

# Annual Report of the Chief Medical Officer, 2018

Health 2040 – Better Health Within Reach

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Joan Reader

Discussion of health often focuses on the financial cost of healthcare. Far from a cost, our health is our primary asset, as individuals, communities and as a nation. Maintaining 'good health' and preventing 'ill-health' is an investment for the future. This is so important that we need to measure and track health in our society. After all, as Peter Drucker said, "What gets measured gets managed."

I look at the future health of England's population in this, my tenth, annual report. As the NHS has been developing its own 10-year plan, I look further ahead. I wanted this report to take an aspirational view of what health could and should look like in 2040 if we commit to it being our nation's primary asset.

Every part of the health system has a role to play in creating a healthier and fairer future. The fortunate truth is that we already know how to make fantastic improvements and prepare for better health that is 'within our reach'. The green shoots of a brighter future are already visible in some parts of our health system. Now we need to develop, plan and scale, harnessing technology (including wearables and AI) to support this.

We need to develop our environment to make the healthy choice the easy choice, thus promoting our health, our happiness and our economy whilst preventing disease.

I hope this report inspires all readers to understand that we can achieve better health in England in 2040 – this can be our shared vision, with each of us delivering our part, in our different ways.

Sally C Davies

Prof Dame Sally C Davies



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This report could not have been produced without the generous input of the following people.

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## Chapter 1

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# Chief Medical Officer's summary

**Chapter lead and author**

Sally Davies<sup>1</sup>

<sup>1</sup> Chief Medical Officer, England

## 01 The future is here...

This year for my annual report, I have chosen to focus upon the health of the public in England in 2040. The NHS is often a source of national pride, but despite this, a narrative of health being a cost to society prevails. As the late Hans Rosling said, “When things are getting better we often don’t hear about them. This gives us a systematically too-negative impression of the world around us, which is very stressful.”

This report offers cause for optimism and I conclude that it is realistic to aspire to better and more equitable health in the next 20 years. As the NHS has developed its long-term plan for the coming ten years, this report looks at the strategic opportunities over the coming two decades for the health of the nation more broadly.

I believe we need to reposition health as one of the primary assets of our nation, contributing to both the economy and happiness. We also must measure and track progress in our development of health as a nation and our fairness as a society in delivering improving health outcomes. We need a composite Health Index developed that recognises this and is tracked alongside our nation’s GDP.

We need to track progress in improving health and health outcomes, to and beyond 2040 with a new composite Health Index that reflects the multi-faceted determinants of the population’s health and equity in support of ensuring health is recognised and treated as one of our nation’s primary assets. This index should be considered by Government alongside GDP and the Measuring National Well-being programme.\* We regularly collect most of the datasets that have the individual measures that could be combined.

### Recommendation 1

I recommend that the Cabinet Office formally explores the development of a Health Index for England, where that index:

- could be a composite index that is inclusive of health outcome measures, modifiable risk factors and the social determinants of health;
- may be disaggregated by composition allowing tracking of performance of each component additional to the overall metric; and
- reflects the multi-faceted determinants of the population’s health.

The investigation should involve the Office for National Statistics, which has experience in index development and should link to their work measuring the United Kingdom’s progress on delivering the United Nations’ agreed Sustainable Development Goals.

My report highlights that we know what we must do to improve health in 2040, and in many circumstances we are already doing it. Effective population prevention, such as the UK government’s Soft Drinks Industry Levy, is already here. Big data and the computing power to make predictive analytics everyone’s business is already here. Artificial intelligence that can diagnose disease earlier and improve prognosis is already here. We need to embed and build upon these innovations to accelerate and normalise implementation of what works across England.

Both prevention and the delivery of healthcare can contribute to a more equitable future. My report discusses the need for continued focus on the social determinants of health and as every cause of death, at every age, is more common in the most deprived, healthcare can directly deliver substantial gains too. For example, my report illustrates that achieving equitable cancer survival in England could avoid 10,000 deaths within 5-years of diagnosis (see ‘Socio-economic inequalities in 5-year cancer survival: avoidable premature deaths among patients diagnosed in England in 2010’ in Chapter 9 of this report).

To deliver the healthier future that is within our reach, we need a new paradigm for research. All health-related data, genomics to social determinants, and every patient contact need to be used to improve the experience, service and prevention for each individual. This dynamic learning and researching environment will require new approaches to evaluation and introduction of technologies that learn and iterate to deliver the best care to patients without delay.

This report has four sections that cover some of the biggest opportunities for health over the next two decades. The first section identifies health as one of England’s primary assets through analysing the links between health and the economy, the local health environment, social health and how the maintenance and treatment of health could be experienced in 2040. The next section of this report identifies the potential health gains and reduction in health inequalities that could be possible with a ‘prevention first’ approach. The third section of this report explores emerging technologies and their potential impact on health promotion, protection and treatment. This section concludes by discussing the ethics of big data, emerging technologies and the fundamental role of mutual trust between the public and health institutions. Chapter 14 explores current and future uncertainties in health and identifying the potential of futures thinking methods to inform and ‘future-proof’ health policy.

\* Office for National Statistics. *Measuring National Well-being: Quality of life in the UK, 2018*. Accessed at: <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/measuringnationalwellbeing/qualityoflifeintheuk2018>

## 02 What is health and what could it be?

**Ambition for 2040** That the health of the whole population is considered one of the nation's primary assets.

Health is generally used to mean the 'absence of ill-health'. Society has a focus on the NHS as an 'illness service' rather than acknowledging the complex interactions in society that influence our health as individuals. Healthcare is often spoken of as a cost to the state and society rather than an investment that generates returns for the individual, communities and the nation. The NHS and public health services are not a burden on our finances – they help to build our future. Moreover, the good health of our nation is the bedrock of our happiness and prosperity – as I have highlighted in my previous reports,<sup>†</sup> *prevention pays*. As the increases in life expectancy experienced over past decades have begun to plateau, I agree with the OECD<sup>‡</sup> – there are a number of factors at play that are affecting many countries, which makes it difficult to ascribe slowing increases to any specific factor or policy.

Health is an asset that we must protect and promote and is affected by the conditions in which we live and work. These conditions can be health-promoting or health-harming, and often governments, industry, and societies are responsible for those conditions, not the individual. We all have some responsibility for our own health, but we are not individually responsible for the house or neighbourhood we are born into, the school we attended, nor the health environment we live in.

The health system must adapt for each individual and ensure both their environment and the care that they receive is helping them achieve 'good health'. One example of this is social prescribing, which acknowledges our expanded understanding of physical, mental and social health and is an opportunity for the traditional health service to utilise, enhance and amplify existing schemes (see Chapter 3 of this report, 'The Local Health Environment'). One size clearly does not fit all, and this requires different types of care accessed through different places and different ways.

## 03 An uncertain future

**Ambition for 2040** That world-leading approaches to thinking about the future are developed and used to inform health and social policy impacting on 2040, creating the capability in the health system to adapt to emergent opportunities and threats to the health of the nation.

The future is uncertain; unless we consider the future and the uncertainties that could affect health, how can we plan effectively and know whether our current plans are 'future-proofed'?

'Futures thinking' is an important part of planning, helping us to imagine what different futures might bring. My report encourages consideration of activities and environments in the light of whether they are health-promoting or health-harming and how much uncertainty they contain as a form of prioritisation for research and policy. In Chapter 14, the authors introduce the 'cone of uncertainty', where they look through the 'lens of now' to health in 2040 to consider different futures for three exemplar areas of interest. The top of the cone represents the best-case or 'utopian' outcome that we might hope for. In contrast, the bottom of the cone represents the worst-case or 'dystopian' scenario. Such a process allows the identification of research and policy considerations to ensure we set the foundations to plan for and protect a healthier future for all.

Futures thinking is vital to planning effective and efficient health environments and services going forward. Strategic leaders in healthcare and public health organisations need to embed futures thinking (and specifically scenario planning) in the development process of long-term plans.

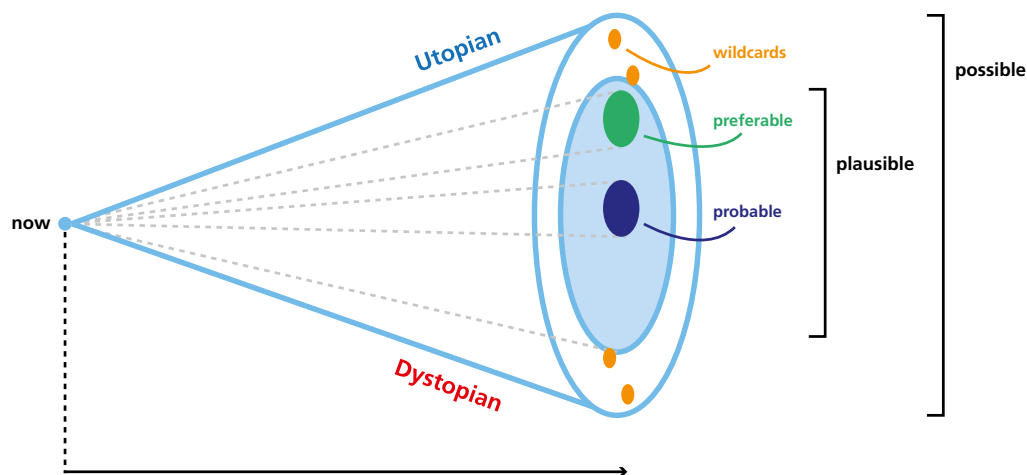
### Recommendation 2

I recommend that the Department of Health and Social Care, and the health system, invest in capabilities for "futures thinking" in health, for example through Policy Research Units.

<sup>†</sup> All of my reports may be accessed online at <https://www.gov.uk/government/collections/chief-medical-officer-annual-reports>

<sup>‡</sup> OECD/EU (2018), *Health at a Glance: Europe 2018: State of Health in the EU Cycle*, OECD Publishing, Paris. Available online: [https://doi.org/10.1787/health\\_glance\\_eur-2018-en](https://doi.org/10.1787/health_glance_eur-2018-en)

Figure 14.2 The cone of uncertainty



Source *The Policy Institute, King's College London*

As we look to 2040, there are numerous scenarios for the health of England, some of which are explored in this report. The evidence throughout this report suggests we are currently at a fork in the road, with two vastly different pathways, both plausible for England in 2040. One scenario concerns me: if certain current trends were to continue and even worsen, we could live in a society where the most deprived are cut adrift from that society. The gap in life expectancy and healthy life expectancy could worsen substantially, aggravated by a digital divide – we must not let this unfair future be our reality.

Alternatively, our society could prioritise health as one of the nation's primary assets, making the health of our nation a source of national pride. This society would bring prevention to the public underpinned by a 'health-promoting environment' coupled with prevention that is personal to the individual. This is the future within our reach.

The final chapter (Chapter 14) in this report specifically looks at the uncertain future for three illustrative areas of varying uncertainty: anti-microbial resistance (AMR), obesity and the impact of technology on mental health.

In my 2011 Annual Report I identified AMR as a leading threat to our future infection prevention, diagnosis and appropriate effective treatment. This chapter states that we are now certain that without significant action, AMR will have a substantially damaging effect upon future health and the global economy.

The future is less clear for obesity. While a dystopian scenario where obesity is the greatest cause of preventable deaths and disability is possible, this is not inevitable; embracing and scaling up the population approaches to obesity and creating a health-promoting environment would allow England to

lead the world in successfully changing behaviours and tackling obesity.

In contrast, the future impact of technology on mental health is very uncertain. There is concern about the potential harm of technologies, particularly social media on mental health and it is important to assess the evolving evidence. Further, we must remain cognisant of avoiding a 'digital divide', which could reshape health inequalities in coming decades. This report however, suggests that the 'connected world' has the potential to transform mental health services and address social isolation.

Despite the many uncertainties, we know that the population will age to 2040. We expect the most rapid period of population ageing to occur in the next 20 years, with the old age dependency ratio<sup>5</sup> rising from 0.27 now to 0.40 in 2040. It is therefore no surprise that estimates suggest a 50% increase in years of life lost due to Alzheimer's disease and other dementias by 2040. Estimates from the Global Burden of Disease Study in this report (see Chapter 14) forecast ischaemic heart disease will remain the leading cause of years of life lost in 2040, but we can expect the current transition of disease burden from cardiovascular disease to cancers to continue. Smoking and overweight/obesity are shared risk factors for both of these diseases and have the largest range between 'better' and 'worse' scenarios in these forecasts. This should be cause for optimism; the epidemic of smoking and obesity and sedentary-related diseases is reversible.

Health and society as a whole must prepare for the future by recognising this change in population. Futures thinking is one way to help challenge our current thinking and prepare.

<sup>5</sup> The old age dependency ratio is the number of individuals aged 65 and older in the population as a proportion of those aged 16-64.

## 04 A culture of health for all

**Ambition for 2040** That healthy life expectancy does increase by five years for all, with the gap in healthy life expectancy between the most and least deprived communities halved.

A healthier working-age population in 2040 is expected to translate into an economy with higher overall productive capacity, increased tax revenues and subsequently reduced spending on health-related social security payments, strengthening public finances (see Chapter 2). We know that investment in health, and the causes of ill-health, pays.

Inequalities in life expectancy have worsened from 2001-2016, with the gap in life expectancy between the most and least deprived deciles increasing from six to eight years in women, and from nine to ten years in men (see Chapter 9). Every cause at every age has a higher death rate in the most deprived communities despite our NHS. This demonstrates that both preventing ill-health through addressing the social determinants of health and the environment and the treatment of ill-health have great potential to deliver a more equitable future.

The majority of people living in poverty now are in working households (see Chapter 4). This report not only highlights the links between poor health, low educational attainment and poor job prospects but also the stark regional disparities and clustering of these links (e.g. the North East of England consistently has high claimant rates). Rebalancing the cost of living with income (earned or otherwise) presents as low hanging fruit to improve the health of the nation. Indeed, I am concerned that social determinants of health such as housing conditions could worsen for the most vulnerable, which would risk a re-emergence of communicable diseases that were eradicated from England decades ago.

Within our reach is an alternative for 2040. A person's health is an important component of 'human capital'<sup>\*\*</sup> – indeed it is pivotal to other components including the development of educational attainment and productivity. The NHS is built upon a social contract: solidarity where we prioritise collective health security and collective wellbeing. Applying this approach of collective wellbeing to the causes of ill-health could have a marked change upon health in England in 2040.

## 05 Bringing prevention to the public

**Ambition for 2040** That the health environment is health-promoting, incentivising and normalises healthy behaviours.

Fifty percent of the disease burden in England is due to four modifiable health behaviours – poor diet, tobacco, excessive alcohol and physical inactivity – which should be cause for optimism. However, projections to 2040 suggest that tobacco will continue to be the leading cause of years of life lost (see Chapter 14). This is not inevitable, and we must take measures now to eliminate tobacco-associated diseases and inequalities over the next two decades. Recent reductions in smoking prevalence in England over past decades are pleasing. However, there are shockingly vast disparities in smoking in pregnancy, with children born in one part of England having a 17-fold higher chance than the least deprived areas of their mother having smoked in pregnancy. This is one contributor to child health inequalities that can and must be addressed. Effectively tackling tobacco and other leading risk factors such as poor diet, obesity, physical inactivity, air pollution and excess alcohol consumption, would transform the health landscape and current inequities in drivers of ill-health such as obesity.

Smoking in pregnancy damages the health of children and contributes to child health inequalities. In 2017/18 there was a 17-fold difference between Clinical Commission Groups in smoking at childbirth.

### Recommendation 3

[I recommend that NHS England and Local Authorities commit to halving existing inequalities in smoking in pregnancy by geography by 2024.](#)

Obesity and obesity-related diseases are among our greatest health challenges. Children and adults in the most deprived communities are at greatest risk of obesity and suffer the burden of obesity-related ill-health earlier, and for longer, than their least deprived peers. Obesity is an inequalities issue.

### Recommendation 4

[I recommend that the UK government ensure that future developments of the Childhood Obesity plan include a specific target to halve current inequalities in childhood obesity by 2030 or sooner, with support for Local Authorities to meet this target.](#)

Chapter 8 of this report identifies interventions that alter the environment for health – 'structural' changes that require little or no action from individuals – are consistently more effective and see the largest population health gains in the most vulnerable communities when compared to individual-based approaches. One example is the innovative, tiered approach to the Soft Drinks Industry Levy, which resulted in

<sup>\*\*</sup> Human Capital is a measure of the skills, education, capacity and attributes of labour which influence their productive capacity and earning potential.

50% of soft drink beverages reducing their sugar content before it was even implemented. These measures are effective and they are also equitable. We must not allow a situation where we look back on this era and regret allowing less effective policies to be implemented because they were either easier or avoided facing difficult trade-offs.

The Soft Drinks Industry Levy has been effective in reducing sugar consumption from soft drinks. In order to mitigate obesity and diet-related diseases, further sustained action is required.

## Recommendation 5

I recommend that HM Government extend the Soft Drinks Industry Levy to sweetened milk-based drinks with added sugar and take action to eliminate added sugar in commercial infant and baby foods.

## Recommendation 6

I recommend that HM Government review the use of fiscal disincentives in relation to foods that are high in sugar and salt and also incentives to increase fruit and vegetable consumption.

I welcome the Secretary of State's vision paper, 'Prevention is better than cure'<sup>††</sup> and his commitment to build upon past success in reducing salt consumption. From 2003 to 2011, an 11% reduction in population salt intake was achieved. This was attributable to the Food Standards Agency's approach to salt reduction, which was transparent, with close monitoring and evaluation, but holding the threat of sanctions to the food industry if reformulation targets in foods were not met. This policy has been emulated across the world. Since 2011, progress on reduction of salt consumption in England has stalled.

## Recommendation 7

I recommend that in 2019, HM Government through Public Health England, set more ambitious targets for salt reduction in food. This should apply equally to the out-of-home sector, which has lagged behind. If these targets are not met then they should be mandated and a range of other interventions considered, including mandating front of pack labelling.

Data driven public health, using predictive analytic models to test public health interventions in silico can allow decision makers both locally and nationally to compare policies. This can help provide sufficient evidence to act, thus encouraging evidence informed policy making for many complex public health challenges.

Those who shape the environment for health should be held to account. We have seen promising first steps, but to fiscally optimise the food environment from producer to plate in order to encourage healthy dietary patterns to be the norm for all, we need sustained and effective action. This approach has to encourage more focus upon the quality, rather than quantity of food produced and sold. Those sectors that damage health must pay for their harm or subsidise healthier choices.

Local Authorities need to be supported with legal powers and tool kits that allow them to improve the health environment for their populations, particularly in areas surrounding schools.

## Recommendation 8

I recommend that the Ministry of Housing, Communities and Local Government explore, with the Local Government Association, how it can better support local government action to encourage healthier food options on the high street.

<sup>††</sup> Department of Health and Social Care. *Prevention is better than Cure*. London 2018. Available at [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/753688/Prevention\\_is\\_better\\_than\\_cure\\_5-11.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/753688/Prevention_is_better_than_cure_5-11.pdf)

## 06 Data driven prevention to target those at highest risk

**Ambition for 2040** That intelligent “predict and prevent” services, integrating advances in biomedicine, technology and behavioural science, are implemented progressively in order to match services to needs. These services enable everyone to have accurate information and support them to engage in positive change.

By 2040, we will be able to accurately predict chronic diseases a decade before they become symptomatic and thus enable individualised prevention measures. Vast progress in computing power and predictive analytics will be able to integrate unstructured data that sits outside of organised and traditional medical databases. This will improve disease progression prediction, allowing optimal preventative and treatment options for each individual.

Point of decision technologies that combine genetic information, nutritional guidelines, behavioural science and emerging technologies using ‘nudges’ in one’s own environment offer the potential to achieve personal behaviour change in specific patient groups (see Box ‘Personalised DNA-based dietary guidelines to nudge the public to better health’ in Chapter 9).

This report identifies wearable technology with novel biosensors that offer continuous monitoring and titration as a way to transform chronic disease management outside of traditional settings (see Chapter 11). Diagnostics’ high predictive value that combine novel biomarkers, genomics and wider clinical datasets will bring the diagnostics laboratory to the patient as part of their daily lives.

These impressive advancements in predictive analytics should be accompanied by tools and support that enable individuals to absorb the knowledge, be empowered and use it. This could make prevention of ill-health a routine part of daily life, particularly for those with chronic diseases.



## 07 The best care, in the best form, for the best you

**Ambition for 2040** That healthcare is delivered through a segmented service that achieves equity of access and uptake through embracing emerging technologies based upon world-leading standards.

Chapter 7 of this report found that multimorbidity is common and will be more common in 2040. By then, we will identify multimorbidity as a non-random series of predictable clusters of conditions and health risks, identifying opportunities for early and effective intervention. I commend the ethnographic research by the Richmond Group's Taskforce on multiple long-term conditions<sup>††</sup> that seeks to understand the lived experience of patients with multimorbidity to ensure the individual is central to how care is delivered in a dynamic landscape. Indeed, by 2040 the current biomedical model of health will be transformed to integrate biomedicine, technology and behavioural sciences to provide personalised medicine in a service that remains personal to the individual.

Multimorbidity represents a substantial health challenge now and is expected to increase in prevalence to 2040. Prevention and treatment need to adapt to effectively manage the non-random series of predictable clusters of conditions and health risks within multimorbidity.

### Recommendation 9

I recommend that research funders, led by NIHR and MRC, commission research to identify and understand the disease clusters that make up common multimorbidity.

### Recommendation 10

I recommend that NICE, alongside specialist bodies, develop multi-disease guidelines for common clusters of disease to avoid multiple single disease guidelines applying to the same groups of patients.

We will evolve from Electronic Health Records to an individualised 'Electronic Health Engine' that integrates high dimensional data about the individual, including social and economic determinants of health, behavioural risks, biomedical, genomic and citizen-generated data, to generate real time dynamic risk trajectories (see Chapter 10). This will inform individualised prevention, management and treatment decisions accessible to both the patient and their clinical and prevention team. Interoperability will be an essential building block to achieving this step-change.

