



Personalised Health and Care 2020

Using Data and Technology to Transform
Outcomes for Patients and Citizens

A Framework for Action

NATIONAL
INFORMATION
BOARD

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Foreword

Better use of data and technology has the power to improve health, transforming the quality and reducing the cost of health and care services. It can give patients and citizens more control over their health and wellbeing, empower carers, reduce the administrative burden for care professionals, and support the development of new medicines and treatments.

In other parts of our lives, we see the benefits of technology: in the way we book our travel and holidays, manage our bank accounts and utility bills, buy groceries, connect and communicate with our friends and family. Digital technologies are changing the way we do things, improving the accountability of services, reducing their cost, giving us new means of transacting and participating. This is more than an information revolution: it puts people first, giving us more control and more transparency.

The job of the National Information Board (NIB) is to put data and technology safely to work for patients, service users, citizens and the caring professionals who serve them, to help ensure that health and care in this country is improving and sustainable. The urgency of this is increasingly evident: the health and care system faces unprecedented financial constraint at a time of rising demand for its services. Technology can help people use care services less by supporting healthier lives; and it can transform the cost of services when they are needed. It is key to helping our NHS meet the efficiency, as well as quality, challenges it faces.

Established by the Department of Health, the NIB is a new body which brings together national health and care organisations from the NHS, public health, clinical science, social care and local government, together with appointed lay representatives. It is charged with developing the strategic priorities for data and technology in health and care to deliver the maximum benefit for all of us, as citizens and patients and to make appropriate recommendations for investment and action.

The NIB helps take forward the ambitions of the Care Act 2014,¹ *the Government Digital Strategy* (2013),² the Department of Health's *Digital Strategy: Leading the Culture Change in Health and Care* (2012)³ and the proposals in the Department of Health's *Power of Information* (2012).⁴

It also builds upon the commitment to exploit the information revolution outlined in the NHS's *Five Year Forward View*.⁵

This framework has been developed based on evidence from many sources, including civil society and patient organisations, as well as directly from service users. As NIB moves to more detailed work on implementation, it will prioritise co-production with citizens, and partnership with initiatives like NHS Citizen. Six lay representatives have also now been appointed to the NIB itself.

This is not a strategy in the conventional sense. It is not a national plan, but a framework for action that will support frontline staff, patients and citizens to take better advantage of the digital opportunity. The NIB will report annually on progress made against the priorities detailed in this framework and review them each year to reflect changing technology and accommodate new requirements from the public and staff. The proposals in this framework are not comprehensive but they represent the core and immediate priorities for delivery of modern digital health and care services.

Later this financial year the NIB will publish a set of 'roadmaps', laying out in greater detail who will do what to transform digital care. We will also publish an evidence base, which captures key knowledge and learning from experience in England and internationally. In parallel the NIB will be testing its priorities and the framework it has proposed with service users, care professionals, care organisations and technology suppliers, so that they may inform its work and hold it – and its members – to account for ensuring delivery of this framework for action.

We welcome your views on these proposals.

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Executive summary

One of the greatest opportunities of the 21st century is the potential to safely harness the power of the technology revolution, which has transformed our society, to meet the challenges of improving health and providing better, safer, sustainable care for all. To date the health and care system has only begun to exploit the potential of using data and technology at a national or local level. Our ambition is for a health and care system that enables people to make healthier choices, to be more resilient, to deal more effectively with illness and disability when it arises, and to have happier, longer lives in old age; a health and care system where technology can help tackle inequalities and improve access to services for the vulnerable.

The purpose of this paper is to consider what progress the health and care system has already made and what can be learnt from other industries and the wider economy. We then set out a series of proposals that will:

- **‘enable me to make the right health and care choices’ – citizens to have full access to their care records and access to an expanding set of NHS-accredited health and care apps and digital information services;**
- **‘give care professionals and carers access to all the data, information and knowledge they need’ – real-time digital information on a person’s health and care by 2020 for all NHS-funded services, and comprehensive data on the outcomes and value of services to support improvement and sustainability;**
- **‘make the quality of care transparent’ – publish comparative information on all publicly funded health and care services, including the results of treatment and what patients and carers say;**
- **‘build and sustain public trust’ – ensure citizens are confident about sharing their data to improve care and health outcomes;**
- **‘bring forward life-saving treatments and support innovation and growth’ – make England a leading digital health economy in the world and develop new resources to support research and maximise the benefits of new medicines and treatments, particularly in light of breakthroughs in genomic science to combat long-term conditions including cancer, mental health services and tackling infectious diseases;**

- **‘support care professionals to make the best use of data and technology’ – in future all members of the health, care and social care workforce must have the knowledge and skills to embrace the opportunities of information;**
- **‘assure best value for taxpayers’ – ensure that current and future investments in technology reduce the cost and improve the value of health services and support delivery of better health and care regardless of setting.**

This framework explains how we, collectively, aim to deliver this change and what it will mean for patients, services users, citizens and professionals.

1. Why do we need to act now?

The health and care system in England has served a growing and progressively healthier population well for decades. However, gaps within the system are becoming increasingly apparent.

The *Five Year Forward View* identified three key challenges for health and care:

1. *The health and wellbeing gap*: If the nation fails to get serious about prevention then recent progress in healthy life expectancies will stall, health inequalities will widen, and our ability to fund beneficial new treatments will be crowded out by the need to spend billions of pounds on wholly avoidable illness.
2. *The care and quality gap*: Unless we reshape care delivery, harness technology and drive down variations in quality and safety of care, patients' changing needs will go unmet, people will be harmed who should have been cured, and unacceptable variations in outcomes will persist.
3. *The funding and efficiency gap*: If we fail to match reasonable funding levels with wide-ranging and sometimes controversial system efficiencies, the result will be some combination of poorer services, fewer staff, deficits, and restrictions on new treatments.

The gaps are exacerbated by the lack of integration across care services – hospital, community and home, clinical and social care, formal and informal settings. This framework addresses the challenge of how to exploit the potential of information technology and data to help bridge these gaps.

While developments in clinical technology have had a revolutionary impact on healthcare over the last 30 years, the same cannot be said for the use of technology and data to improve health and the way health and social care services are delivered. The consumer experience of care services remains much as it was before the mobile phone and the internet became commonplace. For care professionals, from social workers to doctors and nurses, the arrival of the digital age has often been experienced not as a force for good but rather as an intrusive additional burden in an already pressured existence. At the same time the technology industry is investing massively in consumer health products but these are not comprehensively linked to the formal health and care sector.

The failure to use information properly in health and care means people can experience unnecessary levels of preventable ill health. Those using services can suffer harm when it could be avoided, could live in greater pain and distress than they need to, and are less likely than expected to experience a full recovery.⁶ Every day, interactions with health and care services can waste people's precious time. In addition, taxpayers do not get full value: the productivity benefits that come from effective use of new technology – doing more for less – are not widely realised.

As financial pressures grow, and the gap between expectations, demand and resources increases, the need for the care system to make use of the best available technologies has become increasingly urgent. To ensure sustainability, health and care needs to move from a model of late disease management to early health. Information technology plays an essential and rapidly expanding role in empowering people to take charge of their own health, by providing information, support and control.

Any proposition for closing the gap that is forecast between available resource and predicted demand, assumes significant cash releasing and efficiency contributions from technology and data services – and recent research commissioned to support this framework suggests that the potential cost-saving is substantial.⁷

The introduction of new models of care that deliver better health and wellbeing outcomes for people and a better experience when they access services, depends significantly on the commitment, understanding and ambition of local leaders, all health and care providers, the voluntary and charitable sector and communities themselves. Addressing current and emergent challenges requires interoperable and flexible systems and locally championed innovation. By effectively harnessing technology to help reshape care delivery, enabled by flexible costing, pricing and payment models, we will drive down variations in quality and cost-effectiveness while improving safety.

2. Can it be done?

Not only must we act, but we know that it can be done:

- **Many other industries, including safety-critical ones, have transformed their use of information.**

While health and care services have particular, perhaps unique features, they also have much in common with a wide range of consumer-driven service industries that have been transformed in recent decades. Human interaction will always be at the heart of health and care, but that interaction can be better informed, more efficient and better organised if supported by data and technology services.

In the airline industry 70% of flights are booked online and 71% of travellers compare more than one website before purchasing.⁸ A paper ticket was once a critical 'trusted' travel document, yet today around 95% of tickets are issued digitally as e-tickets. In Britain we use our mobile phones to make 18.6 million banking transactions every week; automation of particular services has helped cut costs by up to 20% and improved customer satisfaction. More than 22 million adults now use online banking as their primary financial service.

Four processes appear to underpin wide-scale change driven by technology and data:

1. Many advances come from new, non-traditional, smaller suppliers, often working outside structured, planned initiatives. But while non-traditional suppliers frequently make key, sometimes opportunistic **innovations**, large traditional suppliers remain important not only as a source of scalable, resilient developments but for driving dissemination and diffusion at pace. Both innovation and wide-scale diffusion are facilitated by standardisation.
2. Professional behaviour tends to change more slowly than **consumer behaviour**, challenging the approach taken by existing suppliers, placing a priority on training and retraining.
3. Information is not enough by itself. There have to be **personalised transactions**, leading to consumer control and self-management of end-to-end tasks that deliver tangible benefits and value for individuals. Consumers are rewarded for the time and effort they have to put in. At the same time supplier costs are reduced and revenues increase as new service opportunities are created.

4. The skilling and empowerment of the service user are the result of a **skill transfer** process, which moves skills from the highly skilled to the less skilled and ultimately to the consumer. Crucially, this results in lower-paid staff gaining new skills, as well as an activated consumer.

These processes or drivers of innovation – the changing of consumer behaviour driven by the ability to complete useful transactions and the transfer of skills and costs – require the affected industries to adopt particular and common characteristics.

One compelling characteristic underpinning these processes is **standardisation**: standardisation of processes, datasets, platforms and interfaces. In some cases the standardisation is formal, with the mandatory adoption of industry-wide standards. In other cases standards evolve through convention and informal adoption. Standardisation enables innovation, reduces development costs, lowers barriers to user adoption, speeds up wide-scale adoption and supports an almost infinite variety of bespoke and personalised service offerings.

Transferring transactional skills to the service user requires highly effective **logistics**. Orders have to be processed, bookings confirmed, products despatched, in highly efficient operations. If consumers are to recognise the benefit of their efforts, the near-instantaneous nature of their online interaction has to be matched with equally effective service delivery.

It also requires new approaches to **security and trust**. People's confidence in the safety of their data in the context of the increased risk that digital technologies can pose is critical.

A critical element in establishing that trust and in encouraging consumer-driven transactions is transparency; the availability of comprehensive and comparable **information**. Easy access to information encourages and supports consumer and professional decision-making. Informed choice has a positive impact on innovation, service development and the evolution of standards. The transparency that comparable information brings also helps hold suppliers to account.

