My Healthy Future

The policy context
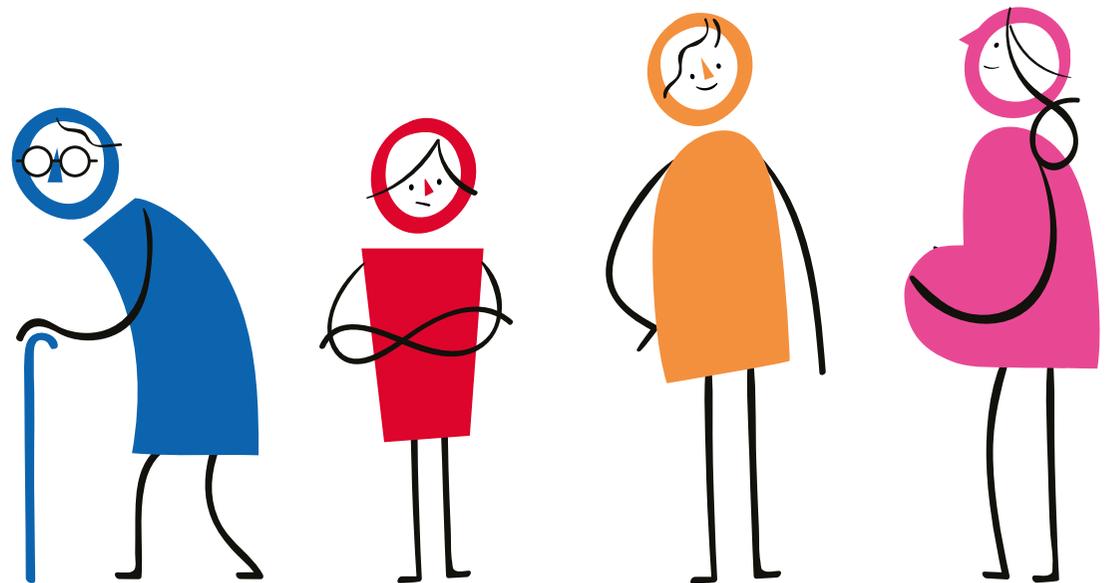
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Introduction

The *My Healthy Future* project presents a vision of the future of healthcare. A vision that builds on emerging and likely future innovative science and technologies, the changing role of individuals in their health and care, and an understanding of relevant wider issues.

Such a vision will be directly influenced by a range of factors including the complex and inter-related challenges plaguing the UK health system, the impact of evolving drivers of change including demographics and cultural shifts, and how health policy has been developed and implemented by successive policymakers.

This policy summary sets out the healthcare policy context in 2018:

The perceived context within which UK health systems operate: the NHS faces a range of complex challenges including financial constraints, barriers to productivity and inequalities of access, that directly influence policy-making and health service implementation efforts

Evolving drivers of change and their impact on UK health systems: from the emergence of digital health technologies, to the evolution of the 'connected citizen', to shifts in demographics, there are dynamic changes taking place in the health system that impact the way healthcare is accessed and provided as well as how health policy develops

How health policy has developed in response to these dynamic factors: key themes or priorities have dominated the evolution of health policy over the past few years as successive governments have responded to changing circumstances and new trends in health and science.

To develop this comprehensive account, PHG Foundation undertook an extensive review and analysis of key health policy documents published by a wide range of stakeholders across the public, private and third sectors between the early 2000s through to 2017. Including reports from the Department of Health, NHS England, Public Health England, parliamentary committees, think tanks, health charities, commercial organisations and independent and government-associated agencies.

For existing health policy, this report relies on documents including the NHS Five Year Forward View, Improving Outcomes through Personalised Medicine, Public Health England's Better Outcomes by 2020 and diverse parliamentary committee reports. These documents and their authors can be found in the appendix of this publication.

Through analysis of these documents, PHG Foundation aims to identify the emergence and evolution of core policy themes, including those that encourage innovation and the integration of health and care. Which provides the framework for our analysis of the evolution of health policy since the early 2000s.
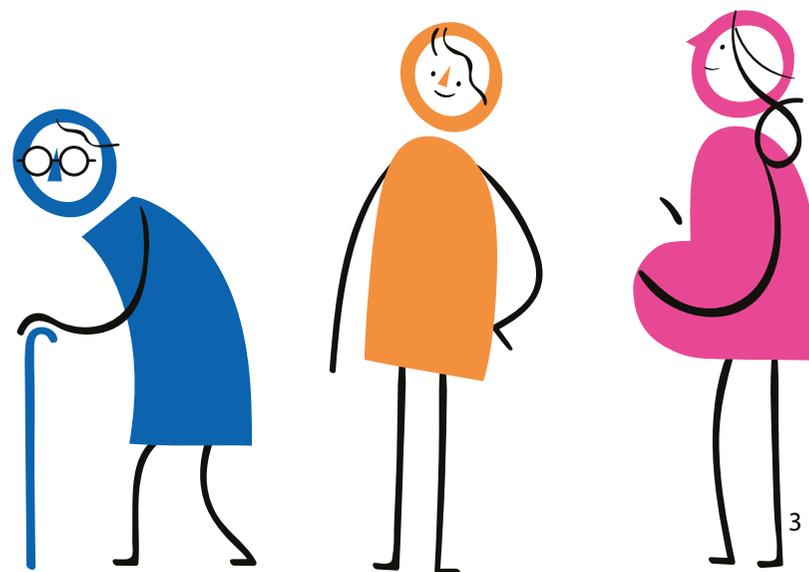
The health policy context

Current state and nature of health and care in the UK

There is widespread agreement amongst professional bodies, health experts of various disciplines and parliamentarians that 'our NHS, our national religion, is in crisis and the adult social care system is on the brink of collapse'.[1] This is unlikely to come as suprise to those who have been following the funding cuts, frequent health system reorganisations and growing inefficiencies at clinical and administrative levels.

Yet there have been improvements in the health service over the past 15 years; according to the NHS Five Year Forward View, 'cancer survival is at its highest ever; early deaths from heart disease are down by over 40%; avoidable deaths overall are down by 20%'. But while the quality of care in the UK may remain high, the NHS is certainly struggling.[2] For example, 'the number of people waiting longer than the Government's set target for emergency hospital care has hit a five-year high in England' while 'more cancer patients in England are facing delays for their treatment than three years ago'. [3,4]

Bridging the gaps

A number of policy documents, beginning with the NHSE's Five Year Forward View and including work by the Care Quality Commission, Public Health England and the National Information Board, acknowledge that the NHS currently faces a complex combination of three widening 'gaps' that continue to threaten its sustainability.[5–7]

Health and wellbeing gap

The health and wellbeing gap refers to the absence of sufficient local and national programmes designed to help people improve their health and wellbeing – preventing people from getting ill where possible and supporting people to stay healthy.[2] This is considered crucial as long term health conditions now take 70% of the health service budget. The gap also refers to 'inequalities in health and health outcome for different groups of people which are often driven by wider socio-economic factors'.[8]

As the NHS Confederation explains, 'preventing illness is critical if the NHS is to remain sustainable'. As 'much of the pressure on the NHS and hospital admissions is due to illnesses that could be avoided…[it is by] supporting people to improve their health and wellbeing through local and national programmes' that 'unnecessary hospital admissions will be avoided and geographic and socio-economic health inequalities will be reduced'.[9]

Care and quality gap

The Health Foundation's 2017 Election Briefing explains that 'quality in health care is a broad concept and not easy to measure,' it adds that 'health care is high quality if it is safe, effective, person-centred, timely, efficient and equitable'.[10] Within each of these dimensions a distinct standard must be set against which the provision of a service can be measured and its quality assessed.

For instance: the NHS has identified targets for the maximum amount of time a patient may be left waiting at A&E or the maximum amount of time a patient may wait between a cancer diagnosis and the start of treatment.[11] Consistent failure to meet a target suggests a fall in the quality of care.