'Intelligent triaging' will have evolved by 2040 to learn how best to achieve uptake of services in each sub-population, ensuring the most rapid, effective and appropriate assessment and management. By 2040 we will have the technology to identify the best mode of accessing healthcare for each individual, whether that is by video call, virtual reality headset or in-person, day or night, as well empowering patients in self-management and control of their conditions. This could reduce inequities in accessing treatment and preventative services (see Chapter 5).

Interoperability will be central to the successful and equitable implementation of emerging technologies. Interoperability must also apply to non-NHS healthcare service providers, public health services and providers of preventative and ancillary services.

### Recommendation 11

I recommend that NHS Digital should develop an open-source infrastructure that reduces the cost and complexity of integrating new technologies with existing healthcare systems, through the open Fast Healthcare Interoperability Resources standard.

<sup>††</sup> [https://richmondgroupofcharities.org.uk/sites/default/files/final\\_just\\_one\\_thing\\_after\\_another\\_report\\_-\\_singles.pdf](https://richmondgroupofcharities.org.uk/sites/default/files/final_just_one_thing_after_another_report_-_singles.pdf)

We are already seeing the potential of artificial intelligence delivering in practice, specifically in imaging and digital pathology. This report highlights many areas of promise for AI, particularly in imaging where quick gains could be achieved across England (see Chapter 12).

As discussed in my introduction, healthcare, as well as prevention, can deliver rapid improvements in health inequalities. AI in imaging is one example that has the potential to reduce geographical inequalities such as in diseases that depend upon time-sensitive imaging (such as stroke). One striking example in this report demonstrates that if cancer survival was equitable, 10,000 deaths within five years of diagnosis would be avoidable (see Chapter 9). Strategically harnessed, emerging technologies will standardise high quality care pathways. This will offer reductions in geographical disparities in the speed and effectiveness of diagnosis, access to and quality of care, to provide world-leading care for all across England.

## 08 New paradigm for research and partnership

**Ambition for 2040** That England has a regulatory, evaluation and commercial framework for health research that embraces emerging technologies with ambition, relevance, and a high ethical standard.

The health system should be a dynamic learning and researching system, where all data and every patient contact is used to improve the experience and service provided to that individual, and to push the boundaries of new treatment and prevention approaches. Co-production with all stakeholders will be pivotal to this success; a health service that is learning with you, about you and for you.

England has long been a leader in both discovery science and applied health research, capturing the unique test-bed research ecosystem of the NHS. The randomised controlled trial is the 'gold standard' for clinical studies for medical interventions, but this approach is often not the most effective method for evaluating either emerging technologies or complex public health problems. Iterative research that allows in silico learning and improvement post-implementation and simulation modelling for complex public health challenges such as obesity, are key to moving fast to improve health.

This report identifies several opportunities for applied health research. To realise this potential requires a realignment of research and healthcare appreciating the interdependencies.

All advances in healthcare must continue to be evidence-based. As emerging technologies develop, a new research paradigm involving novel methods for research and evaluation must also be developed. Emerging technologies, especially those that are dynamic, provide new challenges; 'anticipatory regulation' that is proactive and 'future-proof', cognisant of emerging products and services, would provide a platform to deliver benefits to patients in a safe and expedient manner. Currently, most emerging technologies are classified in the lowest category of medical devices, along with Zimmer-frames and bandages; so, determination of safety and effectiveness is done by the company itself with no requirement for external validation. This holds some risk for patients while also stifling safe innovation that could result in large benefits to patients.

A new approach to the evaluation of emerging technologies that is relevant and proportionate to the intervention while commanding the trust and confidence of patients and clinicians is required. The recently published evidence standards framework for digital health technologies<sup>55</sup> begins to outline the level of evidence required by innovators. We need a proportionate evaluation of the safety of patients before implementation, but then allows the technology to learn dynamically and improve in real time, building in evaluation, thus allowing patients to receive the best care without delay.

Emerging technologies are transforming delivery of health services and improving health outcomes. We need effective frameworks for regulation and evaluation of emerging technologies that while promoting safety allow timely implementation.

### Recommendation 12

I recommend that the Secretary of State for Health and Social Care seeks advice on the best mechanism for developing, delivering and maintaining frameworks for regulation and evaluation of emerging technologies and devices. Decisions should be based upon the following principles:

- Emerging technologies should have safety reviewed (do no harm) by an independent body.
- Evaluation of effectiveness should be both iterative and proportionate to the purpose of the technology.
- Exacerbation of health inequalities must be mitigated against.

As research is conducted on emerging technologies in healthcare, patients and professionals should have confidence in the standardised quality of such research. CONSORT<sup>\*\*\*</sup> reporting standards for RCTs dramatically reduced issues arising from inadequate reporting and improved the interpretability and usability of research findings for clinicians and policy makers alike. Similar standards should be a cornerstone of emerging technologies research in health.

Specific research standards for emerging technologies are required to earn the trust of patients and clinicians, and to enhance interpretability of research findings.

### Recommendation 13

I recommend that NHS Digital should work with the Office for Strategic Coordination of Health Research and Health Data Research UK to develop, consult on and agree an appropriate system for research standards in artificial intelligence health and care research studies for England.

The development of the proposed system should build on the work by the Collaborative Research Group (CRG) on Applied Artificial Intelligence in Healthcare led by the Institute of Global Health Innovation at Imperial College London.

<sup>55</sup> National Institute for Health and Care Excellence. Evidence standards framework for digital health technologies. London. 2018. Available at: [www.nice.org.uk/digital-evidence-standards](http://www.nice.org.uk/digital-evidence-standards)

<sup>\*\*\*</sup> <http://www.consort-statement.org>

Large, representative and longitudinal datasets are essential to developing many such technologies in the NHS; incorporating integration with wider health determinants and citizens-generated data has the potential to be a unique test-bed for such technologies to be developed, and for the benefits to be reaped by patients. The Clinical Record Interactive Search (CRIS) system at the Maudsley Hospital (see Chapter 13) is an example of influential research using integrated electronic health records within a robust, patient-led data governance framework, funded by NIHR.

To ensure that the UK is a leader in emerging health technologies and that the benefits are delivered equitably across all of England, a commercial framework that is standardised across the NHS and health-related bodies is required. This should leverage our national assets, the NHS, and world-leading academia and the life sciences industry to deliver improved services for patients within a robust data governance framework that works for citizens, clinicians and researchers. This requires healthy partnerships, building on the Life Sciences Sector Deal<sup>\*\*\*</sup>, that reduce the risk for partners through representative datasets to develop and improve technologies while delivering for the NHS and its patients.

Health-related data needs to be of a uniformly high standard to facilitate the timely development and implementation of many emerging technologies and predictive analytics. In order for AI-based technologies to effectively serve our population, the health data used to develop that product needs to be representative of us. The UK Government's Code of Conduct for data-driven health and care technology is a welcome and important step in guiding the development of emerging technologies.

## Recommendation 14

I recommend that NHS Digital, with Public Health England and partners, develop and publish best practice standardised guidance for the NHS (hospital trusts, primary care, community hospitals, etc.) on data collection, standards, structure, handling, storage, and sharing for the development of AI tools.

## Recommendation 15

I recommend that the Department of Health and Social Care ensure that 'data banks' are available which are representative of the population of England to allow testing, quality assurance and validation of AI-based tools at scale before implementation into service, and for calibration of AI-based tools developed overseas to the England population for use in the NHS and broader health arena.

The success and sustainability of a health and research ecosystem such as this depends upon the existence of a shared understanding, and acceptance of, reasonable expectations underpinning the relationship between the public, healthcare and research (see Chapter 13). This requires the NHS, research institutions and researchers to constantly prove their trustworthiness, whether from the public or private sector – that they act first and foremost in the best interests of the patients and public.

<sup>\*\*\*</sup> Department for Business, Energy, and Industrial Strategy. *Life Sciences Sector Deal 2, 2018*. London.

# 09 Conclusion

Nothing is inevitable about health in England in 2040. We have the potential to dramatically improve health for all and reduce health inequalities, creating a healthier and fairer future for our children and a stronger economy. To achieve this, and to avoid worsening of health inequalities, health must be seen as one of England's primary assets. We also need to start to measure and track progress through a new composite Health Index alongside GDP. I found in reading the chapters in this report, that now more than ever, an aspirational future is in our hands and that is a real cause for optimism.

If we harness the exciting potential to transform health and the delivery of healthcare, not only will this benefit the health of the nation, but it will also make the UK world leaders in healthcare technologies through an innovative ecosystem based upon world-leading standards that protect and promote the interests of patients and the NHS. The UK could export clinical leadership in emerging technologies globally, as a beacon nation in valuing health fairly in society and in effectively tackling the growing burden of behavioural and lifestyle diseases.

## Chapter 2

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# Health and economic outcomes

### Chapter authors

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# 01 Introduction

Health is not only a crucial component of individual welfare, but also an important determinant of personal and societal economic outcomes. Improvements in health can lead to both a happier and a more productive population. In turn, better economic conditions may improve health. Both poverty and inequality can lead to poor health.

It is at least possible that one could get into a vicious cycle where poor health and poor economic outcomes reinforce one another, or conversely a virtuous cycle.

In addition, other factors like the natural environment or levels of education might be drivers of both economic and health outcomes. The links between health and the economic wellbeing of the population are multiple and complex.

Unsurprisingly there is plenty of empirical evidence of a strong relationship between many measures of health and economic outcomes; the mechanisms that drive this relationship though are less clearly understood. Here, we focus our discussion on why health might impact economic outcomes. However, it is important to note that it can be difficult to disentangle the range of causal mechanisms whereby health, economic outcomes, and other factors shape each other. Policy will always need to be joined up and address multiple factors at once.

A person's health is an important component of 'human capital', which will influence their ability to work and their productivity when in work. Health may be a direct component of human capital – for example, if being healthy enables a person to carry out a particular job to a higher standard – or may promote the development of other human capital, such as increasing educational attainment. If poor health makes some kinds of work more demanding then it may influence whether and how much a person chooses to work. So, at an individual level health will change both the

benefits and costs associated with work. This will have direct consequences for a broad set of economic outcomes.

A healthier population in which there are higher levels of individual human capital is therefore likely to translate into an economy with higher overall productive capacity. Greater capacity to work and higher productivity when in work should in turn increase tax revenues and lower spending on health-related social security payments, and so strengthen the public finances.

We focus here on links between adults' health and their economic outcomes such as employment, earnings and living standards. There is ample evidence that health plays a critical role in the economic decisions made, and opportunities faced, by adults, such as the choice of when to retire (a choice which is becoming increasingly more important given growing demographic pressures) or the ability to perform certain types of roles. Health in childhood plays an important role in determining later life health and human capital: a broad literature has established that adverse events in utero, due to disease and damaging maternal behaviours, and throughout childhood, have strong and persistent effects on cognitive ability, educational attainment and later life outcomes.\* Investments in maternal and childhood health may therefore have large, positive impacts in the future.

In the remainder of this chapter we explore the relationship between health and a variety of economic outcomes. We first look at the direct public finance implications of health, examining public spending on health and social care, as well as on wider health-related spending. We then discuss the *associations* between health and economic outcomes before exploring existing evidence on the *causal impacts* of health on these outcomes. We conclude by discussing how different investments in healthcare and other areas could have meaningful economic impacts in future.

\* For a detailed summary of the recent literature in this area see Almond, D., J. Currie and V. Duque (2017), 'Childhood circumstances and Adult outcomes: Act II', NBER Working Paper 23017

## 02 Health-related public spending

Poor health has negative consequences for the public finances, both because of a greater requirement for public spending on health and social care and on benefits to support people with health problems, and through reduced tax receipts arising from lower employment and earnings.

Healthcare is now by far and away the largest single item of public spending. Figure 2.1 shows how public spending on health has evolved over the past 70 years, both in real terms (adjusting for economy-wide inflation) and as a share of national income. Over time, spending has increased sharply, with the UK government spending £148 billion in 2017-18, or 7.1% of national income, on healthcare. This is equivalent to around £1 in every £5 of public spending.

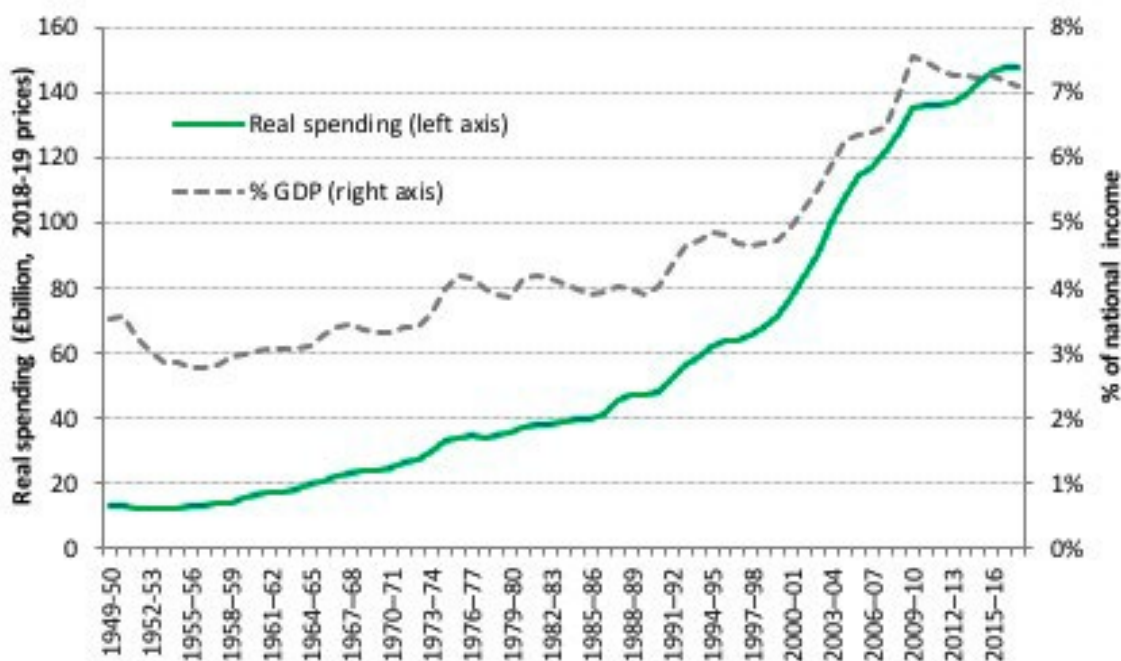
Health spending is only likely to grow in future. Recent estimates suggest that spending would have to increase by 3.3% per year over the next 15 years just to keep up with growing demand and cost pressures.<sup>1</sup> By the early 2030s, health spending is likely to reach around £250 billion a year.

This growth is in part driven by changes to the underlying health of the population. Demand for healthcare increases as the population grows and ages. For example, the average spending on an 85 year-old is five times higher than that on a 30 year-old.<sup>2</sup> With the population aged 85 and over expected to almost double in size over the next 15 years, this will lead to considerably higher spending.<sup>3</sup>

There is also an increasing prevalence of chronic conditions, some of which may be lifestyle related. This is expected to increase the cost of NHS acute care by £30 billion a year in 15 years time.<sup>1</sup> While it is difficult to say how many of these costs could be avoided by investments in preventative care now, it is likely that some of these future costs could be contained if underlying population health was improved.

The impacts of ill health on public spending go far beyond the NHS. Spending on adult social care – largely designed to help those with disabilities or health problems that make completing activities of daily living difficult – was more than £20 billion in 2016-17. Government spending on social security for those deemed unable to work due to poor health or disability is large and rising, both in real terms and as a share of working-age benefits. Spending on the set of income replacement benefits for this group – ‘incapacity benefits’ (of which the primary benefit paid is Employment Support Allowance) – totalled £16 billion in 2016-17, roughly 8 times the sum spent on unemployment benefits. Spending on disability benefits – designed to help with the additional costs of living faced by disabled individuals and paid at various rates depending on eligibility – was £10 billion in 2016-17.<sup>4</sup> Add together spending on healthcare, adult social care and incapacity and disability benefits and the state spends nearly £200 billion a year directly to support those with health and social care need: that’s a quarter of all government spending.

**Figure 2.1 UK public spending on health in 2018-19, prices and as a share of national income, 1949-50 to 2017-18**



**Note**

Nominal health spending data from Office of Health Economics (1955–56 to 1990–91) and HM Treasury Public Expenditure Statistical Analyses (1991–92 to 2017–18). Real spending refers to 2018–19 prices, using the GDP deflator from the OBR in September 2018.

Source adapted from Institute for Fiscal Studies, *UK health and social care spending, 2017*

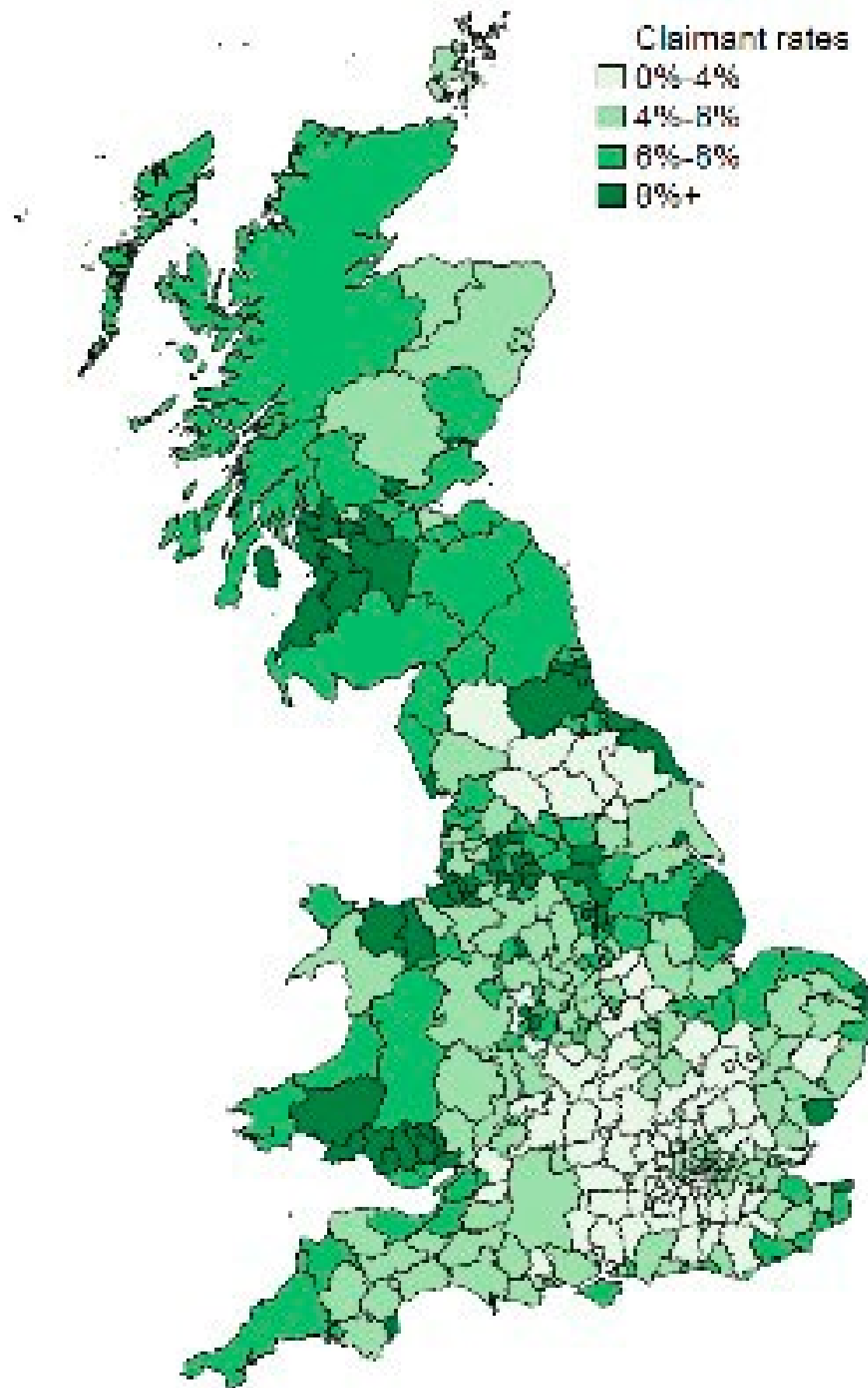


Spending on working age incapacity and disability benefits grew by 18% in real terms between 2007-08 and 2016-17, compared to a 12% rise in spending on other working-age benefits. With further real-terms rises forecast for the future, spending on health-related benefits is set to become increasingly significant in fiscal terms.<sup>4</sup>

There is also considerable geographical variation in the reliance on incapacity benefits. Figure 2.2 shows the range of incapacity claiming rates across Great Britain the United Kingdom in 2016. The proportion of working-age individuals in receipt of incapacity benefit varies dramatically geographically, with a claimant rate of 13% of Blackpool comparing to 2.2% in Hart, Hampshire.<sup>5</sup> In certain parts of the country – the South West of Scotland, South Wales, the North East of England and Merseyside – claimant rates consistently exceed 8%, whereas in much of the South of England the claimant rate is below 4%. These geographical patterns, which became most pronounced following periods of de-industrialisation in the late 1980s, demonstrate the potential for strong and persistent relationships between economic opportunity, health status, and public spending.

Widespread improvements in population health would therefore ameliorate partly offset the underlying problems associated with receipt of these benefits, as well as reducing future public spending in these areas. In approaching these questions, however, it is important to recognise the interplay between education, health, and the geographic dimension of economic opportunities and outcomes.

