 2016](#)). The plans also envisaged linking this website with the NHS 111 triage service using the government's digital identity verification service 'Verify' and eventually allowing local areas to customise their areas of the site and web apps for patients with certain conditions ([National Information Board 2015](#)). It's hoped this single point of access will facilitate easier uptake of online services like those noted in this section. Alongside other funding announcements in February 2016, the Secretary of State announced that £400 million would be available for further developing and running the site until 2020/21.



Separately from the national online presence being developed, current progress in relation to the commitment for online appointment booking and prescribing is reflected by the following:

- **Capability** – Technology is now in place in nearly all GP practices to enable patients to book an appointment online and view or order prescriptions ([Health and Social Care Information Centre 2016b](#)).
- **Awareness** – Around a third of patients are aware that they can book appointments and order repeat prescriptions online ([NHS England and Ipsos MORI 2016](#)).
- **Usage** – Only 7.5 per cent of respondents reported having booked an appointment online in the previous six months. A slightly higher proportion (10.7 per cent) had ordered a repeat prescription online ([NHS England and Ipsos MORI 2016](#)).

### Expanding NHS-accredited health apps for patient use

The market for smartphone health apps is growing rapidly, particularly in Europe, which is forecast to overtake North America as the biggest market by 2018 ([Deloitte 2015](#)). There are now around 165,000 health-related apps available direct to consumers via the two main smartphone operating systems, Apple's iOS and Google's Android ([IMS Health 2015](#)). Like most health systems around the world, the NHS is struggling to implement a consistent regulatory approach in this area.

The National Information Board committed to publishing proposals for the 'regulation, accreditation and kitemarking' of apps by June 2015 to increase public and professional confidence and encourage their use, where appropriate. While a significant amount of work has been undertaken since then, the approach has not yet been finalised. In 2013, NHS Choices launched a Health Apps Library pilot to review and recommend apps. This was followed by a Mental Health Apps Library, offering treatments approved by the National Institute for Health and Care Excellence (NICE) and compliant with Improving Access to Psychological Therapies (IAPT) quality standards. However, in September 2015, researchers discovered that some approved apps were not compliant with privacy standards – for example, risking the 'leaking' of data by sending it unencrypted (Huckvale *et al* 2015). By October 2015, the Health Apps Library had been withdrawn, with the National Information Board instead announcing that it would use learning from the experience to develop a new model of 'endorsement' for apps. In September 2016, Jeremy Hunt announced that a new apps library would be live by March 2017; it was not immediately clear whether this would involve apps endorsed under the new model.

The Secretary of State has separately stated his ambition for a quarter of smartphone users – or 15 per cent of all NHS patients – to be ‘routinely accessing NHS advice, services and medical records through apps’ by March 2017 ([Hunt 2015a](#)). There is no data available to gauge progress against this target, although at the time that the target was announced it was widely reported that only 2 per cent of the population claimed to have had any digitally enabled transaction with the NHS ([National Information Board 2014](#)).

More recently, Simon Stevens announced a new funding route (the Innovation and Technology tariff), which will, for the first time, provide an explicit national reimbursement route for new medtech innovations, including apps ([NHS England 2016f](#)). This is intended to remove the need for local price negotiations, and instead guarantee automatic reimbursement when an approved innovation is used. This will also provide a ‘route to market’ for innovations identified in other programmes, including the ‘test beds’ initiative (*see below*) and the NHS Innovation Accelerator programme, which supports individuals engaged in developing ‘new products, services, solutions or new ways of delivering care’.

### Telehealth and telecare

In the mid-2000s, more widespread use of telehealth and telecare (*see box*) was seen by the Department of Health as key to promoting long-term health and independence and delivering more cost-effective care. In 2006, it commissioned three large pilots known as the Whole System Demonstrators (WSD), which aimed to provide ‘proof of concept’ for the efficacy and effectiveness of these technologies.

