Nesta

THE NHS IN 2030

A VISION OF A PEOPLE-POWERED, KNOWLEDGE-POWERED HEALTH SYSTEM

Jessica Bland, Halima Khan, John Loder, Tom Symons and Stian Westlake

JULY 2015

ACKNOWLEDGEMENTS

This paper was written by **Jessica Bland**, **Halima Khan**, **John Loder**, **Tom Symons** and **Stian Westlake**.

Many thanks to: **Lydia Nicholas** for helping write and develop the stories; **Jullie Tran-Graham** for helping with some of the initial research for Sections 3 and 4; **Helen Kay** and **Sir John Chisholm** for their help with information on Precision Medicine, as well as colleagues at NHS England and the Department of Health; **Michael Hallsworth** and **Hannah Burd** from the Behavioural Insights Team. The Academy of Medical Sciences policy team offered invaluable insight into the emerging discussions on the relationship between stratified medicine and personalised services.

We would like to thank the following people for giving up their time to help us understand the signals of change today and what these could lead to in the future:

Richard Barker, The Precision Medicine Catapult

Jenny Barnett, Cambridge Cognition

Fran Bennett, Mastodon C

Ewan Birney, EMBL–European Bioinformatics Institute

Angela Coulter, King's Fund Visiting Fellow

Andrew Cozens CBE, Acainn

Alisha Davies, Nuffield Trust

Chris Drinkwater, Ways to Wellness

Kevin Fong

Ben Jupp, Social Finance

Dr Steven Laitner, GP and Freelance Health Consultant

Neil Lawrence, University of Sheffield

Max Little, Wellcome Trust/MIT Fellow, Aston University

Nick Loman, University of Birmingham

Richard Murray, King's Fund

Nadim Matta, Rapid Results Institute

Dr Stephen Richards, Care Quality Commission

Adrian Sieff, The Health Foundation

Mustafa Suleyman, Google DeepMind

Ruth Thorlby, Nuffield Trust

Julia Wilson, Wellcome Trust Sanger Institute

Icons for each of the sections were provided under Creative Commons licenses. Some were provided under a public domain license.

Section 1 icon credit: Digital Health by pepf via The Noun Project CC BY 3.0

Section 2 icon credit: Knowledge Transfer by Duke Innovation Co-Lab via the Noun Project CC0 1.0

Section 3 icon credit: Community Health Advocate by Edward Boatman via the Noun Project CC0 1.0

Section 4 icon credit: Big Idea by Edward Boatman via the Noun Project CC0 1.0

The Shape of the NHS in 2030 section icon credit: Architect by Luis Prado via The Noun Project CC BY 3.0

Nesta...

Nesta is an innovation charity with a mission to help people and organisations bring great ideas to life.

We are dedicated to supporting ideas that can help improve all our lives, with activities ranging from early-stage investment to in-depth research and practical programmes.

Nesta is a registered charity in England and Wales with company number 7706036 and charity number 1144091.
Registered as a charity in Scotland number SCO42833. Registered office: 1 Plough Place, London, EC4A 1DE.

©Nesta 2015

THE NHS IN 2030

A VISION OF A PEOPLE-POWERED, KNOWLEDGE-POWERED HEALTH SYSTEM

CONTENTS

EXECUTIVE SUMMARY 4

1. PRECISION MEDICINE 10

2. A HEALTH KNOWLEDGE COMMONS 16

3. HEALTH BY AND WITH THE PEOPLE 21

4. TAKING HUMAN BEHAVIOUR SERIOUSLY 26

THE SHAPE OF THE NHS IN 2030 31

WHAT CHALLENGES LIE ALONG THE WAY? 33

WHAT COULD BE DONE NOW? 36

CONCLUSION 46

EXECUTIVE SUMMARY

This report offers a vision for the NHS in the medium-term future.

Most discussions of the future of the NHS have at most a five-year horizon. They generally begin with a familiar and foreboding list of challenges. An older population with more long-term illnesses and increasing expectations will be expensive to look after. Healthcare productivity has stagnated and further efficiency savings are hard to find. Drug costs are rising. Public funding for health is under more pressure than ever.

These are all serious challenges for the near future. But the longer term, specifically the run up to 2030, could offer more hope. The NHS has the opportunity to take advantage of two powerful and under-exploited sources of innovation that have the potential to make care better and, under the right circumstances, cheaper. These are the rapidly accelerating pace of digital technology, and the power of social innovation.

The report explores how these two trends could make the NHS and the wider health system better. It focuses on four specific changes. Two developments involve harnessing the power of knowledge to improve care.

1. Improvements in digital technologies enable, on the one hand, an explosion in the use of personalised medicine, underpinned by genomics.

2. New digital technologies also allow people to track and analyse their own health data, and to share this and other health knowledge with others in ways that will aid prevention and management of long-term illnesses.

Two developments making better use of the power of people.

3. Social innovation is the key to a revolution in how people are involved in their own care and that of others, improving the quality of care.

4. New insights into human behaviour will improve clinical quality and make it easier for people to lead healthy lifestyles.

This is not to say that there will not be other innovations in healthcare in the coming 15 years: medical science will of course advance, new drugs and devices will be developed, and management practices will evolve. Any future strategy for the health service will need to make the most of these too. It will also need to address head-on issues like the relationship between how services are designed and inequalities in the health of the UK population. Tackling public health issues like obesity will need sustained engagement with the food and drink industry and new approaches to regulation.

This report concentrates on opportunities that Nesta can see coming into focus through our programmes, research and partnerships. Even so, nothing about the future is certain; these innovations have much to prove if they are to have the positive effect on healthcare that we hope they will – challenges that we explore later in the report.

Despite these uncertainties, we believe that people power and knowledge power have an unusually important contribution to make to healthcare in the UK in the coming 15 years. It is one that is sometimes neglected in ongoing debate over the NHS of the future. There are champions for both among health service leaders, pioneering practitioners and a burgeoning community of digital health entrepreneurs. But the potential of people and knowledge power has not yet been absorbed into mainstream media and political debates about healthcare.

The future that this report focuses on may seem far off. Fifteen years extends well beyond the current NHS Five Year Forward View, and for that matter beyond the lives of this and the next Parliament. But preparing for a radically different future requires us to start now. The time to think about the potential of knowledge, power and people power is now. Making the most of people power and knowledge power will require long-term changes in practices, attitudes and behaviours; investments will take time to pay off. If these investments are not made, there is the risk that the NHS will become increasingly unsustainable, even if its near-term challenges are mitigated.

We hope this report, and the possible future that it envisages, will encourage this investment to happen now, rather than postponing until it is too late.

Innovation, technology and the future of the NHS

History shows that major new technologies, from the steam engine to the shipping container can change the world: but not on their own. They only deliver significant benefits when people redesign how they work, and sometimes even how they live, to make the most of them.

Factories were redesigned to take advantage of distributed electric power. Containerisation came into its own when companies developed new international supply chains based on the cheap transport it allowed. Effective vaccination necessitated the development of public health systems and campaigns. In each case, what changed the world was not just an isolated technology, but also the imaginative leaps necessary to make the most of it.

The NHS is the product of a wide range of technologies: centuries of accumulated medical science and clinical breakthroughs; decades of pharmaceutical research; and the political and managerial innovations required to set it up and then to run it.

But information technology and social innovation remain underexploited by today's NHS.

This is because of the steady rise of two trends. The rapid advance of digital technology has been driven by the inexorable advance of computing power and connectivity over the last half century. This enables a system like the NHS to make much better use of the power of knowledge to help patients, and to help them help themselves.

Alongside this, the world has seen a flourishing of social innovation. Governments and citizens have in the last two decades come to realise that social movements can tackle wicked problems that governments find hard to address. At its heart, social innovation involves harnessing the power of people – patients, carers, communities and citizens – to improve health.

These two trends mean that knowledge and people will be increasingly valuable assets for the NHS in the future. Digital technologies make knowledge easier to create: for example, through genome sequencing, routine gathering of biological and behavioural data, or curation of patients' knowledge and insights. Social innovation multiplies the power of volunteers, engaged patients and communities.

> *"We need a system built from today's signature technologies – not the signature technologies of the 20th century. Buildings that provide electricity and people with knowledge will become software and computational power with intelligence in the cloud. And products become services tailored to you, your genes and your behaviour... Things are changing from buildings, people and products to software, services and mobile devices."*
>
> **Andrew Thompson**, Proteus Digital Health, ***Refilling the Innovator's Prescription***

Of course, information and citizen action have always had a role to play in healthcare, albeit a supporting one. Self-care has long been recognised in terms of remembering to take medicine or managing physical fitness. At least two transformational health movements – hospices and first aid – were social innovations then co-opted by official health systems. The NHS has sought to incorporate expert patients into its models of care since the 2000s. On the information side, data on the geography of a cholera outbreak in 1854 led to one of the first local authority public health interventions. The NHS patient number system means that the UK can make decisions about improvement to healthcare based on some of the most detailed health statistics in the world – from morbidity to prescribing data.

But the immense and growing power of digital technology and the renaissance of social innovation suggest that both these trends have much more to offer. This paper is an attempt to imagine what the health system might look like in 15 years' time, if these innovations are fully adopted and the NHS reconfigured around them.

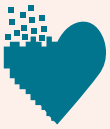
Why 2030?

In an age of strained budgets and regular crises, thinking about what happens in 15 years time may seem frivolous. But when major technological changes are afoot, it is often impossible to understand them without lifting your eyes at least briefly to the horizon.

Thinking freely about the far-off future helps identify changes that may not be urgent today, but could be the beginning of something important. This is not a matter of predicting the most likely advancements. Useful futures projects think creatively about the kinds of services that could be developed based on trends, technologies and movements visible today.

2030 Vision for the UK's health system

Each section in this paper deals with a different aspect of a 2030 health system powered by more people and new kinds of knowledge. But what do the four parts look like when they're put together?



By 2030, precise and rich information about patients means that medical researchers better understand how complex factors interact at an individual level. A stronger data infrastructure linking doctors and researchers means that genetic and other biological data, as well as day-to-day behavioural data, is part of decision-making in the clinic. **(Section 1)**

Self-monitoring technology will be ubiquitous, and used by many to monitor their health. Digital patient portals mean that healthcare is truly personalised – offering people the chance to build their own interaction with the clinic. There are also digitally-reinforced public forums for health discussion, where anyone can engage in debates about health issues and challenge standard practices. There will be a much greater understanding among the public about the benefits and challenges of sharing data. There will be ways for this social movement to reach inside the NHS, and for traditional services to find a way to take on board new kinds of expertise. **(Section 2)**

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 this. Healthcare professionals will work with people to identify emotional and practical support as well as clinical treatments. Volunteers and non-clinical staff will support people to maintain healthy behaviours and access 'more than medicine' services such as peer support networks. Millions of people will be mobilised to volunteer in the community and formal health services. **(Section 3)**

Policymakers will need to take seriously the design of health interventions and treatment, as a powerful influence on the uptake of healthy behaviours. Through understanding behavioural insights, the design of many things – from city centres to medicine packaging – will go with the grain of the rest of people's lives. Healthcare will not take place in isolation, but via a flexible set of services that makes it easy for people to live healthy lives. This may include making it easier for people to undertake exercise and eat well. Health professionals will be better at tailoring treatment and intervention in response to a patient's lifestyle and changing condition. **(Section 4)**

New services have replaced or changed today's institutes of care. Personalised care will be best provided by a frontline that can adapt and respond to patient's needs and expectations. Staff will help patients to create integrated pathways that embed specialist input. They will also have opportunities to experiment with changing the services they provide, through structured schemes for problem-solving and trialling new interventions. **(The shape of the NHS in 2030)**

A financially sustainable NHS

The primary motivation for delivering this kind of health system should be improved healthcare outcomes. But there could also be significant financial gains. These changes could address three drivers of increasing healthcare costs: demands on primary and acute care, expensive but sophisticated treatments and management of long-term conditions.

As with most transformational innovations, these financial benefits are not guaranteed. Community-led care and information technology have had a mixed record of driving cost improvements in the NHS. Their ability to make the health service financially sustainable is dependent on six factors:

Self-management and peer support must translate into reduced demand for primary and acute care services. This would mean people are confident and knowledgeable about their conditions and this reduces exacerbations. They know that data they collect will lead to an alert if they need medical attention. They would visit primary care less and have fewer emergency admissions. Discharge would be quicker for those that do have a hospital stay.

Greater personal responsibility for health must result in the prevention of people developing lifestyle-related health problems. This would also reduce the need for health services and would take some of the pressure off the cost of prescriptions and the need for treatments. There would be wider economic benefits from a healthier population, such as fewer work days lost to sickness.

Precision medicine improves the efficiency and impact of treatment. Precision medicine can increase costs by increasing diagnoses and extending the scope and range of possible treatments available. It also has the potential to reduce costs through efficiency gains, such as reducing the use of ineffective treatments or medications. Better understanding of disease could prevent the expensive complications that come with late diagnosis, delayed or ineffective treatments.

Research will be more quickly translated into treatment. Drug development today is expensive and can take decades to reach patients. Far more accurately targeted treatment development and regulatory processes would permit a number of steps to be executed in parallel. This could cut almost an order of magnitude out of the time to market, permitting lower prices.