- **The public in England are using digital services – and there is evidence of growing demand in health and care.**

In 2014 59% of all citizens in the UK have a smartphone and 84% of adults use the internet; however, when asked, only 2% of the population report any digitally enabled transaction with the NHS.⁹

There is evidence that people will use technology for health and care, given the opportunity. There are 40 million uses of NHS Choices every month, of which some 5 million are views by care professionals who regard this service as a trusted source of information and advice.¹⁰ The internet-based sexual and general health service, Dr Thom (now part of Lloyds online), has seen 350,000 individuals sign up as users.¹¹

In Airedale, West Yorkshire, care home residents have quickly embraced an initiative that gives them the opportunity to tele-access clinicians from the local hospital over a secure video link. A reduction in local hospital admissions of more than 45% has been reported among that group of people.¹²

- **There is good evidence that better use of data and technology improves patient outcomes and the value of services.**

Data and technology improves effectiveness, safety and experience. There is an extensive evidence base about the productivity potential of existing data and technology interventions; for example, a shared electronic health record, linked to transparency; alternative channels for face-to-face consultations with GPs and other professionals.¹³ Also, the way in which telehealth, apps and other digital tools are empowering self-care.¹⁴

Internationally, hospitals like Virginia Mason in Seattle, USA, have demonstrated that the best-practice deployment of real-time data provides safer care and cheaper care. In the UK, heart surgeons have shared data on their individual outcomes for the last decade – and mortality rates in some procedures have fallen by a third, with around 1,000 fewer avoidable deaths each year reported. Recent analysis, building on evidence of existing use of technology in health and care, confirms that real-time record-sharing can reduce care costs, improve safety and halve treatment waiting times.¹⁵

- **The opportunity is now.**

There is now, in 2014, the opportunity to address these issues, establishing both new priorities for the short term and a radically new direction for the next decade. On 23 October health and care leaders in England published the *Five Year Forward View*, which set out a new direction for the health and care system. This new approach is based on central standards, with explicit and extensive permissions to unleash local energy and enterprise.¹⁶ At the same time clinical commissioning groups (CCGs), health and wellbeing boards and local authorities are making important decisions about the disposition of local services. Also, over the next three years a number of major, long-term, contractual arrangements will come to end. These include the remaining local service provider contracts, primarily covering hospital and community services, the contracts covering GP systems and a number of major infrastructure contracts, including N3, the NHS's secure network.

In parallel, the installation of high-speed broadband services into homes and businesses across the country, and the spread of 4G services, continues apace. By 2020 there will be a significant increase in the percentage of over-65s who have smartphones and access to broadband,¹⁷ and a combined multibillion-pound annual purchasing power. Good health and care will be top of their priorities. As a result, a growing number of older people, or those that are going to become elderly over the next decade, will have access to technology and data services in their own homes and on the move, and be enthusiastic and expectant users.

Against this background, private sector investment in technology services for the care system is growing. There is recognition that as a 'follower' or 'laggard' industry, the health and care system has enormous potential to benefit from the experience and learning of others. Recognising both the scale of the domestic and global market, institutions and companies are investing in developing technology and data enabled services focused on health and care. The immediate targets are 'healthy lifestyle' services, often combining wearable devices with remote biometric data analysis, the results of which are interrogated on a smartphone. This architecture is readily transferable to the management of chronic conditions and mental health. Irrespective of what path is followed by the publicly funded English health and social care system, these developments will proceed rapidly, driven by the scale of the global opportunity. The care system will be changed as a result and not necessarily in a manner which reflects public policies and values.

3. Where are we now?

Some past initiatives and investments have had a significant impact. For example, incentives introduced initially in the 1990s have resulted in more than 96% of GP practices installing digital clinical record systems.¹⁸ However, to date the resulting rich records contained in these systems have largely remained inaccessible to patients, with under 4% offered access online. Adopting such systems has had little significant impact on the day-to-day experience of most patients and limited effect on the working practices of most primary care clinicians.

Similarly, most social care providers have adopted computerised records systems, yet these lack the capability to share information with other care professionals. Most hospital information systems remain impenetrable to care professionals outside the hospital gate and there is little or no electronic exchange of information about the 150,000 patients cared for in nursing homes and hospices. This lack of interoperability is a major and fundamental problem, well recognised in successive strategies, which so far has not been tackled successfully.

The record with respect to deriving the performance benefits from past investments is equally mixed. Despite the significant and continuing, centrally supported investment in hospital systems over the last decade, it has been estimated that across the acute sector only around 33% of the potential benefits have yet been realised.¹⁹ The scope to revolutionise mental health services through more extensive and effective use of information technology has also been explicitly highlighted.²⁰

In part, some of the barriers to reaping those benefits are comparatively mundane; a lack of universal Wi-Fi access, a failure to provide computers or tablets to ward or community-based staff, and outmoded security procedures that, by frustrating health and care professionals, encourage inappropriate 'workarounds'. In some cases, the technical solutions delivered have not taken sufficient account of the way clinicians work in practice. Conversely, a lack of commitment to make the necessary changes to clinical practices and operational processes have limited transformation and reduced the scope and scale of benefits. Where hospitals have exploited the potential of their systems, the results have been impressive; but the variation between hospitals, and even between departments within hospitals, is striking.

We must now aim to build on the comprehensive infrastructure available to the health and care system for the extraction, collection, storage and transmission of data. The Spine, and its associated services, handles over 200 million interactions a month, providing a resilient and secure identification service for the whole of the NHS.²¹ The Spine also hosts the summary care records (SCRs) of over 45 million individuals, which are extensively accessed each week by care professionals in hospital pharmacies, accident and emergency departments and ambulance services.²² The Secondary Uses Service (SUS) provides clinicians, researchers and commissioners with one of the world's richest sources of health and care data.

Past investment has resulted in significant advances in some areas but invariably these are isolated. The resulting system architecture is organisationally determined rather than user-focused. Most individuals have numerous care records, for example with their dentist, hospital and GP, which are unconnected and inaccessible. Designed primarily to support the service provider, often principally for administrative and billing purposes, these systems lack transactional functionality, which would support the user in taking control of or managing any part of their own care.

Nor does the current pattern of investment reflect the changing demands for care. While most care is delivered in the home, the current system provides little or no support for informal carers, or those living with disabilities or chronic conditions. There is a striking mismatch between where investment has been made in technology and the upstream drivers of cost across the health and social care systems. Many older people are cared for by the one in three individuals who provide substantial levels of unpaid care every week, with virtually no support from the technology and data services that underpin the formal care system.²³

4. What needs to change?

Better use of technology and data is a prerequisite for supporting and enabling the key developments needed to reshape the health and care system, which are at the centre of the Department of Health's vision for health and care and the NHS's *Five Year Forward View*, in response to increasing demand and constrained resources. These are:

- **the personalisation of care**, including individual wellbeing, self-care, personal commissioning and, in the longer term, the impact of genomics;
- **the development of new models of care and integration of services**, particularly across the divides between family doctors and hospitals, physical and mental health, and clinical and social care, with the objective of providing better, safer services more efficiently;
- **more effective management of service access**, through the provision of alternative sources of information, supporting self-care and better signposting to direct individuals who need professional care to the appropriate service;
- **the reshaping of the workforce**, by improving information flows and access to systems, so that skills and capabilities are enhanced, leading to a step-change in staff productivity.

The proposals set out in this paper are entirely aligned with this developing vision. Taken together, the proposals will initiate and propel, over the next decade, the development of a technology and data enabled care system that has the citizen at its centre.

Approach

The achievement of this vision must be based on a collaborative approach, rather than a centrally driven plan or strategy. The solutions and services must be defined by the service users, the carers and the care professionals, and not by technology ideologues. In addition, the process must be open and transparent, recognising the interconnectivity and mutuality of common purpose that brings together all the providers and commissioners across the care system, whether from the public, independent or voluntary sector. The transformation of our services and

the transition to prevention and self-care requires a fundamental business change and cultural shift, one that ensures that the responsibility for sharing information is understood by everyone throughout organisations and across communities. We hope that technology entrepreneurs will recognise this commitment to open collaboration and embrace a future in which they provide services that are open to others, in this way encouraging yet further innovation.

Given the public interest in the care system, there is a key role for public sector institutions, but this has to be in partnership with citizens, service users, suppliers, care providers and researchers, in order to develop a framework that provides a common, shared direction.

At times, the health and care system has tried highly centralised national procurements and implementations. When they have failed, due to a lack of local engagement and lack of sensitivity to local circumstances, we have veered to the opposite extreme of ‘letting a thousand flowers bloom’. The result has been systems that don’t talk to each other, and a failure to harness comprehensively the overall benefits that come from interoperable systems. In future, we intend to take a different approach. We will be tight on standards and definitions, and clear on expectations regarding interoperability, but we will support local decision-making on systems, programmes, interfaces and applications. Some of the key systems needed will remain national responsibilities, such as the sustainable platform – the ‘electronic glue’ – enabling different parts of the health service to work together, and to capitalise on the wider gains of doing so. We will support local health and care communities, respecting their local needs and priorities and acknowledging their relative digital maturity, to decide upon and procure their own solutions, provided they meet nationally specified technical and professional standards.

Resources

The proposals set out in this paper must also be delivered within available resources. We do not know what a future funding settlement will be for the Department of Health and the NHS, nor for its technology priorities. The *Five Year Forward View* identified that delivering on the transformational changes it proposes and the resulting annual efficiencies could – if matched by staged funding increases as the economy allows – close the £30 billion gap by 2020/21. A recent study for NHS England²⁴ suggests that digital investments deployed as part of transformational change can deliver significant savings – contributing to short-term savings and, in the longer term, to the sustainability of services.

The NIB will be publishing a series of roadmaps and proposals, as detailed below, to clarify the financial, as well as human, benefits that technology can deliver in health and care.

For these reasons, if we are going to transform the way information is used across health and care, then we need to deliver radical transformation in the following areas:

- **‘enable me to make the right health and care choices’;**
- **‘give care professionals and carers access to all the data, information and knowledge they need’;**
- **‘make the quality of care transparent’;**
- **‘build and sustain public trust’;**
- **‘bring forward life-saving treatments and support innovation and growth’;**
- **‘support care professionals to make the best use of data and technology’;**
- **‘assure best value for taxpayers’.**

5. Enable me to make the right health and care choices

CASE STUDY

One in four adults will experience some kind of mental health problem in the course of a year and the World Health Organization predicts depression will become the biggest cause of disability by 2020. **Big White Wall** provides an online service that members can turn to for support in managing their care, with access to clinicians, carers and each other. The service has attracted over 20,000 members who have benefited from quick access to help, guidance and individual live therapy over a secure link. It is now available to almost a quarter of the adult population through the NHS and other private and public sector organisations who have signed up to provide it to their employees. Almost three-quarters of respondents to an internal review said they had talked about something for the first time on Big White Wall, 80% were able to self-manage their condition as a result, and 95% said it helped them feel better.