#### Telehealth and telecare explained

Telehealth refers to the remote exchange of data between an individual and health care professionals. It can be particularly useful in the management of existing long-term conditions such as chronic obstructive pulmonary disease (COPD), diabetes or heart failure. It often includes remote transmission of clinical signs and video or email consultations.

Telecare refers to the remote monitoring of an individual’s condition or lifestyle in their home environment. It aims to manage the risks of independent living, and includes sensors to monitor falls or bed occupancy, for example.

Although early signs looked promising, subsequent evaluations showed no evidence of cost-effectiveness (Henderson *et al* 2013) and mixed results on patient outcomes,

with accompanying commentaries concluding that the government had ‘jumped the gun’ and that uncertainties about the evidence base remained (Goodwin 2012). Despite these results, the WSD pilots were followed by the Department of Health’s 3 Million Lives campaign to promote uptake of these technologies (Coulter and Mearns 2016). Responsibility for this later passed to NHS England, although it is unclear whether the campaign is still running.

According to a recent survey of chief executives of acute trusts, only a minority currently have systems in place for telehealth and telecare; while 108 out of 176 CCGs commissioned telehealth services, spending £15.2 million on them in 2013/14 (Imison *et al* 2016). However, while these numbers appear small, that is not to say that innovation is not happening, particularly in relation to remote consultations and communication.

Telehealth and telecare do not feature on their own in the Forward View; instead, the focus is on testing ‘combinatorial innovations’, reflecting the idea that system-changing gains will come through aligning (often pre-existing) technologies, financial incentives and new ways of working, rather than a single silver-bullet drug or technology. The result is NHS England’s test beds initiative. The first wave of seven test beds was announced by Simon Stevens in January 2016, with implementation under way and ‘rigorous evaluation’ of individual projects expected to last between two and three years (NHS England 2016e).

Although the evidence base for these technologies remains contested, technology can play a role in empowering patients and their carers, supporting them to maintain good health and independence. However, maximising the value of telehealth requires people to be actively involved in their care and for it to be built in to wider service redesign (Coulter and Mearns 2016; Goodwin 2012).

### Digital inclusion

A significant proportion of the population is ‘digitally excluded’ because they lack internet access or have low levels of digital literacy. Evidence suggests that digital exclusion is higher among particular groups including older people, disabled people and ethnic minorities. This is a key barrier to progress because the people with the greatest health needs are often less likely to have the technology and skills to engage with and benefit from digital services. While digital capability is improving, with more and more people (including older people) acquiring the skills to use online health services (Coulter and Mearns 2016), nearly a quarter of adults still lack basic digital skills and 10 per cent have never used the internet (Tinder Foundation 2016).

To ensure that people of all ages and backgrounds have the digital skills to access these new patient-facing technologies, the Forward View committed to taking steps to support 'digital inclusion' (*see box*).

### **Digital inclusion explained**

Digital inclusion involves building capability among individuals and communities so that they are able to use and benefit from the internet and new digital innovations. The Forward View states the intention to develop partnerships with the voluntary sector and industry to support this, to build the capacity of all citizens to access information, and to train staff to support people who are either unable or unwilling to use technology.

Subsequent work in this area includes the following:

- A partnership between NHS England and the Tinder Foundation, which has trained more than 220,000 people, helping them to use online resources to contact their GP, manage medical conditions and choose services, with a particular focus on hard-to-reach communities ([Tinder Foundation 2016](#)).
- To promote digital inclusion, Martha Lane Fox's review included recommendations to ensure free Wi-fi in all settings and to build the digital skills of patients and people who work in the NHS, supporting those in greatest need first.

## 'Secondary uses of data', transparency and consent

The main commitments in the Forward View and PHC2020 in this area are:

- to link hospital, GP, administrative and audit data to support research, quality improvement and risk stratification efforts (ie, datasets for 'secondary uses')
- to achieve comprehensive transparency of performance data - including outcomes and patient feedback - so that:
  - professionals can compare themselves with their peers
  - patients can make informed choices
  - CCGs and NHS England can commission the best quality care
- to allow patients to retain the right to opt out of their information being shared.