Changes to services must result in sustained reductions in errors and increases in effectiveness. These changes include redesigning interactions, communication, equipment and systems in a way which takes better account of the influences on people's decision-making. This could impact multiple aspects of health expenditure, through fewer missed appointments, misdiagnoses, inappropriate referrals and prescriptions, and better adherence to medical treatment.

This must be done at scale. Efforts so far have largely tinkered at the edges of mainstream activity. At such limited scale it is very difficult to fundamentally change expensive legacy systems. Only once changes are at a greater scale will it be possible to reduce the need for expensive buildings or services. The benefits of specialist care centres, provided for patients with similar symptoms will only be realised when these become the basis for healthcare provision.

Structure of the report

This report explores four big ways that knowledge power and people power will affect the NHS in 2030 and the wider health system, through precision medicine, new forms of health data, people-powered health, and the use of behavioural insights.

The report's first four sections cover each of these big changes in turn. They include descriptions of three characters who come into regular contact with health services. Allie is under five with a stay-at-home dad living in a city centre. Bhakti is in her 50s and has diabetes. She has a teenage daughter with physical disabilities and a lot of demands on her time. Colin is in his 70s. His physical health is starting to deteriorate due to age, and his wife recently passed away.

Each section then describes the landscape of services and initiatives that might exist in 2030 to enable these experiences, as well as some signals of change from activities today.

New knowledge used differently

Section 1 concentrates on where new kinds of medical information about individuals will come from, as well as how it is interpreted in stratified care. Section 2 moves onto people managing their own health information and new digital platforms for supporting patient-led research and care.

More people managing health

Section 3 looks at the possibility of a social movement for health: people being trusted to have a more active role in their own health and to look after others, supported by the NHS, as well as people supporting health services. Section 4 explores how insights into human behaviours can help us to redesign health services, products and treatments in a way that reflects better how people live their lives and make choices.

This is followed by a summary of how this will change the function of the NHS (The Shape of the NHS in 2030). The final sections focus on the challenges involved in getting to the best version of this future (What challenges lie along the way?) and ideas for how these changes can be supported today (What could be done now?). Concentrating on the widest gaps between these ideas and current policy, the Conclusion includes four proposals that would support new functions in the health system:

A. Digital platforms and widely agreed protocols for developing new kinds of health knowledge and responding to the latent demand for taking part in healthcare. These should make clear the role of new kinds of knowledge relative to the biomedical model of human health. This needs to support deliberation and negotiation over what is useful for improving health.

B. Prototypes for health data sharing that concentrate on understanding emerging attitudes to digital privacy. These could focus on specific products and services. But should be used as a testing ground for developing publically legitimate governance of health data.

C. An institution that supports and evaluates People Powered Health research. This starts to build an NHS that works as a natural laboratory. It should be easier for frontline staff to experiment with the way they run their services, whether this is adopting behavioural insights or troubleshooting systemic issues.

D. A central institution to set standards and mandate processes that will maximise the clinical and research value of large genomic and other data sets as they become available. The institution will probably be the best place to take responsibility for data best managed at a national level.

1. PRECISION MEDICINE

New knowledge used differently: medical information about individuals and its interpretation into stratified care

Allie's parents decided they wanted to know more about their daughter's health. They signed her up to the national whole genome sequencing trial from birth. Ten million people in the UK have now had their genome sequenced; one million of these were done at birth as part of this national research project. As the longitudinal study has only been running for a decade, most of the research it has produced so far is about new treatments for rare diseases in young children. Allie's grandmother reads up on genome sequencing study eagerly, and sends articles to Allie's parents. Allie's father appreciates this, but has decided to give his mother only limited access to the study's participant portal: she can see the discoveries that Allie's data donation contributed to, but not Allie's full genetic sequence and up-to-date risk profile.

Allie's father attended a prenatal course on precision care for young children. The local nurse practitioner explained a range of molecular-level monitoring options. He chose the longitudinal genomic study because of the early diagnosis and extra access to preventative care it provides. He could have also requested home-monitoring for protein and transcripts in Allie's blood. But he wasn't interested in using this kit just yet, and so just signed up to a newsletter about scientific developments in the area. High levels of noise and air pollution on their street qualify them for household sensors, and access to support systems for recording changes in Allie's sleep patterns and lung capacity. At age two, her lung capacity stops increasing at the usual rate – an early signal that she might have asthma.

Bhakti is grateful that when her physically disabled daughter was young and struggled to communicate they had access to ingestible sensors. These often alerted her to a high temperature or an episode of acid reflux before it was externally visible, and Bhakti and her daughter's doctors could precisely track the impact of medications on her metabolic problems. Over time the data produced a hugely detailed portrait of the condition's progression and the impact of different treatments. Bhakti refused to share the data until her daughter could participate in the decision. They recently discussed the issue. Bhakti's daughter is concerned because her condition is so rare that this intimate information about her body might be traced to her, but wants to help others too. They have scheduled an online conversation with a data technician to discuss possibilities.

Every evening Colin provides a blood sample to the overnight proteomics monitoring system by his bed and every morning he checks the results. He always looks first at the levels of a protein that can develop into a plaque at the base of the brain, causing Alzheimer's disease. This data is fed back into a national research database, which is used to improve understanding of the early biological signals of cognitive impairment.

Colin has an activity-monitoring system, reminding him if he forgets to eat or take his medicine, and raising an alarm if he falls over or is inactive too long. He watched a lot of review videos and participated in an online Q&A with representatives of different brands before deciding on the system and specific sensors he is interested in. He struggled to calibrate the system. So his son rushed round five times in the first week to false alerts of falls, and the system continually nagged him about missed meals and exercises that didn't seem to make sense. Colin and his son used the national patient portal for advice. Colin decided to share data with a team working to optimise routine-learning based at a German university, which is an approved NHS research partner. In return for his data, they offer suggestions on how to calibrate sensors and make him a beta tester for a smarter learning system.

2030 LANDSCAPE

By 2030, healthcare benefits from more precise knowledge about how genes affect different individual's physiology. Detailed data sets on human genetic information (genomics) are complemented by phenomics: data on phenotypes including human proteins, hormones and metabolic processes. These are combined with ubiquitous monitoring devices and sophisticated data analysis technology. Large investments in precision medicine came with heavy R&D costs. More monitoring technology initially meant more diagnoses. Together these initially increased the cost of treatment the UK population. But the gamble paid off. Now, it is possible to quickly and accurately diagnose a condition, and create a treatment plan tailored to the individual using a new generation of decision-support tools. The benefits for precision care are now felt in cost terms as well as clinical ones.

New knowledge fuelled by new kinds of data

Diverse forms of data and knowledge will be used in clinical medical settings. There is better understanding of the multiple factors at play in a single person's condition. Depending on the kind of condition and possible treatment options, a clinician may look for some combination of the following:

Genetics. Most people have had at least some of their genes sequenced during their life. Individual genetic profiles are correlated with different reactions to a given drug. Responsiveness to cancer treatments is related to specific cell mutations. The likelihood of developing certain conditions has a known genetic basis.

Transcripts and proteins. These biological markers are signals of how genetics are expressed in a particular person. Complete sets of this phenomics data, would be part of a biologically-precise picture of human health. There is likely to be more conclusive understanding of epigenetic factors: when the physical environment or lifestyle of previous generations affect a person's gene expression.

Molecular information on disease. Sequencing and other pathology tests are also applied to molecules of infections. It will be easy and quick to profile infections or screen for disease.

Imposed environmental variables. Sensors checking things like air quality, light and noise levels are everywhere. There is more knowledge of how these factors affect human health. Local air quality or lack of open space are already known to affect health.

Comorbidity and polypharmacy. Profiles of patients will make the interrelated effects of multiple diseases and drug regimes clearer.

Lifestyle and diet. These factors interact with treatment and can heighten specific risks.

Targeted treatment backed by strong research

Precision diagnosis is supported by specialist centres, providing treatment and support for individuals with similar groups of conditions or in need of similar care. This reorganisation aligns the care system with the new kinds of precise medicine and profiling that are now possible. Self-monitoring technology updates these profiles and helps direct people to the correct centre when they need care. An expanded MSc programme for NHS staff in genomic medicine has created a generation of genomic medicine advisers in local services.

This is backed by a strong data analysis infrastructure. The pathology lab in each NHS trust manages fewer tests each day; biomarker tests are now used routinely in pharmacies and clinics, without the need for a lab. Self-monitoring data is analysed partly by private

providers, and partly by a distributed network of government-owned facilities. Decisions about whether to change medication or bring a patient into the clinic are then made by local specialist centres. Clinicians in these centres have access to much richer data in order to make a decision about a patient.

This is well-integrated with biomedical and digital health research. Frontline centres are also research facilities, connected to a network of regional research hubs. Together they continue to try to understand the complex interactions between biological, behavioural and environmental factors in an individual. This approach aids faster translation from lab to clinic. Accurately targeted treatment development and regulatory processes permit a number of steps to be executed in parallel. Large biomedical research companies have changed their business model. They work on many more projects at any one time, each of which will be highly effective in people with a specific profile. Treatment is less focused on pharmaceuticals, including more devices and behavioural change too.

Large-scale data analysis – over massive populations with many identified characteristics – requires high-performance computing meaning that there is still one central bioinformatics research campus. This has become the centre of global efforts to create a common language for describing human biology and behaviour, i.e. shared genotype-phenotype standards. Bioinformatics is pushing data scientists to produce more complex models than any other field. New centres in biological computing exist at several UK universities, with funding from technology multinationals.

Precision care from precision medicine

There are clear advantages to healthcare that connects precise information about a person and the relevant medical research:

- Pre-emptive or earlier treatment will reduce the burden of care.
- There will be new kinds of treatment responding to complex features of disease.
- The number of cycles of treatments would be hugely reduced, saving considerable time and money for each patient journey, improving quality of care at the same time.
- For many conditions it will be possible to identify subgroups of patients who all need a similar approach. For these patients assets and working patterns can be optimised to meet demand efficiently.
- These subgroups will change the treatment development pipeline too, allowing more targeted trials and deployment of new techniques.

Section 2 links these changes with patients' access to the health system.

SIGNALS OF CHANGE

Today's medical knowledge is based on the average response to a particular treatment. However, drugs and other therapies do not have identical impacts on everyone; there is wide variation in response, and many people have no response at all. Individual variation in biology and behaviour has a role in explaining these differences. The way that these factors are manifested in the human body is complex and still not well understood.

There are programmes gathering and interpreting the data needed to develop precise medicine. The 100,000 Genome Project is perhaps the most well developed example – sophisticated whole genome sequencing and well developed data collection and

management. There are increasingly accessible tests for molecular data about humans or infectious disease. These might provide the first widely-used precise diagnostics. There will also be new forms of patient data collection and smarter ways to move data around the health system.

Genomically-precise medicine

The UK is home to a trailblazing project offering whole genome sequencing for 100,000 individuals where more knowledge about their genome could lead to better treatment for a rare disease or cancer. The pilot for the project has had a few early successes, **diagnosing some conditions that can be treated**. It's predecessor, Deciphering Developmental Disorders, sequenced part of the genome in over 8,000 children, **finding 12 new genes** that contributed to rare diseases. It's not clear whether the rationale for whole genome sequencing goes beyond those with rare diseases and specific cancers. But the infrastructure created by the 100,000 Genome Project is a valuable first step towards a national healthcare system that is capable of delivering precise, personalised treatment.

There are a number of proof-of-concept examples of the gains that come from more genomically precise medicine. Oncotype DX tests predict a patient's benefit from chemotherapy as well as her risk of breast cancer recurrence. They can **reduce chemotherapy use** by 20 to 35 per cent and avoid costs of $4,359 per patient per year. This is a net saving of $384 annually taking into account the cost of the test. Widespread whole genome sequencing would likely pick up many more relationships between genes and responses to cancer drugs. Increased knowledge about the genetic basis of developmental disorders should lead to more preventative treatments.

The cost of Oncotype DX tests is restricting take up in the UK. Technology improvements are needed to make these treatments more financially viable. There are promising steps forward. Whole Genome Sequencing at scale as part of the 100,000 Genome Project costs less per person than one Oncotype DX test.

Quicker, cheaper biomarkers

Small amounts of data already provide biological markers of disease. A small DNA sample (rather than a whole genome sequence) is enough to provide useful information when looking for a well-known genetic mutation. Cancerous cells produce specific proteins that appear in the bloodstream, which can be used to **predict the patient's response to treatment**. Particular proteins **can be an early sign of dementia** or of potential changes in other physiological factors like the immune system.

Portable tests for specific genes, transcripts or proteins now exist and will become more accessible in the future. Oxford Nanopore's MinION is currently used with a laptop or PC, but future devices may run with a smartphone or embedded in household or workplace devices. The MinION Access Programme offers researchers access to the kit. Early successes for the MinION include detecting the source of a salmonella outbreak in Birmingham's Heartlands Hospital. Sequencing took 15 minutes, followed by two hours of analysis to identify the strain.

It is also likely to become much easier to take samples from people. There are new non-invasive technologies, like those that use ultrasound combined with microwaves to monitor molecules in the bloodstream through the skin. These are likely to face lower regulatory barriers. There are also **microneedles** that can deliver drugs without the risks that come with injections.