The care and quality gap refers to the gap between the availability and quality of services people need and the availability and quality of services offered. This gap is observed 'in the variations in care across the country'.[12]

Frequently referred to as a 'postcode lottery', figures on Clinical Commissioning Group (CCG) performance have revealed that the quality of care a patient will receive varies widely depending on their local health service. This is due in part to the failure of the health service to adapt to the changing health needs of patients living longer and with more long-term conditions. As the House of Lords Long-term Sustainability of the NHS Committee heard in evidence from Sir Muir Gray, 'there is variation present in the system that is wholly unwarranted and which cannot be explained by variation in need or explicit choices made by populations or individuals'.[1]

Funding and efficiency gap

The funding and efficiency gap refers to the expected gap between resources and patient needs of nearly £30 billion a year by 2020/21.[13] In 2015, the Conservative government committed to providing £8 billion to the NHS while relying on the health service to make £22 billion in efficiency savings.

While 'the UK has historically spent less on health when compared with the Organisation for Economic Co-operation and Development (OECD) averages,' organisations like NHS Employers have stressed that the funding and efficiency gap is not solely a question of insufficient funds. [1,13]

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As outlined in the Five Year Forward View, efforts to close the gap focus on maximising the value of the NHS budget by reducing variation in products and services, modernising inefficient services by working differently and harnessing technology, and finally by shifting focus from treatment to prevention of disease in order to reduce demand.

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Drivers of change

Successive governments have developed health and related policies to address the implications of the three gaps outlined above. This includes issues of sustainable funding, health quality and accessibility as well as disease prevention at the local and national levels.

But these gaps are not the only factors that the Government has had to take into account. As the House of Lords Long-term Sustainability of the NHS Committee found, 'while the NHS has evolved considerably since its inception in 1948, the drivers of change are intensifying at a relentless pace and fuelling rising public expectations'. [1]

There are a variety of independent and evolving factors or drivers of change that have a direct impact not only on how health and care may be accessed but also how they may be provided. These drivers have already influenced Government policy and will continue to affect key policy decisions in the future.

Demographics

The latest data released by the Office for National Statistics (ONS), shows that in 2016 the UK population reached a new record of 65.6 million and is projected to grow to 74 million by 2039.[14] This is as a result of natural change (the difference between the numbers of births and deaths) and net migration (the difference between emigration and immigration). Whereas the former results from lower birth rates and longer life expectancy and contributes to the ageing of the population, migrants tend to be of younger working age (between 20 and 36 years).

Overall the trend reported by ONS is of an ageing population: in 2016 18% of the UK population were aged 65 and over, and 2.4% were aged 85 and over. By 2036, the ONS estimates 23.9% of the UK population will be aged 65 and over while the number of people aged 65 and over is projected to rise by over 40% in the next 17 years to over 16 million.[14,15]

By 2040, nearly one in four people in the UK will fall into this age group. Moreover, more than double the number of people in England will be aged 85 and over in 2030 compared to 2010. Of relevance to health and social care is the projection that by 2032, 11.3 million people are expected to be living on their own, amounting to more than 40% of all households.[16]

As the population ages, the prevalence of long-term conditions is expected to rise, increasing reliance on the health service and therefore necessitating increased expenditure from NHS and Social Care to provide diagnoses, treatments and care.

Age UK noted in its report Later in Life, that the increased prevalence of long term conditions will have a significant impact on health and social care, requiring an estimated £5 billion additional expenditure by 2018.[15]

Junior Health Minister Lord Darzi also found in the 2008 NHS Next Stage Review that older people use a disproportionate amount of NHS resources. For example, 'the average over-85 year old is 14 times more likely to be admitted to hospital for medical reasons than the average 15-39 year old. Whilst just 17% of the under 40s have a long-term condition, 60% of the 65 and over age group suffers from one or more'.[17]

It is no surprise then that 'more than two-fifths of national health spending in the UK is devoted to people over 65' and that the growth of this demographic poses clear challenges to the future health service.[18]

Health policy context

Science and Technology 'push'

With the emergence of what has been called the 'second machine age', the twenty-first century has seen remarkable breakthroughs in science and technology. The House of Lords Science and Technology Committee has described 'a tsunami of technological change, driven by the digital revolution, affecting virtually all areas of our lives'.[19]

The incredible potential of these new technologies to improve health outcomes, combined with the government's dual emphasis on expanding the life sciences industry and capitalising on the potential efficiency savings of health innovation, has resulted in massive public and private investments into the healthcare industry. This in turn has fuelled a rapidly growing and transformative biotechnology industry.

The excitement and optimism over new technologies and fields of science has been accompanied by a tendency to overhype new developments or mistake 'fads' for game-changing progress. Science and technology are evolving at such a rapid pace, unlocking new capabilities and raising complex ethical issues, that it is difficult to fully grasp the implications of each new development and accurately predict which technologies will have a transformative influence.

However, the rapid evolution of science and technology will undoubtedly transform the provision and consumption of health and social care in the UK.

Genomic medicine

In 2009, the House of Lords Science and Technology Committee completed their inquiry into genomic medicine, concluding that 'the sequencing of the human genome, and the knowledge and technological advances that accompanied this landmark achievement, represent a scientific advance offering new opportunities for making real advances in medical care'. They stressed the potential applications of genomic technologies for improved predictive and precision diagnosis across a range of diseases as well as new disease classifications and opportunities for more 'personalised' treatments.[20]

The Human Genomics Strategy Group (HGSG) that emerged in 2012 took this further, arguing 'we are currently on the cusp of a revolution in healthcare: genomic medicine…becoming part of mainstream healthcare practice'.[21] The group explained that genomic technologies will facilitate more stratified medicine, enabling not only 'earlier, more accurate diagnosis and prognosis' but 'helping clinicians to select treatments that are more likely to be effective'.[21]

The House of Lords and the HGSG reports make it clear that the ability to understand and act on information about a person's entire DNA sequence or 'genome' facilitates more accurate diagnosis of disease and better informs therapeutic decisions – so that more patients get the right treatment at the right time. It also enhances preventive care by facilitating earlier and more precise diagnoses, including improved identification of those at a higher genetic risk of inherited diseases and a range of common chronic conditions. As the HGSG concludes, 'genomic technologies are more than just another innovation: they present a major step-change in medical practice and public health. They offer tangible benefits across the spectrum of patient care'.[21]

Genomic medicine has proven crucial to the evolution of personalised medicine. While clinicians have always worked to tailor their care to individual health needs, genomic medicine provided new diagnostic information, including individual susceptibility to disease and likelihood of responsiveness to specific interventions. As NHS England explains, the use of genomic technologies and other diagnostics will facilitate earlier detection of disease, opening up the prospect of new treatment options and reducing the growing burden of disease. It will also facilitate more precise diagnoses and 'offers the opportunity to move away from 'trial-and-error-prescribing to optimal therapy first time round'.[22]

Genomic medicine raises a number of questions for policymakers and associated agencies including the NHS and PHE regarding effective implementation of these new technologies into the health service. Chief Medical Officer Professor Dame Sally Davies focused her 2016 Annual Report on genomics and acknowledged the potential of genomic medicine 'to save costs and improve quality of care by targeting treatment, maximising benefit and reducing side effects'.[23] But the CMO also concluded that 'to make this dream a reality across England and secure the vision of NHS transformation needed, as well as build on the 100,000 Genomes Project, we need to: embed national standards; streamline laboratories; and, in a secure environment, agree to use data for our own benefit and others'.[23]

Policymakers and commentators like the King's Fund and the Nuffield Trust have recognised that genomic and other new science and technologies are having a transformative impact on the health service. From advancements in diagnostics to treatment and monitoring, these evolving capabilities carry enormous potential for improved quality of care and access to health services. Digital health technology and the related importance of effective data-sharing in particular have become issues of vital importance to the long-term sustainability of the NHS.[24]

Digital Medicine

'The convergence of science and technology in our dynamic digital era has resulted in the development of innovative digital health devices that allow easy and accurate characterisation in health and disease'.[25] Mobile and digital technology have been combined with the miniaturisation of diagnostic instruments to create wireless and wearable sensors and devices that facilitate health monitoring and early intervention. The Nuffield Trust concluded in 2016 that not only does digital health technology carry the potential to improve resource management and access to specialist expertise but, if implemented properly, these new digital capabilities could lead to more systematic, high-quality and targeted care as well as better coordinated care that fosters greater patient engagement.[26]

Commentators like Dr Eric Topol extrapolate from these developments to suggest that a new era of medicine has emerged, 'powered by unplugged digitization, with the smartphone as the hub'.[27] Where patients are better equipped as a result of this technological revolution, Topol suggests we are embarking on an age 'when each individual will have all their own medical data and the computing power to process it in the context of their own world'. Beyond medical empowerment to medical emancipation, he concludes that the patient will increasingly take centre stage in their own health and care, capitalising on new technologies to shift power away from healthcare professionals and towards the individual.