### 'Secondary uses' datasets

Recognising the importance of so-called 'secondary uses' data (*see box*), PHC2020 set out a target for the National Information Board to agree a core 'secondary uses' dataset that all NHS providers would have to make available to support commissioning, regulation and transparency. The vast amounts of data collected by the NHS is, if shared appropriately using strong safeguards, a significant asset with huge potential to support improvements in care and research. The many beneficial uses of using people's health care data include improving an individual's clinical care and protecting and linking data from different sectors to enhance our understanding of the population's health more broadly.

### 'Secondary uses' explained

Data generated by and held within the health system is used for a wide range of purposes other than providing direct care to individuals. These 'secondary uses' include health research and population risk management, service planning, and providing information to public and professionals about quality and outcomes. Although the potential of the NHS to generate and use data for these purposes has long been recognised, it has not always been realised, partly due to public confidence surrounding data security (*see below*).

First introduced in 2013, NHS England and NHS Digital's care.data programme sought to securely link information about patients held by their GPs with data from the rest of the system, building on more than 20 years of collecting Hospital Episode Statistics (HES) for secondary uses (Appleby 2014). It was already under way when PHC2020 was published; however, progress stalled for a number of reasons, most notably public concern about data security and complications over opt-out procedures (Health and Social Care Information Centre 2016a). This led to a pause in national implementation in late 2014, with the programme being cancelled altogether in July 2016.

Reports have suggested that proposals for a new 'data services platform' are being developed by NHS Digital. This could be used for similar purposes to the care.data programme but it is not yet clear how it fits in to the broader picture or whether, for example, this will indeed enable linking of primary care clinical data to that held elsewhere (Oxford 2016).

### **Transparency of performance data**

The My NHS website was launched in 2014 and was designed to allow people and professionals to compare service performance within their area, and with other areas, across a range of metrics. My NHS fits into the wider push for 'intelligent transparency' (Hunt 2015b), which seeks to expand the comparative metrics available to the public about the quality of care being delivered. The rationale is that competitiveness and a vocation to do the best for patients will drive improvement among clinicians and providers when they can see how they compare with their peers; the government regards this as a key lever in driving quality improvement. Currently, the website amalgamates datasets from a wide range of professional and national bodies on the performance of CCGs and health and social care providers, as well as consultant and specialty outcomes. There is little information available as yet about the extent to which data on My NHS is accessed or subsequently used.

### **Public trust, data security and allowing patients to opt out**

The information generated by the health system is sensitive. Digital technology makes it easier to capture, share and put to use data for direct care as well as secondary uses. Because of this, any lack of confidence or understanding on the part of patients or staff as to how data is handled can be an obstacle to sharing data and making progress on the digital technology agenda more broadly. Discussing a programme to transform and join up services for people with long-term conditions, Sir John Oldham was recently quoted as saying that information governance

restrictions and the ‘computer says no’ mentality remain the largest hindrances to transformation (Oldham 2016).

The Forward View does not refer explicitly to this part of the agenda, but history and key decisions since its publication have prompted even greater recognition of the importance of ensuring public trust and data security, alongside robust methods for patients to opt out of sharing their data.

In September 2015, the Secretary of State for Health commissioned the Care Quality Commission (CQC) to undertake a review of data security in the NHS, recognising concerns that the service had ‘not yet won the public’s trust in an area that is vital for the future of patient care’. The review tracked the scale of data security issues and some of their consequences. For example, in the year ending May 2015, 533 potential breaches of the Data Protection Act 1998 or of the Common Law Duty of Confidentiality were reported – equating to just over one for every million transactions involving staff. Most breaches concerned paper records rather than electronic data.