Figure 2.2 Percentage of 16 to 64-year-olds claiming any incapacity benefits, by local authority, United Kingdom, February 2016



Source reproduced from Emmerson et al., 2017

## 03 Empirical evidence on the association between health and economic outcomes

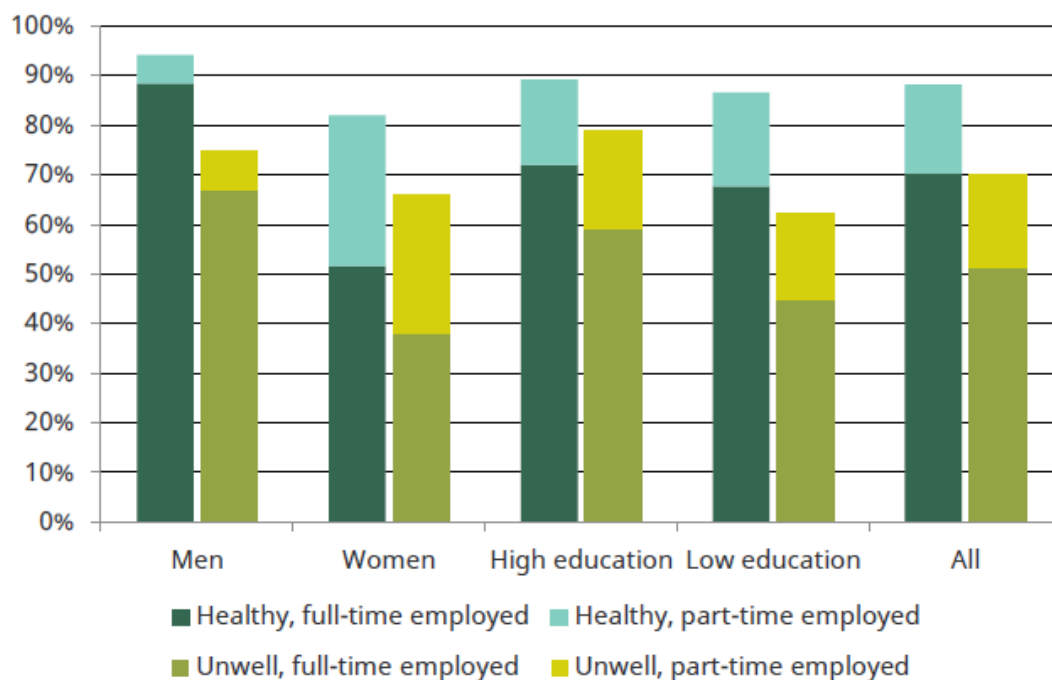
Individuals who are in relatively poor health are less likely to be in employment. Figure 2.3 shows employment rates among those with and without a long-standing illness for different groups of the population aged between 25 and 54 in Great Britain.\* Defining an individual as having a 'long-standing illness' if they report having a physical or mental health condition that has lasted, or is expected to last, at least 12 months, around one in four individuals aged 25-54 had a long-standing illness in 2016-17. In that year, 70% of those with a long-standing illness were in work, compared to 88% of those without a long-standing illness, a gap of 18 percentage points (ppts).<sup>5</sup>

Figure 2.3 also shows the breakdown of employment between full-time and part-time work. This shows that even among those in work, poorer health is associated with working fewer hours, with those in poorer health more likely to work part-time. Figure 2.3 also demonstrates that the employment gap between the healthy and unhealthy is largest for those with lower levels of education. Among those who have a long-standing illness, low-educated individuals are almost twice as likely to be out of work as those who have a high level of education.

In addition, those with low levels of education are much more likely to report suffering from a longstanding illness than are the better educated. For example, 34% of people with low levels of education report a long-standing illness, compare to just 22% among those with high levels of education. These correlations between poor health, poor education and low levels of labour market attachment have been strengthening over time and are illustrative of the multiple problems that some can face.

Figure 2.4 shows short-term and long-term out-of-work rates among 25-to 54-year-olds by health status, gender and education. A person is defined as long-term out-of-work if they have not been employed in the last three years. For men in particular the chart shows how strong these relationships are. Among healthy men only 6% are out of work at all, and just 2% have been out of work for three years. Yet a quarter of men with a longstanding illness are out of work, and one in six has not worked in the last three years. Again, there is a strong relationship between education and employment outcomes, for a given health status. Among those out of work, the low-educated unwell are more likely to be long-term out-of-work than are the high-educated unwell.

**Figure 2.3 Employment status of 25- to 54-year-olds with and without a longstanding illness, 2016-17, Great Britain**



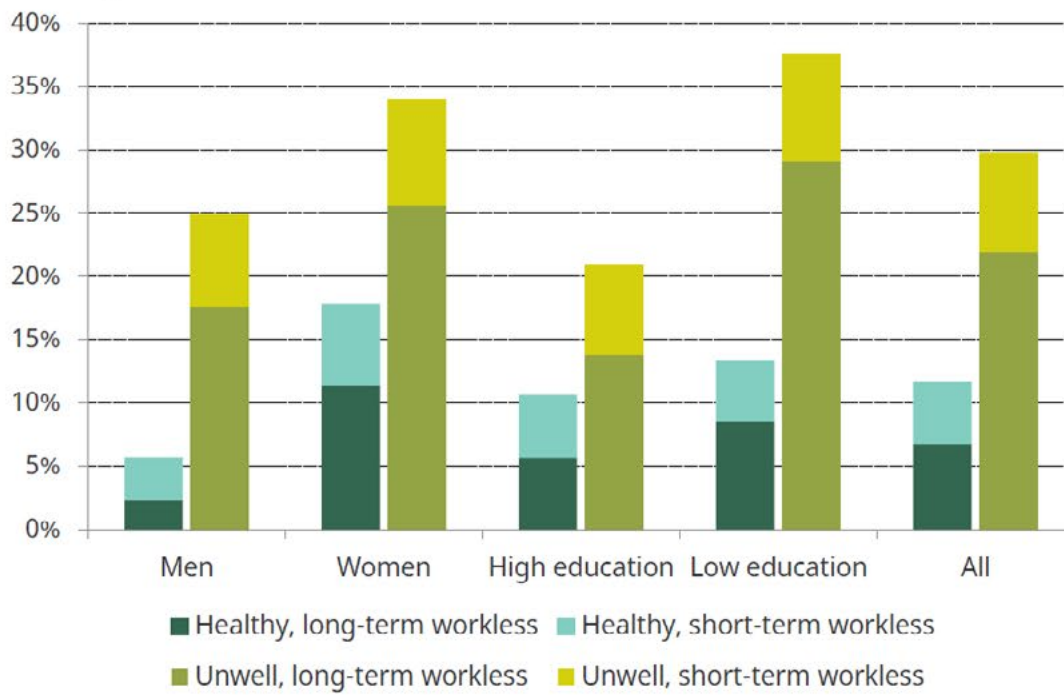
### Note

\* 'Low education' refers to those who finished full-time education below the age of 18; others are 'high education'.

Source Reproduced from Cribb, J., A. Norris Keiller and T. Waters (2018), 'Living standards, poverty and inequality in the UK: 2018', IFS: London

\* Northern Ireland is not covered by the Labour Force Survey used to construct these statistics.

**Figure 2.4 Out-of-work rates among 25- to 54-year-olds with and without a longstanding illness, 2016-17, Great Britain**



**Note**

'Low education' refers to those who finished full-time education below the age of 18; others are 'high education'. A person is defined as 'short-term workless' if they have been employed within the last three years and as 'long-term workless' if they have not been employed within the last three years.

Source Reproduced from Cribb, J., A. Norris Keiller and T. Waters (2018), 'Living standards, poverty and inequality in the UK: 2018', IFS: London

While the difference in the employment rate between those with and without a long-term illness appears to have fallen in recent years, long-term illness remains a very significant potential driver of employment outcomes.\* To place the importance of health in context, being long-term sick or disabled was second only to looking after family as the reported reason for being out of work in 2016-17. In that year, 3.9% of working-age individuals reported being out of paid work as a result being long-term sick or disabled, compared to 2.8% who were unemployed.

The association between health and economic outcomes extends beyond employment. Even after taking into account the decreased chance of being in work poor health is additionally associated with lower earnings, with median earnings lower for those with long-standing illnesses even among those in employment.<sup>5</sup>

Lower employment rates and earnings are also associated with lower standards of living. While incapacity and disability benefits are designed to cushion some of the impact of lost earnings on household income, poverty – defined as having household income less than 60 per cent of the median – is

more prevalent amongst the families of those who have a long-standing illness than those who do not.<sup>5</sup> On an after-housing-costs basis, relative poverty has been between 8 and 14 percentage points higher amongst the ill population than those in better health, over the period 1997-98 to 2016-17. In the most recent data 28% of those with a long-standing illness were defined as being in poverty on this measure. Those in ill health who are poor are also much more likely to be persistently poor and to report material deprivation – an inability to afford certain goods or services – than are the healthy poor.<sup>5</sup>

Those with mental health problems are particularly likely to be in poverty and to report higher levels of material deprivation.<sup>5</sup> The growing prevalence of mental health conditions among those of working age has also had considerable implications for receipt of incapacity benefits. Mental and behavioural disorders are the largest primary reason for the claiming of working-age incapacity benefits, with 49% of cases recorded under this category in May 2016, compared to 31% in May 2000.<sup>5</sup> This increasing importance of mental health conditions, relative to physical health, has been associated with a shift in the composition of incapacity

\* For a discussion of why this difference has decreased, see Cribb, J., A. Norris Keiller and T. Waters (2018), 'Living standards, poverty and inequality in the UK: 2018', IFS: London

benefit claimants away from being strongly age-related and towards being more strongly related to education. In 1998, men aged 55-64 with high education were 2.3 times more likely to be in receipt of incapacity benefits than men aged 25-34 with low education; but by 2016, the younger low-education group of men were twice as likely to be receiving incapacity benefits as the older high-education group.<sup>4</sup>

Thinking about the economy as a whole, better individual economic outcomes for large sections of the population translate into lower or higher levels of aggregate economic activity. To the extent that relatively poor health is the *cause* of lower employment and wages among those with a long-standing illness, large-scale improvements in health would translate into increased levels of overall economic activity. Higher overall levels of employment and wages should also lead to higher tax revenues and lower spending on the health-related benefits described earlier in this chapter (see 'Health-related public spending'). This would improve the position of the public finances and free up resources that could be used in other ways. However, the extent to which the relationships we have described in this section do in fact represent a causal impact of health on economic outcomes is an open question, which we examine in the next section.

## 04 Establishing causal links between health and individual economic outcomes

The evidence presented above shows a strong association between health, economic outcomes and living standards, but it does not prove that poor health *causes* these economic outcomes. There is likely to be a wider interplay whereby lower levels of education and lack of economic opportunity more generally, may drive both poor health and economic outcomes. This could be mutually reinforcing if in turn poor health lowers human capital and living standards. If policymakers want to target improvements in economic outcomes arising from improvements in health then it is important to better understand these causal links.

To address this issue, a broad economic literature has examined the impact of sudden changes – or ‘shocks’ – to health on employment and other outcomes. The idea is that if these health changes are unanticipated, then any changes in worker behaviour following such an event must be caused by the health event itself.

These studies, across a broad range of countries and institutional settings, indicate that declines in health are associated with lower employment, general participation

in the labour force, and earnings. This includes the US, the UK, and many other European countries, although the exact magnitude of the effect varies by setting.\* For example, one study using UK household survey data from the 1990s, found that health shocks among workers aged between 50 and 64 were associated with a large increase in early retirement.<sup>6</sup>

Notably, the negative effects of health shocks on employment are generally found to be greatest among groups with lower attachment to the workforce in the first place, such as older people nearing retirement. This is of particular importance given recent demographic changes to the UK population, with the ageing and approach of retirement for the baby-boomer cohorts, and the policy response of increasing state pension ages. One recent study found that at least one in seven of 55-74 year-olds are limited by their health in their ability to work.<sup>7</sup> This suggests that investments that extend the period that people spend in good health could increase participation in the labour force among older people. This has the potential to have a very significant economic impact.

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\* For an extensive summary of this literature, see Prinz, D., M. Chernenov, D. Cutler and A. Frakt (2018), ‘Health and Economic Activity Over the Lifecycle: Literature Review’, NBER Working Paper 24865

## 05 Conclusion

The relationships between health and economic outcomes are strong. They are likely to go hand in hand. A healthier population is likely to be more economically productive (and to cost the taxpayer less in healthcare and disability benefits) while a more prosperous and equitable society is likely to be healthier.

Teasing out precise causal mechanisms is hard, but it is highly likely that an integrated approach to dealing with health, education, economic productivity and poverty will work better than approaching each in isolation. Not only do health and economic outcomes drive each other but there is also a myriad of channels whereby economic opportunity, or lack of it, can impact the development of an individual's living standards and health, in a self-reinforcing process. This is exemplified in the very strong links between poor educational attainment, poor health and low levels of labour market attachment.

The period up to 2040 is likely to present particular challenges. The most rapid period of population ageing is projected to occur in the years until 2040, with the old-age dependency ratio rising from 0.27 today to 0.40 in 2040, stabilising thereafter.\* This ageing and its associated fiscal challenges reinforce the importance of ensuring that people are healthy enough to work, should they want to, through their 50s, 60s and 70s. With the state pension age rising as a partial response to these pressures, and with the demise of generous occupational pension schemes, more people may feel they need to work longer in any case.

Furthermore, ensuring that those of working age are able to work, where appropriate, and contributing much-needed tax revenues, is likely to become only more urgent over the coming decades as demographic change puts pressure on the public finances through higher health, social care, and pension spending. With this in mind, tackling emerging threats to the population's health in the coming decades, whether that is levels of obesity or the growing prevalence of mental health conditions – or other challenges entirely – is important. Effective support for the health of individuals at all ages will have to should be among the ways in which government facilitates individual's behaviour. This will be important both for people's own the wellbeing of individuals and for the economy as a whole.

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\* Authors' calculations based on ONS population projections. The old-age dependency ratio is the number of individuals aged 65 and older in the population as a proportion of those aged 16-64.

## Chapter 3

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# The local health environment

### **Chapter lead**

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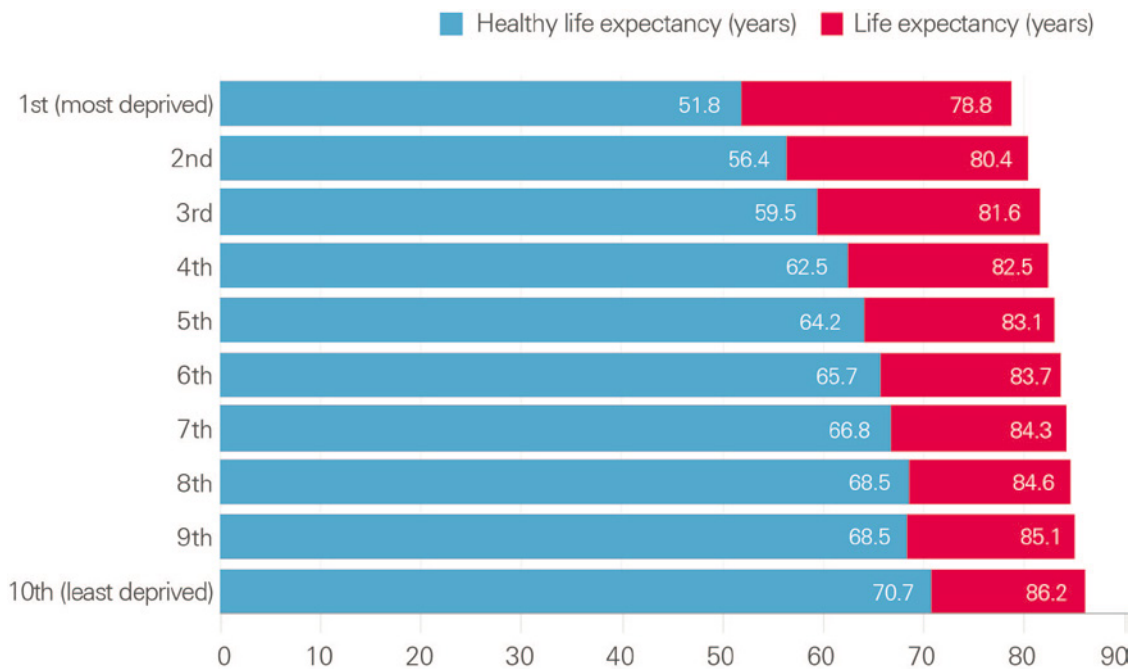


## 01 Introduction

Viewing people’s health as the primary asset for our nation would revolutionise the way decisions are made at national and local levels, putting health and wellbeing at the heart of all policy. By 2040, this could transform our local communities and the lives of the people who live in them. There could be clean air to breathe and warm, secure homes to live in. The built environment could make it easy for people to be active and enjoy green space. The cheapest, and most easily-available food, could be healthy food. Everyone could have enough money to meet their basic needs and have meaningful work to do. Local communities could be places where people turn to each other for support and no-one would be left out.

The health environment includes all of these factors and more. There is abundant evidence that when these conditions are in place, most people lead long, healthy, and productive lives.<sup>1</sup> In this chapter, we consider the evidence for how a healthy environment can improve health. We then explore three fundamental changes at national level that could shift the focus of policy and action from treating and managing disease to creating health in order to provide an enabling context for local leadership. Throughout, we highlight some of the opportunities this would create for communities to lead healthy lives.

**Figure 3.1 Total life expectancy and healthy life expectancy at birth by decile of index of multiple deprivation, females 2014–16**



Source *The Health Foundation, 2018*

## 02 How the environment shapes our health

The environment people live in has an enormous impact on their health through both direct and indirect channels. The direct impacts are perhaps the most widely understood. Polluted air, for example, is known to have a strong, direct effect both on short-term and long-term health outcomes.<sup>2,3</sup> Similarly, damp or cold housing has been shown to have an impact on respiratory health.<sup>4</sup>

The indirect impacts of the health environment have more complex causal mechanisms but nevertheless have a powerful effect on people’s health. The relationship between poverty and poor health has been comprehensively studied over many decades.<sup>1,5,6</sup> While national life expectancy has improved significantly over the past 50 years, certain patterns have persisted. For example, people living in more deprived areas consistently have shorter lives and longer periods of poor health at the end of them. Figure 3.1 shows that women in the most deprived communities in the UK can expect on average to spend 27 years, or one third of their lives, in poor health. Figure 3.2 illustrates some of the mechanisms linking inadequate income to poor health.

Economic and social environments can affect health through material, psychosocial, and behavioural pathways.<sup>7,8</sup>

- The material effects of low income on health include, the difficulties low-income families face in being able to afford a healthy diet.<sup>9</sup>
- The chronic stress caused by having an inadequate income is a physiological mechanism linking poor economic circumstances to poor health outcomes.
- Behavioural pathways include the fact that health-damaging behaviours such as smoking and substance misuse are strongly associated with poor economic and social environments, in particular adverse childhood experiences.<sup>10,11</sup>

While individual choices can mitigate some of these effects, people's choices are constrained and structured by the environment they experience across the course of their lives. For example, choices about diet are strongly affected by the

affordability and availability of healthy food, while choices about physical activity are limited by the built environment and transport infrastructure. Reducing health inequalities will not be possible without action to create healthier environments.<sup>1</sup> Interventions that seek to change behaviour without addressing the wider environmental constraints on choice, therefore, are likely to have limited impact.

Large numbers of people are currently exposed to sub-optimal conditions, which means there is enormous potential to improve health through creating better environments. Ensuring that all parts of the country had the highest levels of air quality, for example, could result in 40,000 fewer deaths each year.<sup>2</sup> With one in five people in the UK currently living in poverty,<sup>3,12</sup> it is clear that the potential to improve the economic environment for large parts of the population is huge. If, by 2040, everyone had the type of environment currently only available to the most affluent sections of society, people would live longer, healthier, more productive lives with fewer years of ill health.

**Figure 3.2 The relationship between money, resources and health**



Source The Health Foundation

\* Joseph Rowntree Foundation define poverty in their report as 'when a family has an income of less than 60% of median income for their family type, after housing costs'.

## 03 National context for a healthy environment

Creating healthy local environments can only be done within an overarching, national context which encourages health creation as a goal of equal importance to wealth creation and values healthy environments at least as much as treatment of ill health. Three fundamental changes in thinking and practice would be required at national level to put health at the heart of our civic priorities and encourage the creation of the healthiest environments possible for local communities:

- An expanded view of health. ‘Health’ would be understood as more than just an absence of disease, it would be seen as a vital asset contributing to social and economic value;
- An expanded view of community success. Civic leaders, be they local government officials, elected councillors, business leaders or civil society heads, would measure success in terms of health of the local population, not just economic output;
- An expanded view of how to intervene. Healthy communities would be understood as an outcome of a multitude of interdependent elements that make up a connected and adaptive system and interventions would be shaped accordingly.

## 04 Expanding our view of health

The British public generally understands health as being an absence of disease (see Box 3.1). This perspective runs through policy making, with the result that much public debate about improving health focuses on better treatment of illness.<sup>13</sup> By contrast, a society which prioritised health would think of it as an asset, a stock which is worth investing in, and something which can be positively enhanced at any age by a healthy environment.<sup>14</sup>

Figure 3.3 outlines the importance of a wide range of physical, economic and social factors as determinants of health. Such an expanded view of ‘health’ could fundamentally change the debate around improving health in England from one which is primarily focussed on health-care services, to one which recognises the vital importance of creating a healthy environment in which people can flourish.

The challenge involved in making this shift can be seen in a poll of public attitudes to the NHS in April 2018, which found much greater support for further investment in emergency healthcare than in preventative public health measures (see Figure 3.4). Recent work from The Health Foundation has identified a number of the cultural models that underlie these attitudes including an understanding of health as an absence of illness (see Box 3.1).

### Box 3.1 An expanded view of health: more than an absence of disease

Qualitative research commissioned by The Health Foundation identified a number of ‘cultural models’ present in public thinking in the UK. The ‘absence of illness’ model was prominent and involves implicitly defining health by what it is not, rather than by what it is. Health is seen as the absence of illness. Health is assumed to be the default state of the body and the mind before the inevitable accumulation of pathologies and dysfunctions over time. Because people define health negatively, in conversations about what good health involves, participants consistently brought up illness and poor health.