Rather than passive observers of this 'tech-tonic' shift in power, individuals are instead actively engaging with it, increasingly demanding greater control over their own health and care. Digital health technologies could therefore reduce the pressures on health services, from GPs to hospitals, by keeping people healthier longer and by allowing those who do fall sick to stay at home.

Health data

The rapid evolution of digital technology has resulted in the ongoing creation of unprecedented amounts of personal data. In 2015, Forbes found that 'more data has been created in the past two years than in the entire previous history of the human race'. With data collection only increasing, Forbes concluded that 'data is growing faster than ever before and by the year 2020, about 1.7 megabytes of new information will be created every second for every human being on the planet'.[28]

The combination of massive datasets of personal information and new technology to analyse and understand that information has already begun to have a transformative impact on health services in particular.

Health policy context

'The collection and analysis of data on a scale or of a complexity that makes the use of such data challenging' – referred to as Big Data - holds incredible potential to improve the provision and effectiveness of health services.[29]

The European Commission Directorate-General for Health and Consumers notes that Big Data already acts 'as a source of innovation in healthcare, accelerating the translational pathways from the laboratory to the patient'. It also plays a vital role in medical and clinical research, 'having already contributed to clinically relevant studies and applied disease research' from cancer and dementia to disease monitoring and prevention. Finally, 'researchers and funders recognise the value of integrating clinical research networks...Connecting existing networks means clinical research can be conducted more effectively, ensuring patients, providers, and scientists form true communities of research in an environment of shared operational knowledge and data'. [30]

While barriers to the use of Big Data still demand attention – including privacy and security concerns, regulatory challenges, system compatibility and effective data-sharing – policymakers have recognised that 'the potential benefits [of healthcare data] could be better quality healthcare, with interventions more precisely tailored to individual patients' circumstances, if their medical and other data can be matched to extensive datasets'.[29]

Social and cultural 'pull'

Public attitudes towards healthcare are changing. A 2015 Care Quality Commission (CQC) survey found that over 40% of people want to be more involved in decisions about their care while the NHS found only half of patients say they are as involved as they wish to be in decisions about their care and treatment.[31]

A 2016 GP survey revealed that 40% of people living with long-term conditions want more support to manage their health and wellbeing on a day-today basis.

Considering that in 2015 people with long term conditions were likely to spend less than 1% of their time in contact with health professionals, this should come as no surprise.[31]

Partly as a consequence of this growing demand for more knowledge of and control over their own health and care, individuals within and beyond the UK are increasingly capitalising on the opportunities offered by digital health technology. According to a recent survey, the use of health apps in the UK more than doubled between 2014 and 2016 while the usage of wearable devices tripled during that time.[32]

A recent survey showed that 37% of the general British public now use some form of fitness, health or well-being technology.[33] The public are therefore actively working to become more knowledgeable about their health and care, paying more attention to their lifestyle and collecting massive amounts of data in the process.

Armed with more health knowledge and an awareness of the potential health implications of digital health technology, individuals are increasingly demanding more from their health service - making more demands on health professionals and seeking more engagement in decisions about their care.

A survey of medical professionals across Europe showed that in all regions patients are less passive than in the past and they expect higher standards of care, more information about their treatment, more involvement in decisions about their care and access to the latest treatments.[34]

Importantly, this enthusiasm for 'connected' citizens using technology to understand and control their own health and care, and particularly their data, has not been reciprocated by doctors in the UK. The reasons for this may include the potential confusion and false positives resulting from patient access to uncurated, user-

captured raw data or a resistance to challenging the traditional divide between clinician and patient.

Just 22% of UK doctors agree that full disclosure should be granted to patients compared with 81% of consumers and nearly as many British doctors believe wearable devices will increase the cost of healthcare as those holding the opposing view.[32]

Sustainability

The King's Fund has warned that, while the NHS continues to be very highly valued, there are serious concerns about its future as key health service targets are consistently missed and deficits continue to grow. Net satisfaction with the NHS may have fallen but there is no evidence to suggest it is valued any less. Instead, polling by Ipsos MORI shows that 'the majority of the population supports the model of tax-funded health care, free to all; however, nearly half are concerned that this model cannot be sustained' and more than half said they expect the NHS to deteriorate over the longer term.[34]

The House of Lords Select Committee on the Long-term Sustainability of the NHS takes a similar view. After considering issues around funding, workforce planning, service transformation efforts, innovation and public health, the policymakers concluded that the NHS and adult social care system is sustainable but not as it is today – things need to change. Recommendations included longer-term planning at the local level, new approaches to general practice and the acute hospital inpatient sector, funding to match financial pressures, and prioritising innovation.[24]

Historically, 'health and adult social care services in England have been funded, administered and accessed separately'.[35] However, demographic trends, including an ageing population and an increased prevalence of long-term conditions, have meant more people regularly interact with and require greater support from both services.

As many commentators including the Department of Health have acknowledged, the integration of health and social care is essential to making efficiency savings, reducing reliance on acute hospital services and keeping people healthier for longer. [36]

Yet organisations like the Care Quality Commission (CQC) have increasingly expressed 'concern about the fragility of adult social care and the sustainability of quality' because of the potential impact on 'people using those services, and for the knock-on effects across the whole health system: more emergency admissions in A&E, more delays for people ready to leave hospital, and more pressure on other services'.[37]

Despite sustainability being a government priority, the House of Commons Public Accounts Committee found in 2017 that the financial performance of NHS bodies had in fact 'worsened considerably'.[38] This includes rising NHS trust deficits, NHS targets consistently being missed and frequent cuts to social care funding.

The CQC recently added that most of the commitments for change constitute relatively substantial investment and the real challenge will be ensuring that they can be carried forward sustainably in the long-term while maintaining the quality of care during this period of change.[37]

Finally, there is also a growing recognition within and beyond parliament that a 'radical upgrade in prevention' is needed to improve lives and achieve financial sustainability for the health and care system.[39]

Health policy context

Since the NHS was created 70 years ago, the focus and practice of healthcare services has transformed: from traditionally offering treatment and supportive or palliative care to management of chronic diseases, rehabilitation and disease prevention.[40]

The evolution of science and technology, including genomic medicine, data analytics, imaging and diagnostics, has facilitated a move away from a 'one-size-fits-all' approach to healthcare to one that allows for earlier and more accurate prediction, diagnosis and treatment. Prevention is an opportunity 'to improve the quality of services for patients whilst also improving efficiency, lowering costs, and providing more care outside of hospitals'.[41]

Globalisation

British people are increasingly aware that the quality and availability of care varies between and within countries. With the emergence of global media and the internet, people can far more easily compare the health systems of different countries and draw conclusions regarding funding, resources and organisational structures. Major international organisations publish country rankings while foreign travel and migration help further spread ideals about alternative approaches to healthcare delivery and entitlements.[42]

In 2008, the Picker Institute and Ipsos MORI identified a number of challenges that globalisation would bring for the NHS, many of which are particularly relevant today. For example, as a consequence of comparisons with foreign health systems, they predicted that there would be growing pressure from the public to change access arrangements. This included the traditional role of the GP as gatekeeper, particularly as waiting times worsen. The joint report also predicted a growing demand for accessibility to new treatments and technologies as a consequence of commercial pressures on public attitudes as well as increased access to health information on the internet.[42]

Rapid economic development and the modernisation of society as well as various medical and public health programmes have been valued through having helped improve the health of the population.[43] Addressed earlier, the global population is living longer due in part to improving standards of living, economic opportunities and the spread of improvements in healthcare, including new technologies and medicines. However, the impact of globalisation also jeopardises the health of the global population through the worsening of certain social and economic conditions including the division of labour, the gap between rich and poor, and the rapid expansion of consumption of consumer goods.