The review highlighted a series of practical concerns – particularly around ‘leadership, behaviours and systems’ – despite finding a widespread commitment to data security. While technology is solving many data security issues, if security levels are left unimproved, it ‘increases the risk of more serious, large-scale data losses’. The review set out a number of recommendations to address these concerns, and clarified that ‘responsibility for data security sits with providers’.

In parallel to the CQC review, Dame Fiona Caldicott, the National Data Guardian for Health and Care, was also commissioned to carry out a review ([Caldicott 2016](#)), the first strand of which covered data security. Many of Caldicott’s recommendations echoed those of the CQC, and she called for a wider public conversation about the benefits and purpose of data use. In general, Caldicott found that people supported sharing of information for the benefit of their own care but had concerns about that information being used for insurance or marketing purposes. To increase public confidence, she proposed 10 new data security standards (including, for example, that all staff should complete annual data security training) to apply to every organisation handling health and social care information. The review also makes 20 recommendations aimed at embedding the standards within all related organisations – something the CQC will now incorporate into its monitoring and inspection activity ([Caldicott 2016](#)).

The second strand of Caldicott's work was to develop a new consent and opt-out model for the sharing of confidential patient data. The review proposed an eight-point model to simplify the process by which patients can opt out of their identifiable data being used for secondary purposes. Alongside stronger penalties for misuse and the creation of tools to help patients understand how their data has been used to benefit others, the proposals for the consent model include the following.

- A person retains the right to opt out of their personal confidential information being used for purposes beyond their direct care. They should only have to state this preference once and then have it respected by all health and social care organisations.
- Even if an individual has opted out, they should still be able to give explicit consent to their information being used for a specific research project.
- The opt-out is reversible, should the individual subsequently change his or her mind.
- The opt-out should not apply to anonymised information or mandatory legal or public interest requirements for sharing information.
- The opt-out will not apply to direct care.

The Department of Health launched a public consultation on the opt-out model and data security standards which closed in September 2016.



# What are the barriers to and opportunities for progress?

## Barriers

### **The bigger picture - managing broader financial and operational challenges**

With providers and commissioners collectively recording the largest combined deficit in NHS history in 2015/16, and performance against key targets deteriorating, the focus is now firmly on dealing with immediate financial and operational pressures. This creates the risk that local funds earmarked for capital investment are switched to support day-to-day spending and that national funding continues to be diverted to other purposes, as happened to technology funds in the past (Illman 2015). More broadly, there is a growing risk that efforts to transform care and transition to a 'paperless NHS' by 2020 may be crowded out by other priorities – not least stabilising performance in the short term. The revised timetable suggested by Wachter ought to be adopted in recognition of the extreme challenges facing the acute hospital system, but efforts should be made to minimise the impact on progressing the broader agenda, such as improvements to patient-facing online services and unlocking benefits for a primary care sector also under pressure.

### **Money - funding change**

While investment in digital initiatives is vital, the proportion of the funding announced in early 2016 that actually constitutes 'new money' remains unclear (Illman 2016), as do the criteria and route of access for local areas and expectations for what this funding will deliver. What has become clearer in recent weeks, however, is that this new money is 'heavily weighted' to the back end of the parliamentary period and national bodies have told local leaders that they should 'have a plan for how you will proceed if we are unable to meet your IT requests' (West 2016). While the recent announcement that more than £100 million will be invested to create acute hospital 'exemplars' is welcome, it remains to be seen as to when and how this money will be made available. More fundamentally, Wachter says that the funding available for acute hospital digitisation across the system is insufficient. If the government is serious about achieving its vision, whether by 2020 or 2023, clarity is needed about the funding available to support this, as well as consideration of whether further funding will be required.