We can improve care and reduce the need to use health and care services by enabling more of our citizens to build up the knowledge, skills and capabilities they need to manage their own care and symptoms. We will achieve this by engaging communities, supporting carers, and developing volunteering in and partnerships with the charitable and voluntary sector. We can develop access to high-quality advice and support at the earliest opportunity. Enabling citizens to interact with existing and new services that are more convenient and efficient will increase satisfaction and reduce costs. A number of new service models will be largely or entirely self-directed (see the case study below).

CASE STUDY

Routine sexual health screening needs to be as quick and convenient as possible to encourage use among at-risk groups. This has often not been the case. **Dean Street Express**, based in Soho in central London, is a walk-in service that combines the latest technology with efficient service six days a week. Anyone who thinks they need a sexual health test can arrive at the service without an appointment, check in via a touchscreen, and complete the self-taken tests themselves or blood tests with the onsite staff. Samples are analysed rapidly on site so results are available quickly, usually within six hours, and sent to the user directly via text message, without the need for a follow-up call or appointment.

The use of digital technologies across all social groups under the age of 60 demonstrates that there is a latent demand to use these technologies to improve management of health and access to care services. However, use of digital technologies remains low in practice in the health and care system. This demonstrates that the system is not currently meeting the needs of those it serves, and that there is a paucity of current offers adding value. To some extent, the health and care system faces particular challenges, as many of its users come from disadvantaged groups and the elderly. Nonetheless, the increased uptake of smartphones and extensive broadband access is overcoming barriers to inclusion.

Digital technologies can transform the ways in which patients and citizens take control of their health and wellbeing. Big White Wall (see first case study above) is an online community that supports more than 20,000 people with mental health issues. Next-generation wearable devices and mobile technologies will help people manage their health better and deal more effectively with illness and disability.

The NHS, as noted above, has made significant progress in developing the digital infrastructure to enable people to access their own data in general practice and to transact digitally, including when booking appointments and ordering repeat prescriptions.

CASE STUDY

University Hospitals of Leicester NHS Trust, actively responding to frustration about the amount of time frontline staff spent on paperwork and the subsequent impact on patient care, set out to use mobile technology to change their staff's working lives. The organisation secured investment from the Nursing Technology Fund for mobile devices, such as iPads and iPhones, and the Nervecentre mobile application software, designed to record patients' vital signs. Effective and efficient recording of observations, as well as handover at the end of shifts, is particularly challenging during the out-of-hours period. Nurses now carry out routine observations using a handheld device, with that data being instantly available to all staff responsible for that patient's care. The key benefit is targeted messaging to services and clinicians who can use that information to identify deteriorating patients. Nurses no longer have to spend hours chasing updates by phone. As a result, staff are more visible to their patients, spending more time at their bedside. Consequently staff morale improves as they are more able to use their skills for caring.

CASE STUDY

Despite a third of the total healthcare budget being spent in the last year of life, many patients and their families complain that they did not receive the care they wanted because the agencies involved didn't know their wishes. **Coordinate My Care**, developed at the Royal Marsden NHS Foundation Trust, is changing this. It lets patients with life-limiting illnesses define a personalised urgent care plan that is shared electronically with all agencies and professionals involved in their care, including NHS 111, London Ambulance Service, GPs, social care and accident and emergency. With over 10,600 registered users and 7,000 clinicians trained, the service is making a big impact on palliative care in London. More than three-quarters of the people who have died while on the programme did so in the place of their choosing, at home, in a hospice or care home. Not only does this improve patients' experience of end-of-life care, but it creates substantial savings for the NHS. An independent evaluation calculated that the reductions in hospital attendance and length of stay achieved through giving professionals access to patients' wishes delivered an average saving of £2,100 per person.

In 2015, all citizens will have online access to their GP records and will be able to view copies of that data through apps and digital platforms of their choice. But it is essential that citizens have access to all their data in health and care, and the ability to 'write' into it so that their own preferences and data from other relevant sources, like wearable devices, can be included. Patients won't have the ability to edit the entries their clinician has made but their comments will be visible. This framework prioritises comprehensive access – with the ability for individuals to add to their own records – by 2018.

While this will support people to take more control of their health and care and to interact with care providers more effectively, it is essential that all steps are taken to ensure transparency and accountability for the safety of this personal data. For this reason, we propose the development of new approaches to building an NHS standard of vigilance for this kind of information.

For data and technology to have a major impact on the care system, users should expect access to digital services, and for providers this will be their default delivery channel. The NHS has achieved global distinction with its existing digital information channel – NHS Choices – by far the biggest resource of its kind in Europe. We must build on that strength and will offer citizens a single point of access, through NHS Choices, to common digital transactions, like booking appointments. In addition, we will improve easy multi-channel access to NHS-accredited information about health and conditions, comparable information about local services, and access to digital services and apps. For this reason,

we propose that NHS England bring forward plans – and test through regional pilots – the integration of the 111 service with NHS Choices and other channels to support citizens to take more control. The national infrastructure that is accessed through NHS Choices will adopt the Government Digital Services identity assurance service (IDA) for citizen access to digital health services, in order to ensure alignment with pan-government services.

The public sector can play a crucial role in fostering and encouraging transformation by initiating and supporting developments that demonstrate the potential of technology and data enabled services and establishing exemplars to catalyse widespread adoption. A national approach to the accreditation and kitemarking of apps, devices and digital services, for example, will help give users, consumers and care professionals confidence to use them. It will help encourage public sector commissioners and providers to adopt these accredited innovations, making them available to patients and carers. It will help ensure that intuitive and compelling applications emerge and flourish, so as to engage and secure commitment on the part of the patient/citizen. We want to provide a particular focus on supporting the development of safe digital tools in mental health and propose to investigate the feasibility of an innovation prize to promote these services.

This framework emphasises the importance of giving the citizen free and accountable access to their own data, while developing seamless real-time digital data flows between professionals and carers to support individuals' health and care. In the future, it will increasingly be the citizen who determines who has access to their data, with care professionals responding to and respecting their preferences. For that reason, we propose to develop a proof of concept, starting with end-of-life and maternity care, to test the wider proposition by supporting people with mobile care records, which they control themselves to ensure their care preferences are respected.

In tandem, the NIB will work with the professional bodies to consider the implications of giving patients access to their records, in terms of the continuing need for an accurate, up-to-date record to be kept by clinicians, nurses, professions allied to medicine, social workers and care workers for professional, regulatory and legal reasons.

The goal is to make safe accountable 'digital' access to care services the norm, where it is appropriate and the service user's preferred option. We need to ensure that the digital opportunity is inclusive. We currently lack high-quality evidence for how best to support certain key communities with information and services. For this reason, the NIB will support the development of a number of pathfinder projects to build better insight into the barriers to digital inclusion. It will also support NHS England to widen its current programme of digital inclusion with the Tinder Foundation; this has already seen more than 29,000 people learn how to go online to support their health and care.

CASE STUDY

As one of 14 integration pioneers, **Leeds**, in partnership with local communities, is using technology as a key enabler to develop new models of care that shift care closer to the home. Based on engagement with the citizen, in collaboration with the local Neighbourhood Network Schemes and two small and medium-sized enterprises, Leeds is using technology with a small cohort of elderly frail patients. They are assessing the benefit that community and informal care networks can have in the co-design of technological solutions in three key areas:

My Care/Support Network: Tools to help citizens capture information and documents and share these across networks of professionals, families and carers – improving exercise, diet and access to services.

Time and Care Budget Banking: Tools to help manage time-banking and personal care budgets, enabling the transfer of high volumes of low-level care from professional to community provision.

Civic Enterprise User Driven App Factory: A platform to enable new businesses/groups to develop apps for citizens, as well as to link citizens to professionals, using the person-centred care technologies.

They aim to use this technology to reduce isolation by improving coordination and communication. It is also envisaged that this approach will improve wider outcomes, such as reducing time away from work for carers. Going forward, the intended result is the creation of a secure, scalable communication, collaboration and information-sharing platform for Leeds, focused on citizens' needs and seamless integration with the Leeds Care Record.

Our proposals to enable me to make the right health and care choices

- i. From March 2018 all individuals will be enabled to view their care records and to record their own comments and preferences on their record, with access through multiple routes including NHS Choices. Initially, this will focus on data held by NHS providers (primary care, acute, community and mental health), but it will be progressively extended to cover other care settings, taking account of the work that local authorities are progressing in regard to personal records. This will create the opportunity for individuals to create and manage their own personal care record. The NIB will publish a roadmap for implementation by June 2015, which will then be integrated into commissioning and regulatory arrangements, where appropriate.

- ii. We will enable all citizens to have a single point of access to all transaction services, including booking appointments and online repeat prescriptions for all care services. This will build on NHS England's existing programme, in collaboration with the government's wider programme led by the Cabinet Office. NHS England, with HSCIC, will publish proposals by June 2015 to consolidate NHS e-Referrals, appointment booking and repeat prescription ordering with NHS Choices, as a basis for providing a single, common portal for all care providers and service users. NHS Choices will be developed to provide a core common platform for all care providers and will be capable of customisation to reflect the specific needs of different localities and communities.
- iii. NHS England, with DH, Public Health England (PHE) and the HSCIC, will publish proposals by September 2015 for linking the 111 service with NHS Choices and other public information channels to create a seamless public information service.
- iv. The NIB will set up a task and finish group with clinical and civil society leaders on the regulation, accreditation and kitemarking of technology and data enabled services, including apps, digital services and associated mobile devices. This is in order to support innovation, and consumer and professional confidence, including enabling GPs to be able to prescribe them. It will publish proposals by June 2015 and kitemaking of apps will begin by the end of 2015. Kitemarked services will be able to use the NHS brand and to be accessible through NHS Choices.
- v. The NIB will support the development, diffusion and adoption of low-cost high-efficacy apps with a particular priority on mental health services, for example for cognitive behavioural therapy. The Department of Health (DH), NHS England, Academic Health Science Networks (AHSNs), the HSCIC and PHE, in partnership with the Behavioural Insights Team and Nesta, will start by launching a dedicated apps innovation prize process in mental health, drawing on behavioural insights and rapid trial methods. The intention will be to develop a series of easy-to-use, personalised cognitive behavioural therapy (CBT) applications, tracking impacts on employment and other outcomes as well as mental health, with trials beginning in 2015.
- vi. The HSCIC will publish by 1 April 2015 the roadmap and the standards that care organisations will need to meet in order to be able to access core transaction systems, including Spine and NHS e-Referrals.
- vii. NHS England will pilot individual digital 'care' accounts in which patients hold not just their records, as above, but also a personal budget, as part of its programme to offer Integrated Personal Commissioning from April 2015.