Population level data collection

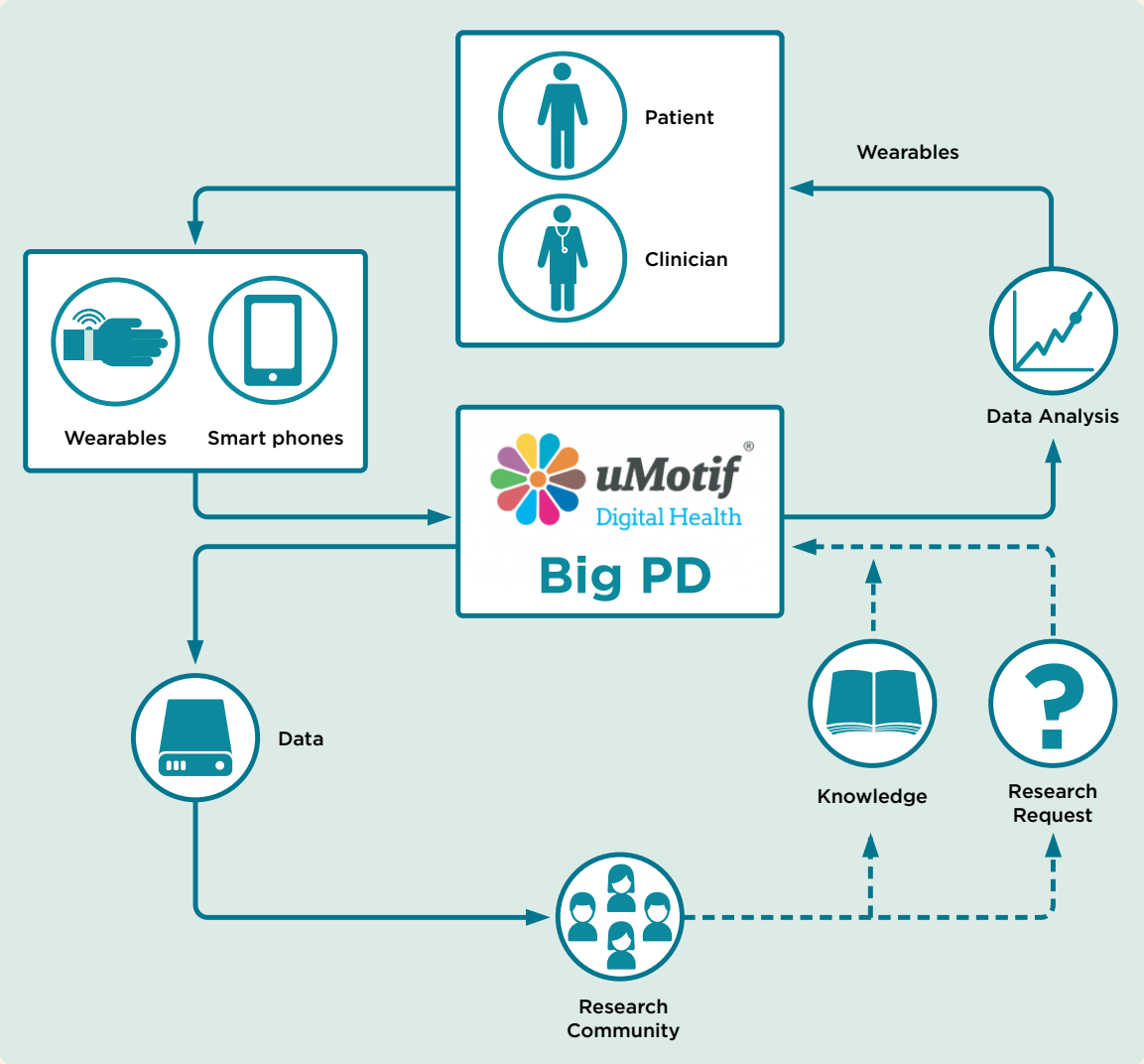
There are some monitoring technologies that have already made it into the clinic. Cambridge Cognition's tablet app for assessing cognitive function is used in GP surgeries across the UK. In the future this kind of tool could be used for a more continuous monitoring of behaviour: providing new kinds of information for researchers and an early warning system for those at high risk of dementia. Neurosky produce consumer EEG kits, which measure brain signals related to concentration levels. They work closely with the research community. Treatment for stroke victims **can be changed in response to real-time information** on the brain activity from patients – in the future this might be done using the portable headset.

> *"When patients exhibit early symptoms of Alzheimer's or Parkinson's, even relatives and friends can find it difficult to recognise them. It might be that tracking patient behaviour through for example mobile phones could allow detection of symptoms for early diagnosis and treatment. My worry is that this would require scanning everyone every day, and is just a bit too Orwellian."*
>
> **Professor Neil Lawrence**, Professor of Machine Learning and Computational Biology, University of Sheffield

Machine learning is a group of computing techniques that may be able to discover new signals of illness or monitor the effects of treatment. It requires huge volumes of data to be effective. It is already employed to automate **the analysis and diagnosis of medical images**. Radiological images are analysed to find features without a doctor there to supervise or direct it. These techniques applied to information from wearable technology could provide a step change in the fine grained information we have about human behaviour and health.

Nesta has developed the idea of digital health communities, as a way to describe new kind of emerging intermediary in this area. Through the Centre for Social Action, Nesta and the Cabinet Office have funded uMotif's Big PD project. This is a data driven community for those with Parkinson's Disease (PD). Drugs to control the symptoms of Parkinson's wear off in hours, vary in their effects unpredictably from person to person, and become less effective through repeated use. The 20 minutes per year that patients spend with a consultant is rarely enough to get this medication right. Big PD aims to use accelerometer and other data to track body movements, and give early warning signs of medication wearing off. Clinicians, and often patients themselves, will be able to medicate much more accurately. This data will also be useful for research and early diagnosis. PD is often present for up to ten years before diagnosis. This is what the ultimate data sharing system, centred on a new digital health community, might look like.

An ideal digital health community's data sharing system



Smart consent

There is range of new tools designing consent systems that are more attuned to people's concerns about how their medical data is used in research. This includes dynamic consent: where participants use a web interface to consent to specific research using their data, and where they can reverse that decision. The 10,000 Personal Genome Project, run through UCL in the UK, offers an online course, in order to ensure informed consent. All participants have to take this before having their genome sequenced. The UK's BioBank process for providing biological samples includes one-on-one consultations before participants give consent. This is an expensive and time-consuming process. Changes to the European data protection legislation will affect consent for data used in research. This will be most disruptive if it requires consent for each research project rather than blanket consent for researchers to use individuals' information in their research.

2. A HEALTH KNOWLEDGE COMMONS

New knowledge used differently: people managing their own health information, personalising their care and creating new kinds of health knowledge

Allie's father used the video-diary function on NHS Citizen to log her responses to 'at home' early years activities like the impact of structured play on cognitive development. It is normal to be involved in these kind of studies. He met some other parents online, discussing the limitations of the standard 'at home' tool for those without access to a garden. They are now working together to develop a new programme of activities that can be done with outdoor space. They've employed an online interaction designer to helped them create the first prototype, but they have yet to raise any seed funding to take it further. There are tax reliefs for investments in health companies that make use of data stored and managed by the NHS – so they are hopeful. The UK's unique, single clinical research infrastructure means the video data can be linked into Allie's medical record and used for future clinical consultations. At a consultation about Allie's early signs of asthma, the doctor pulls up the videos as part of their discussion about whether Allie's day-to-day life has been affected.

Bhakti and her diabetes counsellor chose a monitoring system that lets a specialist centre make most day-to-day decisions, while leaving Bhakti completely in control. In the past Bhakti's management of her diabetes faltered under the pressure of her caring and volunteering commitments. She moved to this new regime after an adherence consultation, which she was invited to after a few missed appointments. Her counsellor pressed the point that while it is natural for her to put her daughter first, an effective carer keeps themselves healthy too. Bhakti decided that for now, the best solution is to delegate as many decisions as possible. She wears a blood glucose monitor on her wrist that uses ultrasound to test her blood through her skin every few minutes. The monitor connects with an app on her mobile phone, which securely sends the data to her diabetes specialist centre. The data analysis system housed at the centre sometimes recommends small changes to dosage and diet, which are checked by a consultant before being sent to Bhakti. Significant changes trigger the system to book an appointment. All the data is available to her should she want it. But for now she chooses to only see validated notifications that require action. Though her counsellor advised continual monitoring of weight and exercise, Bhakti opted to have the app compile and send only weekly summaries, hiding daily figures even from herself. When the data was available at her wrist at all times, she found short-term fluctuations demoralising. For now this system suits her well, and she knows she can engage more actively at any time.

Colin worries a lot about his memory, but perhaps his slip-ups are just part of adjusting to living alone. He often discusses these fears with friends at the local memory cafe. He and a few other members have used a series of memory checking apps. They share concerns about the apps' accuracy. None are fully licensed according to the latest European standards, and results vary between devices and software. Once a month, Colin visits the local pharmacist for more in-depth tests on cognitive function. He gets a free consultation with a pathology specialist to discuss these results, alongside those from his daily proteomic tests at home. Colin's official risk reading has remained unchanged at 'medium' for years. He still struggles to trust this assessment, but is learning to moderate his own worries about ageing with professional advice. After a year of self-monitoring, his pharmacist supports an application by Colin and his friends at the cafe for funding for a research study using the apps and proteomic data. It is a huge relief to be able to do something productive about his worries.

2030 LANDSCAPE

By 2030, sensor technology will be everywhere. Monitoring changes in biological health and behaviour is easy and cheap. Most people use devices that pick up these signals to monitor their own health. The NHS and employers have responded to incorporate these trends into how they provide for health and wellbeing. This data can be easily integrated with existing clinical data.

Smartphones and wearables came first. But soon technology companies were producing portable versions of more complex monitoring systems: air quality monitors, EEG brain sensors and molecular testing kit to find out whether an infection is bacterial or viral. This pervasive data collection allows people to perform new kind of constant, mobile health checks on themselves. It's akin to the dashboard, gauges and alarm signals in a car today, making it easier for patients and their doctors to track what is happening with their bodies.

Most acute care centre appointments are made automatically. When patients arrive at a clinic all of the detailed data about them will have been analysed ready to help diagnose them. These early warning systems have reduced the cost of acute care, particularly for conditions that can be managed through preventative measures. Pharmacists and local health services help people interpret the data they have collected about themselves, referring them to specialists when appropriate. This is vital at a time when most healthcare spending is on managing long-term conditions, which require close monitoring that can now be done outside the formal health service.

There was public concern when portable monitoring technologies first became available. After this period, enforcement of privacy laws increased and a fast growing section of the population demanded easy routes to sharing their data with each other, doctors and researchers. People accept that the advantages of data shared under these conditions greatly outweighs the potential risks.

For some, monitoring technology is part of everyday decision-making. They manage their own care, experiment on themselves, monitor the effect of lifestyle changes and take part in massive online patient data collection exercises to inform medical research and national policy decisions. Something like an expanded version of the NHS Citizen platform provides online discussion platforms. The National Institute for Health Research has programmes to support patient-led research, including managing peer review and developing it into national learning resources.

Others are less interested, but are happy to sign up for whole genome sequencing and regular physical check-ups. Some are more wary of how data about them could be used by doctors and researchers. They maximise their privacy settings on the national digital patient portal.

People in the UK in 2030 will use a digital patient portal for other interactions with the health service too: appointment bookings and contacting specialists and viewing test results. There will be a hugely expanded digital NHS Choices, including 111-Online options for immediate advice from doctors. This and other platforms provide routes into research: experiments in service delivery, advice on how to work with medical technology researchers or take part in large-scale clinical trials.

Public Health England has partnered with media organisations and behavioural insights experts inside the NHS (see Section 4) to provide schemes for people to better manage their own health, which reach 97 per cent of the population.

This system is different from the current frontier of digital health – online appointment booking systems and medical records. It is like peer–to–peer finance compared to an online bank account or eBay rather than a simple online shop. The health knowledge commons offers everyone the chance to integrate their own information and preferences with the health service they receive. They monitor themselves, choose the services they use and support those groups and individuals that want to create new kinds of healthcare.

SIGNALS OF CHANGE

There are initiatives today that illuminate the plausible direction of change.