*“I think good health is waking up in the morning and feeling happy and not being full of aches and pains. Good health is never having to go to the doctors. Ironically, good health is never having to use the NHS. I say ironically because of how much I respect the NHS, but, if I never have to use it, [...] that’s good health.”*

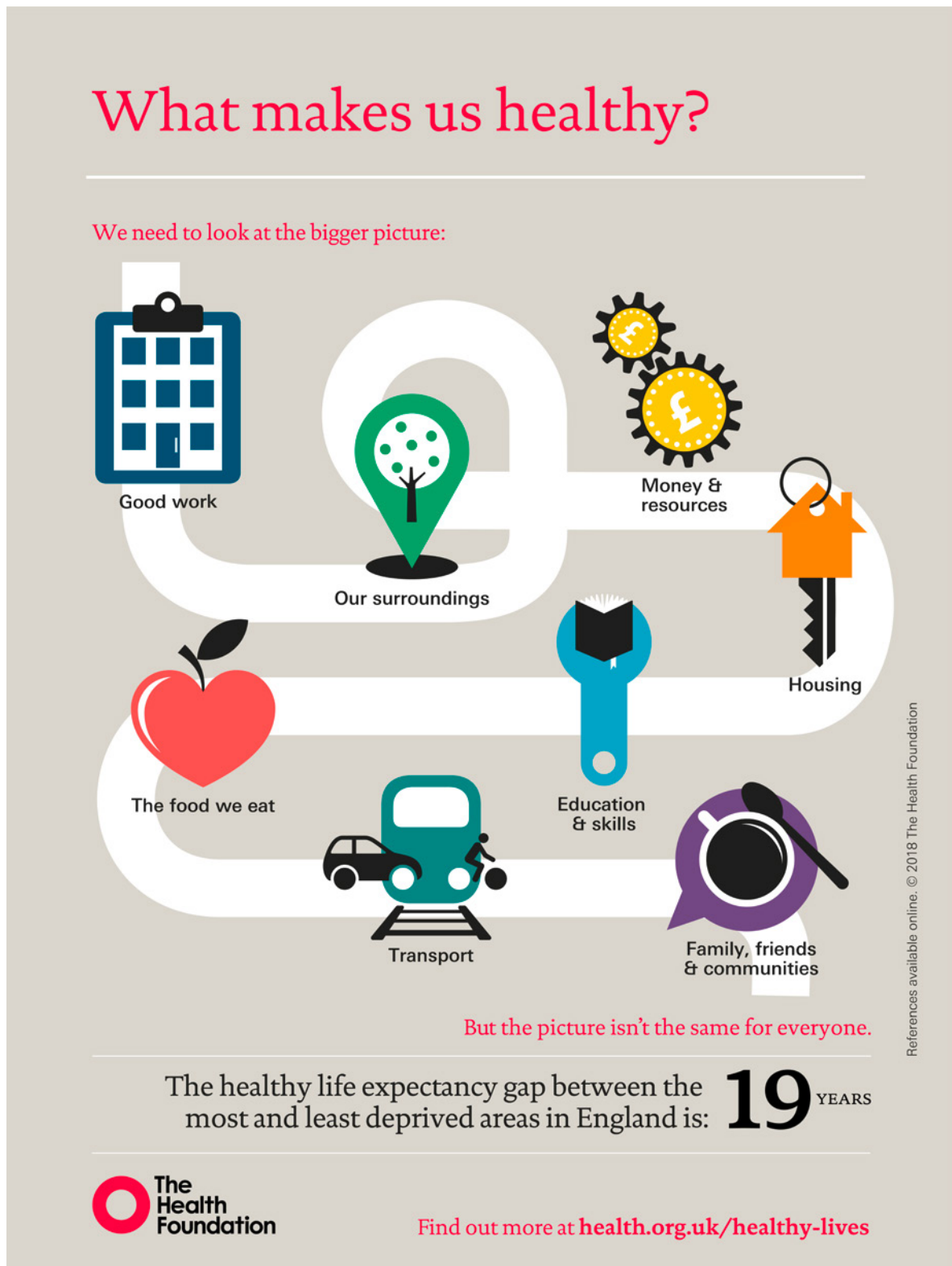
*Public participant.*

An alternative, broader understanding of health held by many public health experts is that good health means people experiencing physical and mental wellbeing, being able to make meaning of their lives, and having the sense of control needed to pursue life goals. This perspective opens the possibility that people can experience good health at advanced ages and even when they have some physical illness.<sup>1</sup>

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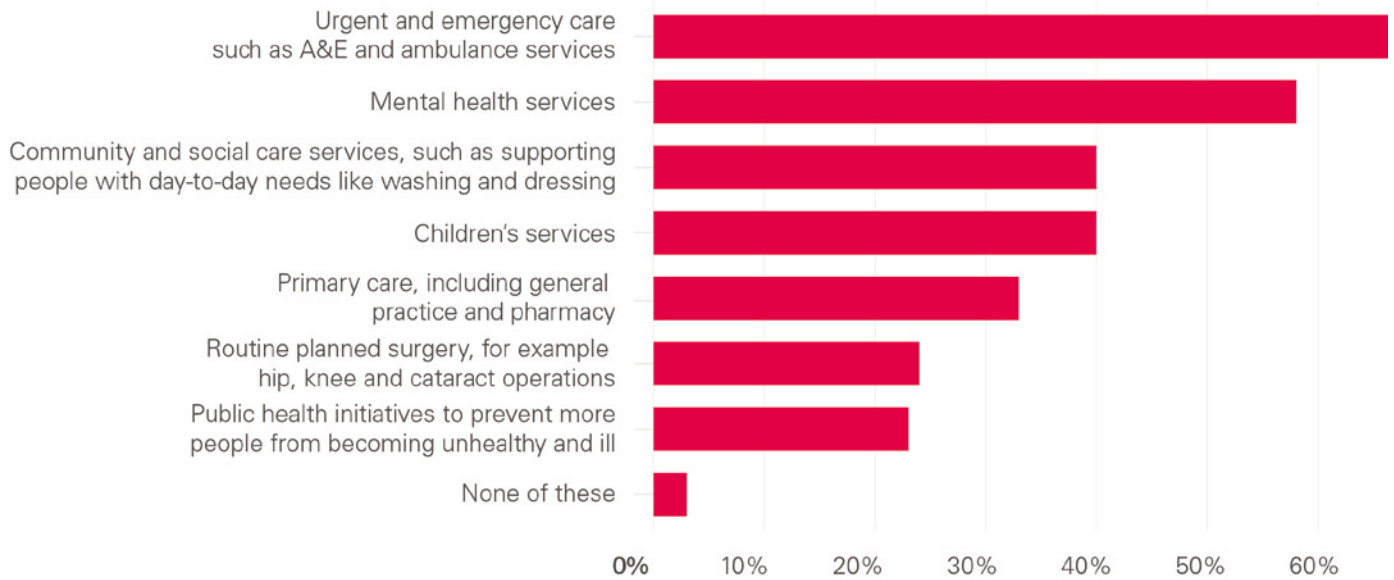
Figure 3.3 What makes us healthy?



Source The Health Foundation

**Figure 3.4 Public priorities for future spending on health and care services**

**If the Government were to devote more funding to health and care services, which three, if any, of the following do you think it should prioritise in terms of spending?**



Source Ipsos MORI (2018) NHS at 70: Public attitudes to the health and care system

## 05 An expanded view of success

An expanded understanding of what it means to be healthy needs to be coupled with new ways of measuring the success of policy at both national and local levels; measures which go beyond traditional economic indicators, such as employment and income. Economic theory often assumes that creating economic growth will translate naturally and inevitably into improved wellbeing yet the unsustainable impact that economic growth can have on the natural environment suggests that this is not necessarily true.<sup>15,16</sup> Indeed, there is no guarantee that economic growth leads automatically to improved health since certain forms of growth can create commercial and social environments which damage health.<sup>17</sup> This is leading to increasing recognition that measurement of economic and social progress should go beyond measurement of Gross Domestic Product to encompass wider measures of population wellbeing.<sup>18,19</sup> The World Bank has called for countries to start measuring 'human capital' as a way of motivating investment in health-enhancing sectors.<sup>20</sup> New Zealand has recently become the first country in the world to commit to setting budgets on the basis of wellbeing rather than economic growth (see Box 3.2).<sup>21</sup>

More rounded ways of measuring success would allow all policy to be evaluated in terms of the contribution it would make to maximising health and wellbeing. This would also allow trade-offs between different forms of capital to be examined and debated in an informed way. The economic benefits of increasing employment rates, for example, could be weighed against the wellbeing problems created by low-quality, insecure jobs.

This way of thinking about and measuring success could transform the way in which decisions are made at all levels, putting health and wellbeing at the heart of all policies. At local level, rather than focussing on economic growth and the financial sustainability of services, the health and wellbeing of the local population would be considered the most important measure of an area's progress. This would lead to different prioritisation decisions being made. Areas such as Sure Start centres, which have seen significant funding reductions in recent years, would be valued not only for the good they do in themselves but also as creating the conditions needed for a flourishing community and local economy.

### Box 3.2 Expanding our view of success: putting wellbeing at the heart of government policy in New Zealand

In 2019, the New Zealand Government will publish its first "Wellbeing Budget", in which priorities will be explicitly structured around intergenerational wellbeing. This is part of a strategy to put population wellbeing at the heart of government decision-making.

*"We're starting from a position where the received wisdom – that creating economic wealth makes everyone better off by creating bigger and better businesses, higher employment, more savings and spending, an increased tax take, and a greater ability for government to support those who are vulnerable or in poverty, ill health or deprivation – is no longer seen as a guaranteed ticket to a better place."* David Lovatt, 2018

A key element of this strategy is the development of a "Living Standards Dashboard" which is being led by the Treasury to give government a more rounded picture of success.

This is thought to be the first attempt by any country to integrate wellbeing formally into its national budget-setting processes. This has the potential to fundamentally change the way in which government decisions are made, opening the door for health and wellbeing to be considered a key measure of national success and a contributor to other forms of development.

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## 06 An expanded view of how to intervene

An expanded understanding of what makes people healthy requires an expanded understanding of the multitude of factors which interact to produce health outcomes. Many of the major health challenges facing the UK population – including rising levels of obesity and poor mental health – have multiple causes and consequences. They are both products of and components in complex adaptive systems. Yet the most common policy responses are approaches designed to change individuals' behaviour or treat clinical problems, without sufficient regard to the context in which they occur. As Rutter et al. put it in 2017<sup>22</sup>;

*“Population health problems that emerge as a property of a complex system cannot necessarily be solved with a simple, single intervention, but the interacting factors within the system can potentially be reshaped to generate a more desirable set of outcomes, through a range of actions targeted throughout the system.”*

A complex adaptive systems approach to many health challenges is required. Organisational boundaries and budgets, and criteria by which services are commissioned and paid for, can all act as barriers to thinking and operating as a system. One example is the complex division of responsibilities and budgets for preventing and treating mental ill health between different parts of the NHS, local authorities, and the education system.<sup>23</sup> Creating an effective community-level response to such complex issues is challenging. It requires decision makers to act as part of a system, thinking beyond the narrow responsibilities of their own organisations and budgets to effect community-level change. At present, such cross-sector thinking is often discouraged by performance management targets which are focused on processes rather than population health outcomes.

Because systems are dynamic and adapt over time in response to changes, taking a complex adaptive systems approach can help in predicting long-term impacts of actions, and planning a long-term approach to improving population health. A systems approach, therefore, needs a different way of evaluating whether and why interventions have had their desired impact, one focused on broader, more dispersed impacts of interventions.

### Box 3.3 Applying a systems lens to young people's mental health

Young people's mental health and wellbeing is now of primary concern to policy makers but the predominant focus remains on early identification and treatment services for mental illness, rather than promotion and maintenance of good mental health. Effective prevention requires a deeper understanding of the many factors that influence young people's mental health, and how these interrelate.

The Health Foundation convened a group of professionals and young people to map system influences on mental health. This process of mapping the system – while just a first step in taking a systems approach – was an effective mechanism for bringing people with diverse roles in young people's lives together, starting conversations, and helping them understand wider perspectives. The resulting map visually demonstrated the breadth of the influences on young people's mental health and highlighted connections not previously recognised by those working in any single part of the system. The map helped identify gaps in current services, gaps in evidence, as well as a mismatch between what was considered important, and what received the most funding.

System mapping exercises will only ever represent the perceptions of those present – who to involve is therefore critical – but mapping of this kind is a valuable first step in planning policy and practice which can influence complex issues and create healthier environments at community level.

## 07 Local leadership for a healthy environment

Changing the national context, in the way described earlier in this chapter, would help to transform community-level leadership.

Local government has a pivotal role to play in creating healthy local environments. At present, however, the ability of many local authorities to make long-term investments in improving health, is constrained by a combination of budget cuts<sup>24,\*</sup> and growing demand for services. In this context, national and local incentives dictate that attention is focused on fixing immediate problems at the expense of long-term investments. This is illustrated by Figure 3.5 which shows that overall reductions in spending on children’s services between 2010 and 2016 were born disproportionately by preventative, health-creating services such as Sure Start, early years education services, and early help (social care). These services have long-term benefits for the whole child population, by creating healthy educational and social environments at a crucial point in children’s lives. Spending on Sure Start and early years services, for example, fell by 44% over that period, while spending on the acute needs of the relatively small number of children in the statutory social care system (children in need and looked-after children) increased by 10% over the same period.

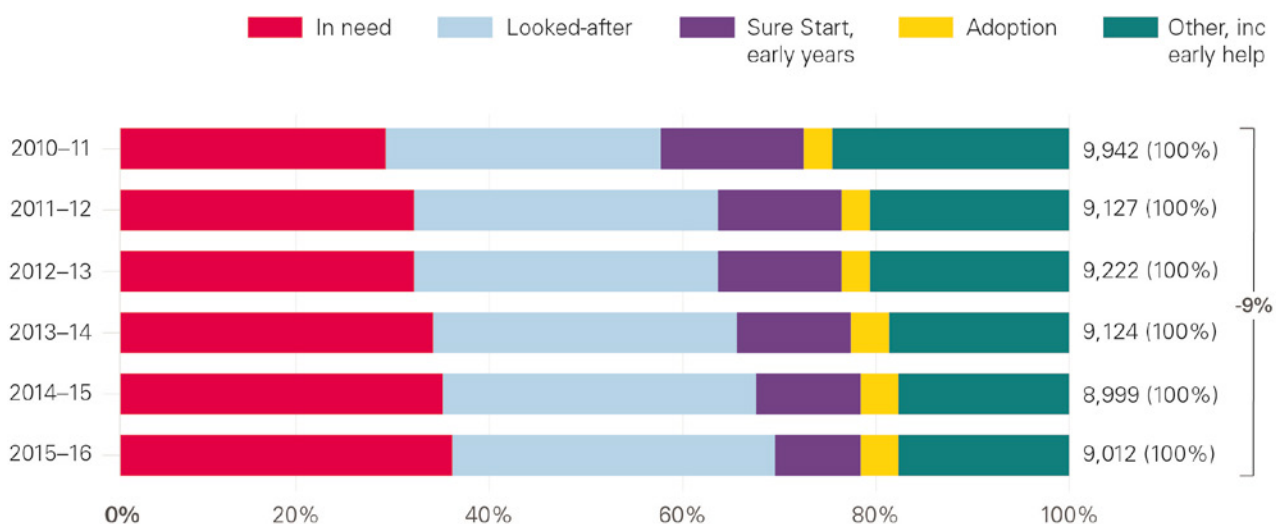
Within a national context that supports the creation of good health, civic leaders would be empowered and incentivised to make decisions differently, prioritising a healthy environment over short-term service provision. Rather than improving people’s health being a niche interest, advocated for by

public health professionals, the health of the population could become a shared value, something which could be seen by all as a common measure of success.

With the financial resources and incentives needed to invest in health and wellbeing, local leaders could prioritise investments in early years services, in green space, and in the infrastructure needed for sustainable, active travel; investments which would enhance health and prevent disease. It could also change the way that local authorities work with other sectors. Rather than attracting private sector investment solely on the basis of its likely council tax contributions, civic leaders could encourage businesses which bring benefit to local populations, and have a strong record on workforce wellbeing. They could also procure services from local organisations which benefit the local community.

The business sector too, has the potential to have a significant, positive impact on health, by treating population health and wellbeing as a core part of their purpose rather than an adjunct to profit-making.<sup>25</sup> However, evidence shows that benefit to local people, even from large business investments in a locality, depends on how they work with local communities. Analysis of Amazon’s investments in the United States, for example, shows that, while the local authorities have often offered large tax incentives to encourage investment, new Amazon warehouses lead to an increased number of warehouse jobs in a county, but no overall increases in employment due to job losses caused in other sectors.<sup>26</sup>

**Figure 3.5 Total spending on children’s services (£ million), across all 152 English local councils, 2010-11 to 2016-16**



Source: Department for Education, Section 251 outturn, total expenditure

Source Department for Education, Section 251 outturn, total expenditure

\* The National Audit Office reported a 32.6% fall in spending between 2010/11 and 2016/17, excluding social care spending.



The voluntary, community and social enterprise (VCSE) sector also has an important part to play in shaping the health environment of our communities. VCSE organisations often have a better understanding of local needs and are better at harnessing local assets than the private or public sectors. Current involvement of the VCSE sector in service planning and provision is limited. Rather than being treated as equal partners who co-design services for their local communities, VCSE organisations are often the subjects of consultation exercises which have limited influence on the final shape of services. Public sector commissioners tend to favour large, generic contracts which provide a range of services across a wide geographic area. The size and complexity of these contracts make it hard for local organisations to bid to deliver them and the resulting services are often so generic that they offer poor access to some of the most vulnerable sections of the population, such as those who need translation services or are stigmatised by their health condition.<sup>27</sup>

Working in close partnership with the VCSE is one important part of a wider approach to empower local people to shape their own health environment. Too often, services are designed and delivered in ways which make people passive recipients of help rather than active partners in making their community a better place.<sup>28</sup> Similarly, prevailing approaches to outcome measurement and performance management tend to reduce complex human experiences to simplified data points, with the result that improvements in outcome measures do not always correspond to improved experiences for service beneficiaries.<sup>29</sup> Making people agents who can design and deliver solutions to their own health needs will be a vital part of creating a healthy environment.

## Box 3.4 Reducing childhood obesity through community-wide action

An example of the way in which local leadership can change the health environment and improve health is found in the EPODE<sup>i</sup> approach to tackling childhood obesity. This grew out of a pilot study in two French towns which successfully reduced levels of obesity compared to control towns which had similar levels of child obesity at the start of the study.<sup>j</sup> Although it took 8 years for improvements to become evident, by 2004 (12 years after the programme started) 8.8% of children in the pilot towns were overweight compared to 17.8% in the control towns. Although this programme began with school-based interventions, the programme quickly widened since:

*“...it was apparent that interventions targeting schools alone were not sufficient, and that progress was only made when the mobilization of the population became more generalized at community level and involved schools, pre-schools, local sports and parents’ associations, catering structures, health professionals, elected representatives, and local stakeholders from the public and private-sectors.”<sup>ii</sup>*

From this initial pilot, the EPODE approach was developed and is described as a “capacity-building approach for communities to... prevent childhood obesity”. The four factors that emerged as being vital to enable this change were:

- 1) political commitment at national, state and local level amongst those able to influence environments and childhood settings;
- 2) sufficient resources to fund services and evaluation;
- 3) support services including social marketing and community work;
- 4) scientific evidence to guide implementation.

The success of this programme in tackling one of the most intransigent public health issues of our time was remarkable and illustrates the importance of the local leadership issues explored above. Nevertheless, efforts to replicate this success have had mixed results with evaluations suggesting that adaptation to local circumstances is critical for success.<sup>iii</sup>

<sup>i</sup> EPODE is a French acronym which stands for: ‘Ensemble Prévenons l’Obésité Des Enfants’ and translates as “Together Let’s Prevent Childhood Obesity”

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### Box 3.5 The potential of policy modelling to inform cost-effective, equitable health policy

*This box was kindly provided by*

*Chris Kypridemos, Brendan Collins, Martin O’Flaherty, Simon Capewell of University of Liverpool*

#### **The utility of Policy Simulation Models (PSMs)**

Innovations in modelling methods and computer science have allowed researchers to develop more realistic, individual-level policy simulation models (PSMs). These PSMs can produce estimates and comparisons of contrasting potential policies to inform a wide range of stakeholders and decision makers. PSMs combine evidence from a range of disciplines and sources such as demographics, surveys (e.g. Health Survey for England), economic data (e.g. Living Costs and Food Survey), and systematic reviews of health interventions. These models can then estimate and compare the cost-effectiveness of specific policies and their potential effects on equity and health.

Randomised controlled trials (RCTs) are currently seen as the gold standard in establishing causality and effectiveness. However, RCTs can be expensive, prolonged and impractical or unethical for some population health issues, such as smoke-free legislation, or applying the UK soft drinks industry levy. PSMs can be embedded at all levels of policy decision making (research strategy, scoping, implementation or evaluation). PSMs cannot provide cast-iron answers about the future, but they can inform decision making, widely used in economics, meteorology, transport and business, but less so in public health.