- viii. The NIB will oversee the launch of a national experiment to give patients a personalised, mobile care record which they control and can edit but which is also available in real time to their clinicians. The HSCIC, PHE and NHS England will, together, establish a national digital standard for people at the end of their life – building on the success of Coordinate My Care in London – (see case study) – so that their care preferences are respected. For parents of newborns, we will encourage digitisation of the personal child health record (the ‘red book’).
- ix. DH, NHS England and the HSCIC, in partnership with the voluntary and independent sectors, will sponsor initiatives to develop and provide technology and data services, to support new ways of delivering care services. These will focus on people with learning disabilities, young offenders and dementia carers.
- x. The NIB will establish a working group with a broad membership, including users and stakeholders, to advise on the impact of data and technology developments on inclusion and equity across the care system, and build on existing programmes, like that between NHS England and the Tinder Foundation.

6. Give care professionals and carers access to all the data, information and knowledge they need

CASE STUDY

Oxford University Hospitals NHS Trust introduced a paper-based early warning chart in 2011 to proactively identify areas where care needed to be improved. Knowing that more could be done, and convinced that an integrated electronic solution would be more effective, the organisation pursued a successful application to the Safer Hospitals Safer Wards Technology Fund. They have rolled out an intuitive electronic early warning scoring system, where real-time data is shared in the right way with the right people (staff, patients, relatives and carers). Tablet computers are integrated with existing monitoring equipment and all key information is displayed in a dashboard, viewable across the Trust, enabling rapid assessment and timely intervention. Patients at risk of sepsis, for example, can be managed earlier and more effectively, with the added benefit of helping to address the risks of increased anti-microbial in the population as a whole. The system also provides a real-time overview of clinical practice against National Institute for Health and Care Excellence (NICE) quality criteria.



MARTIN 55
(Carer of his disabled son)

- Hates it when people only talk to him in consultations and not to Liam directly
- Struggles to find a balance in his life between caring for Liam and having a quality work life and social life for himself
- Wants coordinated support for Liam for both his autism and epilepsy

Martin will be able to monitor the impact of Liam's epilepsy medication and share it with his clinical team so adjustments can be made when required.

Martin will be able to manage a personal care account and personal budget for Liam, so he can choose the most helpful support.

Liam's patient record will include notes about his capacity to understand, so his clinical team can speak to him directly about his care.

Martin will have access to digital tools, digital infrastructure and services that will help him in his role as carer for Liam.

CASE STUDY

Staffordshire and Stoke-on-Trent Partnership NHS Trust is the UK's largest provider of community health and adult social care services. An award from the Nursing Technology Fund enabled the Trust to provide their community-based staff with a remote working capability by equipping them with mobile technology. As a result, significant changes to practice are emerging. The nursing team routinely receive their caseload electronically at home, avoiding a trip into the office. Weekend workloads are being discussed using video calls, and district nurses have video-conferenced the tissue viability team to seek advice on wounds when with a patient, saving specialist referrals. Social care assessors complete financial assessments digitally while in the patient's home. The future vision is to fully exploit access to information at the point of care, enabling clinicians to record and access patient information, make referrals, order equipment and prescribe while out of the office and in real time.

(i) Real-time digital information on a person's health and care

The arrival of the electronic patient record, more than 20 years ago, has delivered enormous benefits, both to clinical practice and research. Despite an increasing quantity of data about patients, few clinicians outside general practice have access to that data in real time and little progress has been made in developing an accessible decision-support system to supplement professional skills.

In addition, we need patient records to be mobile, editable and accessible to all those in the care process, including patients themselves and carers. Digital records must support the delivery of care in the community as much as in the hospital – their mobility, extensibility and interoperability is fundamental.

The evolution and adoption of a comprehensive set of technology and data standards will support interoperability, lower the barriers to innovation and contribute to burden reduction across the care system. Adoption of these standards is also key to maximising the efficiency of current and new care services. Widespread adoption of barcoding for medicines, for example, is proven to reduce harm to patients and also to decrease the cost of pharmacy services.

The scope of the standards should be limited only to what is needed. The development of these standards must command broad-based support, both through formal processes and the promotion and adoption of informal standards and conventions. And the adoption of standards must be based on common interest and supported by the system as a whole through regulation, contracts and accreditation.

The objective is to create a framework of standards that is evolving, reflecting the development and needs of the health and care system. Above all, the framework should be permissive, enabling and supporting innovation and the improvement of care services, and building upon flexible approaches that deliver meaningful and effective use of information technology and data. But there are some basic requirements; an individual's NHS number must be used to identify patients for all care they receive in the NHS and all social care.

It is also necessary to support care professionals, including unpaid carers, to maximise the benefits of information and new mobile technologies for themselves and those they care for.

These proposals foresee a progressive implementation of digital data standards and an end to paper records in all NHS-funded care contexts within six years, supported by a series of core national standards and incentives.

A prerequisite for sustainable services in the future will be that those services are increasingly taken to patients in the community, and providing care out of hospital requires a different way of working. One of the keys to enabling working in community settings is a more mobile, technically enabled workforce. Mobile technology supports clinicians to enable patient self-care, access expertise and increase capacity via virtual consultations, and utilise decision support tools. By capturing data at the point of care it also helps clinicians to evaluate their own work and hence innovate and improve their services. Mobile technology enables new ways of working and process improvements that increase staff productivity, reduce delays and eliminate duplication of effort.

Clinical decision support systems have been prominent in health and care for some time. Current advances in the field of cognitive computing, coupled with the ubiquity of smart technology that records and transmits medical grade biomedical data through digital media and smartphones, indicate that we are on the edge of radical change. The potential to transform remote healthcare assessment and interaction now exists. The NHS needs to explore these advances to fully understand the potential opportunity they present for faster, more accurate diagnosis, patient safety, empowerment and experience, and to transform how remote channels can be used to deliver care. The ability for clinical decision support to be auto-populated with my existing healthcare information (my past), to take real-time feeds of my biometric data (my present), to consider my genome (my future) and to configure the questions that I need to be asked based on this information is all technically possible today. We need to gain a greater understanding of this potential opportunity and be clear as to how we will realise the benefits.

Our proposals for giving care professionals the data they need

- i. All patient and care records will be digital, real-time and interoperable by 2020. By 2018 clinicians in primary, urgent and emergency care and other key transitions of care contexts will be operating without needing to use paper records. This will be achieved by alignment of national technical and professional data standards with regulatory and commissioning requirements. By April 2015, building on the existing interoperability programme, the NIB, in partnership with users and industry bodies, including the Foundation Trust Network and the NHS Confederation, will coordinate agreement on these standards and how they should be 'hard-wired' into commissioning and regulatory oversight.

Guidance to commissioners and providers will be published by June 2015. NHS England will support national and local commissioners to develop roadmaps for the introduction of interoperable digital records and services by providers – including in specialised and primary care – which commissioners and providers will publish by April 2016.

- ii. The NHS number is unique to each of us from birth and key to ensuring that clinicians can share information about us so that we are treated safely. In April 2014 the use of the NHS number as primary identifier in clinical correspondence and as a means of identifying all patient activity was introduced in health and social care via the NHS standard contract and CCG planning requirements. NHS England with DH and the HSCIC will work with commissioners and providers across the care system, including local authorities, to agree how the NHS number can be universally adopted.²⁵
- iii. The NIB will support key standards that help clinicians ensure that patients are safely transferred between episodes of care. We propose the adoption of the Academy of Royal Medical Colleges' publication Standards for the clinical structure and content of patient records,²⁶ with a requirement that all organisations and clinical systems should implement the standards, following consultation and completion of an impact assessment.
- iv. The NIB will prioritise work to build upon the existing standards supporting transfer of care to incorporate informal and personal care.
- v. The NIB endorses the move to adopt a single clinical terminology – SNOMED CT – to support direct management of care, and will actively collaborate to ensure that all primary care systems adopt SNOMED CT by the end of December 2016;

the entire health system should adopt SNOMED CT by April 2020. During this time, we must also work with local authorities to understand and address the implications of this for social care.

- vi. In addition to the work on structured data standards, NICE, in collaboration with other members of the NIB, will convene a forum to support the adoption of semantic web technologies and the further development of established semantic standards, thus improving the management of less structured information within the health and care system.
- vii. It is important that commissioners and care providers can compare how they are making the best use of information technology, digital data and services for their professional staff and service users. The Digital Maturity Index will be a census of digital progress developed by NHS England alongside the HSCIC's work on burden reduction. This tool will track increases in the effective use of information technology, digital data and services, and the consequent reduction in clinical bureaucracy. It will highlight for commissioners and providers the variations in progress between NHS trusts. Key indicators will be published by October 2015 via NHS Choices at www.nhs.uk/mynhs. This work will be extended beyond acute hospitals to other sectors and from March 2016 will be taken into consideration by the Care Quality Commission (CQC) as part of their inspection regime and by Health Education England (HEE) with regard to training accreditation.
- viii. The GS1 standard, which includes the unique identification of patients, products and places, as well as Radio Frequency Identification (RFID) tagging, makes a well-evidenced contribution in health and care. This international standard has been shown to improve patient safety and quality of care by minimising the risk of errors occurring, and is also used for more effective and efficient supply chain management, resulting in significant cost savings. In order to maximise the opportunity that technology offers to promote safe care and productivity, NHS England will, with the HSCIC, develop a joint approach to implement the GS1 standard across the health and care system. This will feature from April 2016 within the NHS England commissioning framework and relevant system specifications.
- ix. In order for real-time direct care data, which supports clinicians, patients and carers needs, to flow across the administrative boundaries of local services, the NIB, with PHE, the HSCIC, DH, the Local Government Association and the integration pioneer sites, will, by April 2015, establish a working group to review the opportunities for integration between local government and NHS infrastructure and data assets.

- x. Information technology has a vital role in incident reporting on adverse drug reactions, device defects and counterfeits. Building on the good work in GP systems the HSCIC will, in partnership with the Medicines and Healthcare Products Regulatory Agency (MHRA), produce proposals to ensure that reporting standards are implemented in all information systems in hospital, pharmacy and other sectors.
- xi. Carers are vital to the sustainability of health and care services and they should also share, and have access to, digital tools to support those they look after, with appropriate consents. In April 2016 the HSCIC will consult on ways of supporting carers, to access digital records.
- xii. Carers and other providers will need access to the digital infrastructure of the NHS that is currently denied to them. The HSCIC will consult with clinical leaders and other stakeholders and publish a plan by December 2015 for the progressive opening up of connectivity with and use of the NHS infrastructure to all care providers and service users, subject to accreditation. This would include low-cost secure access to the N3 network and to SCRs. Plans are already advanced to provide a number of retail pharmacies with access to SCRs by June 2015, with a view to a national rollout and then extension into social service providers and nursing homes.
- xiii. The NIB will work to drive up adoption and optimisation of mobile technologies that enable healthcare professionals, service users and carers to collaborate effectively in the organisation, delivery and evaluation of care in community and home care settings.