Wearables

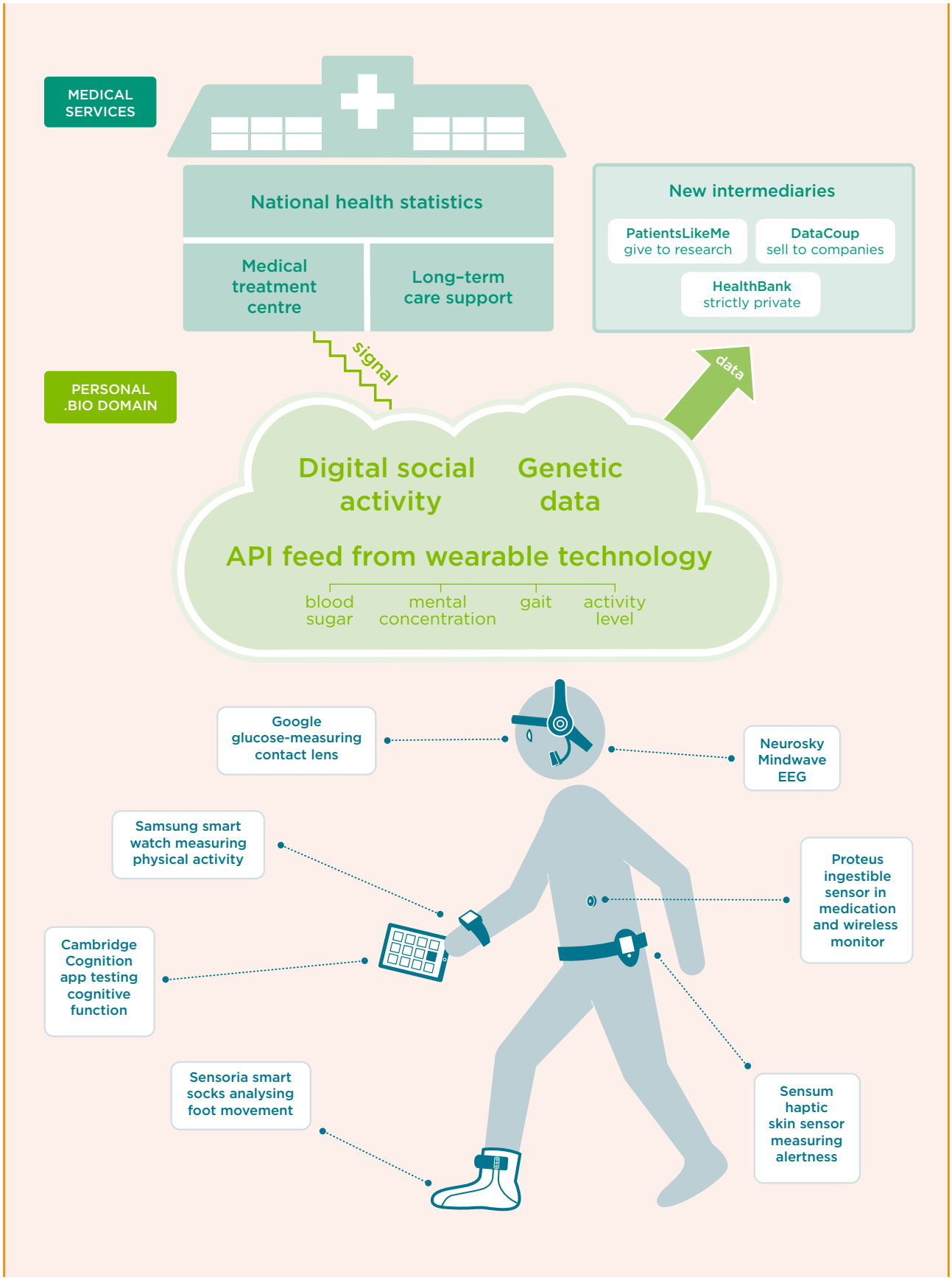
There is a new generation of consumer technologies that we wear all the time – from heartbeat monitors to materials that can **sense haptic skin response**. These are now stretching out into small sensor technology, including **pills with ingestible sensors in them**.

> *"Wearables can empower people, helping them bring much more information to consultations... In 2030, there should be a way for GPs to access this data (as long as they have the patient's permission) and surgeries to be able to do something about it."*
>
> **Fran Bennett**, CEO, Mastodon C

Early adopters of these kinds of technologies are often also innovators themselves, and often want to customise a product.

The quantified self and biohacking movements are fiercely independent groups starting to use these technologies, as well as more interventionist approaches, to monitor themselves and improve their health. The Grindhouse wetware group in the US is one of the most fringe efforts. They have developed their own medical tracking arm implant. The Circadia records body temperature, heart rate, and time. The three–inch long device sits under the skin and automatically transmits information via Bluetooth. It can be programmed to display health warnings—using a smartphone to do the analysis—on the user's skin with LED lights.

A 2014 Nesta report provides a snapshot of the new wave of medical technologies starting to hit the mainstream. The summary of these technologies and associated services was built up into a vision of portable digital health in the future:


MEDICAL SERVICES
National health statistics
Medical treatment centre
Long-term care support
New intermediaries
PatientsLikeMe
give to research
DataCoup
sell to companies
HealthBank
strictly private
signal
data
PERSONAL .BIO DOMAIN
Digital social activity
Genetic data
API feed from wearable technology
blood sugar
mental concentration
gait
activity level
Google glucose-measuring contact lens
Neurosky Mindwave EEG
Samsung smart watch measuring physical activity
Proteus ingestible sensor in medication and wireless monitor
Cambridge Cognition app testing cognitive function
Sensoria smart socks analysing foot movement
Sensum haptic skin sensor measuring alertness

Maturing systems for managing electronic health records

In Denmark, every citizen has had access to a health portal since 2003. They can choose their services, participate in their own treatment choices and take part in 'chat rooms' where patients and their relatives can meet others and consult health professionals. The portal provides the 150,000 Danish health professionals with information to make evidence-based decisions. At first 30 to 40 year olds used the service most. It is now used equally by 60–70 year olds. Although the two groups vary in the kinds of services they use. In comparison, after almost a decade and several hundred million euros, the Dutch parliament stopped the roll-out of digital health records in 2011 because of privacy concerns. A new system has now been approved. It has more transparency built-in; it will show patients which clinicians and researchers access their records and when. The different passage of digital health records in countries, so close in culture and politics, illustrates the sensitivity needed in designing these services.

A reinvigorated digital public space

There is a continued public appetite for trustworthy health information. The NHS Choices website has had over one billion visitors so far. NHS Citizen is being developed as a digital platform for supporting wider public engagement with health issues and health services.

The idea of a digital public space is being discussed in the context of the BBC's case for renewing its Charter. This centres on designing new ways to access ever growing library of digitised media, including educational materials.

> *"So what would the 'Digital Public Space' look like? It should have all the original values of the 'Analogue Public Space', plus some amazing new features and services that were previously impossible or unimaginable... To get there, perhaps we may need help from the source that created the BBC in the first place – an ambitious desire for there to be an infrastructure constantly developed in the public interest."*
>
> Tony Ageh, BBC Controller of Archive Development, **OpenDemocracy.net**

Patient communities

Patient organisations are increasingly spaces of innovation. The novelty of their approach lies in the use of their experiential and clinical knowledge to make themselves part of the networks of experts on their condition. These groups do not want to be relegated to the role of fund raisers and passive providers of data but are increasingly engaged in the process of producing and circulating knowledge that is critical to their condition. **The AKU Society** in the UK recently used crowdfunding to finance a clinical trial into the rare disease their members suffer from. They also have an active online forum and clinical partners.

Consumer data protection

Debates about personal data protection for consumer continue. A Spanish man recently won a case against Google, forcing the company to remove some sites from searches for his name – creating a right to be forgotten. New initiatives like a yearlong **Citizens' Advice's project** are pushing against a culture of 'ticking, clicking and hoping for the best'. There have been promising privacy-protecting technologies in recent years, from personal data stores to apps that alert users to the details of the terms and conditions they sign up to. New European data protection legislation may improve oversight on how companies use consumer data. But this will depend on the final legislative decision and how it is implemented nationally. The link between consumer and health data is likely to get closer, as will the kinds of issues that come to the surface.

3. HEALTH BY AND WITH THE PEOPLE

More people managing health: people looking after themselves and each other, supported by the NHS.

At her first meeting with Allie's parents, the midwife noted that they struggled to engage with aspects of shared decision-making. The session was at risk of becoming a one-sided explanation rather than a true discussion. So the midwife asks if they'd like to be provided with a link worker: someone trained in motivational interviewing, communication and health advocacy. He finds that Allie's parents are enthusiastic and opinionated about their daughter's care but unused to engaging in open discussion with health professionals. Hearing that Allie's dad's plans to be a stay-at-home father, and that they have no family and few friends nearby, the link worker suggests trying out a number of local parent groups, including a 'what works' club which teaches data capture and coding skills alongside parental coaching. Allie's father is reluctant at first but joins because it also gives him a valuable qualification in embedded solutions. He stays because he appreciates the new-joiner crèche's advanced educational toys and the friendships that develop with local parents.

When a series of group sessions that measure breathing after exercise show Allie has the first indicators of asthma, her father is concerned, but glad they can act soon to slow its progression. His motivation to support the what works club soars and he starts to volunteer at the crèche, which Allie loves too. He appreciates that he can use his developing skills to support others while spending time with his daughter. Allie's father's detailed feedback on health services they receive earn him an enhanced Peer Support Premium, which is paid by the local services commissioner to the club. It becomes clear that local air pollution has contributed to not just Allie's asthma, but to many other local children too. The club decide to use the peer-support money to fund an analysis of the data from their NHS-supplied air pollution sensors. They use this to launch a successful campaign to lobby the Council to put traffic calming measures into local roads.

Bhakti is a qualified expert carer, paid to run three therapeutics sessions a week helping parents of under-fives with severe physical disabilities. She received similar peer support when her daughter was young, but as the sessions were run by a small charity they waxed and waned according to the unpaid, unregistered teachers' caring commitments. Bhakti was a member of the national support group for her daughter's genetic disorder and a local group supporting people with severe physical disabilities. Both groups were part of a national campaign by patient-led groups for recognition of expert carers' skills and value. She was in one of the workshops in which NHS and patient representatives debated how expert patient qualifications would be taught and assessed, and their work remunerated. She brought in data from a survey of over 1,000 families' experiences of missing training, and a comparison of the cost to the NHS of trained versus untrained carers. This became part of the business case that led to a formalised expert patient training programme.

Colin has osteoarthritis in his knees. He struggles to do the gardening he used to enjoy, but knows exercise is important, despite the pain. He joins a group that matches people who have completed courses of gardening therapy for depression with people who can no longer manage their gardens alone. The volunteer gardeners' arrival twice a week motivates Colin to push himself. Over the summer they become good friends and in autumn they share the

rewards of their vegetable plot, laying out a healthy feast as part of a street party. Colin invites another volunteer who assisted his wife whenever she was discharged from hospital after her surgeries; she is impressed and relieved to see how active he has been since the bereavement.

Colin used to resent trips to the primary care clinic – each visit marked an occasion when his pain medication failed. But he recently started helping other older people use the personal health portal in the clinic's preparation area. His enthusiasm for wearables and data resonates with the other older clients more than younger volunteers have in the past. He has more patience with their mobility challenges. From his wife's last years, he empathises with many people's difficulties managing their own health and medication while mainly focused on a partner's care. One person he helped then convinced him to join her at an exercise session designed for people with arthritic joints. The specialist sessions have really helped his pain.

2030 LANDSCAPE

In 2030, most people feel in control of their health and know there is support to help keep them healthy – whether that's managing a specific health condition or just doing more exercise. When clinicians diagnose someone with a major health condition, they also connect them to other people with the same condition to get emotional and practical support at a critical time.

It is routine for health coaches and service navigators to work alongside clinicians and patients to enable people to choose and control the social and medical support they need to live as well as possible. Non-clinical professionals are now integrated within health service teams to create a bridge of support between the clinical world and life at home.

More widely, local communities donate their time and skills to health services. Volunteers are often motivated by their own positive care experiences and good will towards the NHS. Others have ambitions to work in health themselves. Volunteers are trained and given structured roles that complement paid healthcare professionals. Ex-health professionals are 'on call' to volunteer in over-stretched health services at times of high pressure, such as in winter months.

Beyond formal health services, there are many more ways to support other people. Day-to-day acts of kindness build vibrant and strong neighbourhoods and they also directly improve health and wellbeing – for the giver and the receiver. Older and previously isolated neighbours are better supported and more able to live independently for longer.

The NHS has become a network that routinely works with volunteers, carers, voluntary sector organisations and social enterprises alongside traditional NHS roles. Healthcare is understood to happen as much in local community groups and between neighbours on the same street, as in hospitals.

The shift has radically changed the relationship between professional, patient, and society:

Helping ourselves. People are supported to look after themselves better and be in control of their health. Clinicians work with patients to develop individual health goals and connect them to services that give people the skills, knowledge and confidence to live better with health conditions. Those who are less active in their own health receive dedicated support, such as from a peer coach or social sector broker.

Helping one another. People actively support others in peer-support networks to deliver social, emotional and practical help. Some networks are related to specific health conditions such as diabetes or stroke. Other networks enable people to be active citizens by connecting, for example, with older, isolated neighbours.

Helping healthcare. There are clear routes for people to contribute at scale to local health and care services, including volunteering that achieves clear outcomes and ways for communities to co-design services with health professionals. There are formal opportunities for volunteers to help across the NHS, creating a stronger link between citizens, communities and the health service.

New kinds of consultation

Section 2 points towards the range of channels people would have to communicate with the NHS in 2030, such as digital patient portals or health monitoring systems that feed data into the NHS. But it is the interaction with professionals in the NHS that represents one of the most fundamental changes. More collaborative conversations between people and healthcare professionals shift power towards the patient, creating more people-powered and person-centred care.

Consultations are now structured to encourage and support patients to be active participants in their own health. The waiting room has been remodelled as a preparation area, where individuals can log into their personal health portal, which displays their most recent test results with explanations, asks them to upload their recent wearables data to be considered in the consultation and has guides on how to set an agenda for a consultation. When the consultation starts, the patient and doctor agree a joint agenda focused on goals that are important to the person. The care planning process then establishes the combination of clinical and social interventions that will help them achieve these. Afterwards there is the opportunity to debrief with a health service volunteer, reflect on the consultation and arrange any additional support such as a health coach or care navigator. Local and online peer-support communities are suggested using the expanded NHS Citizen platform, along with other resources from medical research charities and patient organisations. With thanks to Adrian Sieff at the Health Foundation for his input in developing this scenario.