Studies have shown that greater income inequality tends to bring greater inequality of opportunities, including health, and lead to more unequal outcomes, which are reinforced across generations'.[44] Furthermore, the disruption of the labour market as a result of various factors including technological change and digitisation has also facilitated job insecurity, skills shortages and a potential decrease in standards for some.[44] Some scholars also point to globalisation as a contributing factor to the growth of urban obesity, the rapid spread of infectious diseases and the prevalence of diseases associated with the internationalised tobacco industry.[45]

Evolution of medicine

In developing their concepts of personalised medicine, the NHS acknowledged that medicine has traditionally 'been built around clinical teams specialising in a particular organ system working back from a patient's symptoms to arrive at a diagnosis'.[31]

Although physicians have always tried to adapt patient care according to the patient's physical, psychological and social circumstances, the ability to do so was often constrained by the limited availability of biomarkers and tools to assist with this characterisation. The resulting 'one-size fits all' approach to treatment was consequently based largely on treating patients according to their broadly diagnosed condition, with little means of further stratification.

More recently, based to a great extent on the evolution of genomic medicine but also propelled by advancements in other fields including imaging and diagnostics, there has been a clear shift towards 'personalised medicine'. This refers to an approach to medicine based on 'combining and analysing information from our genome, with clinical and diagnostic information and then comparing that with data from others' in order to 'help determine our individual risk of developing disease, detect illness earlier, provide an accurate diagnosis, and determine the most effective interventions to help improve our health'.[31]

Commentators such as Nesta have concluded that personalised medicine will increasingly challenge the traditional relationships between patient and health professionals and force policymakers and providers to reconsider how health services are provided. This is a consequence of the growing recognition that patients are different and health is determined by a wide range of factors including genetic profile, lifestyle choices and other environmental factors.[46]

Furthermore, as personalised medicine evolves, 'people will have much greater opportunity to help themselves and others achieve a healthy life; they will be better supported by the NHS to do so; and healthcare professionals will work with people to identify emotional, practical and clinical support'. 'Policymakers in particular will need to take seriously the design of health interventions and treatment as a powerful influence on the uptake of healthy behaviours'.[46]

While the NHS was initially developed to provide largely episodic care, generally treating people when they fell ill, it has increasingly been noted by diverse agencies including the NHS and Monitor that this care model will not be sufficient to meet the health needs of a growing, diverse and ageing population with high rates of chronic diseases, obesity and mental health problems and there needs to be a shift towards prevention and early diagnosis.[47]

The top three causes of premature death in the UK are heart disease, lung cancer and stroke. Collectively they place a heavy burden on the NHS, social care and society. While the treatment or management of long term conditions such as these is still allocated an overwhelming percentage of the NHS budget, many of the behaviours that contribute towards the development of long-term illnesses like these leading killers are actually preventable. And yet prevention has not been given the appropriate attention.[48] It is now accepted by a wide range of commentators and policymakers that prevention represents better healthcare and will be essential if the health service is to survive current pressures.

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Evolution of health policy

Keeping up

Successive governments have responded to the pressures and drivers of change in a variety of ways, which can be summarised in four main themes:

- Encouraging innovation
- Integrating health and care systems
- Empowering patients
- Promoting personalised medicine and prevention

The following sections provide an overview of these evolutions in health policy.

Evolution of health policy

Encouraging Innovation

The potential for innovation to improve the efficiency and effectiveness of the NHS, and grow the life sciences sector in which the UK maintains a competitive advantage, has been a key tenet of Government policy for decades. That support has grown in recent years, peaking in 2016/17 with increased funding and more ambitious policy. The coalition government of 2010 identified innovation and research as key priorities, stressing the importance of health research and the use of new technologies for 'the development of new, more effective treatments for NHS patients'. Using genomics as an example of promising new discoveries, the government stressed the need for new approaches if productivity and quality were to be improved as well as the need for new research to grow the UK life sciences industry.[49]

Recognising that innovation was not being accelerated and implemented as expected, the Department of Health collaborated with the NHS in 2011 to publish 'an integrated set of measures that together support the adoption and diffusion of innovation across the NHS and set a delivery agenda that will significantly ramp up the pace and scale of change and innovation'.[50] Key findings included the need to 'establish a more systematic delivery mechanism' for implementing innovations; to 'improve arrangements for procurement to drive up quality and value', and to mandate 'the adoption of high impact innovations in the NHS'.[50]

This review, combined with the government's 2011 Plan for Growth and a review of the life sciences industry led by the Office for Life Sciences, comprised the UK Strategy for Health Innovation and Life Sciences. 'The aim of this strategy [was] to ensure the UK maintains and builds on its world leading position for life sciences, that the potential of life sciences to contribute to UK growth is realized, and that the UK remains and grows as an attractive location for investment now and in the future'.[50]

Since 2011, economic growth and health improvement have underpinned successive innovation policies. By 2013, the NHS announced that it had delivered or was in the process of delivering on all of the commitments outlined in the 2011 review. For example, 'the largest roll-out of tele-health anywhere in the world' was underway; 15 new Academic Health Science Networks were expected to be up and running in the new financial year; a new legal duty for CCGs and the NHS Commissioning Board to promote innovation had been introduced; investment in the Small Business Research Initiative had doubled; and a series of Innovation Challenge Prizes were launched.[51]

The Five Year Forward View highlights an important distinction between innovation in clinical technologies, including diagnostics and new treatments, and innovation in digital technologies. This strategy proposes specific steps 'we will take to speed innovation in new treatments and diagnostics,' including harnessing clinical technology to lower the costs of randomised controlled trials, expanding programmes designed to accelerate innovations in the absence of full trial data, supporting best approaches to rolling out high value innovations, and exploring new mechanisms to more rapidly translate a discovery into clinical practice.[52]

As digital technology has evolved, policymakers have increasingly appreciated that the better use of data and technology has the power to improve health, transforming quality and reducing the cost of health and care services. They also embraced its potential to 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.[53] The House of Lords Select Committee on Digital Skills acknowledged the potential for Big Data, 3D printing and robotics to transform healthcare and medicine.[54] The proposed Industrial Strategy Challenge fund will focus in part on accelerating' leading-edge healthcare and medicine' while countless policymakers have reiterated the need to provide individuals with the necessary digital tools to facilitate personal responsibility and shift care from hospital beds to the home.[55]

Funding for innovation

The development of innovation infrastructure has been reflected in the largely consistent growth of government funds earmarked for science and innovation. Initially, there was an ambitious goal to increase R&D spending to 2.5% of national output by 2014. Instead, spending fell from 1.77% to 1.72% of GDP in 2012 and by 2014, it was reported that a smaller percentage of the nation's output was going into R&D than it did in the mid-1980s.[56]

However, the 2015 Autumn Spending Review included £1 billion for new technology over five years as well as over £5 billion for health research and development.[57] More recently, the 2016/17 budget included a range of challenge prizes, accelerators, grant funds, social investment and other funds totaling £4.2 billion for UK science and innovation. This was part of a larger £23 billion over five years earmarked for innovation and infrastructure.[58] In addition, in June 2016, the Conservative Party committed to raising the percentage of GDP spent on research from 1.7% to 2.4% within ten years, in addition to reaffirming earlier commitments to protect science funding with a total investment of £26 billion over the period 2016–17 to 2020–21.[59]

Most within and beyond parliament have welcomed the growing investment in UK science and innovation as a vital strategy to remain globally competitive. For example, the House of Commons Science and Technology Committee reported in November 2015 that, while 'Government spending on the science based [had] been protected since 2010', the UK had 'fallen behind its competitors in terms of total R&D investment and this will put UK competitiveness, productivity and high-value jobs at risk if it is not reversed'.[60]

Importantly, a special report from the same committee in September 2017 acknowledged that 'the Government envisages a relative shift of focus in funding towards innovation… [which] reflects a changing world…but it also reflects a Government desire to reassess the relative weight given in funding different areas of research'.[61]

Beyond technology to care systems

Over the past five years, government policy has increasingly reflected the realisation that physical innovations in digital technologies and new treatments must be supported by innovations in the ways health and care are actually provided. Reflected in various NHS documents and government policies, it is made clear that closing the care and quality gap requires 'combinatorial innovation'.[52] This means both single-issue innovations that improve the quality of a particular patient group's care as well as system-wide innovation to help ensure its effective implementation.[62]

The *Five Year Forward View* begins by acknowledging the implications of various drivers of change, including demographics and evolving 'opportunities that science and technology offer patients, carers and those who serve them'. Consequently, it suggests 'we need to take a longer view…to consider the possible futures on offer, and the choices that we face'.[52]

In addition to shifting greater control to patients and accelerating useful health innovation, the longer-term strategy places a great deal of emphasis on 'diverse solutions and local leadership'. As the Government had 'just taken the unique step anywhere in the world of entrusting frontline clinicians with two thirds - £66 billion – of our health service funding', CCGs have since been expected to take greater ownership over driving change, including innovation, in their local health systems.[52] This was an early sign of the decentralization of innovation and has since been reiterated in key policy documents including the CQC *State of Care report* and the *Accelerated Access Review*.