(ii) Comprehensive data on the outcomes and value of services to support improvement and sustainability

CASE STUDY

Kent County Council Public Health's vision for whole systems intelligence emphasises the need to have a cultural shift from analysing data at an organisational level to analysing information across the complete patient pathway or citizen's journey in using health and care services. Analysis reflects various socio-economic and environmental factors that contribute to health and wellbeing. In this regard it is about the effective sharing and management of information at a citizen level, scaled up to a population level to effectively understand the holistic nature of integrated care and the many confounding factors that affect health and social care outcomes and a person's resilience to improved wellbeing. A number of related projects have been undertaken or led by Kent County Council Public Health since early 2012, some of which have been acknowledged nationally as examples of excellence in integrated intelligence supporting integrated commissioning. These include: (i) Kent & Medway whole population risk stratification analysis; (ii) Kent LTC year of care programme; (iii) palliative care funding review (data linkage); (iv) community falls prevention service evaluation; (v) modelling community and mental health bed capacity in Kent.

Better data about the quality of care received by patients is essential to improving care outcomes. It is vital for effective commissioning and regulatory surveillance, and for the development of new medicines and treatments. Understanding trends and patterns in the costs – and effectiveness – of health and care is key to ensuring that the best value is achieved for taxpayers and the productivity of public resources is maximised.

Many of the recommendations of the Francis Inquiry²⁷ focus on the critical importance of accurate and timely analysis of so-called 'secondary uses' data for the delivery of safe and effective care. One of the triggers for the initial investigation into Stafford Hospital was research that indicated it had unusually high death rates derived from such data. At present we do not have the ability to investigate quality in a similar way for most out-of-hospital services.

As we move progressively towards real-time digital record-keeping, as described above, we will achieve the objective of collecting all the information required to support direct clinical care and the analytic needs of health and care, once and once only at the point of care. In the interim, it continues to be critical that we adopt a pragmatic step-by-step approach to unlock the rich insights available today.

For these reasons, this framework prioritises the safe development of linked administrative data for all NHS-funded episodes of care, including the care.data initiative; the development of data standards to support new costing, pricing and payment systems to incentivise innovative new models of care; and the improvement of the quality and coverage of clinical audit and disease registration across care services.

It is essential that citizens have confidence in all uses of their data and are able to make a decision about whether to share it. Detailed proposals on setting a new standard of NHS vigilance are contained in section eight.

Over time, it is intended that the HSCIC will become the single repository of sensitive data for secondary uses but this ambition can only be achieved when we ensure that it will not cause disruption to existing data assets in health and care. For this reason, the HSCIC will consult with partners on proposals – and an appropriate roadmap – to achieve that outcome.

The care system needs transparency of clinical outcomes but also of patient and public experience and satisfaction, both qualitative and quantitative. More than 4 million people have rated local hospital services since the introduction of the Friends and Family Test in April 2013 and many have volunteered online comments on the care they received. This real-time conversation is already driving measurable improvements in the quality of care²⁸ in wards and accident and emergency departments across England.

We also know from existing NHS research and the work of organisations like Patients Like Me that patient-reported outcomes data is vital to ensure accurate insight into care quality and to support innovation. For that reason, this framework proposes a series of experiments to develop the evidence base to support better use of patient experience and outcome data in health and care.

CASE STUDY

Chronic obstructive pulmonary disease (COPD) affects 1 million people in the UK and costs the NHS £491 million a year, much of that expenditure incurred in secondary care. COPD exacerbations account for over a million bed-days a year in England. Patients living with COPD want to be active partners in the management of their condition and appreciate the value of personalised information. When given the right support, they are keen to take recommended self-management steps and engage with clinicians to demand and create better care. **The COPD checklist project**, developed by NHS Redbridge CCG, University College London Partners and Health Analytics, tested the impact of providing COPD patients with personalised information on their condition and the level of quality they should expect to receive in their care, the performance of their local primary and secondary care providers, together with information on care costs. It used a traffic-light system indicating where each patient's care was (or was not) meeting expected NICE standards of access and quality.

Our proposals for ensuring that information is used to improve the quality of care

- i. By June 2015, the NIB will agree a core 'secondary uses' dataset that all NHS-funded care providers have to make available to support commissioning, regulation and transparency. The dataset will be reviewed regularly and developed in line with general and specific confidentiality requirements, for example those applicable to fertility treatments as regulated by the Human Fertilisation and Embryo Authority (HFEA).
- ii. The NIB will, as part of that initiative, consult with care providers in social, domiciliary and residential care on the development and publication of appropriate datasets, to provide an effective insight into the safety and quality of their services.
- iii. Subject to ongoing evaluation, and with full safeguards, the care.data programme to link hospital and GP data will be extended nationally to other care settings to enable safe data-sharing for better analysis of care outcomes.
- iv. NHS England and Monitor will develop data standards to support new costing, pricing and payment systems to incentivise new models of care to deliver best outcomes and value for patients.

- v. The NIB with clinical leaders will review how best to improve coverage and quality of clinical audits in all care contexts, and PHE will establish a single comprehensive national rare disease registration service that collects and quality-assures data on all rare diseases across the whole population.
- vi. DH will publish, by December 2015, proposals to ensure that all central data requirements will be collected once, and that, in future, the vast majority of all central requirements will be through extractions at source.
- vii. The HSCIC will work with NICE to create a new Indicator Library service, which provides access to all the quality-assured nationally agreed indicators, and details the statistical methods that are used to construct them.
- viii. By 1 April 2015 the HSCIC will publish for consultation its proposals to deliver an enhanced suite of data services, which could provide a core element for the collection and sharing of data and records at the national level.
- ix. The HSCIC, CQC, Monitor and NHS Trust Development Authority (NHS TDA) will publish by October 2015 data quality standards for all NHS care providers, including the progressive improvement in the timeliness accuracy and completeness with which data is entered into electronic records and made accessible to carers and patients. The CQC will from April 2016 take performance against these data quality standards into consideration, as part of its regulatory regime.
- x. NHS England will lead on a new Insight Strategy, to be published by April 2015, which will set out proposals for making better use of patient outcome and experience data, including Friends and Family Test, public surveys, Patient Reported Outcome Measures (PROMs) and related measures, social media analysis, online ratings and feedback.
- xi. NHS England will work with providers and patient groups to launch new experiments during 2015 to develop patient-centred outcome measures in specialised services and in maternity, and test the potential for their use in reimbursement for services, giving patients a role in determining how much a provider is paid based, in part, on their view of the outcome.

7. Make the quality of care transparent

Every citizen has the right to access information on the performance and outcomes of the health and care services that they pay for, and to be equipped to make informed choices about their health and care. Making information available in an open and accessible form can also galvanise improvement in those services, as care professionals and their organisations observe, compare, learn and adopt practice from others.

Although a vast amount of information is already available, it is not as easy as it should be for people to find what they need and, despite the increasing quantities of data collected and extracted, care professionals are often frustrated by the inaccessibility, quality and timeliness of both aggregated and personalised data.

The My NHS website, part of NHS Choices, was developed to support transparency, opening data to public scrutiny and driving improved performance. It draws on existing data on a range of services – currently hospitals, local authority social care and public health, mental health hospitals, GP practices and a range of surgical specialties – and presents it in an accessible and comparable format.

My NHS was released as a ‘beta’ site in September 2014 and will, over time, include more datasets. As My NHS develops, our health and care system will become the most transparent in the world.

CASE STUDY

In the past, comprehensive data on health and social care services has been hidden or too difficult to use. This makes it hard for patients and the wider public to gauge the quality of local services, and impossible to hold local commissioners to account. **My NHS**, a new service available through NHS Choices, is changing this by making health and social care data transparent, openly available and easy to use. Anyone can use the service to see how their local hospital measures against a range of key quality indicators, how the local authority performs on the delivery of adult social services, and how public health services as a whole are doing within a local area. Data is presented in the form of simple, intuitive dashboards and available in raw format for those interested in more complex analysis. The range of information available will increase over time. Ultimately, by making data transparent we will help drive up quality and shape even better services.



JOHN
(General Practitioner)

- **Aims to deliver the best quality of care for his patients**
- **Wants to know that the data he shares is accurate and being used appropriately to benefit the whole system**

Having motivated patients contribute to their own care record will help John understand his patients better and provide better care.

John wants to be able to monitor his patients through their care journey so he can help them make the right choices.

John will be able to compare the performance of his practice fairly against other practices with similar challenges and demographics.

John will be able to provide better care and advice to his patients as new intelligence from linked health and care data emerges.

The development of My NHS is not simply a matter of making data available because we are able to do so. It signals an important shift in culture. In the past, we have too often relied on national, top-down targets to improve performance in the health and care system. As we develop a system that uses data and technology to provide personalised care, national targets become less and less relevant. Instead, clinicians will take personal responsibility for the care that they provide. This will be underpinned by comprehensive clinical information, and a culture of transparency that ensures organisations and individual professionals are able to compare the quality of the services that they provide with their peers, and are held to account through the power of openness and transparency.

We know that the appetite for information on services will only grow. As My NHS develops, DH will coordinate a programme of work with a range of partners to make recommendations on what data should be collected and made available to drive improvement across all types of services.

Proposals for changes to the data to be collected and the metrics made available on My NHS to improve services will be presented collectively by the NIB to the Secretary of State for Health on an annual basis.

In compiling these proposals, the NIB will take into account:

- the need for data and metrics to be understandable by citizens as well as professionals;
- the overall framework for national data collection and the development of data-sharing initiatives, like care.data and the National Tariff System;
- the need to reduce burdens on care providers; and
- work to develop and align the outcomes frameworks for the NHS, public health and social care.

Our proposals for making the quality of care transparent

- i. DH, in partnership with NIB and a range of partners and stakeholders, will develop proposals for further developing the range and depth of data made available to the My NHS service on NHS Choices. This exercise will be completed by the end of 2014.
- ii. By March 2015 DH will set out proposals, in consultation with key NIB members, including NHS England, CQC, PHE and the HSCIC, for enhancement and extension of the My NHS service on NHS Choices.
- iii. NIB will collate and present annually to the Secretary of State for Health proposals for changes to the data to be collected and the metrics made available on My NHS to improve services, taking account of factors including the need to reduce burdens.
- iv. DH, with NHS England, PHE and the Local Government Association, will consider how to further align the public health, NHS and adult social care outcomes frameworks and how they should relate to the need to make information routinely transparent.

8. Build and sustain public trust



FRED 81

(older adult with deteriorating health)

- Wanting to preserve his independence as he grows old
- Has age-related hearing and sight problems and sometimes finds it hard to be understood
- Values the community services that enable him to connect to others

Fred's son, Alan, will be able to help him organise appointments and prescriptions, even though he lives many miles away.

Fred's patient record will highlight his hearing difficulty and make it clear he needs more time in appointments.