Mobilised communities add strength and depth

Health volunteers tangibly improve the experience and care provided in hospital, clinics and other formal health settings. They are involved in every stage of a patient journey. In hospital and clinical settings, volunteers perform new roles that are now seen as essential. They provide a combination of pastoral and practical care for patients and help people to use digital technologies. They accompany them before and after operations, help people to use new assistive health devices and organise self-management plans.

Outside of formal health services, volunteers and non-clinical paid staff support people to take control of improving their health, such as losing weight or doing more exercise, or to make new friends in their own neighbourhood. Expert patients and carers play a semi-professional role as coaches, therapists and leaders of groups with similar medical experiences or care needs, alongside voluntary or social enterprise sector professionals or clinicians. This adds a new dimension to healthcare by creating networks of volunteers and non-clinical professionals that support people to take control of their health, maintain healthy behaviours and stay on top of their health conditions on a day-to-day basis.

Many neighbourhoods now have networks of first aid responders who can attend to some emergencies before ambulances, and can deal with some situations which do not require hospitalisation. It is normal to participate in schemes like Shared Lives Plus, providing family-based care and support for people who would otherwise be in specialist health and care settings. There are tailored volunteer packages to enable people to settle well at home after an extended stay in hospital, where transition is foreseen as potentially difficult.

This level of volunteer and non-clinical support requires interventions that are backed by robust business cases and ways to attribute positive outcomes to specific changes. Health service procurement leaders have redefined their role in response. They now actively support local partnerships of charities, social enterprises and user-led organisations. They aim to actively develop the market of volunteer and non-clinical support to respond to local needs. Funding is designed to follow local activity and funding entitlements are used to make financing this support easier. Commissioning uses many different legal and reward structures, such as alliance contracts that bring together multiple providers who share risk and reward and work towards a single set of shared outcomes. Contracts are increasingly based on producing specific, agreed outcomes.

Reducing demand for services

People helping themselves, one another and health services represents a set of new social movements for health: changing the basics of how the health system approaches the prevention and management of health, in particular long-term conditions. The impact for the NHS is improved care, better outcomes and lower costs:

- Practical care and support that prevents exacerbations and hospital admissions and accelerates discharge.
- Reduced isolation and loneliness, strongly linked with ill health and high healthcare usage.
- Fewer, but more effective, clinical visits and consultations.
- Improved patient experience and care while in hospital and other health settings.
- People have improved confidence, mood and wellbeing which positively reinforces overall health.

There is a golden thread of patient confidence, capability and motivation that makes many of these changes work. So with People Powered Health must come with a more granular understanding of what motivates people to become active in their health. Section 4 describes services that make the most of human behaviour – amplifying the effects of more people involved in health services and more people managing their own health.

SIGNALS OF CHANGE

> *"We have not fully harnessed the renewable energy represented by patients and communities"*
>
> NHS England, ***Five Year Forward View***

A people powered NHS is a health and care system that is for people, by people and with people. **Nesta's People-Powered Health programme** (2011–13) supported six schemes that bring power to the patient and the community, supported by clinicians. The programme involved five types of practice:

More than medicine. Non-clinical support that gives people the skills, knowledge and confidence to improve their health and wellbeing, such as health coaching.

People helping people. Peer support that gives people emotional and practical support to live well with long-term conditions; this can be online or offline, in groups or one-to-one.

Redefining consultations. Clinical consultations that are genuine partnerships between professionals and people, focusing on people's goals and 'prescribing' both clinical and more than medicine support to enable them to achieve these goals.

Networks and partnerships. Statutory and social sectors harness their combined knowledge and expertise to commission, design and deliver holistic and integrated healthcare services focused on what people need to improve their health.

User co-design and co-delivery. A health system driven by the people within it, not by the institutions that provide care, requires deep engagement by people using services in all stages, from design and delivery to evaluating the service.

These and other forms of person-centred care have demonstrated benefits for a health system. ***The Business Case for People Powered Health*** estimated a 7 per cent reduction in the commissioning budget if these approaches were put into practice at scale, through decreasing A&E attendances, reducing hospital admissions, reduced length of stay and decreased patient attendances. **The Realising the Value programme**, recently commissioned by NHS England, will outline the health value, financial value and wider social value in care that gives people and the community more control.

New models of people helping people

There are already good examples of high-impact volunteering models in a health and care context. **The Centre for Social Action Innovation Fund** supports, for example, a British Red Cross scheme in which older people are supported at a time of crisis, such as bereavement, by a highly-trained Red Cross volunteer. The Fund also supports national patient charities to develop their peer-support networks, including networks focused on sight loss, stroke and lung disease.

Also run by Cabinet Office and Nesta, the **Helping in Hospitals programme** works with hospitals to use simple techniques to increase the impact of their volunteers. These include:

- Asking nurses what jobs they wish they had time to do that volunteers could help with, such as holding a patient's hand to reassure them before surgery.
- Training volunteers in specialist skills like reminiscence games for patients on dementia wards.
- Developing hospital-to-home services to support patients to settle in successfully at home.

The Cabinet Office and the National Tripartite group (NHS England, Monitor, the NHS Trust Development Authority and the Association of Directors of Adult Social Services) also run the **Reducing Winter Pressures Fund** – using social action to help older people stay well, manage their conditions or recover from illness or injury, reducing pressure on hospitals.

Coalitions for change

This person-centred agenda is recognised at the national level, including the recent NHS Five Year Forward View and national coalitions have been formed to make progress at a local and national systems level – including **Think Local Act Personal** and **The Coalition for Collaborative Care**. The partners come from across health and social care, charities, professional associations and community and voluntary organisations.

Investment in preventative work

Key to scaling these practices will be financial models that enable upfront investment to fund preventative work. There are a handful of Social Impact Bonds (SIB) in this field already. Ways to Wellness in Newcastle focused on 'social prescribing', in other words, non-clinical interventions to achieve sustained lifestyle change and better self-care among people with long-term health conditions. Ways to Wellness were in Nesta's People-Powered Health programme. The SIB was launched in 2015 and will run for an initial seven years. Partners include Bridges Ventures, Big Lottery Fund and the Cabinet Office and have attracted investment of over £1.5 million on an outcomes payment basis linked to improvement in health outcomes.

4. TAKING HUMAN BEHAVIOUR SERIOUSLY

More people managing health: insights into human behaviours help redesign health services, products and treatments to reflects how people live their lives.

Allie's mother has always struggled to maintain a healthy weight. During prenatal sessions with their midwife and link worker, she said she would like to eat more healthily and lose weight because she was concerned that being overweight might have a negative effect on her baby. The midwife helped Allie's mother to develop her own plan to live more healthily. The link worker mentioned a local healthy cooking course. Allie's mother went along and found she enjoyed it. She met lots of other parents. Some, like her, wanted to eat more healthily. Others go because while they already eat healthily they want to meet new people. Those who have attended the group for years, now lead the cooking course. She is inspired when the course leader explains that she herself joined to lose weight due to worries about her first pregnancy.

The midwife also invited Allie's mother to try a commitment device that linked the amount of exercise she does with rewards. She chose to connect it to a set of her favourite games, and set herself limits on the amount of time she could play them in relation to exercise completed. As often happens, when given the freedom she was stricter on herself than the device's default.

Bhakti gets a lot of personal satisfaction from running expert carer sessions for other parents of children with severe physical disabilities. But after the exhausting, emotional work of delivering the training, all the required administration and evidence gathering can feel like a chore. The prompts and submission processes for admin and feedback collection are carefully designed to be as engaging, effortless and immediately actionable as possible. The analysis of previous data is prominently displayed, so she can see the reasoning behind the data collection: the impact of improvements to sessions, both in her own group and scaled-up to the countrywide programme.

Bhakti's daughter has played a massive multiplayer online game for seven years using a system adapted to her physical disabilities. The game now has features which enable her to take part in experiments, some of which earn her vouchers and rewards offline. These help researchers to test hypotheses about the impact of campaign messages, or the structuring of costs and incentives which could one day inform public health campaigns. This is helpful for researchers as it can be quick and cheap to experiment, but usually a secondary phase of research is required to test the ideas in real-life scenarios before it is formally adopted.

Colin uses the health service to help with a number of problems and worries: for his osteoarthritis and his worries about cognitive decline and to support him living alone after losing his wife. When Colin comes into contact with services, his personal information and care history now pre-populates their IT systems by default. In the past, Colin was wary of sharing this information and had removed consent for information to be shared between services. But this meant he repeated his story every time he met a new care provider. It also meant that they were reliant on the information he provided; sometimes he made mistakes or left out important details that he didn't think were relevant. He decided to try a new joined-up system.

Since then, providers have found it easier to respond to Colin's individual needs, given his complex conditions. It is rare that they do not have all the information that they need to treat Colin. There are few data-sharing glitches because the system has been designed over several iterations with local providers.

Colin always has appointments scheduled after lunch. Recent research carried out in three NHS Trusts found that people like him were best able to take on board new information in this time slot. They based this profile on the medicines he takes and his health conditions. Colin completes a short feedback questionnaire after appointments to allow the NHS to monitor whether these findings are consistent with his individual case.

2030 LANDSCAPE

The NHS in 2030 has benefited from a commitment to understanding the factors that influence human decision-making and behaviour. At the beginning of the 21st century, the biggest users of behavioural science were private sector businesses like supermarkets and internet businesses, who used insights from psychology, data collection and rapid experimentation to understand their customers and make more money. But in 2030, the NHS is now considered to be a global leader in its use of behavioural insights. It uses them to reduce clinical errors, to target programmes better, to make treatments more effective, to improve patient engagement and to promote the healthy activities which prevent ill-health.

Eliminating human errors that lead to poor health

In 2030, far fewer things go wrong in hospital and in doctor's surgeries. This is not primarily because people are smarter, but because the system is better designed to reduce the likelihood of mistakes. The process of diagnosis and prescription will be enhanced by access to greater data resources and analysis than an individual doctor can keep hold of. But this means they will need sophisticated decision-support tools to help them make the most of these digital resources.

Clinicians make decisions based on prompts and supports which anticipate natural human biases or the presence of fatigue and stress. Medical information – from the results of blood tests to scans to monitoring completed in the home – is more saliently presented, based on rigorous testing of design templates, language, colours and visuals. Technology functions as a reliable failsafe, making the use of faulty heuristics unnecessary and freeing clinicians to focus holistically on the individual case in front of them.

The equipment, medical settings and technology of 2030 make it easier for the right decisions to be made. These refinements include new simplified decision-making guides which use a short selection of 'Yes/No' questions to support primary care decisions. These filter essential information, anticipate a decision-maker's likely biases and provide them with risk and prevalence information that is simple and easy to digest. Information about cost and peer-norms are also routinely presented when ordering tests and prescriptions to encourage the appropriate use of resources.

Wearable technologies alert doctors to their risk of decision fatigue in the same way that a sports coach today can be alerted to a sportsman's risk of physical fatigue in real time during games. New technology enables doctors to be prompted when there are factors which might be adversely affecting their decision-making, such as the time elapsed since they last had a break, the number of decisions they have made that day, or number of patients consulted.

Healthy behaviour is more common

In 2030, people find it easier to make healthier behaviours habitual.

Early attempts to influence people's habits by providing evidence of the consequences were mixed. The key to success was not just providing more facts but understanding through a process of behavioural psychology and experimentation how to present propositions so they have maximum effect.

All aspects of the way the NHS interacts with its users, from public health campaigns to the way appointments are administered, have been designed to go with the grain of how people live their lives. This makes it easier for people to adhere to treatment regimes when they are ill or at increased risk of ill health. The vast majority of appointments are kept because patient communications are targeted and there are carefully designed and timed reminders. People's goodwill for the NHS, which has always been high, is maintained and underpinned by finding new ways for people to get involved, and by fostering feelings of reciprocity.

The NHS does things that make lives easier, such as appointments that fit around their schedules, remote consultations and wait-free access to services, even at short notice. This is achieved through accurate prediction of demand for health services, based on close analysis of people's health-seeking behaviour. Accurate anticipation of these demands feeds into the design of services and staff rotas, making the NHS proactive, rather than reactive. People repay the favour by helping with trials, providing feedback, being more responsive to change, and sticking to plans they jointly agree with their doctor.

There has also been progress in working with food retailers, architects and town planners to use design to prompt healthier choices, or to direct people's automatic reactions to the environment towards healthier options. For instance, the design of the public realm now makes it easier to walk or cycle than to drive in most city centres. The Department of Health has made some progress in partnering with supermarkets, fast food restaurants, alcohol and tobacco companies to develop and adopt business cases which engage consumers differently, prompting them to make healthier consumption choices. The companies found this preferable to stricter regulations and higher duties, and analysis suggests that it has had some positive impact on reducing the consumption of 'vice goods'.

Designing, testing and improving frontline services

There are Experimental Service Change Units within regional NHS directorates. They can help the frontline to design, co-ordinate and evaluate experiments, in partnership with external organisations and research institutions. The units can help spot opportunities for rapid experimentation. They then facilitate a partnership with research institutions to design and implement trials. Behavioural insight trials are added to a live database of all randomised control trials (RCT), to avoid replication. Knowledge of this database is higher among health professionals and there are high levels of enthusiasm to participate.