This trend in policy has accelerated since 2014 with the introduction of new organisations and a reorganization of service delivery in the NHS.

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For example, the flagship New Care Models programme and vanguard sites are designed to address care, quality and funding gaps. Focusing on out-of-hospital care and population health, they are designed to help keep people well, and bring together home care, mental health and community nursing, GP services and hospitals. They will also join up the often confusing array of A&E, GP out of hours, minor injuries clinics, ambulance services and 111 so that patients know where they can get urgent help easily, seven days a week.[62]

Similarly, the *Five Year Forward View* set out the intention to develop a small number of 'test beds', designed to evaluate the real world impact of new technologies offering both better care and better value for taxpayers, and particularly included testing them together with innovations in how NHS services are delivered.[63] It also lays out commitments to expand NHS operational research, RCT capability and other methods to promote more rigorous ways of answering high impact questions in health services redesign.

Particularly revolutionary, it even makes reference to exploring the development of health and care 'new towns' where design will address modern services from scratch, with fewer legacy constraints and integration of health and social care with other public services such as welfare, education and affordable housing.[52] Innovation has therefore been embraced quite emphatically and only time will tell if these new approaches to service delivery and integration alongside innovative technologies and medicines will pay-off.

Embracing the evolution of digital innovation

Progress has been reflected in the creation of new institutions and new roles focused on facilitating innovation and digitisation of the NHS. The coalition government introduced a framework focused on using data and technology to transform outcomes for patients and citizens. The National Information Board was established in 2014 to monitor progress. Some organisations like the Health and Social Care Information Centre have given way to more modern organisations like NHS Digital. A range of new roles have been introduced such as Chief Clinical Information Officers, who were introduced to every trust, supported by a cadre of trained, professional clinician-informaticians, to oversee NHS clinical digitisation efforts.

According to Personalised health and care 2020, local implementation of digital innovations is to be driven by 'local digital roadmaps' that detail how local areas aim to improve digital technology, strategy and organizational leadership and deliver the paperless vision by 2020. The NIB Annual Report explicitly acknowledges that lessons of the past suggest we should focus at the national level on specifying standards and promoting interoperability, while also identifying and driving the desired outcomes and benefits. But local partnerships should be allowed to develop and implement the solutions. In addition, meaningful, widespread clinical and patient involvement must be central to the design and implementation of a digitally transformed, integrated health and care service

New treatments and diagnostics

The Five Year Forward View included a commitment to accelerating useful health innovation and references a long list of steps to be taken in order to speed up innovation in new treatments and diagnostics. For example, the NHS Innovation Accelerator is designed to improve uptake of high-impact innovation for patient, population and NHS staff benefit. Delivered in partnership with all 15 Academic Health Science Networks across England, the aim is a better coordinated approach to introducing innovative technologies into the NHS.

The Accelerated Access Review similarly focused on how to speed up access to innovative drugs, devices and diagnostics for NHS patients and each of these programmes were supported by considerable funding from the state.

Yet it has become increasingly clear that the identification and acceleration of innovations is not the real challenge when promoting innovation. There is a distinction to be made between discovering or funding the creation of innovations and their implementation. It is the effective implementation of valuable innovations across the health service that has proven challenging and the discovery of new and useful innovations still does not result in their automatic uptake or routine use.

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Integrating health and care systems

Since 1999, when the Health Act allowed local authorities and the NHS to pool budgets and merge care services, successive governments have supported local bodies to collaborate and trial various approaches to integrating care. However, these efforts have tended to be isolated, inefficient and ineffective. Furthermore, shifts in policy emphasis and reorganisations promoting competition within the NHS complicated the path to integration.

After reviewing the evolution of government policy, it seems only in the last few years has a more comprehensive approach taken root in a culmination of growing trends and best practice.

Localism

The coalition government made localism a key priority in its legislative agenda and a key motivating concept underpinning much of its subsequent policy initiatives. Health was no different as the government moved to enhance the role of local authorities in the provision of healthcare.

Billions of pounds have been transferred from the NHS to local authorities over the years to promote better joined-up working. More fundamentally, the Health and Social Care Act 2012 embodied a massive reorganisation of the health service including giving local authorities a new set of duties to protect and improve public health, along with a new responsibility to commission certain clinical services. And it gave local authorities considerable scope to determine what actions it will take in pursuit of that general function.

As policy has reflected, 'there is no single way to integrate health and care'. [64] Consequently, a key policy theme has been that local authorities should tailor local solutions to local problems, using all the levers at their disposal to improve health

and reduce inequalities. They are expected to create a twenty-first century local public health system based on localism, democratic accountability and evidence.

In practice then, integration has increasingly come to mean care and support built around the needs of the individual, their carers and family. Tim Kelsey echoed UK health policy when he insisted, 'we must put citizen and patient voice absolutely at the heart of every decision we take in purchasing, commissioning and providing services'. [65]

As an example, Kelsey refers to Torbay, an area with a high proportion of over-65s, discussions driving integrated care were characterized by a fictitious 85-year-old with a range of care needs. Rather than traditional supply-driven models of care provision, integration has embraced local health and social care provision that is flexible, personalised and seamless. [66]

Improving efficiency and effectiveness of health and care

The number of people with complex health needs continues to rise. This means there are more people struggling with more than one health problem who therefore require a combination of health and social care services. Unfortunately, these services generally don't work together very well. Instead, care and support is often fragmented, delayed or duplicated, which can result in missed opportunities to prevent needs from escalating and intervening early. [67] Too many people end up in hospital unnecessarily or stay there too long. Some receive the same service more than once – from the NHS and social care organisations – or an important part of their care is missing.

Successive governments have consequently pursued the integration of health and care services so services work together to give the best care based on a person's particular circumstances and where taxpayer money is consequently used more effectively. [68]

This has proved challenging. Firstly, there is the challenge of creating a culture of cooperation and coordination between health, social care, public health, other local services and the third sector.

More fundamentally, there have been efforts to end the institutional divide between physical and mental health, primary and secondary care, and health and social care. The emphasis is instead on providing a seamless service focused on the individual within their own home.[67]

Embracing technology and data

As highlighted in the NHS Personalised Medicine Strategy, integration extends beyond joining up services to include the integration and analysis of patient data. In order to capitalise on the massive amount of data being collected and 'maximize the true value of the information available about our health, we need to bring together genomic, clinical and diagnostic, medicines, and lifestyle data. It is the integration and analysis of this information that forms the powerhouse for personalised medicine'.

Already in 2012, the Department of Health's *Information Strategy* described how information can be used to drive integrated care across the health and social care sector, both within and between organisations.

This was followed in 2013 with the *Integrated Care: Our Shared Commitment report*, which emphasised the 'need to fully embrace the extraordinary potential presented by new technology and shared information. This can help local services to plan more effectively and will help doctors, care professionals and others to give people far better and far more tailored services. It will also give those who are able the ability to manage their own conditions, gaining a degree of independence'.[67]

As an example, the report references evidence that the use of telehealth and telecare, if implemented as part of a wider integration between health and social care services, lowers mortality rates significantly and reduced emergency hospital admissions.

Consequently, the report includes an expectation of all local leaders to 'share individuals' data where this improves the quality and safety of care and support through shared decision-making'.