With his son's help, Fred will be able to choose the best care support to help him maintain his independence.

Fred will be able to share his experiences of health and care services without the worry of repercussions.

This person is a model and used here for illustrative purposes only.

Our success at putting information to work more effectively for patients and carers is dependent on sustaining the trust and confidence of the public in the collection, storage and use of their sensitive personal data. The health and care sector is not alone in being the subject of considerable scrutiny on how it uses such data. It must respond positively to that scrutiny. There will have to be a continuing process of establishing a consensus between citizens and care professionals on how their sensitive personal information is used, based on a transparent understanding of the uses to which the information is put and the benefits for service users and the wider community.

Our objective must be to establish an approach to collecting and using data that is adopted across the care system as a whole, by all participants, whether users or providers of care services or suppliers of clinical systems or apps. Without such a consensus, service users and care professionals will be faced with confusion and fragmentation, and the barriers to interoperability and integration will be increased. At the same time, we need to ensure that current approaches to information governance (the rules that determine how sensitive information is collected, and

protected) and data security, which in some cases are perceived as a barrier to delivering safe and effective care, meet the needs of a modern, digitally enabled health and care system.

We will only sustain public trust by establishing a transparent approach to information governance and data security. This approach must balance concerns over the use of sensitive data with the need to deliver safe and effective care, establishing an 'NHS' standard of vigilance, which reflects the public's inherent trust in the NHS.

Over time, we will strengthen the governance of the use of personal data by:

- reducing the number of organisations that collect and hold sensitive care data, other than for the purposes of direct care;
- moving to a consent-based approach to data-sharing, so that all citizens know and can agree to the use made of their data; and
- strengthening the oversight of the use of confidential data.

Independent oversight and scrutiny is vital to building public trust in the way that people's information is used and protected. As the new National Data Guardian for health and care, Dame Fiona Caldicott, one of the most authoritative and informed independent voices on issues relating to the use and protection of patient data, will provide an oversight and challenge function to the use of personal health and care information by organisations other than providers of direct care.

Dame Fiona will be able to scrutinise and challenge organisations across the health and care system without invitation or constraint. Her findings, and any subsequent advice, will be open and transparent. An independent voice, acting on behalf of citizens, she will play a vital part in building and sustaining public trust.

In addition, the health and care system will address the growing threat to cyber security, balancing the practical needs of service users and care professionals with the requirement to maintain the security of data and systems.

Our proposals for building and sustaining public trust

- i. Dame Fiona Caldicott, supported by her current Independent Information Governance Oversight Panel (IIGOP), will take on the role of National Data Guardian for health and care, with a remit to provide public and transparent scrutiny and challenge about the safe use of personal health and care information.
- ii. DH will, at the first suitable legislative opportunity, seek to place the role of the National Data Guardian on a statutory footing. In doing so, DH will consult on what powers the National Data Guardian should have and how those powers should be exercised. This will include consideration of any sanctions that the National Data Guardian should be able to bring to bear on those who misuse personal health and care information.
- iii. Under the auspices of the NIB and the National Data Guardian, a working group will carry out a wide-ranging public consultation on how the care system should handle the dissemination and use of sensitive data. This will develop proposals that enable citizens to access a transparent audit that records the uses made of their patient data for secondary purposes and details the benefits for health and care that have resulted.
- iv. By April 2016 NIB will publish, in partnership with civil society and patient leaders, a roadmap for moving to a whole-system, consent-based approach, which respects citizens' preferences and objections about how their personal and confidential data is used, with the goal of implementing that approach by December 2020. This roadmap will continue to recognise that there are certain circumstances where securing explicit consent by a citizen is not operationally possible, nor desirable on every occasion, for example in the management of notifiable and infectious diseases. It may also not support the individual's best interests, for example in the care and support of vulnerable adults.
- v. Based on the work already commissioned by the Secretary of State for Health, the HSCIC will publish by October 2015 enhanced data security standards and requirements for all publicly funded providers of care.
- vi. DH will develop proposals to further strengthen the role, responsibilities and functions of senior information risk owners and information asset owners in the health and care system.
- vii. The HSCIC will, by October 2015, relaunch the Information Governance Toolkit to reflect enhanced information governance and data security requirements.

9. Bring forward life-saving treatments and support innovation and growth



TANYA

(Local authority social care manager)

- Demand for her services is increasing and they already struggle to meet it
- Needs consistent and quality data to help design her services to deliver the best value for money
- Wants a more joined-up approach with the NHS better to serve patients better

Seeing the fuller picture of patients and their needs will help Tanya to work with NHS colleagues on better joined-up care.

Tanya will receive more structured training to gain further knowledge and skills so she can make the best use of data to plan services.

Implementing national data quality standards will give her confidence she is providing and receiving accurate data.

Tanya will receive guidance on security and interoperability standards she needs to include when procuring services.

Our objective is to establish England as one of the world's leading centres for innovation in digital health and care services. In particular, we need to make sure that we have developed the right approaches to ensuring the NHS is capable of maximising the benefits of the data revolution that is heralded by developments in life sciences research – particularly genomic science. Genome sequencing offers huge potential for improving treatment for some of the most aggressive life-threatening illnesses. Recognising the role of Genomics England in building a new national data asset, we are currently in the pilot stage of delivering the prime minister's challenge a multimillion-pound initiative to sequence (map) 100,000 individual genomes by 2017. By combining existing NHS expertise in functional genomics and expanding knowledge through the extension of whole genome sequencing, we will be better enabled to predict, prevent and more precisely diagnose disease, and personalise treatment.

Better data will not just enable patients, service users, citizens and professionals to benefit from genomic science but could transform life sciences and research fundamentally. It will drive new approaches to health and care that transcend traditional delivery boundaries, embrace new technologies and establish new partnerships across geographies and clinical and diagnostic specialisms. It will aid rapid implementation of the innovation pipeline from discovery to adoption and spread into clinical practice. It will transform diagnosis. We can create new collaborations between the NHS, technology companies and patients to unlock the potential of data, technology and digital to create products for smarter, faster and better healthcare and thereby grow the digital health sector, an emerging area of UK innovation.

The creation of an open infrastructure and a transparent framework of standards will be key enablers in encouraging research and innovation. However, more needs to be done. Enhanced support for innovation will require a realignment of available investment funds, including future Technology Funds, the development of new investment flows, and the strengthening of partnerships with the research community, including AHSNs, Catapult centres and industry. We have an opportunity to combine different technologies and changed ways of working in order to transform care delivery through 'combinatorial innovation'. The stated ambition of the Five Year Forward View is that the NHS will become one of the best places in the world to test innovations that require staff, technology and funding all to align in a health system, with universal coverage serving a large and diverse population.

The NHS has not had a good history as a technology customer or partner. As a result, the UK health and care system is viewed by many as a difficult market. Although the NHS is only 3% of the global health market, it has an internationally respected reputation and brand. The UK has a vibrant consumer market and a large technology-literate consumer population, both young and old. Furthermore, the UK is a renowned centre of health research and one of Europe's leading technology hubs.

The life sciences industry is a central plank of the UK economy. The health data held, primarily by the HSCIC, PHE and the data, clinical trial and researcher service Clinical Practice Research Datalink (CPRD), is world class and a major asset for the UK. For drug benefit risk research the UK is also world class with many hundreds of approved studies being undertaken every year. Increasing the ability of scientists to combine the UK's strengths in technology and medical research with our health data could transform the power of medical research in this country and is a key objective of this framework.

Many global technology companies are already investing heavily in the health and wellbeing sector and there are good examples of UK entrepreneurs creating innovative new business propositions, such as Babylon. However, the UK has yet to exploit fully its significant assets and competitive advantage.

The objective is therefore to build on successes and create a stronger partnership across the care sector with industry and research, which will help drive innovation, create a virtuous circle of economic growth for the UK and transform care services for the nation.

There must also be recognition and support for greater variation in models of service provision between localities informed by local priorities, as local health and care economies explore different solutions and approaches. The development of the local and national infrastructure must also make specific provision to give support and access to new solutions, with positive encouragement to user and care-professional led groups. We will therefore seek out opportunities to learn from innovative work developing elsewhere, notably the Better Care Fund pioneer sites, and the Smart Cities initiative, which is being led by the Department for Business, Innovation and Skills.

Our proposals for bringing forward life-saving treatments and supporting innovation and growth

- i. NHS England and DH will set up a working group with Genomics England, the HSCIC and other relevant scientific bodies to ensure that the NHS is capable of supporting the future agenda on genomics and molecular pathology datasets at scale, building on the current programme to sequence 100,000 whole human genomes.
- ii. DH will work with industry representatives, the AHSNs and Academic Health Science Centres, the NIB and cross-government partners to develop an industry strategy describing how:
 - a. the health and care system will work to encourage partnership with the consumer digital and data industries;
 - b. barriers to innovation will be removed;
 - c. data services will be developed to support discovery science;
 - d. real-world evidence can be used to support the discovery and development of new medicines and treatments;
 - e. an online ‘matching’ service will be developed that will offer health and care organisations and suppliers (particularly small and medium enterprises) the chance to share information about needs, requirements and offers.

- iii. DH will engage NIB members, industry, the research community and the public on the appropriate commercial arrangements for accessing and using data assets held by the HSCIC and other public bodies in the care sector, to ensure that these assets are used to the greatest advantage of the country as a whole while ensuring citizen concerns are addressed.
- iv. From April 2016 currently available Technology Funds, and any new ones, will be invested in innovative solutions, to support existing service providers to implement significant service change, and to stimulate new offerings that enable integration and care coordination between services, where individual citizens and their carers through access to information are enabled active partners in their health and care.
- v. Further procurements under the General Practice Systems of Choice (GPSoC), up to April 2018, will be used to stimulate the supply of new and innovative systems for out-of-hospital services, with a particular focus on integrated care services and supporting citizens and carers. In addition new forms of 'software-as-a-service' clinical systems to support new providers of primary care services will be encouraged. NHS England and the HSCIC, in consultation with service users and suppliers, will publish a prospectus for these new requirements by June 2015.
- vi. In partnership with the AHSNs, the London Health Commission, the HSCIC, NHS England and PHE will together support the development of five further Technology for Care innovation centres, where possible based on existing, successful local centres, such as the Catapult centres.
- vii. NHS England with other members of the NIB, including DH, will develop a small number of 'test bed' sites alongside our AHSNs. They would serve as real-world sites for 'combinatorial' innovations that integrate new technologies, bioinformatics, new staffing models and payment-for-outcomes. UK and international innovators will be able to bid to have their proposed discovery or innovation deployed and tested in these sites. We will involve frontline staff to an unprecedented extent in the design of innovations, and in implementing the necessary system changes.
- viii. The NIB will explore the contribution of information and technology to the development of health and care 'new towns' announced in the Five Year Forward View.
- ix. The NIB will work with Healthcare UK to agree a joint approach to developing commercial and international opportunities for exploiting the innovations and experience of using data and technology from across the English health and care system.