There is a similar platform for patients, patient groups and healthcare providers. For patient associations and peer-support groups, participation is incentivised through the provision of feedback which helps them to improve the support they provide and makes their role more rewarding. Some of these experiments happen in a simulated environment online, including integration with some mass multi-player online gaming worlds. These tools are often cheaper, or avoid difficult ethical issues with real-world experimentation, but application is still limited and real-world testing is still required should online results be positive.

The use of behavioural insights is governed by consent from the public. Public discussion forums for behavioural insights have been set up online – using the new digital platforms mentioned in Section 3 – to agree the terms on which government and health authorities can responsibly pursue behavioural change initiatives. This provides the public complete transparency about plans to test and use behavioural insights, and the ability to raise concerns about these plans. A deliberative discussion is used to explore these concerns, and in some instances the public can stop the testing of behavioural insights.

SIGNALS OF CHANGE

Behavioural science has been used successfully by private sector companies for decades, and is now an increasingly common tool in public policymaking. For governments it is the aim for policymaking to be informed by the likely impact that policy decisions will have on human choices and behaviours. It seeks to understand the wide variety of influences on behaviour and decision-making and patterns of health-promoting or -harming behaviours. It then aims to use this knowledge to inform the design of environments, products and systems that make it easier for us to make healthier choices.

There is huge potential for the health sector. Many people eat unhealthily, drink too much alcohol, smoke cigarettes and don't exercise enough – behaviours that are set to exert increasing pressure on the health system. Through behavioural insights we are beginning to understand how this can be tackled. Our decision-making is heavily influenced by various mental shortcuts, such as being loss averse or focussing only on experiences of the present moment, whilst failing to take long-term costs and benefits into account. Often these shortcuts are helpful – enabling efficient decision-making in the face of multiple considerations – but at other times they can lead to choices which are harmful to our health.

Behavioural insights can inform various actions to make healthy behaviours more likely by changing the architecture of choice, through the careful design of incentives and disincentives, reinforcing positive social norms or reducing the 'friction' we experience in forming healthy habits. Research has already found some powerful insights about the influences on decisions and behaviour in a health context:

Commitment Devices. Signing a symbolic contract has been shown to increase success in performing a regular physical activity.

Decision Fatigue. The cumulative effect of making repeated care decisions increases the likelihood that primary care clinicians prescribe unnecessary antibiotics for acute respiratory infections. This offers an opportunity to create an intervention which makes antibiotic prescription when tired impossible.

The Cabinet Office report *Applying Behavioural Insights to Health* provides more examples:

Defaults. Including a 'prompted choice' of organ donation on application forms for driving licenses increased the percentage of people signed up to donate organs from 38 per cent to 60 per cent in Illinois.

Visual Prompts. A supermarket chain in New Mexico, USA increased the amount of fruit and vegetables its customers purchased (without affecting profits) by creating a visual prompt in its trolleys which marked out one section for fruit and vegetables.

Incentives. The Step2Get Initiative which combined an interactive game, swipe card technology and a reward scheme increased the number of children who walked to school by 18 per cent.

Reciprocity. Schemes which offer reciprocity for time spent volunteering to deliver social care have been found to be successful in different contexts. Japan was one of the first countries to test this model and now has over 400 local schemes. A pilot of the scheme in a London local authority found it increased volunteering and delivered a positive cost–benefit ratio.

At present, the use of behavioural insights is considered a relatively niche and discretionary activity. Public Health England and the Department of Health have dedicated behavioural insights teams, but outside of these central bodies behavioural insights are relatively underused. Yet encouraging healthy behaviour is one of the most cost effective things a Government can do. Moreover, there are behavioural aspects to almost everything the NHS does, from the daily work of professionals through to the organisational decisions taken in commissioning groups, arm's length bodies, regulators and in the Department of Health.

This approach is not a replacement for other governmental levers, such as legislation, regulation and taxation. Instead, behavioural insights complement these levers. They can be used to make other approaches more effective, or to evaluate them for effectiveness and unintended consequences.

Behavioural insights are a good fit for supporting innovation in the health service. They can be cheap to implement, manageable for existing staff to adopt, measureable using existing data sets, scalable and provide immediate pragmatic improvements to services.

THE SHAPE OF THE NHS IN 2030

It is not just NHS users but also the staff that might experience a very different health system by 2030. The institutional layout and ways of working could be fundamentally different. People are doing much more to look after themselves. They come into the clinic with more knowledge about their own condition and a stronger idea of what they need from a health service. This chapter draws on some of the changes in Sections 1–4, imagining more fully what this means for the kinds of jobs, information infrastructure and institutional arrangement of the health service in 2030.

WORKING THE NHS IN 2030

By 2030, the jobs available inside the NHS are radically different. So are the ways of working.

A partnership approach between healthcare professional and patient is now standard and particularly well-developed for those with complex conditions. These partnerships focus on people's needs and equipping them to self-manage. Professionals understand themselves as expert partner rather than instructor.

At the same time, other paid or voluntary staff have an equally critical role to support patients to engage in collaborative care so that they have the skills, knowledge and confidence to do so.

Training for doctors, nurses and other healthcare professionals, both pre and post registration, now has a significant emphasis on the role that they as a professional can play in empowering their patients. This involves core components run by people with lived experience of long-term health conditions, who coach trainee professionals in a person-centred approach to care. Healthcare students are trained to a high standard in motivational interviewing techniques and coaching. Secondments working with independent patient groups are common.

Surgical and clinical productivity is increased through specialist healthcare settings, where doctors gain greater exposure to complex and difficult cases. These improvements mimic a factory-line model of production, which has been argued to enhance clinical and surgical skill. They also make use of the thesis that standardised processes, like checklists, reduce errors. Such specialist centres employ fewer people than in the equivalent services at the moment. There creates a greater reliance on a smaller number of highly-skilled people, whose increased productivity reduces the strain on the system.

Automated diagnostics are used everyday by many people. Clinicians can play a more active role in research and have more data to use in diagnosis and treatment decisions. These also reduce the tasks that frontline staff have to do, creating more time for them to engage in collaborative care. Pharmacies have a significant role in analysing patient monitoring data.

Making change happen in 2030

The NHS has become expert at continual rapid experimentation, learning and adaptation. The frontline is now the main driver of innovation, backed up by local leadership and by technical and analytical support to ensure change is data-driven. This combination – of an empowered frontline, facilitative leadership and real-time data – makes the NHS the largest organisation in the world that has cracked the code on continuous adaptation and change. This emerged out of continual experimentation with organisational models for devolving decision-making to local health systems while building an NHS-wide culture of experimentation, results-orientation, and people-centric care.

In 2030 the focus of NHS analysis teams has shifted from providing regular snapshots of activity in the system, to analysing what is working in real time. These teams have become an in-house technical capacity for experimentation analysis, working across services and geographies. They offer feedback on changes to services, or experiments with behavioural insights. They can quickly spot emerging changes in patterns of demand and call for resources to be reallocated as a result. They use combinations of data to segment patients, configuring services and interventions that best respond to their needs. Their work is ingrained in day-to-day practice and easily accessible by a wide range of staff.

2030 Institutions

The NHS estate looks different in 2030, with fewer large facilities and more smaller community settings. The move towards People Powered Health and community based care has finally reached a scale at which some big hospitals can reduce in size, and district hospitals have closed altogether, or been reconfigured as community health resources where a range of clinical and non-clinical groups support communities to live healthier lives. There are more polyclinics, and health professionals are increasingly co-located with other public services, creating more accessible health services. This diversity in primary care is supported by common data infrastructure. This set of standards and protocols for data analysis and storage is shared with pharmacies, which manage patient monitoring data.

WHAT CHALLENGES LIE ALONG THE WAY?

So far this paper has described an optimistic vision of the opportunities created by 2030 health service where knowledge and people power are starting to have a positive impact. But there are challenges that could trip up these opportunities along the way.

Challenges in creating a knowledge-powered system

Managing uncertainty in the pace and direction of medical research

There is huge uncertainty in the speed and direction of change in the science and technology developments that underpin precision medicine. A healthcare system that makes the most of these is one that flexes to unexpected breakthroughs and setbacks. It will also need ways to manage much more precise information about the patient, and new care pathways that respond to this detailed information. This will takes decades, partly because a radical reorganisation of a large a structure cannot happen quickly and partly because it's not yet clear what kind of new treatments precision medicine research will lead to.

Making certain data management reflects patients' values

National systems or platforms for managing sensitive information will time and time again come up against issues of trust. For some, it must be clear what will happen because they have sequenced their genome or who else is sharing and commenting on their input into a forum on diabetes services. When people agree to take part in specific research studies, it is not the detail of consent forms that matters; it is a **subtler judgement of trustworthiness**. As information circulates more freely, it will always need to be designed with this constraint in mind.

Avoiding monitoring that doesn't improve health

More data on patients can lead to earlier diagnosis and prevention of disease. This is often assumed to save the health service money. But in some cases, **screening costs can exceed the potential savings** from avoided treatment in cases in which only a very small fraction of the population would have become ill. At a larger scale, monitoring technologies could lead to a worried well and risk of mistaken self-diagnosis. Without partnerships between technology and healthcare providers, this data may not be suitable for use in the clinic. For instance, when it is not clear who data comes from, only which account was used to produce it, then that data cannot be used in a diagnosis.

Creating a smart collective intelligence

This scenario, particularly Section 2, assumes that digital platforms will improve collective problem-solving. Some define the kind of platform that does this is as a **hybrid, diversity-aware collective adaptive system**. This kind of collective intelligence combines humans, machines and different kinds of knowledge in a system that is aware of itself enough to keep learning. The diversity this refers to is in those using the system; it has to be inclusive, adding another reason addressing health inequalities. It also requires, for example, patient-led research to provide more knowledge creation than confusion. It must be smart enough to keep learning from new medical research, public campaigns and feedback from service users as it emerges. Only then is it likely to deliver at scale exchange and production of ideas, which no individual, group or machine can alone.

Challenges in creating a people–powered system

Building evidence from experiments in the health services

The evidence base is still not mature enough to justify large shifts in the allocation of commissioning budgets. Practice on the ground indicates significant impact, but more research is required to establish a rigorous understanding of which interventions work, for whom, and under which circumstances. It also requires a wider view of what counts as a valid outcome – incorporating biomedical indicators but not being limited to them. This would be helped by a better evidence base. As a result of lack of robust evidence, many social sector organisations providing People Powered Health are poorly funded and financially insecure. The strain on NHS finances also makes it hard to free–up funding to pay for preventative programmes.

Although People Powered Health and behavioural insights do not have to be evaluated through Randomised Control Trials (RCTs), there are many advantages to doing so. RCTs are perceived as being expensive and time–consuming – this does not have to be the case. The NHS needs access to the technical capacity needed to experiment robustly, rapidly and inexpensively on itself.

Reducing health inequalities

Some aspects of a more knowledge–powered system could increase health inequalities. Patient portals in the US are **used mainly by white, educated people**. UK citizens who have taken part in medical research are **twice as likely** to be interested in learning more about all aspects of medicine development as those without experience. But services focused on activating people might be able to mitigate some of these changes.

Patient activation measures (PAM) are a way to evaluate an individual's knowledge, skill, and confidence for self–management. Socio–economic status is already a determinant of health. But a **high PAM score predicts positive health outcomes** better than factors like ethnicity and age. Implemented well, interventions can increase activation, and potentially reduce inequalities. This requires a strong understanding of what motivates different people. Support will need to be structured in ways that resonate with a diversity of people and communities, including poorer or more marginal groups. There remains a risk that interventions to increase patient activation favour those with most financial or social resources at their disposal.

Designing attractive volunteering schemes

Volunteering must be easy to integrate into different lifestyles – not just for the retired, for example – if volunteering at mass scale is to be achieved. Roles also need to be designed in ways that complement those of paid professionals and achieve additional value. Implementation of mass volunteering will have to balance local differences in context and ownership with the desire to adopt these practices at scale and understand which models of volunteering are most effective.

Activating doctors as well as patients

There are significant challenges in reorienting professional development from expert instructor to partner and collaborator. This future scenario challenges those trained in a biomedical model of health, which comes with a specific understanding of whose knowledge is valid and on what basis. Some professionals recognise that a combination of social as well as clinical support is required to enable people to self–manage and are committed to creating pathways focused on people's own goals. They could be described as 'activated' in an analogous way to patient activation measures (PAM). Others find it is difficult to reconcile new models with their professional training. In that sense, these professionals have low

'activation' scores and are less likely to engage with People Powered Health.

Building public legitimacy for NHS experimentation

It is not clear how to deliver consent from all potential patients for an NHS that is experimenting with new services. This is a particularly acute problem when those experiments are built on behavioural insights. The idea of using behavioural insights to 'nudge' behaviour has been interpreted as government overstepping its remit by attempting to influence individual behaviour. There need to be bodies that can reflect these concerns in the design of new experiments.

Balancing experimental services with efficiency

Freeing staff to allow them time for collaborative care with patients, in a way that motivates and empowers them, means finding more efficient, production–line like approaches to other aspects of healthcare. But it's unclear how much of healthcare can be plausibly delivered through specialised centres. This will rely on more computerised systems to profile patients and make recommendations for where they are referred. A series of specialist centres that rely heavily on automated, unchecked referral systems would run the risk of creating unintelligent and inflexible healthcare. The health service will need to find a way to become more efficient and more compassionate at the same time.