#### **Applications**

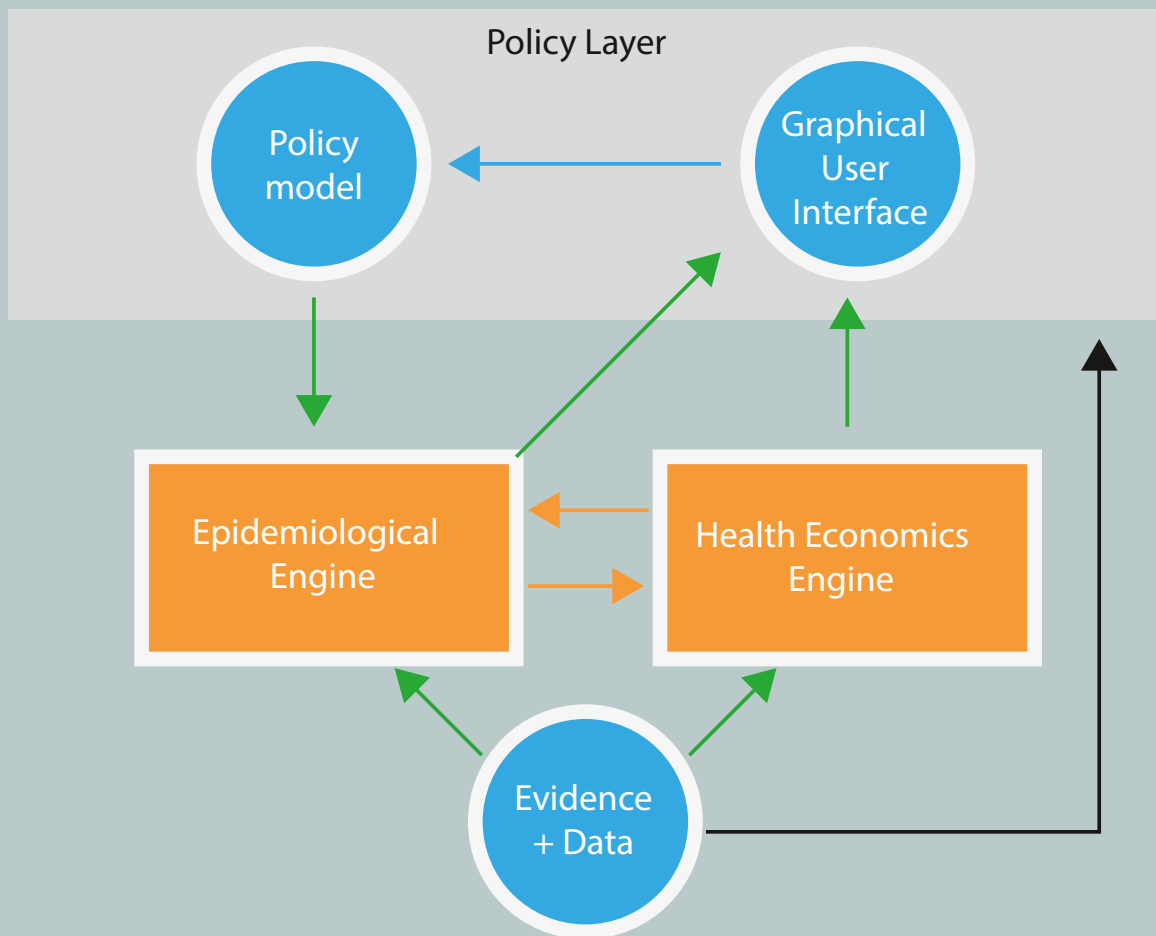
We recently used our IMPACTNCD model to estimate the cost effectiveness of different future scenarios for NHS Cardiovascular Disease Health Checks across the UK, and in a city such as Liverpool. This work, co-designed with stakeholders, helped decision makers to quantify and understand the potential effects of changing how Health Checks were commissioned and how this could impact health inequalities locally. We modelled five scenarios: (A) current implementation of a NHS Health Check; (B) current + implementation ‘targeted’ toward most deprived areas; (C) ‘optimal’ implementation which assumes optimal coverage, uptake, treatment, and lifestyle change; (D) current implementation plus structural population-wide interventions targeting unhealthy diet and smoking; Scenario (E): these structural interventions plus ‘targeted’ implementation.

This suggested that combining Health Checks with diet and tobacco policies would make primary cardiovascular prevention much more effective. The results have fed into the local CVD strategy and have informed Liverpool decision making and future commissioning.

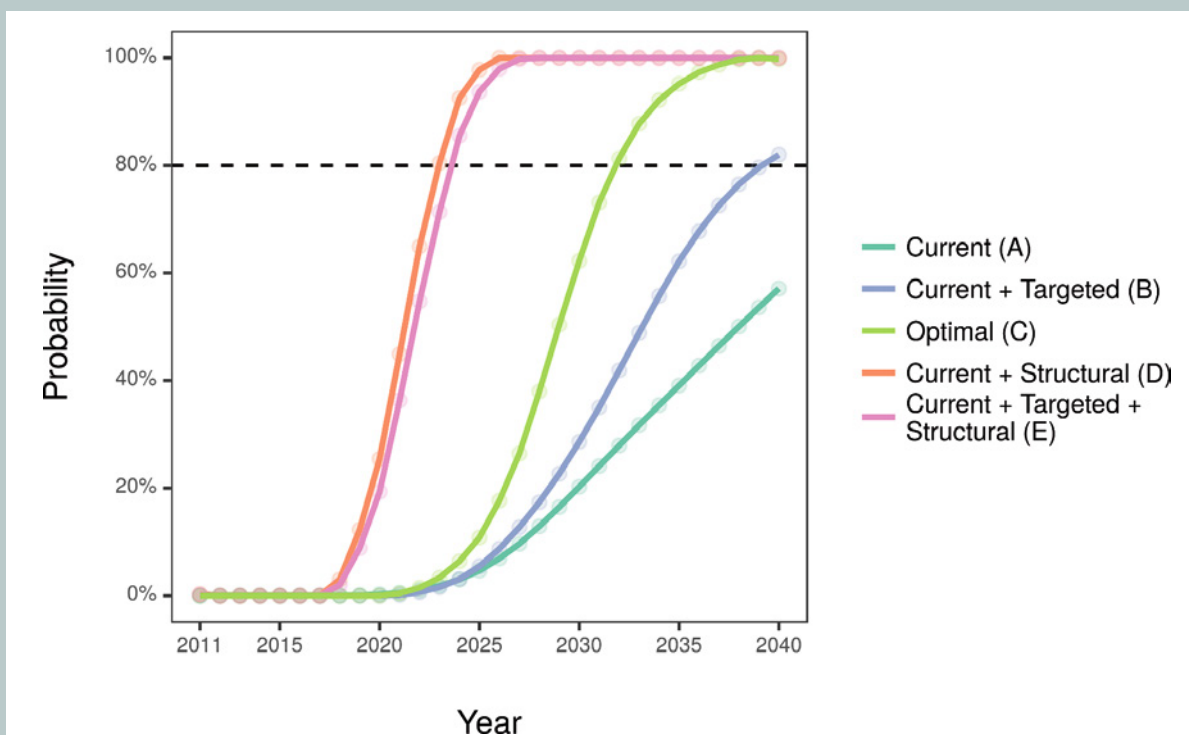
#### **Future Applications**

In the future, Life-course PSMs will be able to include wider determinants of health (including income, education, employment and housing) and compare diverse disease and economic outcomes. Making these applications “open source” and open access will ensure that they are more transparent, open and participative, and minimise unnecessary duplication of work. Such PSMs might offer user-friendly interfaces enabling decision makers and analysts to create and test their own scenarios, an exciting future indeed.

**Figure A** Generic structure of policy simulation models



**Figure 3.6B** Comparison of probability of cost-effectiveness over time (based on £20,000/QALY threshold) of Health Checks scenarios for Liverpool, from 2010-2040



### Box 3.6 Healthcare and devolution in England

*This box was kindly provided by  
Martin Rogers, Policy Officer, British Academy*

On 1st April 2016, Greater Manchester gained control of its combined health and social care budgets, more than £6 billion per annum. Further devolution of this nature has the potential to greatly impact the landscape of health services. But devolution poses the question which gets far too little attention: do people want national standards, or local variation?

The devolution enacted across the UK from the late 1990s saw Scotland, Wales and Northern Ireland gain greater powers and responsibilities for many areas, including their health services. So far this devolution has been fairly uncontroversial beyond issues around the Barnett formula. Resulting in Scotland offering certain services free at the point of use not available in England. Now areas within England are beginning to experience some devolution, starting with Greater Manchester. Devolution within England initially focused on economic growth but has become increasingly about the 'integration of services'. This has the potential to impact service delivery.

No devolution agreement can include any of the Secretary of State's core duties, and no devolved areas are exempt from national NHS requirements. Health services in Greater Manchester will remain centrally regulated and subject to the NHS Mandate, for example. But plenty of other aspects are in scope for local control.

In theory devolution has the potential to improve health services, not only by being better tailored to local needs but by becoming place-based and thus comprehensive. There are three primary areas of health devolution in Greater Manchester: commissioning, public health and integration. Borough-level Health and Wellbeing Boards were established in an attempt to ensure that services are provided in a joined-up way.

British Academy work on devolution has identified support for greater devolution of health services to integrate, adapt and tailor services to local areas. Our work highlighted a desire among the stake holders we engaged for services to be tailored to the needs of an area rather than subject to direction from the centre. We touched on the importance of integrating services, specifically moving from service provision and regulation which to assessing outcomes in a specific area.

Advocates of devolution say that it has the potential to improve health by providing place-based, comprehensive and integrated services that are preventative as well as reactive. But how comprehensive and integrated the services are may be crucial to their success e.g. increased spending on mental health may be ineffective if other services or actions place greater demand on mental health services.

Nor is integration and localisation a panacea. Integration can be effective in terms of treatment but it is not a way to provide services on the cheap. And the question of money and resources is a live one for questions of devolution because there remains a question about divergence. The upside is the ability of places to tailor services to their area. But the other side of that coin is the risk of 'postcode lotteries'. Services in areas with many older people can be set up to cater for their needs, while areas with younger and more diverse populations will have greater freedom to adapt to those needs. Many of the stakeholders we worked with were positive about the freedom from central direction.

But divergence in service quality, access and availability between areas is controversial. The public tend to be resistant to 'postcode lotteries' in service provision. Our work highlighted that politicians are reluctant to devolve responsibility without an accompanying system of accountability that is sufficiently robust. This is especially the case in devolved politics as those at the level of the central government may be blamed by the public for 'post code lotteries' even if devolution means that they are not responsible.

So far, Greater Manchester has taken the first steps towards health devolution. But to have a truly functional, devolved healthcare system it may be necessary to devolve accountability. Thus far there has been a level of administrative devolution. Political devolution must surely follow to complete the package. Devolution can only be truly established when service users and politicians do not blame central government, but engage locally to discuss and debate choices.

The success of devolution for healthcare may rest on the devolution of not only powers over the direct aspects of health but on greater powers over the wide variety of factors which impact health, and accountability for them. But without specific measures which act as a muscular system of redistribution and equalisation in the widest sense, devolution may threaten to reinforce existing inequalities. The balance between local empowerment, central accountability and redistribution is one that must be openly discussed, and ideally settled, before devolution can truly move forwards.

*The insights in this piece result from a roundtable held in Manchester in January 2018. Attendees included a former Minister of State in the Department of Health, central and local government officials, health professionals and academics.*

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## 08 Conclusion

The vision set out in this chapter, of creating a health environment which allows people in this country to flourish physically, mentally and socially, is aspirational but not unachievable. It would require fundamental changes to the way health is understood, the way decisions are made and the way resources are prioritised at every level. Yet, the examples highlighted throughout the chapter show that many of the necessary changes in thinking and practice have already begun in some areas. The challenge is to create a national climate in which these ways of working become the norm, rather than the exception. How this would look at community level would vary from place to place, as communities work together with civic leaders to shape their environment in ways that are best suited to local conditions and values. If this happened, by 2040 the health environment in this country could be one which enables people to live healthy lives as part of a healthy society.

## 09 Chapter authors' suggestions for policy

- A legislative framework is put in place requiring the long-term impact of policy decisions on health and health inequalities to be considered, following the model of Wales' Future Generations Act.
- Measures of wellbeing and human capital – which more fully incorporate health – are developed and used to inform decision-making at national and local levels.
- The UK Corporate Governance Code should require businesses to report impact of their action on the health and wellbeing of employees, customers and communities.
- A cross-government health inequalities strategy be developed and implemented with delivery backed by accountability mechanisms at national and local levels.

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## Chapter 4

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# Social health

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### 01 Introduction

For every individual and family, health comes first: it is the wellspring from which all other human experiences flow. When we think of our health, typically the first thing we think of is our physical health: are we absent of disease or injury, fit enough to comfortably perform the tasks of daily living, and eschewing those behaviours that we know are bad for our health such as smoking, drinking too much or overeating?

Yet as early as 1946, the World Health Organization argued for a broader understanding of health, defining it as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” In England, there is greater recognition that there can be no health without mental health, even if the reality of NHS funding and service provision does not reflect so-called ‘parity of esteem’.<sup>1</sup>

It is now well established that health is, in part, socially determined.<sup>2</sup> As Wilkinson and Pickett conclude in their works in 2009, more equal societies are both happier and healthier.<sup>3</sup> It is perhaps unsurprising that living in poverty, in inadequate accommodation, dependent on benefits or precarious, insecure work, is bad for individual health. What is less well understood is that inequality is bad for people at the top of the income distribution, too.<sup>4</sup> More equality is good for everyone.

Yet the idea of social health goes beyond the social determinants. Our health is not only determined by our economic circumstances, but also by the quantity and quality of our social relationships.<sup>5</sup> Humans are social beings: it is therefore reasonable to believe that health is not only an individual concern but also a social construct. It is well established that obesity is bad for our health, increasing the probability of diseases ranging from cancer to cardiovascular disease. It has now been demonstrated that the chance of becoming obese increases substantially for those who have an obese spouse or friends.<sup>6</sup> In the other direction, it has been suggested that recovery from addiction can be ‘socially transmitted’.<sup>7</sup> So, relationships matter for health.

Our relationships are structured around the places where we spend our time; at work or school, with our families and in our homes, and as part of our communities. We have allowed each of these to be degraded in recent years<sup>8</sup> and our social health is suffering as a result. There is an opportunity to rethink how we live and work to make lives better for everyone.<sup>8</sup>

### 02 Social health and young people

In the 21st century, our social relationships are online as well as ‘in real life’. Childhood and adolescence is being reshaped by technology. The younger generation can now learn about and experience the world as never before, where the possibilities for a deeper and richer education are almost limitless. But technology has opened up a new realm of harm: for example, children may be abused online or introduced to their abusers online.<sup>9</sup>

There are wider questions about the nature of children and young people’s experiences and how they are changed by technology. For example, cruelty and humiliation may be captured on camera and spread through social media; embarrassing moments may become indelible. There may be pernicious effects on self-esteem of a constant stream of idealised lives and lifestyles, often fictional and unattainable. The Children’s Commissioner found that children aged 10 to 12 were increasingly concerned with ‘keeping up appearances’ online.<sup>10</sup> For some teenagers, norms of sexual behaviour are now determined by pornography, shaping behavioural expectations of both genders.<sup>11</sup>

Social media is structured around the idea that popularity is the ultimate objective – the quantity of followers, and not the quality of relationships, is what matters most. The business model of social media is based on advertising: the greater the amount of time spent on social media, the greater the potential revenue. It is interesting to note that executives of some of the world leading social media companies exercise caution regarding their children’s use of social media. In this age of technological disruption, a major rethink of the role of social media is required. It is therefore welcome that the Chief Medical Officer has been asked to commission a review of the existing evidence pertaining to social media and the mental health of children and young people.

In April 2018, there were 389,727 ‘active referrals’ to mental health services in England for people aged 18 or younger (of which 47,910 were new referrals and 42,455 people under 19 were discharged during the month).<sup>12</sup> Recent research by Institute for Public Policy Research has found that for people under 25, the highest priority for the health service to invest in should be mental health.<sup>1</sup> While greater investment in provision of mental health services is necessary and welcome, we need to treat the cause, not the symptom.

## 03 Social health for working-age adults

For most working-age adults, work itself is the area in urgent need of reform. Where work was once a reliable route out of poverty – itself a major determination of health status – today a majority of people living in poverty are in working households.<sup>4</sup> Good quality work is good for our mental and physical health, and provides social connection and meaning and purpose as well as income.<sup>13</sup> But the rise of precarious, poor-quality work has created the extraordinary situation where being in poor quality work has been associated with higher levels of allostatic load (chronic stress related biomarkers) than peers who remained unemployed.<sup>14</sup>

In April 2018, ONS estimated that at the end of 2017 circa 900,000 people in the UK were working to ‘zero-hours contracts’. While a small number may appreciate the flexibility, it is obvious that the lack of certainty about working hours increases stress for some individuals and families.<sup>15</sup> But a national workforce managed and structured in this way also destroys social capital. Irregular hours and a constant churn of colleagues means there is little place for social connection.<sup>4</sup> Even simple things like breaks have been eroded: in 2015, a BUPA survey found that less than one-in-three workers take a proper lunch break each day.<sup>16</sup> There is little room for relationships in non-stop working days, in a country that already works the longest hours in western Europe.

Family life has also changed with a shift from extended families living in one location together to the nuclear family, with extended family dispersed over larger geographical areas. In some instances, this could result in poorer social and support networks for both children and parents, and for older people too. This deterioration of the social health of families has correlated with an increasing rate of relationship breakdown. Raising a family is hard, and it is even harder for a parent on their own.

Social tension, trauma and dislocation in the family has an impact on physical and mental health. Poor marital quality and relationship stress has been associated with poor immune and endocrine function as well as depression.<sup>17,18,19</sup> Evidence suggests that emotionally stressed childhood environments have a negative impact on adult health and these effects percolate throughout the life course.<sup>20,21,22</sup> An ageing population presents significant challenges in caring for older people; the social care funding gap – i.e. the gap between costs and revenue – is projected to reach £2.1 billion by 2019/20.<sup>23</sup>

The strain is particularly felt by women. As female labour force participation has risen, women are increasingly bearing the ‘double burden’ of breadwinning and caregiving responsibilities. ONS analysis of time-use data suggests that women undertake 60% more unpaid work than men in the UK.<sup>24</sup> Most women have more choice and self-determination than their predecessors enjoyed. However, deep-seated cultural attitudes may still lead to pressure being applied to some women to conform to more ‘traditional’ roles, or combine their professional work with care-giving to an extent that would not be expected of their male counterparts.

## 04 Social health and communities

Our social health is under strain at work, at home, and in our communities. There has been a decrease in the proportion of people who meet socially with friends, relatives or work colleagues at least once a week.<sup>25</sup> Between 2010 to 2011 and 2013 to 2014, there was a deterioration in the proportion of people saying that they had a spouse, family member or friend to rely on “a lot” in case of a serious problem; this fell from 86% in 2010 to 2011 to 84% in 2013 to 2014.<sup>25</sup> People spend less time socialising with friends or pursuing ‘collective hobbies’ and more time glued to screens, whether watching television, playing video games, or binge-watching drama.

Social isolation in communities is associated with adverse outcomes. A recent study in *The Lancet* found that the mortality rate for socially excluded populations is nearly eight times higher than average for men, and nearly 12 times higher for women.<sup>26</sup> A large-scale international study found that over seven years, having adequate social relationships was associated with a 50% greater survival rate compared with individuals with poor social relationships.<sup>27</sup> The same study concluded that the magnitude of the association between having adequate social relationships and overall survival was comparable with quitting smoking. Loneliness and social isolation also increases strain on public services. Individuals that are socially isolated are: 1.8 times more likely to visit a GP and 1.6 times more likely to visit accident and emergency services.<sup>28</sup>

The effect of loneliness is felt most acutely by older people. According to Age UK, in 2014 nearly half of people in the UK aged 65 and over said that television or pets were their main form of company, more than 40% of people aged 65 and over in the UK felt out of touch with the pace of modern life and 12% say they feel cut off from society.<sup>29</sup> However, people who took part in behaviours that promote physical health were more likely to feel their community was a good one to grow old in.<sup>29</sup> Social ties are often harder to sustain as one gets older. Given the increasing proportion of older people in our society, the role and importance of social health is likely to increase.

## 05 Hope and health

Our behaviour is shaped not only by our present circumstances but by our expectations for the future. In a state of despair, where the future holds no promise, alleviating malaise by smoking, drinking or taking drugs is an understandable, if destructive, response. The current opioid crisis in the United States and the blighting of communities in Britain by synthetic drugs such as ‘spice’ could be characterised as ‘diseases of despair’. There can be no doubt that addiction treatments must be provided to people who need them. But there is a bigger obligation on society: to provide hope – the realistic belief that things will be better in the future – to every community. This requires a rethinking of work, our economy and society.

Throughout human history, people have always sought to make sense of the world through stories that connect individual experiences to a greater narrative. From tales told under the shade of a tree to the richness of folklore and oral histories, humans have used stories to transmit knowledge and to make sense of their lives.

Over time, human societies valued sense-making so greatly that it was given institutional form, including religious institutions, ancient guilds, universities, Royal Societies, parliaments and news providers. Healthy criticism of organisations is welcome – they can help them to improve. However, incessant assault on the reputation of trustworthy organisations can be to our collective detriment.

Hope is a promise made in the present by those with the power to shape the future. The persistent degradation of politics, such as the bitterness of divisive referendum campaigns in 2014 and 2016, may be bad for our health. Our collective social health would be better in a society which values constructive discourse over manufactured schisms. Societal leaders, in all areas of life, could model better behaviour in this respect.

## 06 Author's suggestions for policy makers

The first step to renewing our social health is to recognise it. If we understand that health is socially constructed as well as determined, then we can take steps to promote it. It might be tempting to conclude from this analysis that the answer is a return to the past: recreating old forms of industry and work; promoting the nuclear family and marriage; and subsidising traditional institutions. To attempt to return to the past would be a fundamental error. We cannot bring back the past, nor should we aspire to; instead we must embrace the future. We must build new collective institutions to promote social health in the 21st century.

There are four practical steps that we could take. First, we could protect and safeguard the health and wellbeing of young people through greater regulation of social media. The recent IPPR Commission on Economic Justice proposed a 'duty of care' for social media, with social media platforms required to have a licence to operate in the UK, just like other utility providers. This could be combined with a new investment in mental health services for children and young people, based in schools.

Second, we could promote better, more meaningful work. There are various ways in which this can be done to improve the quality of work and raise wages – from increasing the minimum wage to the Scottish government's adoption of a 'fair work' standard. The potential effects of collectively aligning the school and work day could be reviewed and assessed. This might relieve the pressures of childcare for many working people and promote better family life.

Third, there could be a radical boost to social prescribing and significant investment in peer support in the NHS to shift it from a 'sickness service' to a 'health service'. In July 2018, Secretary of State for Health and Social Care, Matt Hancock MP, announced his priorities for the health and social care system,<sup>30</sup> which included more use of social prescribing. Technology facilitates the introduction of social prescribing at pace and at scale in a way that has not been possible before; it is incumbent upon us to seize the opportunities of technology to strengthen our communities and our social health.