- x. Each of the members of the NIB have a key role in creating and supporting opportunities for innovation and stimulating demand for the adoption of new service models enabled by information technology and data. Monitor will play a key role in setting tariffs, which can be used in innovative ways to improve models of care, such as integrated care pathways. The new National Tariff System will enable future tariffs and payments to be more flexible and enable more cost-effective and efficient care. NICE will extend its guidance development programmes to further support innovation.

10. Support care professionals to make the best use of data and technology



JANE 48
(Living with cancer)

- **Wants to be given the best possible quality treatment for her condition**
- **Finds navigating the system confusing and finds it frustrating to have to keep repeating herself to numerous clinicians**
- **Wants to understand her type of cancer, her options and have information that is relevant to her so she knows what to expect**

Jane's patient record will include information about her condition and medication so she doesn't have to keep repeating herself.

Should her condition worsen Jane will have her care preferences respected at the end of her life.

Jane will be able to see who has accessed her patient record and why.

New treatments may help Jane beat her cancer for good and prevent it from returning in the future.

This person is a model and used here for illustrative purposes only.

Health and care organisations must discard old ideas about IT skills. In future, all members of the health, care and social care workforce must have the knowledge, skills and characteristics that are necessary to embrace information, data and technology, appropriate to their role.

It is vital that the leaders of all health and care organisations are seen to champion information and digital capability as core enablers of effective decision-making, service quality, safety, effectiveness and efficiency. They must empower chief clinical informatics officers or CCIOs (drawn from medicine, nursing and the allied health professions) and social care informatics officers to lead local transformation programmes that support the take-up of information and technology and lead improvement. Informatics specialists (e.g. health and care analytics, clinical informatics, clinical bioinformatics, health informatics science) will have an increasingly critical role, which must be supported by knowledge frameworks and career pathways and reflected in job descriptions, competency frameworks and personal development and training.

CASE STUDY

Assessing a patient with severe burns quickly and effectively within the first hour of arriving in an accident and emergency department, and working out how much fluid to give them, is key to improving their chances of survival. Traditionally, it involved making 19 separate calculations using pen, paper and written protocols. These take up valuable time and, in the middle of a high-pressure situation, it is possible that mistakes with serious, life-threatening consequences are made. The **Mersey Burns app**, developed by the CCIO, frontline clinicians and developers at **St Helens and Knowsley Health Informatics Service**, replaces these complicated, manual assessments with a user-friendly mobile app. Using a touchscreen, the doctor can shade the area of the patient covered by the burn, add the patient's weight, age and time of injury. Built-in logic does the rest. It tells the doctor not only how much fluid the patient needs, but sends details of the injury straight to the regional burns unit that will receive the patient once stabilised. A study comparing the Mersey Burns app to the paper process in simulation wards showed that it took, on average, 15 minutes less to work out the correct fluid calculation – a significant portion of that first 'golden hour'.

The scale of this challenge must not be underestimated. There are approximately 1.6 million social care staff and 1.4 million NHS staff in England. In healthcare alone there are over 300 different job roles and HEE commissions 129 structured programmes of education.²⁹ The workforce accounts for the majority of spend, around 70% of the average health and social care provider.³⁰ As part of wider change management, employers must engage with their staff and staff representatives to implement new approaches to care with appropriate workplace training and sufficient time allocated to enable staff to become effective users of new technology. The *Health Education England Strategic Framework 2014–2029*³¹ recognises that workforce plans must take responsibility for making this happen at a local level. National organisations must play their part in ensuring that professional regulation supports this agenda.

The NHS in England and Wales currently employs over 47,000 health informatics staff working in a profession that is still not widely recognised, either by the specialists themselves or by others working in health and care. As a result, we do not systematically plan for or develop this crucial professional role, where there is a global, competitive market for their skills.

It is also key that we engage staff in driving forward the digital revolution themselves and for this reason we will support the launch of Code 4 Health – a programme to support health and care professionals, and carers, learn how to develop apps and other digital services.

Our proposals for supporting care professionals to make the best use of data and technology

- i. By April 2016 HEE, working with the HSCIC, will introduce a new knowledge and skills framework for all levels of the health, care and social care workforce to embrace information, data and technology in the context of a rapidly changing digital environment.
- ii. A consortia group of NIB members and stakeholders, including the NHS TDA, HEE, Monitor, the NHS Leadership Academy, the Association of Directors of Adult Social Services (ADASS), the Society of Local Authority Chief Executives (SOLACE), NHS Confederation and the Foundation Trust Network, will lead on the development of a training programme for boards and senior leadership teams across health and care. This will support executive and non-executive directors in the development and implementation of technology strategies as part of wider service redesign and change management.
- iii. The HSCIC will establish a framework contract and panel of suppliers, including the best-performing NHS Trusts and Foundation Trusts, to provide easily accessible support on digital strategies, process reengineering, managing change, benefits optimisation and systems implementation.
- iv. By April 2016 the HSCIC will work with national and local partners to agree a revised definition of the health, care and social care informatics profession.
- v. The NIB and its Strategic Clinical Reference Group will, with clinical leaders, develop proposals to support an emerging federation for the informatics profession. The longer-term vision involves the development of a Faculty for Health Informatics for medical practitioners and a Federation for Informatics Professionals for non-clinicians. The latter will launch an Informatics Career Framework to support the development and professionalisation of informatics specialists. The federation will engage with stakeholders to determine whether a voluntary registration-based model or professional regulation is appropriate.
- vi. DH, HEE and Skills for Care will work with the professional regulation and education bodies to ensure that by April 2017 their core curriculum and associated knowledge frameworks contain the relevant knowledge, skills and characteristics to enable the workforce to embrace information and technology in the rapidly changing digital environment.
- vii. NHS England will develop proposals for Code 4 Health by June 2015.

11. Assure best value for taxpayers



MIKE
(Integrated Care co-ordinator)

- Mike's service provides integrated care pathways and shares resources between mental health, primary, social and acute care
- His work involves working with many different organisations and he experiences silos and has difficulty sharing data
- He worries that there are vulnerable people who are falling between the gaps in his service and struggles to prioritise those who are risk

Using standardised Transfer of Care Documentation will ensure patients are safely transferred between episodes of care.

Mike will be able to see who is most at risk and prioritise pro-active interventions that will enable them to stay independent for longer.

Mike and his team will be able to contribute to the consultation on the development and publishing of datasets that cover their services.

Mike will be able to draw on greater intelligence to help him better understand Mental Health outcome measures.

Considerable resources have been invested within the NHS in administrative and clinical systems, primarily for NHS and Foundation Trusts and GPs. The priority now is to maximise the benefits from those past investments and focus any future investment on those areas that can deliver the greatest impact.

To deliver care to millions of people every day, health and care services are increasingly dependent on an infrastructure of systems and processes, which allow data to be collected, moved, stored and analysed at multiple locations. To optimise benefits from past investments will require coordinated action, using commissioning contracts, regulation and transparent information on performance, combined with expert support on change management, logistics and business process reengineering.

At the same time, as discussed above, there are significant gaps in this infrastructure, constraining interoperability, to the extent that the movement of data between service sectors and access to common platforms for transactions can be difficult, and posing major barriers to service integration and improvement.

In building the future infrastructure, the care sector should, wherever possible, adopt common approaches with the rest of the public sector and the wider economy. By providing common shared platforms, this infrastructure will encourage innovation, lower the barriers to new service developments, enhance operational efficiencies for providers and ensure service users have a genuinely 'joined up' and coherent experience.

National infrastructure should be limited and focused on those services and functions that are best 'done once'. A good illustration of this is the need for common bridges to support the exchange of data with accredited apps and service providers, to provide people with a seamless interchange of information about their health and care. The infrastructure must also, for example, provide commodity-level transactional services through an open, common digital platform based on the success of NHS Choices.

As existing national contracts expire, such as the GPSoC framework, maximum flexibility will be used both to signal to the supplier market the nature of future priorities and to shift current deliverables towards the goals of technology enabled, personalised care services.

Future investment support to care providers must reflect the changing priorities for the care system, both in terms of the resource pressures and the changing characteristics of the demand and need for care. For example, it is especially important that health and care organisations collaborate on those areas requiring investment to implement the provisions of the Care Act.

The focus of investment support will therefore shift to areas of maximum opportunity and leverage, such as services supporting older people, those with chronic conditions and people providing informal care. This will support service transformation, through the development of integrated, self-commissioned services that are increasingly personal and preventative in nature.

It is increasingly important that local organisations invest in information and technology services that support service transformation and deliver tangible returns on investment, particularly in terms of staff productivity. A recent study suggested very significant returns from basic automation of core hospital administrative services and the implementation of 'lean' approaches.³³ This research indicated that more systematic use of barcoding could yield savings of up to £400 million, for example. This framework, therefore, prioritises the achievement of these productivity benefits by aligning commissioning, regulatory and provider priorities to achieve them.

At the same time, we need to create an environment that encourages local innovation, especially where this is based on localities or communities with

common interests. These could involve traditional groupings of care providers, but may also reflect new relationships with entrepreneurial technology suppliers. This is already happening in many communities that are progressing delivery of local integrated care record systems. Exciting work is emerging from the integration pioneers programme and other local service integration initiatives. These will continue to provide essential insight, learning and practical guidance to support local rollout of service integration.

Our proposals for ensuring best value for taxpayers

- i. The NIB will publish by March 2015 a roadmap for alignment of existing national programmes with the core outcomes of this framework to maximise their cost and clinical benefits, together with proposals for the termination of ineffective investments. It will set out a strategic standard for initiation of further national programmes and a clear ambition for the benefits of future national investment in technology.
- ii. Following the completion of the current local service provider contracts in April 2016 and when requested by care providers, the HSCIC will support the creation of local buying consortia, as already established in London and elsewhere to support Trusts make the best possible procurement decisions.
- iii. The GPSoC contract for the central purchasing of GP systems and associated technology ends in April 2018, and NHS England and DH will consider carefully whether it is appropriate that it continues as a national contract or whether funding for GP systems should be incorporated into the capitation payments made to primary care providers, who will then be free to purchase systems from any supplier, subject to meeting national data and technology standards.
- iv. Security and interoperability standards for common services to be purchased directly by care providers, such as email, will be published by 1 April 2015, which will allow them to connect to the national infrastructure and provide confidence for inter-organisational transactions.
- v. DH, in consultation with the NIB, will develop proposals for national investment in the digital development of the care system beyond April 2016. This work will draw on the experience of the Technology Fund, and will take a broader perspective across all sectors within the care system. It will inform wider decisions about health funding in the next spending review.

12. How can we make it all happen?



KATE 25
(Josh's mum)

- Her family is her highest priority, in particular her three year-old son Josh
- She wants to be confident she will be able to get the best care for Josh when she needs it
- She wants to share her experiences with other mums and learn from them

Kate will be able to quickly find out what to do and where to go by calling 111 or visiting NHS Choices.