### **Incentives - supporting NHS leaders to deliver**

There have been few incentives for NHS leaders, particularly in acute trusts, to attempt large-scale transformation involving digital technology. In his review, Wachter highlights the experience of Cambridge University Hospitals NHS Foundation Trust (Addenbrooke's), where the teething problems associated with the ambitious roll-out of a hospital-wide digital system attracted negative media coverage and criticism from the Care Quality Commission. Such experiences may deter others who are considering digitisation and create a culture of risk aversion among those leading this change. Leaders need more support to deliver this transformation, recognising that change of this nature is complex, can take time to yield benefits, and may impact in the short term on an organisation's ability to meet operational targets. We agree with Wachter when he argues that regulators and commissioners must display a degree of 'tolerance' to providers attempting implementation of electronic health records.

### **Momentum - avoiding further delays in implementation**

Progress was swift in moving from the strategy set out in the Forward View to a national plan as set out in PHC2020, but implementation of these plans and support for local areas has been delayed by electoral purdahs and changes in personnel and policy (eg, STPs). While we welcome the realism provided by Wachter's recommendation that the deadline for going digital should be extended to 2023, if accepted by the Secretary of State this will require careful handling in order to maintain local momentum and enthusiasm. Local areas are rightly being given greater autonomy over planning and decision-making, but they urgently need clarity in a number of areas (for example, on the criteria for funding and levels of support), and no further delays.

### **Capability and skills - tackling digital exclusion**

Simply making services or devices available is not enough to ensure uptake, as we have seen with the early roll-outs of various online services. At the very least, raising public awareness of what is available and continuing to improve and simplify technology will also be important. While access to the internet and digital capability are improving, digital exclusion remains a key barrier. Education programmes and the continued engagement of organisations dedicated to widening digital participation, such as the Tinder Foundation and Doteveryone, are necessary to ensure that everyone can access the services they need.

### **Stakeholder buy-in - extending clinical engagement**

Clinical engagement is vital to any effort to secure better value from NHS care, and efforts to develop and spread technology are no different. Historically, the NHS has struggled to work with technology partners in ways that put the needs of clinicians and patients first. This manifests itself in clunky systems for entering clinical data, or in alerts so numerous that clinicians end up ignoring them or turning them off. In his report, Wachter emphasises that successful implementation of health IT ‘entails both technical and adaptive change’, which therefore necessitates ‘sustained engagement of front-line users of the technology’ ([National Advisory Group on Health Information Technology in England 2016](#)). Individual examples of good user-centred design and clinical engagement abound (see [The King’s Fund 2016a](#); [Imison et al 2016](#)). In addition, clinicians must be given sufficient time and space to develop and implement new ways of working.

## **Opportunities**

### **Alignment - strengthening links to and benefits from wider system transformation**

It is promising to see funding to support digitisation more closely linked to whole-system transformation through the local digital roadmaps and STPs ([National Information Board and NHS England 2016](#)); this could help ensure that technology investments are aligned with the wider priorities of local systems. We also note that a number of places developing new models of care are integrating better use of data and technology into their work to transform the way care is delivered. The recently announced ‘global’ and ‘national’ exemplars should also ensure that their work is aligned with wider transformation efforts.

### **Pull factors - the direct relationship between public/patients and digital technology**

There are numerous apps and devices designed to help people stay healthy or manage long-term conditions, and these are likely to continue to become more accurate and easier to use. Moreover, the data they generate could represent an opportunity to learn even more about people’s health (at both an individual and population level). The NHS should continue efforts to understand the role that such apps and devices can play in engaging people to improve how they manage their health. The developing app endorsement recommendations and the NHS Innovation and Technology tariff are opportunities to provide clear signals as to their quality and benefits, moving further towards clinicians being able to advise on, recommend or even prescribe their use. In the longer term, the digitisation vision

may expand to look at new ways of integrating individually generated data with health data stored by the NHS.