Finally, we need a radical rethink of the last third of life. Despite an ageing society, there has been no serious attempt to come up with a better way for older people to live well – so that the last third of life is characterised by dignity and full participation in communities. Interventions could range from a 'sure start to retirement' programme to investment in collective institutions at a local level. We need to rethink our approach to housing, healthcare, employment and so many different areas. Crucially, a holistic approach is required.

## Box 4.1 Scenarios for health in cities in England in 2040

*Text kindly supplied by the students of the Autumn 2018 Oxford Scenarios Programme*

### **Oxford Scenarios Programme (OSP)**

In October 2018, the Chief Medical Officer's Annual Report 2018 served as one of the live cases for global professionals attending the University of Oxford OSP. The participants working on the CMO case applied the methodology being taught over the five-day programme to develop scenarios on the question of "What might cities look like in 2040 and how might this effect public health?". Scenario planning is an innovative and effective way of exploring uncertainty and different perspectives on the future to improve choices in the present.

Two groups each developed three scenarios. Group one's scenarios were:

#### **1. Déjà vu**

Deja Vu described a continued worsening of current conditions. In this scenario, there is increasing pressure on public support systems and a widening divide within communities. This results in fewer services for those most in need.

#### **2. Silent disco**

Silent disco assessed the potential impacts of emerging technologies in society. In this scenario, technology helps ensure that the provision of services is optimised according to the level of local need. However, this benefit is offset by risk of individual isolation and loneliness through dependence on devices and wearables, exacerbated by increased unemployment through automation.

#### **3. Team spirit**

Team Spirit focused upon a societal movement of collectiveness and solidarity with individuals enjoying more leisure time due to technological advances. In this scenario, there is a reduction of demand upon the social care system because of increased peer support and a more engaged civic society.

Group two's scenarios highlighted similar themes:

#### **1. Coronation Street**

Coronation Street described a world where communities are 'tight-knit' and disparate from each other. As such, the first point of detection of decline in a person's wellbeing is fellow community members, with professional medical and wellbeing services conveniently co-located in residential buildings. In this scenario, work patterns are flexible and a basic level of income and healthcare is provided by the state.

#### **2. Dr Who**

Dr Who explored the impact of an individual's life centred around artificial intelligent (AI) personal assistants (PA). The AI PA takes care of many things including being the first point of detection for a person's decline in wellbeing and initiating corrective actions such as making healthy food choices, prescribing exercise or ordering supplements. While efficient, this dependence on AI risks leading to growing inequalities (specifically by age and digital ability) and a decline in human interaction.

#### **3. The Good Life**

Good Life assessed a world in which green space, active transport options and healthy living are prioritised with happiness being a key measure of the health and wellbeing of people. In this scenario, technology use and human interaction are more balanced. However, these positives risk being offset by developments such as increasing allergies in children growing up in very clean environments.

These scenarios, in conjunction with other contributions to this report, helpfully informed the Chief Medical Officer's (CMO) vision of Health in England in 2040. The participants' positive attitude towards the health opportunities technologies could offer was particularly exciting, with the CMO also impressed by the participants accompanying considerations of the potential negative impacts on health inequalities that some technologies could impose.

*Professor Dame Sally Davies, Chief Medical officer, would like to express her sincere appreciation to the participants and faculty of the Autumn 2018 Oxford Scenarios Programme. The participants developed the scenarios about health in cities in 2040, led by Programme Director, Professor Rafael Ramirez and supported by Trudi Lang.*

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## Chapter 5

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# How will health be experienced in 2040?

### Chapter lead

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# 01 Introduction

Health is at the heart of our humanity, an incomparable asset we cherish but which we sometimes neglect and mistreat.

“So long as I’ve got my health, that’s what really counts” we often say or hear others gratefully acknowledge.

The idea that health is our greatest asset is an old one. The poet Virgil said that “our greatest wealth is our health”. Rather more recently, the World Bank’s commitment to universal health coverage reflects an assumption that “health is a foundational investment in human capital and in economic growth – without good health, children are unable to go to school and adults are unable to go to work.”<sup>1</sup>

The experience of health has always been held in a web of trusted relationships and connections between people and their families, often whole communities as well as the doctors and nurses and other trained professionals on whose expertise and judgement we rely.

But we’ve arrived at an interesting moment in the evolution of health and care.

It represents a new round in the perennial contest between humans and machines, between health as a human endeavour and health as an increasingly technology-fuelled interaction in which the value of a human touch can sometimes feel as if it is being diminished.

Machine learning and artificial intelligence (AI), for example, offer the prospect of health as an automated, slightly impersonal exchange in which humanity struggles in a (false) trade-off with precision and reliability. It certainly does not have to be that way and could just as easily transform the human dimension of care as more of the work at both end of the spectrum – the detail and drudge of basic transactional elements of care and the ability to discern and diagnose with more confidence and accuracy – is taken up by powerful technology.

The prospects of technology for better health and care, and for a lift in wellbeing, are very appealing and very exciting. We must keep in mind that, despite their dazzling impact, many of the technologies we’re becoming familiar with are still in their early stages of development. We do not know how they will evolve, but experience tells us we can expect it to be rapid, intense and often unexpected.

For example, the field of AI is currently dominated by two components of AI – natural language programming and machine learning. The former is mostly delivered by chatbots or digital assistants that often mean the encounter might feel impersonal. But these tools are improving all the time and it is feasible that by 2040 encounters that we currently experience as lacking in humanity may start to feel very personal and human.<sup>2</sup> There is growing evidence that, even at these early stages of their development, the differences between humans and machines are becoming less easy to discern.<sup>3</sup>

By 2040, there is every chance that technology could release the human element of healthcare to do what it does do

best – to relate, to empathise, to engage and to discern. Perhaps the trade-offs implicit in previous rounds of the machine-human contest will disappear, or at least diminish.

But that implies an ability for us to untangle some of the big questions of power, control and authority and unsettling dilemmas of ethics and public and private morality with which many of the new technologies come freighted.

Two important ideas inform this brief exploration of the way in which we might expect to experience health and care in 2040.

One is that, in many respects, the future is already here. Many of the seeds of change and reform in health have already been planted, and will manifest themselves in what we experience in 20 years. If we look closely enough, we can discern much about the trajectory of the future and can therefore predict, or at least prepare, for it.

The second message, though, flows directly from the future’s uneven and often unfair distribution in terms of opportunity, access and choice.

Our collective job as policy makers, service designers, clinicians and frontline health workers and as patients, families and communities too, is to engage the future with an equal and ethical commitment to both its astounding technical, especially digital possibilities and its irreducible humanity.

Holding those interdependent, sometimes competing instincts in balance is how we should define the stewardship imperative for leaders at every level in our evolving health and care system.

## 02 Healthy, wealthy and wise

“Early to bed, early to rise,” the old adage counsels, “makes a man healthy, wealthy and wise.” The idea that health and wealth have a deep and intrinsic connection is compelling:

*“Health comes first, for all of us – our family, friends, neighbours and colleagues. Good health is the purest form of wealth: it allows us to lead the best version of our life possible and is the wellspring from which all our other experiences are derived.”*

*Institute for Public Policy Research, ‘Better Health and Care For All, A 10-Point Plan For The 2020s, The Lord Darzi Review Of Health And Care Final Report’, June 2018*

It is also true that what a nation invests in its health – pushing the boundaries of science and innovation, training and paying doctors and nurses and many others in the business of health care design and delivery, exporting health products and services – is an increasingly vital source of national economic strength too.

How people might experience a more integrated, data and digital infused model of health and social care over the next 20 years, cradled by the nexus between health and wealth – individual, community and national – is the focus of this chapter. **The future is already here.** The management writer Peter Drucker once noted that the best way to predict the future is to look around you.

“We waste time and energy,” he suggested, “making more and more extravagant guesses about what things might look like in 20 years or 50 years, forgetting that many of the products, services, capabilities and attitudes we will encounter in that future are already being built. The future is often, hiding in plain sight right under our collective noses. Of course, we always have to be prepared to be surprised. We should never discount the impact of “black swan” moments that seem to come from nowhere and wreak their special kind of havoc.”<sup>4</sup> But, at any given time, a surprisingly large proportion of the future’s architecture and trajectory is already in place or at least discoverable by having a good look around us.

Technology writer and futurist William Gibson had a slightly different take on the future. For Gibson, “the future is already here. The problem is that it is not very evenly distributed.”<sup>5</sup> What that suggests is that understanding the future is only one part of the challenge. The other, and perhaps the most important part, is to understand how the future’s inevitable lumpiness plays out in its unequal impact on the lives and aspirations of different individuals and communities and to see if there are things we can do to make it less uneven. This chapter assumes we can understand a lot about the 2040 healthcare experience by looking at what is happening right now in, and between, four domains:

- The mix of existing physical, human institutional, social and cultural **assets** that we already have

- The combined effect of several well-established and rapidly unfolding **social and economic trends** whose individual and combined effect we are still exploring
- Current and emerging changes in **technology** and the rapid proliferation of new tools, platforms and capabilities with far reaching implications for policy and behaviour
- And finally, **the performance of the current system** of health and care, including institutions, practices, capabilities and culture.

The rest of this chapter examines how changes in the four domains impact each other and, together, form a crucible of change from which the patterns of experience for healthcare in 2040, when we will get to celebrate the NHS at 92, are already being forged.

## 03 This particular moment

Right now does feel like a particular moment for the evolution of health and care, as it is already proving to be for so many other domains. Just think of the revolutions we continue to experience in retail, entertainment and the media, for example. In fact, it is hard to think of an area of our commercial, public or civic lives not impacted by a deep sense of “big step” transition. And there’s no reason to assume that the health and care sector can be immune.

### *What does it mean?*

These are some practical questions with which we should interrogate the future to understand the implications for our individual and collective experience of health:

- Are we going to be in a position to exercise greater control and accountability for the health and care services we need?
- Can we assume powerful new combinations of “data + digital” will make it easier for us to make better decisions about, and to more easily and effectively monitor, our own health?
- Will we see patients and carers and families more reflexively engaged in designing and delivering health and care services?
- Will we have equal access to shared medical records that make healthcare more reliable and simpler to navigate without risking the security of our data and our privacy?
- Is a vision of “good” for the kind of health and care system we want – fair, affordable, with a sense of agency and control for people, patients and communities, ethical and human as well as technically brilliant and cutting edge – accepted and widely shared?

Generically, healthcare is confronting the same exciting but unsettling tests of its shape and performance that other sectors face in the face of new opportunities and risks from the digital age.

Technology’s advance is increasing in both its pace and intensity. According to Peter Diamandis, Founder and Executive Chairman of the XPRIZE Foundation, “the future is arriving faster than you think.”<sup>6</sup> As AI continues to break new territory and as pervasive digital networks link people and things in an increasingly tight mesh of connectedness – data, ideas and communication – the performance of many familiar institutions is being tested.

But there are also some very particular dilemmas for health and care grounded in some big questions, for example:

- In the wake of the 70<sup>th</sup> anniversary of the NHS, can the UK design and sustain the health and care system it needs and wants, and which is fit for contemporary and emerging conditions? While many acknowledge the need to invest in prevention, we continue to spend on reactive, demand-led service provision; there is little integration of health and social care and limited accountability wrapped more obviously around the needs of patients and of communities.
- Can we preserve and augment the necessary space for people and communities in a domain which, despite its voracious appetite for clever technology and smart machines that can save money and save lives, remains in the end a profoundly human venture?
- Can we grasp the unprecedented opportunities of a ceaselessly evolving digital age to shift patterns of power and control away from large, impersonal institutions and systems towards greater autonomy and confident self-direction by people, families and communities for their own health and well-being?
- Are we smart enough to work out how to enjoy the productivity and life-saving potential of new digital platforms for health and care without trading away vital and legitimate protections for privacy and security?

Healthcare in the UK, as it does in most comparable modern, industrialised countries, faces a particular moment as these challenges crowd onto a policy agenda forged by their interaction. This is a moment posing uncomfortable challenges to our policy making and investment processes, only made more difficult by declining trust in institutions of public governance and significant stress at the frontline of much of our health and social care system.

## 04 How things change

The experience that people have in their interactions with large systems is shaped by the speed and intensity with which those systems adapt to shifting conditions and circumstances. Healthcare is one of our largest and most complex systems. How it changes is never straightforward. One way to understand that process, whose rhythms determine so much of the quality of experience – what people see, touch and feel – is to understand the “pace” layers of change. The “pace layer” framework for understanding large, complex systems change comes from work by renowned futurist, strategic thinker and Internet pioneer Stewart Brand. Brand’s work on the pace layer model is set out in his book, ‘The Clock of the Long Now’,<sup>7</sup> in which he explains the natural order of change in complex systems. Brand explains that the different layers in a large system move at a different pace. And it is from the interaction between those different layers, and the different combinations of speed and intensity with which they accommodate change, that our experience of that system emerges.

This brief rehearsal of the 6 layers comes from an analysis of their application to systemic reform in education, a world whose dynamics of complexity, risk and opportunity are similar in many ways to healthcare.<sup>8</sup>

- The fastest layer, **fashion-art**, moves in minutes and months. It is irreverent, engaging, and self-preoccupied. At this layer, a society’s culture is set free to experiment, albeit sometimes irresponsibly, learning through creativity and failure.
- The barrage of ideas and propositions generated from the fashion layer gets sorted out at the **commerce** layer. Whether at age-old bazaars or modern-day stock markets and digital crossroads such as Etsy and eBay, commerce brings people together to make sense of new ideas that capture our attention. Commerce tames and harnesses the creative energy of fashion so that society can benefit from it.
- In turn, **infrastructure** changes more slowly than commerce. It is high-cost, high-yield, and delivers delayed payback to society. It provides foundations and platforms for society to operate – among them transportation, communication, energy, and education. It is refreshed and modernised through the innovations from upper layers while being protected and validated through governance and culture.
- Moving down a layer, the job of **governance** is to serve the larger, slower good for society. It provides stability. It preserves what we hold to be necessary and true. As Brand points out, social and political revolutions want quick change, demanding that governance moves faster than it is capable of, frustrating society. The constraints of governance force reflection and pause, which can be paralysing or empowering.

- Even slower to change, **culture** is the essential work of people as they gather to make sense of and integrate the many facets of life together on earth. It includes religion, language, and the enduring behaviours and social norms that help to provide constancy across centuries and even millennia.
- The slowest-changing layer is **nature**, with the earth and the human body changing slowly over millennia. Nature’s power is immense when unleashed, whether as the processing capacity of the human brain or as the magnitude of earthquakes and hurricanes.

The experience of healthcare in 2040 will be determined in large measure by the extent to which changes at the “fashion” and “commerce” layers (wearable and ingestible health monitoring apps for example) can be accommodated by shifts in infrastructure (new digital networks and reliable, safe connectivity for example).

And changes in both those layers, in turn, need to be supported by changes in governance, culture and “nature” (in our case, the bedrock of politics, institutional design and the very human assumptions and expectations that determine what we expect, demand and will tolerate from our health systems).

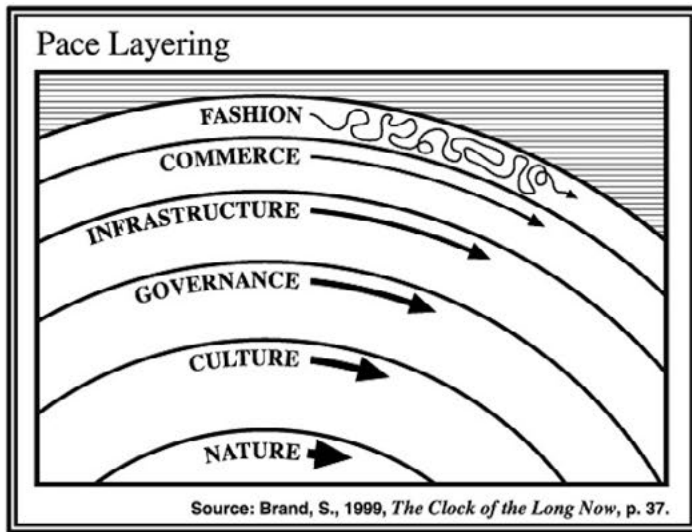
Brand makes the point that “the fast layers innovate; the slow layers stabilise. The whole combines learning with continuity”.<sup>9</sup> So experience will be forged by changes *in* each of the pace layers as well changes *between* them. Right now, it is fair to suggest that the ability of the governance and culture layers, for example, let alone the bedrock values and habits of “nature”, are struggling in healthcare reform and innovation to accommodate the pace of change in and between the other layers.

If you think about the way people will experience health and care into the future, the contours and content of that experience will be determined largely by the interaction of pace layers. Technology and taste will continue to change rapidly as new tools and “apps” come and go, fuelled by the ceaseless churn of fashion and commerce. Investments in infrastructure, changes to governance and the big systems that manage our health and care services and the underlying settings of culture and mind-set, laid down over long periods of institutional habit and practice, will inevitably take longer to respond.

It is from the interaction of those layers, each of which move at a pace consistent with their own needs and conditions, that the experience we encounter will be made.

As a rule, the experience of health and care will be a positive one to the extent that the different layers of change broadly, align. Where they do not, and where different expectations of the rate at which the larger systems and structures of health and care can respond to rapid innovation and change, people are more likely to experience delay and frustration.

Figure 5.1 Diagram showing 'Pace Layering', as described by Stewart Brand



Source adapted from Brand, S., 1999, *The Clock Of The Long Now: Time and Responsibility*, p.37

## 05 Experience 2040: the parameters of change

The experience of healthcare in 2040, for the people and institutions who will be most directly impacted and involved, will emerge from the interaction of trends already disrupting four domains – the stock of assets on which we can draw, the combination of several big social and economic trends, what is happening in technology and the performance of the current healthcare system.

### 5.1 Assets

There are physical assets to begin with – hospitals, clinics, scientific laboratories, machinery of virtually every type and complexity to aid the diagnosis and treatment of more and more diseases and conditions.

There are people assets too, of course, the body of doctors and nurses and frontline health staff and those in allied health professions, as well as the people with skills and experience in health policy and management,

There are institutional assets, not least being the NHS itself, with its established systems and processes and ways of making decisions and investments and its architecture of management and delivery. Institutional assets include the norms and capabilities of the existing policy making machinery of central and local government and the different methods and tools that have developed over many years for decision making and accountability.

Technological developments remain hostage to underlying infrastructure assets of connection and transmission. We should expect the digital world to create new, and erode old, sources of value. Health leaders will need to engage appropriately with payers and providers, as well as with policy makers and regulators, to ensure value is being created for the patients they serve, and they are adaptive to their needs.

And finally, there are assets of social capital, trust, collaboration, held in complex webs of relationship and interaction. The real question, though, is what shape is that asset base in and, how well does it match the scale and ambition of the task ahead? How well equipped are these organisational, institutional, policy, social, cultural and technology assets for the work of health and care in the next 20 years, given that so many of them have been built over decades, for the most part grounded in an era whose contours and demands were very different from those that are shaping the future? And are these assets in the right place to maximise access and value for those in the system – clinicians and healthcare staff and policy makers and patients and families – at the right time and with the right mix of cost and quality?

### 5.2 Social and economic trends

These are likely to include things like patterns of demographic change, rapid urbanisation, climate change, shifting trends in individual and population health conditions and statistics, the impact of unruly patterns of inequality and opportunity, changing social and cultural preferences and behaviour, new ways of work and organisation and disturbing patterns of institutional and personal trust.

Demographics is an obvious place to start. In line with much of the rest of the developed industrialised world, the UK is getting older.<sup>10</sup>

- The UK's population is set to grow and age significantly over the next decade, becoming the largest – and most diverse – country in Europe by 2030.
- The number of people over 65 will increase by 33 per cent – compared to a mere 2 per cent increase in the number of working age adults – while the number of over 85s will nearly double over the same time period (ibid).
- This is a sign of success which should be celebrated, but it will also drive a rising tide of chronic illness – including cancers, mental illness and dementia – which will require a significant shift in the model of care in the NHS and social care system.
- It will also see a rise in the number of people requiring end-of-life care, which is the costliest part of someone's health and care journey.<sup>10</sup>

By 2030, the UK will have 5 million fewer doctors than a growing population needs. That is going to have a big impact on preparing and distributing a workforce with different patterns of skill and expertise than we have been used to. The nature of work too, and the way work is organised, is changing as technology fuels more distributed and flexible patterns of working which challenge enduring notions of control, management and accountability.

It also implies a dramatic shift away from managing demand to investing in a more integrated and substantial way in wellbeing and prevention.

Changes in technology are shifting the relationship between humans and machines and between automation and the role of judgement and empathy.



Is it possible that, by 2040, trends in AI and data analytics, reflecting a steady democratisation of information and knowledge, will transcend the trade-off between the economic and human dimension of health and care implicit in Henry Mintzberg's analysis quoted at the start of this chapter? Or, at the very least, can we expect that how we want to bundle together the power of technology and the yearning for empathy and understanding will increasingly be determined by patients and citizens themselves?

New patterns of social, health and economic inequality are emerging, often tangling in complex interactions whose impact on particular combinations of people and place is creating a stubborn architecture of disadvantage. As Darzi showed in 2018,

*"... inequalities in England are significant. Women in the most prosperous areas of the country live, on average, seven years longer and have 20 additional years of good health than those in the poorest areas."<sup>10</sup>*

Our cities are growing in size, complexity and potential impact on health and wellbeing. How we design cities, the extent to which they accommodate, and actively encourage, a lifestyle of activity and interaction for social and physical health are becoming more urgent challenges. Some cities are experimenting with a whole-of-city approach that makes health the concern of every function of the city and all dimensions of its work. In Coventry for example, that approach has seen the life expectancy gap between the most affluent and most deprived narrowed, school readiness at five improved, as well health outcomes, life satisfaction and employment.<sup>10</sup>

The impact of behaviour on health risk and opportunity has been understood for a long time. We know that four behaviour-based conditions account for an increasing proportion of the costs and impact on the health system. We are living longer but not always living better or more satisfying and healthy lives. The World Health Organisation<sup>11</sup> notes that the evidence does not always suggest that longer living means healthier living, even though it could and should. Policies that erode existing inequalities and which recognise the risk that ageing simply reinforces entrenched inequalities of opportunity and advantage are necessary to spread the potential of better health over longer lives.