WHAT COULD BE DONE NOW?

A people-powered, knowledge-powered NHS would look profoundly different to the NHS of 2015. This transition will require continual experimentation, feedback and adaptation, as we learn more about what works and what doesn't. It's not possible to know in advance all the changes required to realise this vision of an NHS in 2030. But there are broad categories of changes that will be necessary for the system to shift:

- Designing a system with greater public legitimacy and higher levels of individual engagement.
- Building the foundations for services designed to offer diverse roles for more people.
- Creating a natural learning system within the NHS.
- Establishing a common data infrastructure that can handle new sources and quantities of data.

Some of these changes are happening anyway. In the Conclusion, there are four proposals for action (A–D) in areas where new initiatives are required. Where these link to ideas in this section, they are highlighted in the text below.

Supporting the individual's role in the health system

> *"Technological advances require parallel progress in the communication of value, risk, and uncertainty to the public in ways that foster trust and enable informed choice and optimum engagement"*
>
> **Horne et al.**, A new social contract for medical innovation, letter in *The Lancet*

Medical research leaders in the UK have called for a new social contract for medical innovation, where greater attention is paid to the public interpretation of medical knowledge, and delivers services sensitive to how much individuals want to know about their biological and genetic status. It is one where patients' own goals, preferences and actions are valued. This will require new kinds of interactions between health service and individuals, designed to reflect the diverse ways people want to interact with those services.

New relationships between patient and professional

> *"If you haven't persuaded practicing clinicians then it's hard to see how this would be taken up. Care is delivered by clinicians – they must be persuaded"*
>
> **Richard Murray**, Director of Policy, King's Fund

The interactions between professionals and patients heavily influences how everyone thinks about their own role in healthcare. Shifting the emphasis of these interactions towards collaborative care planning requires changes in the way doctors and nurses are trained and supervised. And it is an opportunity to rethink conceptions of self-care, expanding it to include activities currently in the domain of professionals with expert knowledge. This transition has already begun in some areas, such as the Ryhov Hospital in Jönköping, Sweden, where patients are trained to administer their own kidney dialysis. In England, targets for numbers of patient care plans have distracted some healthcare professionals from the reason for care planning – it is a tool for doctors and patients to make decisions together.

This approach could be extended by piloting of new approaches to consultations and self-care: flipped consultations, where tests and symptom checks are done outside of the consultation room and appointments are used to actively plan care; group consultations, in which there is one clinician and several patients with the same long-term condition in an active learning environment; or expanding 'Health Checks' to 'Life and Wellbeing Checks' to take account of wider determinants of health including social factors.

One way of supporting patients' engagement with doctors is to provide access to their own data more easily, or move data into services they want to use. This could include **a better system for accessing the GP API**, which apps for appointment booking or offering new care services could be built on.

Clinical decisions today are based on parcels of data, not continuous monitoring. Data from new monitoring technologies runs the risk of creating a rift between patient and physician if their perceptions of data legitimacy differ. To mitigate this risk, other intermediaries in the healthcare system could take on a larger role, offering access to and consultation on the output of monitoring devices.

Mass public engagement

There is an opportunity to build a platform for a new scale of public engagement with health issues. This would support public campaigns, health education and debate beyond NHS Choices' and Public Health England's current remit. The ambition should be to deliver a large scale change in how people understand and manage their own health; NHS apps and BBC campaigns like 'The Girl Can' are the first steps in this direction. ***This could be a way to deliver part of proposal A***.

But mass communication needs to be carefully designed to avoid producing a service that encourages a large number of worried-well, and increases the number of unnecessary treatments or consultations. Mass engagement can easily bias who it reaches by the communication channel it uses. Large-scale audience engagement would be best done in partnership with media organisations that are used to this kind of communication.

Making sense of new kinds of knowledge

From biohackers to patient organisations, there are independent efforts to produce new medical knowledge and where people with treating themselves. Supporting what are informal and dispersed efforts requires tools that work well with these kinds of networks. They also need initiatives that finds ways to bring experiential knowledge to bear inside the health service. The Centre for Evidence-Based Medicine's **governance and transparency work** supports health professionals and patients who want to challenge the status quo in medical research and practice.

This campaign–based approach could be extended to a more permanent function that helps structure health knowledge from outside the current research and clinical system – so that it is useful inside that system. This might include direct support for patient organisations already trying to do this. ***This could be a way to deliver part of proposal A***.

Services built on public values

There are already legitimate demands from patients to get more back from sharing data and participating in their own care. These need to be dealt with more directly. In 2014, care.data – an initiative to extract data from NHS primary care medical records in England unless patients have purposefully opted out – proved publicly controversial. This was curious because the current protocol for access to hospital patient data had existed since 2012. Anonymised information can be linked together to enable studies using detailed information about individual patients. Media debates over care.data reiterate the need for a **social, rather than just legal, license to operate** for research that uses NHS patient data.

There needs to be more information on why people give their data to research. At the moment, researchers pay a small fee to access NHS patient data. This covers data storage and data cleaning costs. But some patients may prefer the NHS to make a profit from sharing their data, especially if the researchers work for a pharmaceutical or technology company. Others may want to put restrictions on who accesses their records or are more interested in hearing about the results of the research.

Improved understanding could be delivered through schemes that prototype for new kinds of data sharing with the health service and researchers including trialling consent mechanisms. More generally, there needs to be an independent initiative to quickly develop responsible governance of data–driven health research and treatment. This could include research that maps out appropriate constraints on data sharing and models for managing these, overseen by an expert group that includes legal advisers, social scientists, data scientists and clinical researchers. ***This could be a way to deliver proposal B***.

> *"One of the most important roles for central government in the coming years will be to ensure that local and professional applications of behavioural approaches are rigorously evaluated, and the results made available for communities to debate and adopt as they see fit"*
>
> Institute for Government and Cabinet Office, ***MINDSPACE: Influencing behaviour through public policy***

Trials based on behavioural insights must be built on shared values for what is ethical and in the public interest . To do this, there should be transparency about what is happening: from the design of experimentation through to dissemination of results and diffusion of new approaches. It needs to be clear to any member of the public looking at the use of behavioural insights in health that experimentation is not being treated as an end in itself. This could be addressed by a government advisory committee responsible for overseeing health service experimentation that has positions for citizen representatives.

The foundations of new people-powered health services

An institution for People Powered Health research

> *"[Person centred care] is often spoken about as if it is soft, but it isn't. We should apply the same rigour to this as we do to other health treatments"*
>
> **Adrian Sieff**, the Health Foundation

Interventions that increase self-care and non-clinical support are usually complex and difficult to replicate faithfully. There needs to be a new high-profile organisation to generate more evidence, starting from strong foundations: academic credibility, sustained funding, diverse expertise and a clear mandate. The Coalition Government signalled its commitment to life sciences research with the cutting-edge Francis Crick Institute. There should be the same commitment to People Powered Health. It is important that the institute can quickly demonstrate value and build momentum.

Government should seed-fund a partnership of academic, charitable and government institutions undertaking groundbreaking research and development into patient and community participation in health and care. The institute should support design of new care pathways focused on prevention and with a significant role for community engagement. ***This could be a way to deliver proposal C***.

The Institute would provide a high-benchmark for evidence-gathering. Through standard templates, it could aggregate and analyse programme evaluations. It should invest in models that translate large quantities of research and evaluation data into information to support service commissioning or care planning.

Visible proof-of-concept for behavioural insights

The Behavioural Insights Team (BIT) was able to demonstrate its effectiveness through a simple experiment which used different letters to test which was most likely to increase self-assessment tax return completions. This showed the approach worked and led to a mandate for wider application.

BIT recently trialled simple interventions in partnership with Public Health England. They sent, for example, different randomly-assigned text message reminders to see which is most effective at reducing missed appointments. Published results for these trials are expected soon – an opportunity for the NHS to promote this kind of experiment.

A few more centrally-delivered experiments will help the NHS workforce and the public understand what behavioural insights can achieve. This proof of concept is needed to provide momentum for a more dispersed culture of experimentation in the NHS. The Behavioural Insights Teams and Public Health England could work together on a small number of cheap and widely applicable interventions. From these, they could start to build a presence across the UK health system, through a sustained attempts to promote these results, and the approach that generated them.

Mobilising volunteers

A national brand would add status and recognition to the value created by high-impact volunteering. But any new organisation would have to avoid a one-size-fits-all approach, responding carefully to what motivates people to volunteer in health – often a passion to

support local people and services in their local area. A national campaign would create a light-touch way to bring together schemes such as King's College Hospital Volunteers and the St. John Ambulance and Community First Responders, so that citizens willing to give time know where to find opportunities.

To mobilise a new generation of volunteers, there also needs to be new kinds of opportunities. This means more digital technologies like the **Good SAM app** that links registered first aiders with people who need emergency help. There also needs to be more high-impact opportunities for volunteering, such as reserve support for services and emergency response. The roles must be drawn up to complement those of paid professionals, adding additional, measurable value that is important to patients and carers.

> *"The conundrum is that this has to be generated by patients and professionals on the frontline, but we also know that the 'let 1,000 flowers bloom approach' doesn't tend to lead to rapid change. There is a place for a strategy which is dominated by individual patients and professionals taking the initiative, but which has a supportive and proactive national framework. We need ways for funding to support where local activity is happening and to trust that, rather than grant funding arrangements"*
>
> **Ben Jupp**, Director, Social Finance

Smart funding for peer support

The ability to galvanise local activity – such as peer support for people with long-term conditions – is crucial for a People Powered NHS to succeed. But for many peer-support groups, local funding is based on grants that are small, insecure and short term. To more effectively fund peer support and patient groups, public money must follow local activity. This would be used to test an alternative approach to existing funding models for the community and voluntary sector.

One way to manage this is through a dedicated central fund, matched locally, to allocate funding to local volunteering and peer support where the interventions are backed by solid evidence. This should pay a small per-person Peer-Support Premium, based on there being a minimum number of members or volunteers in a group. They would have to gather impact data in return.

The NHS as a natural laboratory

Every day in the NHS there are opportunities to test the impact that small changes have on existing systems. A national service provides the opportunity for both natural and deliberate experiments, which, if fully leveraged, would yield significant insights and robust improvement mechanisms.

The key to experimentation at scale is an engaged and supportive frontline. The frontline is the best place to test new approaches and for successful ideas to be embedded in work cultures and practices. But there needs to be demand for these approaches in order for them to be taken up.

Structured schemes for experiments

The most relevant schemes in this context are those that can address common problems, but are delivered locally. There are structured programmes that focus on prototyping solutions to clear, identifiable problems. These encourage improvements that are grounded in the reality of delivery. While the 'perfect' solution remains lost in committee, a visible improvement builds momentum for change at scale. The Japanese principle of Kaizen is used to design frequent trials of incremental changes. The Rapid Results Approach uses 100–day sprints to stimulate innovation and collaboration across organisational boundaries.

There are two common themes in these approaches:

- **Experiments not prescriptions**
  An iterative approach, based on disciplined experimentation, is faster and more reliable than rigid planning when dealing with complex systems.
- **Empowerment not direction**
  Only frontline staff have the detailed knowledge required to properly configure combinations of innovations, and get them to mesh with working practice and patient needs.

Rapid Results schemes use a measurable goal set by the local teams at the frontline with the support and permission of their local leadership. The teams might choose, for example, to work towards a percentage reduction in hospitals admissions for the frail population, in 100 days. Each team has a senior sponsor from local leadership and coaches from Nesta and the Rapid Results Institute to support them to **'act their way into a new way of thinking'**. This kind of approach loosens up institutional boundaries by creating innovation and collaboration across a whole local system. It also creates local accountability and ownership of change.

These 100–day Rapid Results teams can create the local 'pull' for the ideas, solutions, and tools that are outlined in this report, and they can become the engine for adapting these, combining them in new ways, and developing new ones that fit the local context. By design, these create stressors on the local systems that cause them to adapt and evolve.

Nesta, in partnership with the Rapid Results Institute, is adapting the approach to the UK health care context, starting in health and care systems in Essex. The initial signs are very encouraging. Scaling this work beyond Essex can help fast–forward the future we are envisioning in this paper.

Embedded behavioural insights

Behavioural Insight experiments require a certain level of technical capacity: the ability to design experiments which produce valid and reliable results, to implement them effectively, and to analyse the results. It would be inefficient to try and create this capacity in every health setting. Instead, there needs to be a small number of teams which can provide technical support to the wider NHS.

These teams could disseminate results from finished trials and suggest changes to practice, improving productivity and outcomes without the need for time–intensive or expensive change processes. They would engage frontline professionals in the development of new approaches, improving the chances that they succeed. ***This could be supported through proposal C.***

A data infrastructure fit for purpose

The NHS is able to link to longitudinal records of the primary, secondary and tertiary care delivered to a diverse population of over 60 million patients. The UK has a strong national clinical and biological research base, with points of participation for citizens, researchers and clinicians. In this system there is the space to support cutting edge R&D and develop new treatments and services – with the flexibility to change tack when things aren't working. But the data infrastructure that pulls all this together needs to look radically different.