Josh's patient record will include everything clinicians need to know to quickly give him the best treatment and support when he is ill.

Kate will be able to share her experiences of local services and read about their performance on MyNHS on NHS Choices.

Intelligence from linked data will better inform clinicians of the risks associated with different treatment options, should Josh need it.

This framework is an unprecedented commitment by the national leadership of health and care in England to create the conditions that prioritise the delivery of the digital opportunity for citizens. To ensure delivery, national and local action needs to be properly supported and accountable.

Implementing the NIB framework: national support

DH is accountable to Parliament for the performance of the health and social system; the framework within which services are delivered; the governance arrangements that are in place; the way in which the system is regulated and held to account; and the way that the system is resourced.

DH has appointed an informatics accountable officer (IAO) to have specific responsibilities in relation to the provision of information technology, the use of data and implementation of the NIB framework. It has also appointed a national information director to chair the NIB. These initiatives represent a system-wide commitment to ensure delivery of this framework, including getting the right relationship between national standards and drive, and local freedoms and innovation.

The NIB will have an ongoing role in scrutinising the effectiveness of the framework and the actions agreed, developing responses to system-wide challenges and ensuring that the actions of its members are coordinated to deliver its objectives. It will publish an annual review of the framework and its implementation. The IAO will have two continuing roles: holding the system to account for delivery of the actions set out in this framework; and oversight of the investment portfolio, to ensure that it is aligned with the aims set out in the framework.

In addition, DH will develop a digital support service for national bodies sponsored by the department, to help promote the digital transformation of health and care services, ensure compliance with government-wide national digital standards, and review their overall performance on this basis.

Implementing the NIB framework: local support

The framework contains a number of proposals for ensuring that local health and care commissioners and providers are supported to take advantage of the information revolution. NHS England, for example, will work with commissioners on development of local roadmaps for digital interoperability to be published in 2016; providers will be supported in a number of ways, including the development of business change training support for boards and senior leaders of Trusts, and the development of new educational programmes for clinicians and healthcare professionals.

We have also heard from many GPs, for example, that developing an NHS kitemarking scheme for apps and digital information tools for their patients would increase their confident use of these services. In addition, the NIB proposals foresee significant new initiatives in widening digital participation among carers, patients and the general public.

In addition, NIB confirms the important role of AHSNs, among others, in promoting adoption of digital services, and prioritises the development of new relationships with industry and entrepreneurs of all kinds so that the NHS remains at the cutting edge of innovation and science.

We will develop programmes, with partners like Nesta, that use approaches to engage early with real users, develop ‘combinatorial’ approaches to local system change, and produce evidence of impact using experimental and quasi-experimental methods. As the framework suggests, these could include open innovation methods, challenge prizes, accelerators, grant funds and social investment.

Implementing the NIB framework: principles of development

Over the next few months, working through a range of task and finish groups, we will publish in a greater level of detail our plans to support delivery of this framework. These plans will be developed in collaboration with users and partners across health and government.

Digital services will be delivered in line with the guidance provided in the Government Service Design Manual. We will deliver those services in an agile way, and design services that are capable of frequent, iterative improvement. We will ensure that all parts of the health and care service have appropriate digital capability in-house, including specialist skills. We will provide support and guidance for delivery teams on how they can build digital services in line with the Government Service Design Manual. We will work with the Cabinet Office and CESG to provide guidance to delivery teams on how to apply the new Government Security Classifications policy to digital services within health and care. This work will be linked with our wide-scale public consultation on how sensitive healthcare data should be disseminated and handled.

We will take advantage of the ever-decreasing cost of technology through increased use of commodity technologies and simple, flexible procurement routes, such as G-Cloud and the Digital Services Framework. We will develop an action plan to improve competition within the health technology market to obtain better-value services and save money for the taxpayer while ensuring that plans are in place to safely and efficiently exit from key contracts coming to an end over the next few years.

Our ambition is to create 'health-as-a-platform', using technology to break down silos, join up services and reduce duplication. We will adhere to the government technology code of practice and make use of cloud technology where appropriate. We will ensure a level playing-field for open-source software with delivery teams required to demonstrate an active and fair consideration of using open-source software. This will take account of the total lifetime cost of ownership of the solution, including exit and transition costs. We will default to open by working in the open and ensuring all new source code is open and reusable, and published under appropriate licences, unless there is a convincing reason not to.

NIB Members

Care Quality Commission	David Behan, Chief Executive Emma Rourke, Director of Intelligence
Health and Social Care Information Centre	Andy Williams, Chief Executive Linda Whalley, Head of Policy and Planning
Health Education England	Ian Cumming, Chief Executive Steve Clarke, Director of Finance
Health Research Authority	Dr Janet Wisely, Chief Executive Stephen Robinson, Corporate Secretary
Human Fertilisation and Embryology Authority	Peter Thompson, Chief Executive Nick Jones, Director of Compliance and Information
Human Tissue Authority	Alan Clamp, Chief Executive Allan Marriott-Smith, Director of Strategy and Quality
Medicines and Healthcare products Regulatory Agency	Dr Ian Hudson, Chief Executive John Parkinson, Director Clinical Practice
Monitor	Dr David Bennett, Chief Executive Neil Stutchbury, Director of Knowledge Management
National Institute for Health and Care Excellence	Sir Andrew Dillon, Chief Executive Alexia Tonnel, Director of Evidence Resource
NHS Blood and Transplant	Ian Trenholm, Chief Executive Aaron Powell, Interim Director of ICT
NHS Business Services Authority	Nick Scholte, Chief Executive Nina Monckton, Head of Information Services
NHS England	Simon Stevens, Chief Executive Beverley Bryant, Director Strategic Systems and Technology Dr Paul Rice, Head of Technology Strategy Prof Jonathan Kay, Clinical Informatics Director
NHS Litigation Authority	Catherine Dixon, Chief Executive Tom Fothergill, Director of Finance
NHS Trust Development Authority	David Flory, Chief Executive Iain Wallen, Director Information and Analytics

Public Health England	Duncan Selbie, Chief Executive John Newton, Chief Knowledge Officer
Association of Directors of Adult Social Services Informatics Network	Terry Dafter, Chair
Cabinet Office	Liam Maxwell, Chief Technology Officer Anni Hartley-Walder, Deputy Director Operations
Department of Health	Una O'Brien, Permanent Secretary Andy McKinlay, Deputy Director Financial Management and Improvement Glen Mason, Director of People, Communities and Local Government Mark Davies, Director Partnership and Information Peter Knight, Deputy Director and Head of Information Intelligence
Independent Information Governance Oversight Panel	Dame Fiona Caldicott, Chair
Local Chief Information Officer Council	Dylan Roberts, Vice Chair
Local Government Association	Rob Tinlin, Local Authority Representative Chief Executive, Southend-on-Sea Borough Council
Strategic Clinical Reference Group	Professor Terence Stephenson, Chair Professor Martin Severs

Six lay members have recently been appointed, details of whom will be announced following publication of this document.

Overview Timeline of NIB Framework Milestones

2014

2015

2016

2017

2018

2019

2020

- By March 2015, proposals will be set out for the enhancement and extension of the MyNHS service on NHS Choices.
- By March 2015, NIB will publish a roadmap for alignment of existing national programmes with the outcomes of this framework.

- By June 2015, the NIB will publish proposals on the regulation, accreditation and kitemarking of technology and data-enabled services, including apps.
- By June 2015, NHS England to develop proposals for 'Code 4 Health'.
- By June 2015, the HSCIC will develop proposals with industry for personal data usage reporting.

- By April 2016, the NIB will agree a core 'secondary uses' dataset that all NHS-funded providers will have to make available.
- From April 2016, the CQC to take performance against the data quality standards into consideration as part of its regulatory regime.
- By April 2016, HEE will introduce a new knowledge and skills framework for all levels of the health, care and social care workforce.

- **By 2018, clinicians in primary care, urgent and emergency care and other key transitions of care contexts will be operating without the use of paper records.**
- From March 2018, all individuals will be able to record their own comments and preferences on their care record.
- Until April 2018, procurements under GP System of Choice will be used to stimulate the supply of new and innovative systems for out-of-hospital services.

- **From March 2015, all citizens will have online access to their GP records.**
- By 1st April 2015, HSCIC to publish the roadmap and standards care organisations will be required to meet to be able to access core transactions systems.
- From April 2015, use of NHS number as primary identifier in clinical correspondence and for identifying all patient activity will be mandated in health and care.
- By April 2015, the NIB and partners will coordinate agreement on national technical and professional data standards required to achieve digital real-time and interoperable care records.
- By April 2015, NHS England to publish new "Insight Strategy" for making better use of patient outcome and experience data.

- By September 2015, proposals will be published for linking 111 with NHS Choices.

- By October 2015, HSCIC, CQC, Monitor and NHS TDA will publish data quality standards for all NHS care providers.
- By October 2015, the HSCIC will publish enhanced data security standards and requirements and will re-launch the Information Governance Toolkit.
- By October 2015, Digital Maturity Index key indicators for NHS trusts will be published via NHS Choices.

- **By 2017, 100,000 individual genomes will have been sequenced.**
- By April 2017, core curriculum and associated knowledge frameworks will contain the relevant knowledge, skills and characteristics to enable the workforce to embrace information and technology.

- **By 2020, all care records will be digital real-time and interoperable.**
- By April 2020, the entire health system will adopt SNOMED clinical terminology.

Comments on the framework

You can send comments on the framework via

Email: NIBFramework@dh.gsi.gov.uk

Post: NIB Secretariat, Room 2N12, Quarry House, Quarry Hill, Leeds LS2 7UE

Social media: [#health2020](https://twitter.com/health2020)

The NIB will publish a summary of what we heard during this process in a response to the framework. Comments may be made public if we receive Freedom of Information requests for this information.

Your comments will contribute to the implementation plans, which will outline in greater detail how we will achieve the ambition outlined in the framework.

The framework will be reviewed annually during its lifetime, to reflect changing technology and accommodate new requirements from the public and staff as they engage with the process.

The framework will be evaluated.

The implementation plans will be accompanied by appropriate impact assessments.

- 1 Care Act 2014. Available from: <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>.
- 2 *Government Digital Strategy* (2013). Available from: <https://www.gov.uk/government/publications/government-digital-strategy>.
- 3 Department of Health (2012). *Digital Strategy: Leading the Culture Change in Health and Care*. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213222/final-report1.pdf.
- 4 Department of Health (2012). *Power of Information*. Available from: <https://www.gov.uk/government/publications/giving-people-control-of-the-health-and-care-information-they-need>.
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‘Enable me to make the right health and care choices’ – citizens to have full access to their care records and access to an expanding set of NHS-accredited health and care apps and digital information services.

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