Technology especially, mixing with other social and economic forces, is changing patterns of workforce engagement, eroding many traditional career paths and, in some cases, eliminating whole classes of jobs and tasks. People are living longer and potentially working longer but at a time when work and job-related identity and security are both becoming more contingent and often highly precarious. Science is discovering and inventing at a rate that often challenges the absorption capacity of many of our institutions and social and cultural systems. New insights into the impact of climate change and other environmental challenges provide alert us to new and very basic challenges to health and wellbeing, like access to clean air and water and the sustainable provision of healthy and affordable food.

The loss of trust in institutions across politics, religion, business and civil society makes the business of change and navigating the difficult economic, social and cultural dimensions of reform that much harder. According to Rachel Botsman's analysis<sup>12</sup>, the erosion of institutional trust is being balanced by the emergence of "distributed" trust:

*"A new world order is emerging: we might have lost faith in institutions and leaders, but millions of people travel in cars with total strangers, exchange digital currencies, or find themselves trusting a bot. This is the age of "distributed trust", a paradigm shift driven by innovative technologies that are rewriting the rules of an all-too-human relationship."*

*Rachel Botsman, 'Who Can You Trust? How Technology Brought Us Together – and Why It Could Drive Us Apart', published by Penguin, 2017*

## 5.3 Technology

Technology and health have always been joined at the hip, but their symbiotic relationship has already broken new territory with startling consequences.

The litany of this next dramatic phase in one of our oldest stories, the interaction between humans and machines. Our understanding about their implications is embryonic. But AI, machine learning, nanotechnology, the uncharted oceans of data now being fed by an Internet of Things in which everything is connected to everything, better and cheaper Internet access, new power in mobile devices that can learn, guide, intrude and influence, either on their own or in new combinations, are testing many of our inherited notions of power, control, authority and accountability.

In many ways, these new capabilities promise new influence over the norms and standards we can expect, and will increasingly demand, as patients and consumers in healthcare. Technology is already amplifying the “voice of the patient”, which will be harder to ignore in new debates about changing policy, regulations and standards. Taking that further, as Generation Y and X, and their successors in Generation Z and beyond, become more dominant – we can expect their digitally native instincts to play out more actively as they age into 2040.

At least one measure of the potential and uncertainty of this new territory is the extent to which many technology “giants” (e.g. Amazon, Google, Microsoft etc.) are rapidly positioning as major players in the health and care business.<sup>12</sup> We see the emergence of new roles – health coaching, genetic counselling, patient concierge – driven by access to new tools of digital health monitoring. Genomic sequencing is becoming cheaper and more prevalent – at \$100 a test (or less) this is opening up new opportunities to manage risk and treatment and to predict conditions whose early treatment changes dramatically their prognosis. Gene editing by platforms like CRISPR are being harnessed for public health outcomes, genetically modifying mosquitoes for example. Successive generations of health “wearables” are being tried and tested, modified and improved at pace and scale. AI algorithms are getting better faster (the US Federal Drug Authority has approved the first AI application that does not require a human clinician to certify its results.<sup>14</sup>)

One trajectory of these developments is the democratisation of specialist medical knowledge or at least the spread and distribution into many more hands the ability to perform some tasks that were previously reserved for those with formal qualifications. That becomes especially significant when it creates opportunities for access to specialist help in areas and for communities and populations that are missing out now. These trends offer the prospect of more personalised care, of reducing variations in the quality and safety of care and enabling better, faster research and trials to become a treatment option for some patients (reducing “bench to patient” time) and accelerating access to innovation.

Blockchain or distributed ledger technologies are going through their own version of the “[hype cycle](#)” predicted by many to offer opportunities for radical shifts in power and accountability, and therefore in stocks and flows of trust across the health and care system. By some predictions, it will be another 10-15 years before some of that promise is realised at scale, if only as a function of the new infrastructure required. But we can expect blockchain innovations to disrupt insurers, make outcome contracting more realistic, and usher in the potential to address some of the fragmented information flows from which much of the health system still suffers. Blockchain platforms, with a capability to combine trust with access to data (including electronic health records) might also reduce the cost of care by disintermediating the “middle services” and bring patients closer to their care providers.

According to one analysis,<sup>15</sup> the combination of health data exchanges, ownership of and access to self-generated health data (think sleep patterns, exercise outcomes, heart rate patterns, glucose levels) and the ability to see and exchange all of this information in trusted exchanges, is already redefining dimensions of the patient experience.

The health experience implications of these developments are likely to include a great sense of control and autonomy for patients and consumers, a more confident and trusted process of sharing data about patients that should fuel better diagnosis, improved prediction and earlier intervention for prevention and the ability to fashion more tailored packages of care and support to suit individual needs and circumstances. But the chances of that promise being realised depends on whether the culture and systems of health policy, funding and delivery can match the rapid evolution of what technology innovation will make possible (and bear in mind with many of these technology innovations, including AI and blockchain, we are still in the early stages of an evolution process which, by 2040, will have given us more powerful versions or whole new capabilities as well).

Think back to the pace layers of change – innovation in “fashion” and “commerce” bump up against the slower pace layers of infrastructure and governance. Those layers have to adjust and that cannot happen as fast as the earlier layers might like. How fast those changes translate into practical experience for patients, families, clinicians and policy makers depends on the adjustment process within and between the pace layers themselves. That means that the adjustment process between the pace layers is likely to become a major policy and design challenge for health and care system leaders.

All of these changes in technology come armed with big implications for cost and investment, and therefore for the politics of healthcare. But the pressure from patients, and from clinicians and frontline health and care staff too, for access to more digital tools like those they are becoming used to in other parts of their lives – banking, retail, entertainment, travel – will set up a formidable contest. There will likely be a clash between the relatively short financial cycles from which healthcare payers and funders work, and the longer cycles of change and response across the system. By 2040, could we aspire, for example, to have multiyear investment plans at a local level, integrating health and social care budgets, with more personalised budgets for patients?

And as well as the promise of convenience and responsiveness, these are tools that will challenge some of the “one size fits all” standardisation instincts of a health and care system that will be challenged by the tech world’s instincts for customisation and individualised attention.

At its best, technology will augment and amplify the human dimension of health and care. At its worst, the battle could see a sense of control slip further away from people and steadily undermine their instincts for connection, empathy and accountability.

New technologies, science and understanding of human behaviour are making the benefits of early diagnosis and intervention more and more obtainable. Genomic sequencing, big data and machine learning can shift us from ‘diagnose and treat’ to ‘predict and prevent’, technology can help us monitor our health remotely and make better decisions, while behavioural economics allows us to ‘nudge’ people towards a better lifestyle.<sup>10</sup>

## 06 Three underlying trends

Three underlying trends are interacting to offer unparalleled opportunity and some considerable new risks as they redraw many of the familiar boundaries of the human-machine relationship.

### 6.1 Combination of machine learning and AI

One is the *combination of machine learning and AI* that is already changing the way we discern, diagnose, predict, prevent and treat. The work of Benevolent AI in the UK would be a good example of the way in which the “powerful union between humans, technology and science” is working new territory with our most potent and plentiful natural resource – data. <https://benevolent.ai/about-us/>

The only thing holding us back is a combination of imagination and the “stickiness” of culture and practice in our institutions and models of care that inevitably slow down the pace of adoption and diffusion. That’s going to challenge our collective capacity to inform new AI-fuelled capabilities with the requisite frameworks of ethics and risk mitigation.

### 6.2 Data

The second is *data*. Our biggest challenge now is not whether we have enough data but whether we can combine the limitless potential of machines and the perennially limited potential of human judgement and decision making to use the oceans of data in which we are already swimming. And we should be careful to call out different dimensions of data. It covers electronic medical records, the collection and use of phenotypic and genetic data, data around performance and outcomes at an individual and population level and so on. And further, it will engage a wider range of data about the social determinants of health – in areas like housing employment, retail patterns, income and inequality data – whose impact on health intervention and outcomes will be increasingly critical.

Across these different dimensions, and others, the data-enriched world of healthcare planning and provision offers a new lens into health and the practice of medicine (drug discovery, effectiveness of interventions, real world evidence, understanding of the quantified self). A 2018 report by REFORM<sup>16</sup> pointed out the substantial and practical benefits that can flow from good data collaboration practice. For example: the report notes that:

*“... when GPs and hospitals share information, they can identify which patients are most at risk of unnecessary hospital admissions, reducing admissions by up to 30 per cent. Better information sharing between mental health nurses and police has seen the number detained for mental health issues reduce by 80 per cent in some areas.”*

*Sarah Timmis S, Heselwood L, Harwich E.. Sharing the benefits, How to use data effectively in the public sector. REFORM. August 2018.*

A review of the reform implications of the NHS at 70<sup>17</sup>, noted several changes, many of which are fuelled by new ways of making better use of data, that we’re likely to see in the way health and care are organised and consumed, including:

- Delivering on the promise of shifting care out-of-hospital and into the community, which could become a “complete game changer” for the NHS itself.
- Local people, rather than local hospitals, will become “the epicentre” of a new health service. (This resonates with work like the “people powered health” prototypes pioneered by Nesta<sup>18</sup>, exploring better ways to draw on local collaborative designs for some of the best innovations in health, care and wellbeing are creating a new form of power. Power that motivates and mobilises both citizens and staff. Power that connects citizens with the health, care, community and voluntary sectors to find new ways to support people to be healthy and happy.)
- The wealth of data available on patients and places will become the main currency of the Health Service.
- The NHS will take better advantage of its unique cradle-to-grave dataset to shift from a “repair” to a “prevent” service; genome data will help people understand their likelihood of developing a disease and modify behaviour accordingly.
- Wearables and real-time data will provide patients with a wealth of information about their health which, if used responsibly together with different payment mechanisms like personal budgets, will enable people to choose more tailored health care packages and live healthier lives, for much longer.
- Patterns of use of health facilities and services will break the bounds of a 9-5 model which will have implications for the deployment of, and new patterns of working across, the health and care workforce

Machines will assume more and more of the work of making sense of the data, so much of which they will also be generating automatically from a world in which everything is intelligently connected to everything. New lines are being drawn in the distinction between machine acuity, precision and reliability and the realm of empathy, discernment and human judgement.

Pathways of care are being tested and often found wanting as they confront the speed, intensity and openness with which information and knowledge is forged and distributed. In a world that is becoming too big to know (and we probably passed that point some time ago), ‘the smartest person in the room is the room’.<sup>19</sup> That raises governance, ethical and operational issues we have not encountered before.

### 6.3 Revolution in a combination of mobility and device formats

A third underlying trend is a revolution in a combination of *mobility and device formats*. More and more of our technology is becoming wearable or ingestible. It is smaller, more powerful and is already patrolling the border between pervasive and invasive.

These are trends that hold within them the seeds of unparalleled benefit for better health and wellbeing and for the performance and productivity of the organisations and systems that serve the people who will enjoy the results. And they are busy outstripping our ability, and perhaps our willingness, to harness their contribution to pedestrian rhythms of human direction and accountability. Today, 73% of UK citizens have access to a smart phone, and 90 per cent have access to the internet,<sup>20</sup> yet only 2% of the population report any digitally-enabled transaction with the NHS.<sup>10</sup>

## 07 Current system performance

In July 2018, in a debate in the House of Commons<sup>21</sup>, Minister of State for the Department of Health and Social Care, Stephen Barclay MP made this observation at the conclusion of a long discussion about the performance of the NHS:

*“Alongside the significant funding injection that the Prime Minister [recently announced] the NHS must also deliver productivity...*

*...we need to deliver more care in the home and not have acute trusts soaking up so much investment. We need dynamic reconfigurations without acute trusts being the sole focus of our attention. We need service changes but... they must be taken forward with clinical leadership and in a way that delivers trust.”*

*HANSARD. NHS Trusts: Accountability. HANSARD Volume 644, Column 937.*

In May 2017 an Ipsos Mori poll carried out for The Health Foundation<sup>22</sup> reinforced some persistent themes in attitudes towards the NHS and social care services. For example:

- Protecting the NHS from cuts is important to the majority of the general public – 88% selected “the NHS/health care” as a main area of public spending that should be protected.
- Nine in 10 people (88%) agree that the NHS should be tax funded, free at the point of use, and provide comprehensive care for all citizens. This is up marginally from 85% in 2015. The proportion of people giving the maximum possible agreement (a score of 10 out of 10) has increased from 49% to 61%.
- Nearly two-thirds of people think that taxes should be increased to fund the NHS – 64% would prefer to see increased taxes rather than reduced levels of care (9%) or reduced spending on other services (17%).
- Only 12% of people think the general standard of NHS care has improved over the past year, although slightly more (14%) think it will get better over the next year. Forty-four per cent of people think the general standard of NHS care has worsened over the past year. Almost half (48%) think it will get worse over the next year.
- For social care, just 8% of people think it has improved over the past year, while 50% think it will get worse over the next year.

Two obvious points are reinforced by these insights. One is that the NHS remains a trusted institution whose performance is at or close to the heart of the experience of health and care for many. And the other observation is that the way in which the NHS contributes to the experience of care depends on its performance. Reforming and, in some instances, transforming the way the NHS works implies big changes to the experience of care.

The performance of the current systems of health and care here and around the world are characterised by these four dilemmas:

- Pathways of care and treatment are struggling to slip the bounds of the decidedly analogue age in which most of them were forged to change their shape fast enough to accommodate the risks and opportunities of the digital era
- Patterns of investment and reform remain uneven and unreliable, veering from feast to famine in cycles of decision making and implementation that seem increasingly adrift from the demands of long term transformation
- Examples of integration and collaboration, in which the different pieces of the health and care system line themselves up in ways that make sense to those they seek to help, remain intermittent and unusual; the scale and spread of good practice and what makes good sense from a health and care point of view remains elusive. We remain hamstrung in our search for ways consistently to do what we know.
- The search for ways to link trust, delivery and accountability into a coherent model for institutional and management reform up and down and across the health system remain urgent but elusive.

The result is that the evidence, vision and aspiration for the kind of health and care future we want, and that will transform its experience for those who stand most to benefit, may be drifting further apart from the institutional and operational machinery to get the job done.

We know what we want but appear to lack the tools to do the job. One promising line of inquiry comes from Jennifer Dixon, Chief Executive of The Health Foundation:

*“A real revolution to improve care must begin on the frontline of the NHS: with staff and patients... Historically, reform has been transmitted from government, or NHS central command, through to institutions via their managers. This route will be too slow by itself to be effective... Reform must now be turned on its head... Staff and patients need to support improvements. This more diffuse approach – faster evolution – is less showy than upheavals from the centre. But it is also less risky and is likely to be far more effective. For politicians, here’s the paradox: the best way to sustain the UK’s favourite institution ... may well be to let go. It’s worth reinforcing too that this focus on the front line has to work together with the development of a digitally native workforce.”*

*Jennifer Dixon, Opinion on the National Health Service, ‘How the UK healthcare system can spend its extra funding well’, Financial Times, June 2018.*

# 08 The taxonomy of experience

In 2040, our current Generation X will be aged 60 or older, millennials will be 45-60 and Generation Z will be comfortably middle aged. We should keep that in mind in the discussion about what all of this means for the experience of healthcare in 2040.

But let's have a quick look at what shaped experience in the first place, which is often a function of four things:

### Access

Under what conditions people can access the experience in the first place? Are there barriers of cost and distance for example that make access difficult or impossible? If quality has been maintained or improved, the same is not true for access to services. There has been a serious decline in the number of people receiving state funded social care.<sup>10</sup> This has pushed more and more responsibility onto informal carers and left many without the support they need.<sup>10</sup> In the NHS, timeliness on everything from ambulance responses, to access to A&E, to getting a GP appointment has deteriorated.<sup>10</sup>

### Cost

The second dimension is pretty obvious. Clearly, you cannot experience what it is like to use an iPad or climb to the top of the Eiffel Tower if you cannot afford to pay for the privilege. But in this case, cost is not just about money. It is also about time, effort and the ability to navigate the particular landscape of opportunity in which the experience is nested.

### Control

Control is the third dimension of experience and, for most of us, the most important. How we feel about the experience of most of the things we encounter in life – catching the train, doing our work, eating at a restaurant, going to see the doctor or checking in for an operation in hospital – is a direct function of the degree to which we feel we are in control of the way that experience unfolds. In many situations, and certainly in healthcare, control also engages our sense of autonomy and authority, the ability to “read” what is happening to us (a kind of legibility perhaps) and whether or not what is happening to us is infused with empathy and humanity.

### Performance

No experience is going to be rated highly if, at the end of the day, the interaction from which the experience is formed does not deliver the result you want. In the health context, as in many human service settings, the question of performance is closely linked to the other dimensions of experience, especially control. Being pushed from pillar to post in a complex array of events that takes no account of your needs or fears is always going to end up feeling like a bad experience.

So, if a combination of access, control, cost and performance are the chief determinants of experience, how do they map to the possibilities of experience health and care in 2040? The future usually comes in two colours.

We either get it right. Or we get it wrong. Or to put it another way, the future either happens to us or we have at least some influence on the way in which it unfolds and impacts on people and communities with an eye to questions of fairness, choice and accountability.

To bring together the analysis in this chapter, the implications for the experience of health and care in 2040 are tested against these four elements. The analysis suggests what getting it right or getting it wrong might mean for health and care in 2040.

	We get it right	We get it wrong
<b>Access</b>	<ul style="list-style-type: none"> <li>■ Easier and more equal access to services and support through more even funding strategies, policy design for better service mix and spread</li> <li>■ Creative mix of digital and physical methods of communication and delivery</li> <li>■ Increase % of eligible people receiving social care</li> <li>■ Rising health and digital literacy and confidence across all population groups – rising use of wearables and other digital tools for self-care and monitoring</li> <li>■ Different workforce models that use a mix of telehealth and improved skills other frontline staff to make care more evenly spread and affordable</li> </ul>	<ul style="list-style-type: none"> <li>■ Rising inequity: increasing health related gaps, marginalising populations, no access to new therapies/ medicines for a majority of patients; spiralling costs of care; reduction in life span vs. other countries...</li> <li>■ Fewer effective choices about quality and safety in care for more people as the experience of health care divides sharply between a new and entrenched set of “haves” and “have nots”.</li> </ul>
<b>Cost</b>	<ul style="list-style-type: none"> <li>■ Lower rate of increase in costs and some absolute reductions, and higher productivity through new models of care</li> <li>■ Cheaper service models without sacrificing necessary interaction and a human connection</li> <li>■ More consistent and predictable funding and investment streams – longer-term, integration funding models</li> <li>■ More use of automation to reduce friction and costs</li> </ul>	<ul style="list-style-type: none"> <li>■ Continuing unpredictable cycles of spending to keep up with spiralling costs and harsh austerity measures when that becomes politically and economically unsustainable</li> <li>■ Disconnected funding undermining efforts to integrate care models and innovation</li> </ul>
<b>Control</b>	<ul style="list-style-type: none"> <li>■ Rising sense of agency and autonomy for patients and families and carers</li> <li>■ A good mix of “human” and “machine” determined by patients themselves to maintain the touch and empathy of care</li> <li>■ More autonomy and room for decisions across the health and care system for staff and local leadership</li> <li>■ Confidence leads to experimentation and innovation to respond to shifting local context and conditions</li> <li>■ Digital tools used to increase transparency and legibility of care (more use of dashboards, eHealth records etc.)</li> <li>■ Better “satisfaction” scores reported from patients, families and carers</li> </ul>	<ul style="list-style-type: none"> <li>■ Disengagement by patients, families and carers in their own healthcare</li> <li>■ Too much central control and direction that risks alienation of local commitment, speed of response and capacity for innovation and experimentation</li> <li>■ Rising fragility of the system and loss of resilience to respond to tougher conditions, unexpected challenges such as pandemics, natural disasters, rapid technology</li> </ul>
<b>Performance</b>	<ul style="list-style-type: none"> <li>■ A system that is more responsive to patient needs and circumstances reflected in steady improvement in “dashboard” measures around patient and citizen satisfaction, costs and productivity</li> <li>■ A better match between different models of self-directed and professional-directed care and support to match shifting needs across acute and longer term conditions</li> <li>■ Care and support that matches need</li> <li>■ A steady shift in resources towards prevention and early intervention</li> <li>■ Measurable improvements in the design, delivery and culture of safety and quality across the health and care systems</li> <li>■ Attracting and retaining requisite talent</li> </ul>	<ul style="list-style-type: none"> <li>■ Declining public support and political impatience with a system that fails to respond to changing needs and feels more unequal and patchy in outcomes and benefits</li> <li>■ Harder to attract and retain a requisite workforce of talent, energy and commitment</li> <li>■ Poorer outcomes for quality and safety and rising incidents of poor quality care that results in injury or death and undermines political and cultural confidence, which in turn erodes the foundations for investing in better quality and productivity</li> </ul>



### 09 Conclusion: agency, choice and equity

The trajectory towards 2040 is one of steadily increasing democratisation of all aspects of health and care – data, expertise and decision making for policy and spending. In this case, democratisation means making the health system as open, legible and accountable as possible to the people who use it, work in it and pay for it either directly or indirectly through taxation and investment for the public good.

Health and care as we head towards 2040 could increasingly be “people-powered” by changing the nature and distribution of power and accountability in a system in which “demands are increasing for knowledge, decisions and control to be shared between citizens and professionals, and between communities, frontline staff and senior leaders.”<sup>18</sup>

Agency, choice and equity are characteristics of a health system made for, by and with the humans whose care and wellbeing remain its overriding ambition. In the health care system of 2040, ethics and empathy will play as much a part in determining experience as must economics and efficiency.

Similarly, and with an equally fierce obsession to put the experience of those who use it at its heart, we can surely find the right mix of machines and people to amplify health’s human dimension.

Our health system will prevent and predict more often and with greater confidence and accuracy as much as it will continue to respond and recover with speed, competence and compassion.

And all the while, with rising strength and capability in the background, policy, leadership and technology will be playing at the top of their game to fashion a system that helps us make choices to build our health as our greatest asset. Together, they will get better at aligning the different “pace layers” of change to smooth the more uncomfortable disruptions from inevitable and ceaseless change.