Redesigning health and care systems

Through the new care models programme, complete redesigns of whole health and care systems are being considered. NHSE explains that this means fewer trips to hospitals with local surgeries offering more services, having one point of call for family doctors, community nurses, social and mental health services, or access to more tests closer to home. The new care models also involve joining up the often confusing array of A&E, GP out of hours, minor injuries clinics, ambulance services and 111 so patients know where they can get urgent help easily and effectively.

The Integrated Care Pioneers programme was established in 2013 and the number of exemplars 'developing and testing new and different ways of joining up health and social care services across England' more than doubled by 2015. Every health and care system in England has also by now produced a Sustainability and Transformation Plan, providing the system-level framework within which organisations in local health and care economies can plan effectively and deliver a sustainable, transformed and integrated health and care service. These plans work in collaboration with the Better Care Fund, such that financial planning and overall direction of travel are expected to be fully aligned. [64]

However, barriers to building an integrated system across the healthcare system persist. For example, in 2014 the National Audit Office reported that the success

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of the Better Care Fund required 'more effective support to local areas; better joint working between health and local government; and improved evidence on the effectiveness of integration schemes'. [69]

In 2017, the NAO found that, based on data up to June 2015, local areas were making slow progress in implementing their plans under the Integrated Care and Support Pioneers Programme and were not integrating services at the scale and pace envisaged. Barriers included financial constraints, cultural and professional boundaries and insufficient support for local bodies to effectively share information.[69]

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Empowering patients

Whether it is 'putting patients first', 'patient empowerment', or 'person-centred care', the policy of encouraging a greater role for individuals in their own health and care has been an explicit policy goal in the UK for at least 20 years. [70]

In 2008, patient experience became a key part of the national definition of quality in healthcare and in 2012 that was codified in the Health and Social Care Act. [71] Both PHE and NHSE have long professed a commitment to not only putting patients at the heart of all they do but also putting more power in the hands of patients in order to provide the best outcomes in the world. [72]

By 2012, the notion of 'a greater voice for patients' had expanded beyond care plans and patient involvement in planning discussions to offering patients more opportunities to make choices and providing the right information to make informed decisions. [73] It was even explicitly enshrined into law with the passage of the Health and Social Care Act 2012.

Patient empowerment has since continued to evolve, with a growing emphasis on personal responsibility as emphasized by Secretary of State for Health Jeremy Hunt, as well as increasing the direct control patients have in managing their own health, including 'staying healthy, making informed choices of treatment, managing conditions and avoiding complications'. [74, 75]

Unfortunately, the King's Fund concluded in 2014 that 'it still feels to many that 'putting patients first' is more of an aspiration than a programme of action; that the reality lags behind the rhetoric… [with] pockets of good practice [and] a lack of systematic progress'. [70] As acknowledged in the NHS Five Year Forward View, 'the health service has been prone to operating a factory model of care and repair, with limited engagement with the wider community, a short-sighted approach to

partnerships, and under-developed advocacy and action on the broader influencers of health and wellbeing'. [75]

The *Five Year Forward View* acknowledged the shortcomings of past policy efforts to accelerate patient empowerment and set-out a revised agenda with new policies and initiatives for the twenty-first century. It committed the NHS to 'improve the information to which people have access – not only clinical advice, but also information about their condition and history'. It also laid out digital and technology strategies designed to encourage patient control. [75]

Recognising the crucial role digitisation and new technology plays in patient empowerment, it confirms that 'within five years, all citizens will be able to access their medical and care records and share them with carers or others they choose'. A commitment is also made to 'support people to manage their own health – staying healthy, making informed choices of treatment, managing conditions and avoiding complications'. This includes ensuring patients have choice over where and how they receive care, blending health and social care funding via new Integrated Personal Commissioning, in addition to care plans and voluntary sector advocacy and support. [75]

Rights and responsibilities

On the most basic level, person-centred care was initially reflected in policy documents publicising the rights of patients and the general public when interacting with the NHS. The NHS was established in 1948 on three core principles including a free service at the point of delivery, provided on the basis of clinical need rather than the ability to pay. [76]

With the creation of the NHS Constitution in 2009, and over the course of its subsequent iterations over the years, citizens have long held the right to access the health service, to choose between services and to be involved in discussions

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and decisions about their own healthcare as well as in the planning of healthcare services more broadly. Patient and public rights also include the right to respect, to give consent and to the confidentiality of information.[77]

As the earliest NHS Constitution acknowledged, patient rights such as those listed above come with certain responsibilities that the public, patients and staff owe to one another to ensure that the NHS operates fairly and effectively. For example, with respect to maintaining health and preventing disease, patients are expected 'to recognise the significant impact on their own and their family's health, and they should take some personal responsibility for it'. Responsibilities include 'avoiding dangers to your health, maintaining a healthy lifestyle and avoiding the hospital unless absolutely necessary'. Patients are also expected to participate in important public health programmes and provide accurate information to NHS staff.[77]

The King's Fund notes that 'fundamental to this discussion of rights and responsibilities is an acknowledgement that both involve a transfer of power. Many of the rights allocated to patients seek to empower them, challenging the balance of power and control held by providers and health professionals. At the same time, it is recognised that as patients are allocated greater powers and control, the balance of responsibility also shifts, and patients must increasingly play a role in maintaining and managing their own health'.[70] This perspective has been more strongly reflected in British health policy over successive governments.

For example, prior to 2015 there was little explicit reference in policy documents to patient responsibility in terms of an expectation that patients make every effort to live a healthy life. The first NHS Constitution does make a reference to the individual responsibility to 'recognise that you can make a significant contribution to your own, and your family's, good health and well-being, and take some personal responsibility for it,' but beyond such 'a recognition' or general public health campaigns encouraging citizens to avoid habits like smoking and drinking excessively, personal responsibility was not explicitly encouraged as an expectation by the government. [78]

Recognising that citizens are best placed not only to manage their own long-term conditions but also to prevent them, in 2015, Secretary of State Jeremy Hunt announced the start of a national conversation regarding the 'need for personalised responsibility to sit squarely alongside system accountability'. He observed that, 'the best person to prevent a long term condition developing is not the doctor - it's you. Which is why last year, following changes to the GP contract, the number of GPs offering their patients online access to a summary of their medical record has risen from 3% to 97%'. Hunt concluded by emphasising the need for 'a new social contract' embodying 'a revolution in personal responsibility to match the revolution in health and care provision'.[70]

This remains an underlying current of the government's approach to facilitating patient empowerment, complementing policy efforts to encourage patient involvement in their care and equipping patients with the necessary technology and information.

Personalised care and support planning

Defined by the Coalition for Collaborative Care in 2014: 'Personalised care and support planning encourages care professionals and people with long-term conditions and their carers to work together to clarify and understand what is important to that individual. They agree goals, identify support needs, develop and implement action plans, and monitor progress. This is a planned and continuous process, not a one-off event'.[78]

Focused predominantly on those individuals living with multiple long-term conditions, but equally applicable to the increasingly frail older person or those in recovery, an early NHSE handbook explains that 'personalised care and support planning acts as a system pre-condition for providing support for self-management'.[78] Not only does it ensure health professionals acknowledge the particular issues

facing an individual but it allows that individual to feel more involved in their health and care.

A 2014 study by Cochrane, though based on moderate evidence, also concluded 'that involvement in personalised care planning probably led to small improvements in some indicators of physical health,' suggesting the inclusion of individuals in their own health and care actually helps improve health outcomes.[79]

More recent NHS guidance and other health policy documents still reflect these early conclusions. Describing personalised care and support planning as 'proactive conversations,' NHS statutory guidance for CCGs and NHSE states that these conversations 'should focus on what matters most to that individual (their personal goals) and the support they need to manage their health and wellbeing'.[80]

It should be clear then how this kind of care and support planning is intended to facilitate self-management, which 'recognises individuals as experts in their own lives, having acquired the skills and knowledge to cope as best they can with their long term condition'. Initiatives like the NHS Involvement Hub and 2016 Community Grants are designed to build on this by supporting people to develop their knowledge, skills and confidence to get involved in the design and delivery of health services.[80]

As the King's Fund concludes, 'By recognising patients as experts in their own health and by providing support to develop understanding and confidence, self-management leads to improved health outcomes, improved patient experience, reductions in unplanned hospital admissions and improved adherence to treatment and medication'.[81]

It becomes apparent from a wide range of policy documents that personalised care and support planning, and patient empowerment initiatives more generally, have focused overwhelmingly on improving the management of long-term conditions

and has not necessarily been promulgated for the purposes of more personalised prevention of disease.