### **Getting consent right - raising the standard of public discussion**

The recent Caldicott and Care Quality Commission reviews present an opportunity to increase public understanding and acceptance of data sharing in the NHS. The recommendation for a simplified and standardised approach to enable people to opt out of their personal confidential data being used for purposes beyond their direct care is necessary but not sufficient on its own; patients also need to be clear on the purpose, practice and protections associated with data sharing – as does everyone working within the NHS. This means pursuing Caldicott's recommendation for a broader conversation with the public about the benefits of using health data and the way that data is handled. Data sharing is essential to conducting high-quality research and delivering improvements to patient care. There are many important benefits to be gained from secondary data use. For example, our ability to link and analyse health data enables us to understand more about the causes of disease and identify and tackle inequities in access to care.

### **Lessons from elsewhere - learning from experience both here and abroad**

The NHS can learn lessons from both here and abroad in relation to implementation. In England, learning can be taken from pioneering areas that have rolled out integrated records; areas that have been part of national programmes like the test beds; and other beacons of digital innovation (see [Castle-Clarke et al 2016](#); [The King's Fund 2016a](#); [Ham and Brown 2015](#); [Naylor et al 2015](#)). At the moment, few hospitals can serve as great examples because of previous problems associated with electronic records; the new programme to develop exemplars recommended by Wachter could help here. To take full advantage of the experiences of these frontrunners, a rolling programme of evaluation from NHS England – perhaps akin to that in place for the vanguards and promised for test beds – would be particularly valuable. It could contribute to our understanding of what works, where the real gains lie, and how to share learning between local areas. It was heartening to see this as one of Wachter's 10 recommendations.

# Conclusion

It is clear that the government and national bodies consider better use of information and digital technology to be a priority for the NHS and have set out an ambitious vision that seeks a balance between national and local decision-making and alignment with wider system transformation.

However, the backdrop against which this is taking place – one of unprecedented financial and operational pressures within NHS organisations – means there is a risk that expectations may be unrealistically high. Delays in key national policies and a lack of clarity on investment continue to present additional barriers. We therefore welcome the Wachter report's recommendation that the timetable for 'going digital' be extended from 2020 to 2023, as well as the suggestion that further consideration be given to whether current funding is adequate.

It is important to be clear that any potential cost savings from digitisation in health care will require up-front investment and will take time to deliver. With the funding made available to date uncertain and backloaded, the contribution to the financial challenge will not be of the magnitude predicted by some. In any case, focusing too heavily on cost savings and 'going paperless' detracts from the ultimate aim – to improve outcomes, efficiency and patient experience.

The low uptake of online services by patients in primary care and slow progress on a number of other fronts (*see Appendix*) demonstrate the difficulties for the NHS, first in getting the technology right and then in unlocking the benefits so that the technology in place is used to full effect. In addition, the care.data experience underlines the importance of explaining the potential benefits of technology to patients and the public, while at the same time reassuring them about data security. Users need to be more involved in digital innovation, and organisations need to explore how people want to engage with digitally enabled services.

Finally, despite a clear national vision for digitisation and a mandatory planning process to implement it, progress remains patchy beyond primary care. This is partly due to the barriers outlined above, but also reflects the fact that progress remains reliant on a carrot-and-stick approach from the centre, trying to drive take-up at local level. New efforts to articulate the fundamental case for change to local leaders and clinicians may be needed; without them, transformational digital change is

unlikely to be realised for some time. On this point, we agree with the Wachter report that successful implementation of this agenda will entail ‘both technical and adaptive change’. The importance of engaging and involving clinicians and frontline staff in the design and roll-out of new technology should not be underestimated.