Data for service innovation

> *"We need to talk about the realities of how complicated and difficult our IT infrastructures often are within the NHS; the problem of hospitals with countless clinical information systems, whose data are hard to access, poorly archived and poorly integrated, remains ubiquitous. These debates – about the future of innovation in healthcare – need to include the truth of where we are in terms of the maturity of our data–sets and the state of our IT infrastructures."*
>
> **Kevin Fong**

For people working in institutions, ways of working are encoded in information systems. Implementing a change in workflow typically requires changing information systems. This means changing the configuration of software. So the easier it is to do this, the better. At present, frontline staff do not find it easy to make changes. Information flows are baked into the initial design of systems or are only changed during occasional formal reorganisations.

Cambridge University Hospitals NHS Foundation Trust's new eHealth system came with training for more than 100 of the Trust's staff, qualifying them to adapt the software themselves. This may still be a fairly inflexible process, but it is a move in the right direction.

Often there is little expectation that frontline staff want data beyond average treatments times and patient responses. Getting access to data beyond these aggregate results is possible, but time consuming. Analytics teams should be available to NHS staff, helping them find and use the data most relevant to their work and to any changes they want to make. These should come with interfaces for staff to access data, which need to be as simple and intuitive as those on a smartphone.

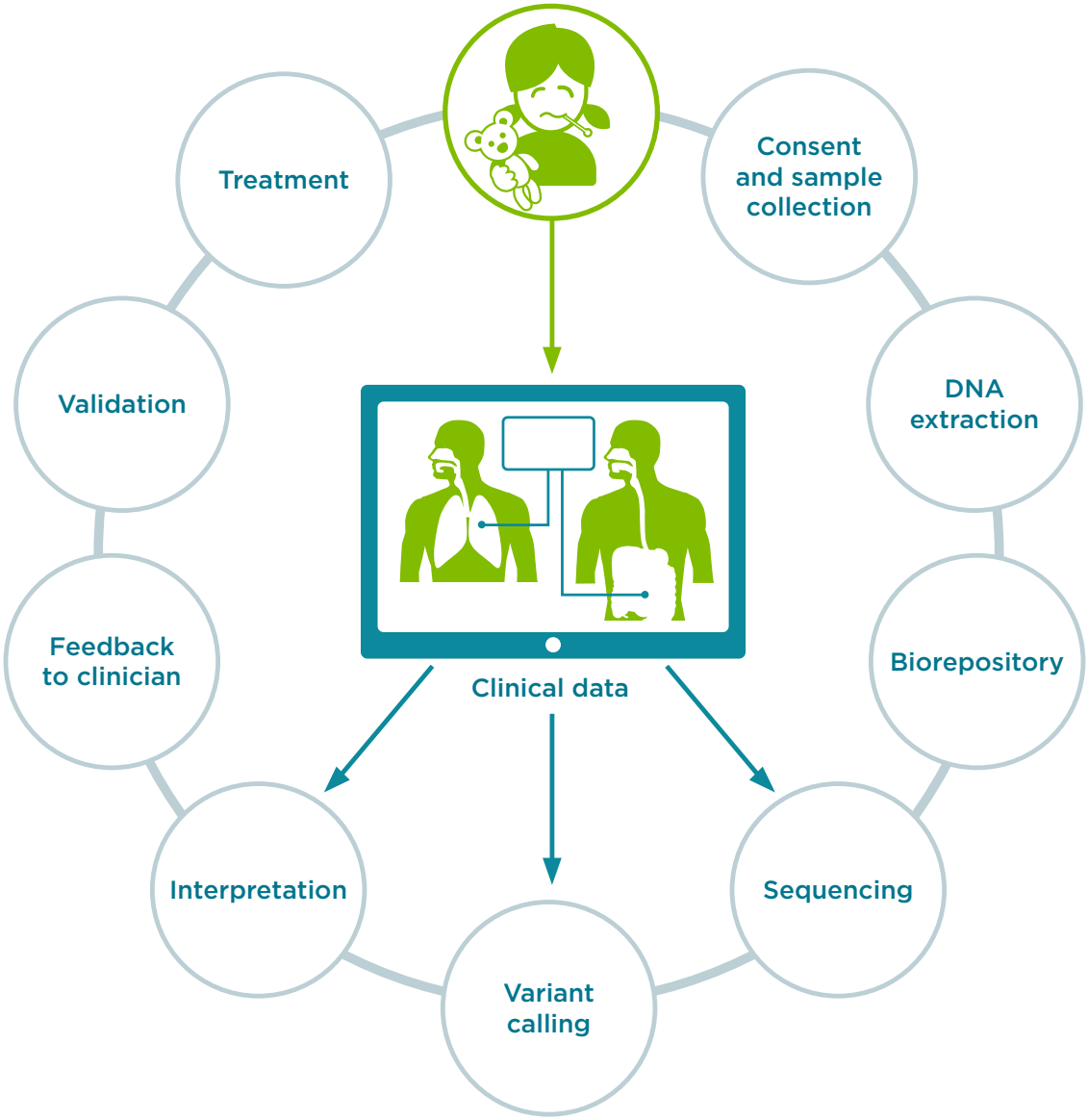
Integration with medical research

> *"We have a medical strategy, across Europe. But it looks very different for each country. Healthcare is fundamentally national and research is fundamentally international. So the way that research turns into care will be different in each country."*
>
> **Ewan Birney**, Associate Director, EMBL–European Bioinformatics Institute

Research institutions often have stronger overseas networks than integration with the health service. More and more medical research will be based on the individual rather extrapolation from clinical trials. This means that research needs to be more embedded in the national system that provides that kind of access to patients.

The 100,000 Genome Project has put in place a strong loop between clinical and research community that leads from a patient providing a sample through to treatment. It runs through a new protocol for data collection, diagnosis and treatment.

Step–by–step processes from whole genome data collection to treatment



A whole genome sequence needs to be compared to other peoples' in order to call out its specific variants. This is then combined with details about the patient's full physical condition. Researchers then examine this profile of the patient's in order to send an interpretation back to doctors. It remains the doctor's responsibility to decide on a formal diagnosis and treatment.

This kind of protocol should be embedded further inside healthcare. Some efforts already exist. New NHS Genomic Medicine Centres are recruiting patients, taking samples and providing consultations for the 100,000 Genome Project. They extend to tests beyond whole genome sequencing; **a series of molecular pathology nodes** in the UK will bring biomarker research closer to clinical practice: working with the research base, pathology and genetic services and industry.

Industry partnership will support the translation of this research into treatment. Biopharmaceutical companies in the GENE Consortium each contribute £250,000 and at least one full-time employee to the 100,000 Genome Project, in return for access to genome sequences and relevant clinical data. They have encouraged the formation of Clinical Interpretation Partnerships involving more than 2,500 clinicians and scientists focusing on specific diseases or cross-cutting themes. As precision medicine progresses, there needs to be a more diffuse research and analysis centres, including partnerships with industry, that close the loop between clinical and research settings.

Genomics England, the body set up to deliver the 100,000 project, is the gatekeeper for the new standards and systems for data sharing. This creates a single point of access for researchers and standard forms for data, which mean results are useful to the global research community. The cost of sequencing was reduced tenfold by using a single supplier.

A central authority overseeing precision medicine will be vital for building the research infrastructure, including standard formats for data and access to patient records. It will also co-ordinate access to developments in underpinning technology like new sequencing kit or data analysis tools. ***This could be a way to deliver proposal D.***

Integration with new kinds of patient data

New services need to be developed where not just our records but our devices are intimately connected with the healthcare system.

This is at first likely to include data from wearables like heart beat or activity monitors. R&D partnerships between research funders and large technology companies, analysing behavioural and physiological data from wearable devices, could be incredibly powerful. The Government could play an early role in brokering some of these partnerships.

Wearable technology does not necessarily provide clinically useful data. Data need to demonstrate its provenance – where and when it was collected and from whom – to be useful for healthcare. Conformity marking (the CE mark) in Europe means that producers of low-risk medical devices can self-certify that they meet relevant European Commission directives. This regulatory advantage should continue. But the requirements should be updated to improve the clinical relevance of devices that fit in this category, including wearable technology. Building on the British Standards Institute and the Medicines and Healthcare Products Regulatory Agency's recent efforts to provide **sophisticated data standards for health apps**, medical devices manufacturers should show they have made attempts produce data that users can use in their medical consultations.

Medical devices that test 'phenomics' – particularly biomarkers like proteins in the blood – are increasingly portable and almost cheap enough for a consumer market. The UK has an opportunity to lead this new market. Technology development is already linked into the health service and research community, see Nanopore example in Section 1. There is **new government funding for small companies** that can support a complex biological data analysis. There also needs to be direct support for companies producing cheaper, portable tests for physiological signals.

What needs to happen too

Even if all of these initiatives were put in place, there are many things that could still make a knowledge-powered and people-powered health system inconvenient and expensive. To be clear about what these are, here are some of the things that would need to happen, and others that would need to not happen for this 2030 vision to produce a better health service:

What needs to happen	What needs not to happen
More patient engagement leads to greater disease prevention and healthier lifestyles.	More patient engagement leads to expensive and unnecessary screening and monitoring.
Volunteers add additional capacity to paid staff – they take on some of the tasks that over-worked staff were unable to get to, freeing them up to deliver higher-value work.	Volunteers are providing additional services in some areas. Expectations of levels of care have increased everywhere, leaving staff to manage additional tasks in areas with fewer volunteers.
Expert patients and carers provide peer support to patients from all social-economic groups, reducing demand for long-term care services.	Expert patient-led groups are only used by educated, middle class people, who use the groups to access more health resources.
Precision medicine reduces the number of unnecessary, expensive treatments. It improves prognosis for many conditions, especially through early diagnosis.	Precision medicine is biased towards the most engaged patients, leaving at-risk groups with few new treatments and needing long term support for persistent symptoms.
New specialist services produce efficiency gains. The cost of a single treatment is lower, and success rates are higher.	Specialist services create new silos, leaving patients without treatments that respond to all their symptoms.
Locally managed changes to services create bespoke initiatives, configured around patients' needs.	Diverse programmes for service innovation mean that general lessons are not learnt. They fail to overhaul key regulation like information governance.
Technologies that measure biological and behavioural signals are cheaply incorporated into consumer electronics and purchased by most patients directly.	The NHS provides large numbers of costly monitoring devices, as data cannot be incorporated into care unless it is collected by an approved device.
Most people support and take part in testing and use of behavioural insights to improve their health and health services.	Behavioural insights are poorly tested and are seen as arbitrary changes imposed on people, undermining goodwill for the NHS.

CONCLUSION

The changes to healthcare imagined in this paper would add up to a fundamental shift in how people understand health and who is responsible for managing it. By 2030, there may be new kinds of knowledge, new ways of using it and new kinds of people involved in health support and services.

There will be many other profound changes that affect the health service. But these are the ones that Nesta can see coming into focus, through our funding programmes, our research and our partnerships.

The way to these large-scale changes is obscured by uncertainties. Not only are the effects of other shifts in the health system impossible to predict. There are also serious challenges in designing successful knowledge and people-powered systems. The pace and direction of change in technology and attitudes to health are hard to forecast. Digital platforms that enable new kinds of collective health intelligence may never emerge. The assumption that there is an unexploited appetite for health volunteering might just be wrong. It's difficult to see a single structure of institutes and initiatives that would be future-proofed against this range of possibilities.

And there is another reason why understanding how to respond to these opportunities is difficult. They are not the same in nature to historical options for health reform. Reforming the social contract between and health service will require policy and support mechanisms that can respond to the changing rules of engagement. This is not about restructuring the traditional institutions of healthcare. It is about a setting up today the cogs and gears for a set of new functions that support healthcare in its broadest sense. These could include:

A. Digital platforms and widely agreed protocols for developing new kinds of health knowledge and responding to the latent demand for taking part in healthcare. These should make clear the role of new kinds of knowledge relative to the biomedical model of human health. This needs to support deliberation and negotiation over what is useful for improving health.

B. Prototypes for health data sharing that concentrate on understanding emerging attitudes to digital privacy. These could focus on specific products and services. But should be used as a testing ground for developing publically legitimate governance of health data.

C. An institution that supports and evaluates for People Powered Health research. This starts to build an NHS that works as a natural laboratory. It should be easier for frontline staff to experiment with the way they run their services, whether this is adopting behavioural insights or troubleshooting systemic issues.

D. A central institution to set standards and mandate processes that will maximise the clinical and research value of large genomic and other data sets as they become available. The institution will probably be the best place to take responsibility for data best managed at a national level.

These are not big initiatives compared to the scale of the UK's health enterprise; they are suggestions for how to lay the groundwork for a strategic shift that harnesses the value of people and knowledge power.

Nesta will take on some of these challenges. We will work in partnership to make change happen. As an organisation, we already fund projects, generate research and lead programmes that focus on the value of knowledge and people in healthcare. In the future, we will build on this to better understand and champion the systemic changes they lead to. Our ambition is to become a hub for restless innovation and critical debate. We want to challenge the institutions and norms of the health service, making sure that those that exist in 2030 are fit for purpose and not accidents of history.

Nesta...

Nesta

1 Plough Place
London EC4A 1DE

research@nesta.org.uk

@nesta_uk

www.facebook.com/nesta.uk

www.nesta.org.uk

July 2015

Nesta is a registered charity in England and Wales with company number 7706036 and charity number 1144091.
Registered as a charity in Scotland number SCO42833. Registered office: 1 Plough Place, London, EC4A 1DE.