Shared decision-making

Patient empowerment and the notion of personalised care and support planning are inextricably linked to the concept of sharing decision-making between health professionals and their patients.

As the Health Foundation explains, shared decision-making refers to 'a process in which patients are encouraged to participate in selecting appropriate treatments or management options'. Consequently it concludes that 'both parties must be willing to share information and accept responsibility for joint decision making. The clinician must provide patients with information about the diagnosis and treatment options and the patient must tell the clinician about their preferences'.[82]

Describing a vision of the health service in 2022, the final Wanless report published in 2002 began by establishing the central role of patients in healthcare services. 'Patients are at the heart of the health service of the future. With access to better information, they are involved fully in decisions – not just about treatment, but also about the prevention and management of illness'.[83] These ideals have been increasingly reflected in policy documents and initiatives over the years. Successive NHS Constitutions[84] reiterate the underlying principles of the NHS including services that reflect the needs and preferences of patients, their families and their carers. Statutory guidance for CCGs and the NHS further explained what involving people in their own health and care actually means:

'Supporting people to manage their own health and wellbeing on a daily basis; supporting them to become involved, as much as they want or are able to, in decisions about their care and giving them choice and control over the NHS services they receive; focusing on what matters to the individual within the context

of their lives; commissioning services that routinely provide individuals with the information, care and support to determine and achieve the outcomes that matter to them'.[80]

Moving from a system of 'informed consent' to 'informed choice,'[83] the Health and Social Care Act 2012 actually changed the legal framework of the debate by making it clear that the NHS Commissioning Board and CCGs have a duty to promote the involvement of patients and carers in decisions about their care and treatment, and to enable patient choice. This included ensuring choice of general practice, diagnostic test provider and choice of treatment. Policies that followed have continued to stress that the NHS should support individuals to promote and manage their own health while health services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and carers.[84]

The NHS Constitution was updated to include a pledge to involve patients in care planning discussions and to offer them a written record of agreements made. In 2009, personal health budgets were introduced as a pilot programme designed to give patients more control over deciding where, how and when particular NHS services would be provided. These budgets became a fundamental right of all patients in 2014 and while the Care Act placed them on a statutory footing, the *Five Year Forward View* called for a 'major expansion' in their availability.

Yet by 2014, NHSE revealed that less than half of patients were not aware of their legal right to choose a hospital or clinic for an outpatient appointment, and less than two fifths of patients said they were offered a choice of hospital by their GP. In the same year, the King's Fund reported that 'national patient surveys show that around half of hospitals inpatients and one in three people using GP services said that they were not as involved in decisions about their care as much as they wanted to be'. Picking up on a deeper and more concerning trend, the report concludes that

'these figures have remained broadly static for a decade or more, suggesting that no systematic progress has been made'.[70]

Patient and public involvement in wider healthcare planning

The duty to involve patients and the public in health and care extends beyond shared decision-making to their inclusion in wider health service design and delivery. This legal duty to involve patients and the public in commissioning processes was introduced through the National Health Service Act 2006. The following year, the House of Commons Health Committee report on Patient and Public Involvement in the NHS recognised the potential of patient and public involvement 'to play a key role in both NHS and social care services by bringing about service improvement and improving public confidence'.[85]

While the establishment of Community Health Councils in 1974 was the first real attempt to represent the public's interest in NHS delivery, the Committee welcomed the range of developments that had taken place over the following thirty years. From Overview and Scrutiny Committees and Patient Advice and Liaison Services to Independent Complaints Advocacy Service and Local Involvement Networks, the Committee concluded that the particular structures are unimportant. Instead, 'effective patient and public involvement is about changing outcomes, about the NHS and social care providers putting patients and the public at the heart of what they do'.[85]

In 2016 the NHS published five distinct frameworks for patient and public participation in each of the services it is responsible for commissioning, reiterating the need to 'involve people early on, not as an afterthought' and to 'involve people in ways that are appropriate to their needs and preferences'.[86] This was echoed in the NHS Patient and Public Participation Policy published in 2017, which explicitly refers to the responsibility of all NHS staff to consider the need for patient and public participation in their work and undertaking this as appropriate.[87]

The more general statutory guidance for CCGs and NHSE on patient and public participation in commissioning health and care reiterated the Health Committee's findings ten years earlier. Acknowledging the current resource constraints facing the health service, the guidance stressed that 'listening to what our communities have to say about what works and doesn't, and supporting people to make healthier choices and make their own decisions about health and care is critical to long term sustainability of health and care services'.[88]

Data and technology

Since the early 2000s, successive governments, agencies, third sector charities and others have increasingly come to appreciate the critical role of data and technology in facilitating and accelerating patient empowerment.

In 2012, the Department of Health Information Strategy set-out the crucial role of shared patient records and one routine NHS number to building a genuine partnership between patients and health professionals while a separate Digital Strategy announced that, 'a health information revolution that puts patients in control of their health and care information, and makes services convenient, accessible and efficient, is now a major priority for the Department of Health'.[89]

An NHS-commissioned report by National Voices in 2013 reiterated that a key element of person-centred and coordinated care is the ability of any individual to see his or her 'health and care records at any time, decide who to share them with and correct any mistakes'.[90]

Recognising the importance of engaging with communities and citizens in new ways, to involve them directly in decisions about the future of health and care services, the NHS Five Year Forward View highlights patient empowerment and personalised care as a key priority.

In order to help realise this vision of more personalised care, the framework document lays out three keys steps:

- Improving the information to which people have access

- Doing more to support people to manage their own health, including making informed choices and managing conditions

- Increasing the direct control patients have over the care that is provided to them

Acknowledging the value of NHS accredited apps, fully interoperable electronic health records and data-sharing platforms, it argues that 'technology – including smartphones – can be a great leveler' and can improve patient experience regardless of age.[75]

It concludes that 'we will take steps to ensure that we build the capacity for all citizens to access information, and train our staff so that they are able to support those who are unable or unwilling to use new technologies'.[75]

Personalised Health and Care 2020 actually provides a framework for using data and technology to transform outcomes and patient experience, stressing that the 'better use of data and technology…can give patients and citizens more control over their health and wellbeing'.[91]

For example, it prioritises comprehensive access – to patient data by citizens and clinicians, including data from relevant devices like wearable devices – by 2018. Recognising that, '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', the framework highlights the need and proposes ideas for how to make 'safe accountable 'digital' access to care services the norm'.[91]

In an effort to accelerate this technological transformation and encourage a 'radical permanent shift in power towards patients,' Secretary of State for Health Jeremy Hunt emphasized in 2015 the role of new technologies like mobile health apps, myNHS data sharing platform and online booking tools as the foundations of Patient Power 2.0 – 'embracing technology to give patients real control of their own health and care'.[92]

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Promoting personalised medicine and prevention

As commentators and agencies like Monitor have acknowledged, the NHS was originally developed to provide largely episodic care; treating people when they fall ill and provide palliative care.[93] But it has become well established, both within and beyond parliament, that health and care systems geared toward treating short-term sickness rather than preventing and managing long-term mental and physical conditions 'will not be sufficient to meet the health needs of a growing, diverse and ageing population with high rates of chronic diseases, obesity and mental health problems'.[93]

Consequently, successive policies and reports have echoed the conclusion that a 21st century NHS will need to deliver care that meets the health needs of today and focuses more on preventing illness and supporting individuals in maintaining active and healthy lifestyles.[94]

In 2008, Prime Minister Gordon Brown argued that the challenge facing the NHS was to drive improvements in the quality of care. 'We need a more personalised NHS, responsive to each of us as individuals, focused on prevention, better equipped to keep us healthy and capable of giving us real control and real choices over our care and our lives'.[95]

Yet the 2010 Coalition Government that followed found prevention still did not enjoy parity with NHS treatment. Acknowledging that public health funds instead 'have too often been raided at times of pressure in acute NHS services and short-term crises,' a White Paper in 2010 announced a firm call to prioritise public health and called for 'a new approach…emphasising more personalised, preventive services that are focused on delivering the best outcomes for citizens'.[96]

With the evolution of science and technology, health policies increasingly began to reflect a shift towards more personalised medicine focused on better prediction and prevention, earlier diagnosis, more effective treatment and effective self-monitoring. For example, the 100,000 Genomes Project launched in 2014 has been sequencing genomes, enhancing our understanding of the genetic basis of diverse conditions and providing insights into the prediction and prevention of disease, thereby enabling more precise diagnoses.[97]

The NHS Five Year Forward View has since acknowledged that, 'medicine is becoming more tailored to the individual; we are moving from one-size-fits-all to personalised care offering higher cure rates and fewer side effects'.