# Appendix: Summary table of commitments

## 1: Rolling out fully interoperable electronic health records across all care settings

Commitments	Date	Progress
Clinicians in primary care, urgent and emergency care and others will be operating without paper records by 2018	2018	<p>Vast majority of GP practices already run a clinical IT system.</p> <p>Beyond primary care:</p> <ul style="list-style-type: none"> <li>• information in acute trusts is less digitised, structured and easily shareable</li> <li>• community trusts are in a slightly better position</li> <li>• mental health trusts seem further ahead.</li> </ul> <p>Local digital roadmaps to put in place the 10 paperless 'universal capabilities' for 2018 are being produced after a three-month delay to 'align' with the STP planning process.</p>
Care records will be digital, in real time and interoperable by 2020	2020	No measures for 'real time' yet.
A set of national standards and interoperability requirements would be agreed in 2015 and adopted widely across the system by 2020 to support roll-out of electronic records	Set 2015 Adopted 2020	<p>Progress on the standards set in 2015:</p> <ul style="list-style-type: none"> <li>• NHS Number: nearly all trusts use this as primary identifier for 90%-100% of information shared.</li> <li>• Using 'SNOMED CT' standards for clinical terminology: majority say they are not yet using SNOMED.</li> <li>• Using the 'dm+d' devices and medicines standard: majority not using it but quarter of acute trusts are using it.</li> <li>• Using the AoMRC standard structure for records in transfers of care: mixed, most say they are using the standard but not yet for all transfers.</li> </ul> <p>Open interface programme has started for primary care (GP Connect) with the first due to go live in early 2017.</p> <p>No similar programmes for health record systems in secondary care (yet).</p> <p>Code4Health community of interest set up.</p>

## 2: Patient-facing services

Commitments	Date	Progress
All citizens to have online access to their GP record from March 2015	March 2015	<p><b>Capability:</b> in place for 92.1% of practices for online access to the full record.</p> <p><b>Awareness:</b> low, with only 5.2% aware their practice offers records online.</p>
Full patient access to GP records by 2016 (taken to mean access to full detailed coded record)	2016	<p><b>Usage:</b> low, with 0.9% of patients surveyed having used this facility.</p>
Make online access routinely available for booking GP appointments and repeat prescriptions	Ongoing	<p><b>Capability:</b> now in place in nearly all practices.</p> <p><b>Awareness:</b> higher than records access - around a third of patients know they can do this.</p> <p><b>Usage:</b> 7.5% and 10.7% of respondents to GP patient survey said they had booked an appointment online and ordered a repeat prescription online respectively in the previous six months.</p> <p>Target of 10% use set by Martha Lane Fox, rising annually.</p> <p>Target of 15% access through apps announced by Jeremy Hunt in 2015.</p>
From 2018, the record accessible online will include information from all health and care interactions	2018	<p><b>Capability:</b> 35.8% for letters; 54.7% for test results - further behind than records access.</p> <p><b>Awareness:</b> data unavailable.</p> <p><b>Usage:</b> stats relatively low (around 90,000 times each by March 2016).</p>
Individuals able to record comments and preferences on their own care record	March 2018	No central data we are aware of.
To expand the set of NHS-accredited health apps for patient use	June 2015	<p>NHS Health Apps library withdrawn in 2015.</p> <p>Awaiting a new approach to endorsement.</p> <p>A new condition-specific apps library is promised for March 2017.</p>
Publish proposals to extend My NHS and NHS Choices	March 2015	Published in early 2015.
Promote uptake of health innovations by creating 'test beds'	Ongoing	Test bed partnerships finalised in late 2015.



### 3: 'Secondary uses', transparency and consent

Commitments	Date	Progress
To link hospital, GP, administrative and audit data to support research and commissioners' quality improvement and risk stratification efforts (ie, 'secondary uses' datasets)	2016	Core secondary use dataset has not been agreed. Related to the care.data (now cancelled) delay.
To achieve comprehensive transparency of performance data - including outcomes and patient feedback	Ongoing	My NHS website launched in 2014 and expanded as part of 'intelligent transparency'. Expansion plans announced early 2015.
Allow patients to retain the right to opt out of their information being shared	Ongoing	Caldicott 3 review completed in 2016 with proposals to simplify opt-out procedure with a 'global' opt-out.
Data security proposals	Oct 2015	Data security and CQC role consultation ends at the same time as Caldicott (2016).

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