The NHS Personalised Medicine Strategy of 2016 highlights the evolution of technological and scientific advances to conclude that we must consider not whether we should go down the route of personalised medicine, but instead how we can best respond and adapt so that those who could benefit have the opportunity.[98] It stresses the importance of personalised medicine not just for those suffering rare diseases but also for the many others who have or are at risk of developing other common diseases. Personalised medicine is also acknowledged as a key aspect of the strategic approach to meeting the health and wellbeing challenge, facilitating the identification of predisposition markers or underlying processes to predict future disease and thus improving targeted disease prevention.

A recent NHS report, *Improving Outcomes Through Personalised Medicine*, supports the vision for the future set out in the *Five Year Forward View*, adding that 'personalised medicine with science and innovation at its core is integral to making it a reality'. It announces 'the dawn of a new era in medicine that will need to move and evolve at the scale and pace of scientific and technological advances if real improvements for patients and the public are going to be made'.

Evolution of health policy

Assuming the NHS will evolve, the NHS document concludes by predicting 'the changes we might see in the coming decade':

- A new taxonomy of medicine based on underlying cause and personal response
- Integrated clinical services taking a 'whole body' approach
- Tailored, optimized and more effective therapies for better outcomes
- New NHS relationships with academia, industry, patients & patient groups

With the necessary foundations in place, the NHS is working to strengthen the infrastructure necessary to support a more personalised approach to health and care. This includes improving informatics, developing data standards, capitalising on the 13 Genomic Medicine Centres, developing specialist genetic and molecular pathology laboratories and finally working with Health Education England to sure the workforce is sufficiently trained and knowledgeable.[98]

Public Health

The *NHS Next Stage Review Final Report*[95] set out the initial vision of a service fit for the 21st century. The result of a collaboration with thousands of frontline clinicians, patients and others, the report stresses the importance of comprehensive wellbeing and prevention services customised to meet the specific needs of local populations. Obesity, alcohol abuse, drug addiction, smoking, sexual and mental health were identified as key issues of focus for prevention services. These health issues continue to reappear in health policy documents, up to and including the public health strategy for 2016-2020.

Since Lord Darzi's review, successive governments have reiterated the importance of prevention. The 2010 *Healthy Lives, Healthy People* white paper stated that 'at the population level, it is not better treatment, but prevention – both primary and secondary…which is likely to deliver greater overall increases in healthy life expectancy'.[96]

This was echoed and expanded in the 2012 White Paper *Caring for our Future* where the Government concluded that 'we should do everything we can…to prevent, postpone and minimize people's need for formal care and support' while reiterating a commitment to a 'preventive, people-centred, productive NHS that encourages and supports individuals to take responsibility for their own health and well-being'.[99]

Later in 2012, Health Education England (HEE) was established in part to help ensure health professionals were focused on promoting prevention while Public Health England (PHE) was created the following year with the specific purpose of protecting and improving the nation's health and wellbeing, and reducing health inequalities.[100]

Yet by 2014, the Department of Health still estimated that 70 percent of the NHS budget was being spent on long-term conditions while only 4 percent of the total healthcare budget was being spent on prevention.

The government proceeded to introduce a range of initiatives focused on propelling the prevention agenda. For example, Sustainability and Transformation Plans were introduced in 2015 with a key mandate to implement a clear prevention strategy 'with particular attention on national priorities of obesity, diabetes and locally identified priorities to reduce demand and improve the health of local people'.[101]

While their impact is difficult to measure after only a few years, a recent report from the King's Fund and Nuffield Trust found that 'London's STPs often lack clarity on how ambitious goals to prioritise prevention and early intervention will be delivered in practice'.[102] Missing details include specific aims, funding and who will be responsible for implementation.

In fact, both the 2015 NHS Five Year Forward View and the 2016 PHE strategy framework acknowledged that public health prevention policies have not yet reached the desired level of success, with a third of men and women not getting enough exercise, almost two thirds of adults overweight or obese and deepening health inequalities.[103, 104]

Derek Wanless' 2002 report stressed that 'unless the country took prevention seriously we would be faced with a sharply rising burden of avoidable illness'.[105] Acknowledging that this warning had been ignored, the *Five Year Forward View* concluded that a failure to get serious about prevention will mean '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'. It concluded that 'the future health of millions of children, the sustainability of the NHS, and the economic prosperity of Britain all now depend on a radical upgrade in prevention and public health'.[104]

The *Five Year Forward View* acknowledges the complex drivers of change that challenge the traditional structure and provision of healthcare. Stressing the need for a longer, five year view 'to consider the possible future on offer and the choices we face,' the document emphasises the need for 'a radical upgrade in prevention and public health,' far greater patient control over health and care, a more integrated system catered to the individual rather than a complex bureaucracy and a move away from a 'one size fits all' approach toward radical new care delivery options.

Innovation should be embraced throughout with the ultimate goal of not only reorganising care around the individual patient but ensuring that care can be provided on a more personalised basis.[104]

Genomics

Running parallel to public health policies designed to combat major public health problems such as obesity, smoking and poor mental health, successive governments have supported innovations in science and technology to improve health outcomes.

They have increasingly embraced personalised medicine and its ability to improve prediction, diagnosis, treatment and disease monitoring. Personalised care, tailored to people's individual health needs is not new but as new possibilities have emerged, policies have reflected a growing interest and commitment to capitalising on the incredible opportunities.

In 2003, the Human Genome Project was completed and the government put forward as justification for further investment the aspiration that 'greater knowledge of genetics will have a major impact on our understanding of human illnesses and herald a step-change in disease prevention, diagnosis and treatment'.[106]

Further research and charting of the genetic causes of a wide range of common and rare diseases led the House of Lords Science and Technology Committee to conclude in 2009 that, while it would still be several years before prediction of common diseases will lead to the realistic possibility of disease prevention, the use of genomic tests will have a dramatic impact on disease diagnosis and management.[107]

Motivated by the knowledge that genomic data could support personalised targeting of preventive interventions to those in whom they are most likely to be more effective than harmful, the government established the 100,000 Genomes Project in 2014. This marked the first substantial initiative designed to enhance our understanding of the genetic basis underlying various conditions. Sir Bruce Keogh described the project as a move 'to a new model of diagnosis and treatment based on an understanding of underlying genetic causes and drivers of disease and a comprehensive phenotypic characterisation of the expression of disease'.[108]

Evolution of health policy

Consequently, the NHS has regularly emphasised the potential for the project to 'improve the prediction and prevention of disease, enable new and more precise diagnostic tests, and allow personalisation of drugs and other treatments to specific genetic variants'.[109]

The most recent annual report of the UK Chief Medical Officer focuses exclusively on genomics because, as Professor Dame Sally Davies emphasises, 'genomics is not tomorrow. It's here today'. She goes on to note that, 'while the use of genomic technology for the diagnosis and treatment of disease is evident, its role for disease prevention is less obvious at this time'. [110]While there may not yet be sufficient

evidence for this next phase of genomic medicine, there are great opportunities for genomic insights to inform the prevention of serious ill health as well as specialised diagnosis and intervention.

As Genomics England continues its efforts to one day implement a national genomic service across the UK, there is still great a great commitment by the British government to the potential for genomics to offer further transformational change to disease prediction, diagnosis, treatment and monitoring.

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The PHG Foundation is a non-profit think tank with a special focus on how genomics and other emerging health technologies can provide more effective, personalised healthcare and deliver improvements in health for patients and citizens

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