## 10 Authors' suggestions for policy makers

- The experience of health and care by patients and families should be at the centre of the policy process; patient and clinician experience, and the experience of the wider community in their interactions with the health and care system, should be the touchstone against which investments and decisions about change and policy reform are tested and measured.
- Policy reform and new investments in technology for health and care should allow patients and health experts to perform "at the top of their licence" to achieve a truly human-centred health and care system.
- Investments in new digital, collaboration and learning and intelligence technologies should empower patients and families, helping them to make better choices and facilitate greater equity.
- The policy challenge towards and beyond 2040 is to manage the interaction of the different "pace layers" of change across the health and care system and, as far as possible, to smooth the interaction between relatively fast changes in technology and patient and community expectations and the slower investments in infrastructure, culture and governance. The policy imperative is to align, as much as possible the speed and intensity with which change happens across and between the different layers.
- The changing relationship between humans and machines should be tested against the pursuit of choice, trust and empowerment for patients, families and communities.

### Box 5.1 How health may be experienced in 2040

*Text kindly supplied by Sinead MacManus, Health Lab, Nesta*

Michael and Sara have just found out that they are having a baby girl. They decide to call her Allie and she is born on 1st January 2040. Allie's parents want to give her the best start in life so they opt into the national whole genome sequencing programme which is offered as part of the prenatal package of care on the NHS.

Allie's father attended a prenatal course on precision care for young children to find out how Allie's genetic makeup could affect her health in the future. Off the back of this, Allie's parents decided to consent to Allie's genetic sequence being shared with their GP on the secure NHS platform. This means that if Allie gets ill, her GP can custom design the right treatment for her genetic makeup.

Sara is interested in optimising her and Michael's health while they are still in her 30s. She decides to get their gut biome tested and sequenced so they can see if their current diet and gut microbiota are compatible, or whether there is inflammation, which is linked to diseases such as obesity and Parkinson's.

Sara uses a voice activated chatbot on her phone linked to her GP hub to order a home testing kit which arrives by post the next day. Two weeks later they get the results back which shows that Michael has a predisposition for type 2 diabetes. After a video consultation with a health

coach at his GP surgery to discuss the results, Michael decides to cut sugar out of his diet and takes up running.

Michael decides to share his gut data and diet on a regular basis with a health tech startup who is an approved NHS research partner. In return for his data, they offer personalized diet and meal planning suggestions crowdsourced from people with a similar biome to his.

Michael wants to keep well for his growing family, so he trials different types and durations of exercise to see which helps him the most. He uses a combination of cheap NHS-provided wearables and his smartphone to monitor the data and the effect of his lifestyle changes. Michael uses the NHS's OpenHealth platform to pull together his medical records and data, as well as the data from his wearables, smartphone and home testing kits. This means that he has an overview of his health data and can use it to inform his discussions with his doctor and health coach.

Because of Michael's predisposition to diabetes, her parents sign Allie up to a national genetic research project and donate Allie's genetic data. In return for sharing Allie's data, they get access to the latest research from scientists as they uncover and screen for genetic patterns underpinning diseases like epilepsy and type 1 diabetes.

## Box 5.2 Babylon Health

*Text kindly supplied by Mobasher Butt, Babylon Health*

*Please note – this is one example of such technology and should not be read as an endorsement by the Chief Medical Officer.*

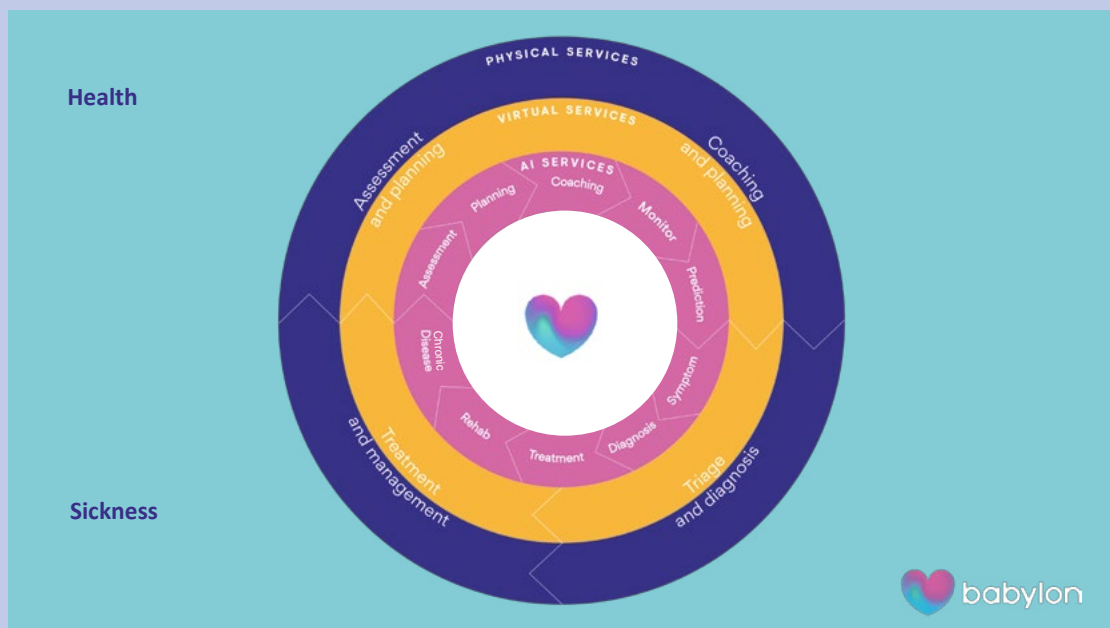
Babylon Health has created an innovative healthcare ecosystem that aims to deliver as much care as possible through the use of Artificial Intelligence (AI) and virtual services in order to help achieve its mission of making healthcare affordable and accessible to everyone globally.

Babylon’s approach is captured in a conceptual framework where the patient journey starts at the inner ring, focusing on using AI to deliver both preventative and therapeutic care through self-serve applications (Figure A). In cases where the user requires interaction with a clinician, they move to the middle ring of virtual services where sophisticated forecasting technology enables the user to connect with a clinician within minutes, 24 hours a day, 365 days per year. The video recording and medical notes are made instantly available to the user after the consultation. The outer ring of more conventional physical care services is reserved for those 10-15% of cases that cannot be managed in their entirety via virtual consultation.

Babylon has deployed this technology in a number of different healthcare settings globally, including within a significant partnership with the NHS; it’s ‘GP at Hand’ service, which allows users to switch their NHS GP to this ‘digital first’ primary care service, is the first of its kind in the NHS’ 70 year history.

Babylon’s work in Rwanda, where such technology has been deployed nationally in collaboration with the Ministry of Health and the Rwandan Social Security Board has led to funding from the Bill and Melinda Gates Foundation to support further roll out in other parts of East Africa.

**Figure A Babylon’s Circle of Care**



Source Babylon Health 2018

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## Chapter 6

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# Demography

### Chapter lead

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## 01 Introduction – where we are now

The estimated population of the UK in mid-2016 was 65.5 million, 55.3 million of whom were in England.<sup>1</sup> By 2041, the Office for National Statistics (ONS) predicted that this figure would rise to 72.9 million, with England seeing the greatest increase of the four nations. To examine how this population might look, first we will review where are now in terms of life expectancy in England and Wales, compared to other European Union (EU) nations. We will then consider the changes that may be seen in structure of the population in terms of age, life stage, and gender by 2040 in the second section.

### 1.1 Life expectancy

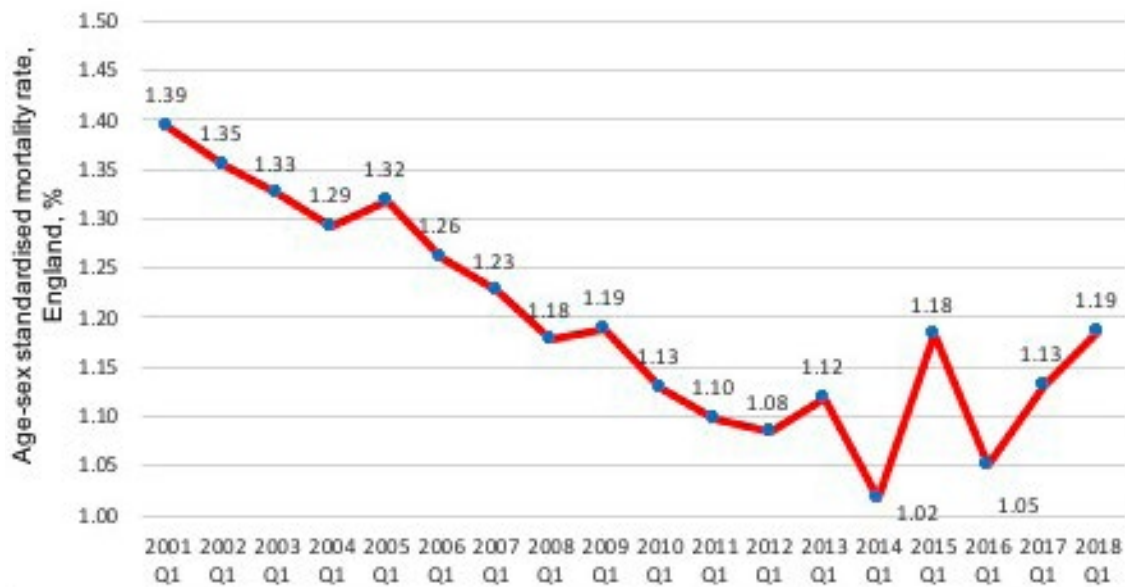
Period life expectancy, derived from age-specific death rates in a given year, is widely used as an indicator of how well a country is performing in improving the health of its people. It has been improving steadily, albeit with some small fluctuations, for decades in high income countries. However, in recent years, these improvements have stalled in England and Wales and, in some older age groups and in some places, it is even declining.<sup>2</sup> There are similar concerns about Scotland and Northern Ireland, but these have been studied less intensively. When the rate of improvement in life expectancy has slowed, stopped, or reversed elsewhere in the past, for example in Eastern Europe in the 1980s, after data artefacts, epidemics, wars, major natural disaster, or mass migration have been excluded, the outcome has often pointed to substantial societal problems.

Figure 6.1 shows the age-sex standardised mortality rate for England from 2001 to 2018, as a percentage.<sup>3</sup> Figure 6.2 shows the resulting trends in life expectancy at birth as reported by the ONS from 1840 to 2016.

After 2010 there is a clear slowdown in the rate of improvement of life expectancy, and increase in age-standardised mortality. The reasons have been the subject of much speculation. Proposed explanations include cohort effects, reflecting influences on health and mortality long ago, or contemporary phenomena such as the lethality of seasonal influenza could play a role. However, several studies have also suggested that the austerity measures, introduced by the coalition government that was elected in that year, could also be playing a role,<sup>4</sup> given the sections of the population most affected and the timing of policy changes, as the long term year on year increases in spending on health and social care slowed dramatically.<sup>5</sup>

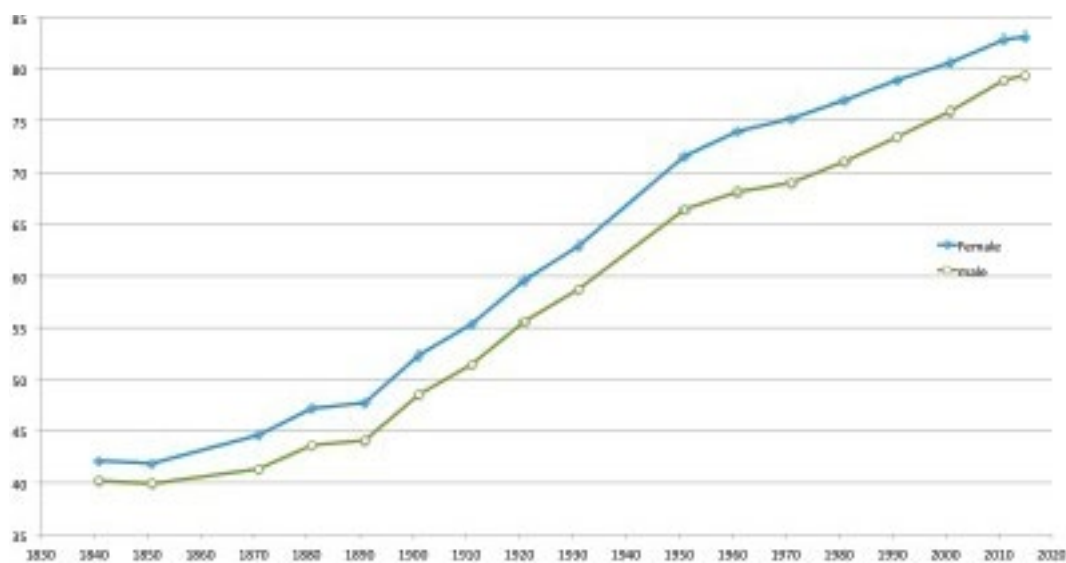
This last explanation finds support in an examination of changes in life expectancy at different ages. Consistent with the general trend, life expectancy at older ages had been rising steadily, if anything with a slight acceleration in the period immediately prior to 2011. Table 6.1 presents the change between consecutive three-year averages (to smooth annual fluctuations). A very similar trend is seen for men and women, and for life expectancy as measured from either age 65, age 75 or age 85. In every case, the size of improvements declined markedly after '2008-2010' and '2009-2011'. What is especially worrying is how the oldest groups have experienced actual declines in the most recent period. The worsening of life expectancy for women over 85 years was first raised as an issue of immediate concern over three years ago,<sup>6</sup> yet it received little attention then and little since, despite becoming much worse year on year.

Figure 6.1 Age-sex standardised mortality rates for England Quarter 1 2001-2018



Source ONS data, 2018

Figure 6.2 Life expectancy at birth in England and Wales, 1840-2016



Source ONS data, 2018

Table 6.1 shows how what started in 2012 worsened dramatically in 2015, when deaths rose by 5.6% – the largest annual percentage increase since at least the 1960s,<sup>7</sup> a decade that saw both an influenza pandemic and the return of substantial numbers of elderly, often frail British citizens from what had been colonies.<sup>7</sup> While there has been a slight recovery in the most recent data, the improvements are still less than half the size of those observed until 2010/11. So what might have been expected if the earlier trends had continued? We now compare observed life expectancy with what would have been predicted using regression techniques with data for the years centred on 2010, thereby generating an 'expected' life expectancy.

## 1.2 Trends in life expectancy for those over 65 years of age

As noted earlier, those over 65 have borne the brunt of the deceleration in life expectancy gains, as measured by the crude differences in life expectancies.<sup>8</sup> On the following page we show what would have happened if the favourable trends up to 2009-11 had continued, and compare that to the observed life expectancy, using data reported by the ONS, for people of ages 65, 75, and 85 years.<sup>9</sup> Note the axes in Figures 6.3, 6.4 and 6.5 do not start at zero because it would be misleading to imply that zero was a plausible possibility.

**Table 6.1 Change in Life expectancy In England and Wales between overlapping time periods by age/sex (years)**

From	To	Age 65		Age 75		Age 85	
		Male	Female	Male	Female	Male	Female
2004-06	2005-07	0.23	0.16	0.16	0.12	0.05	0.06
2005-07	2006-08	0.20	0.14	0.14	0.11	0.05	0.04
2006-08	2007-09	0.22	0.20	0.16	0.15	0.06	0.07
2007-09	2008-10	0.22	0.19	0.18	0.16	0.07	0.08
2008-10	2009-11	0.28	0.28	0.22	0.23	0.12	0.15
2009-11	2010-12	0.15	0.08	0.11	0.05	0.01	-0.01
2010-12	2011-13	0.12	0.06	0.06	0.04	0.01	-0.01
2011-13	2012-14	0.11	0.07	0.07	0.05	0.02	0.01
2012-14	2013-15	0.04	0.00	0.01	-0.02	-0.01	-0.04
2013-15	2014-16	0.08	0.06	0.07	0.06	0.05	0.04

Source ONS, *National Life Tables, England & Wales, 2004-06 to 2014-16*

The gap between the expected and the observed values varies from 0.49 years in females at age 65 years to 0.20 years in males at age 85 years by 2014-2016. The gap continues to widen with each year that passes.

However, it is not the slowing in improvements that is the most concerning. Although that should be considered an amber warning light, demanding urgent investigation at least, any reversal in life expectancy should be considered a red danger sign. A reversal can now be seen clearly for three groups following the change between 2012-14 and 2013-15. For female life expectancy at 75 years, there was a fall from 13.11 to 13.09 years, for females at age 85 years a fall from 6.85 to 6.80 years, and for male life expectancy at 85 years a fall from 5.85 to 5.84 years.

\* In the 1960s there was an influenza epidemic and also the immigration of many elderly frail people from the former British empire who had to arrive quickly before immigration controls began.



Figure 6.3 Life expectancy age 65, England and Wales

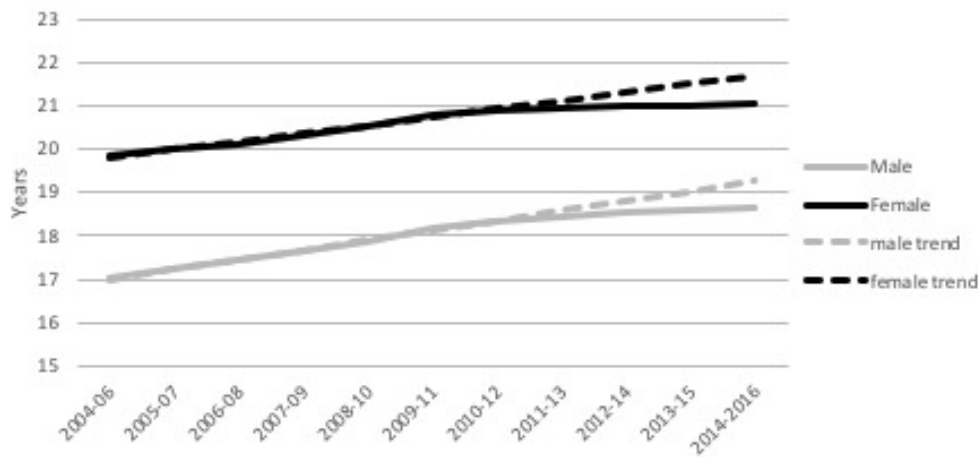


Figure 6.4 Life expectancy age 75, England and Wales

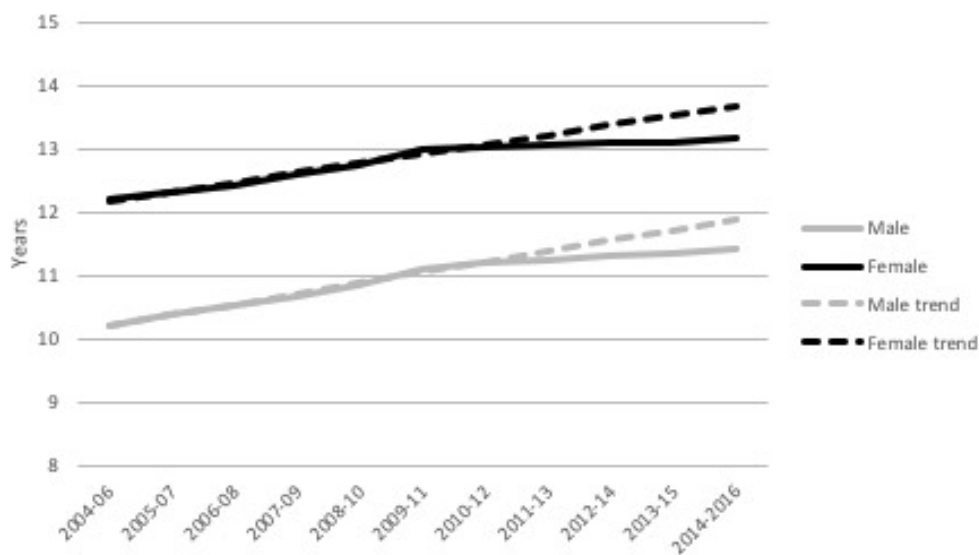
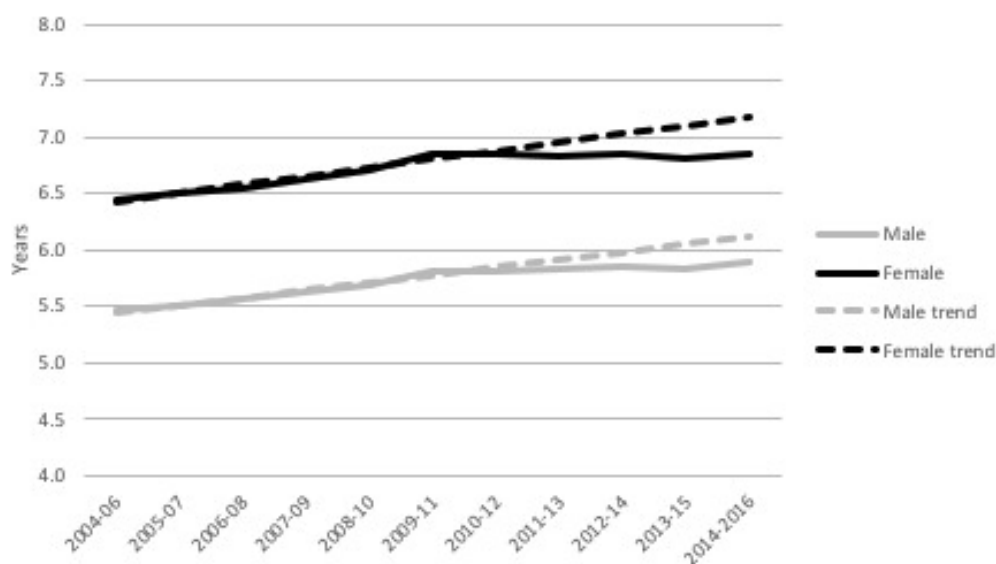


Figure 6.5 Life expectancy age 85, England and Wales



### 1.3 Comparison to other EU countries

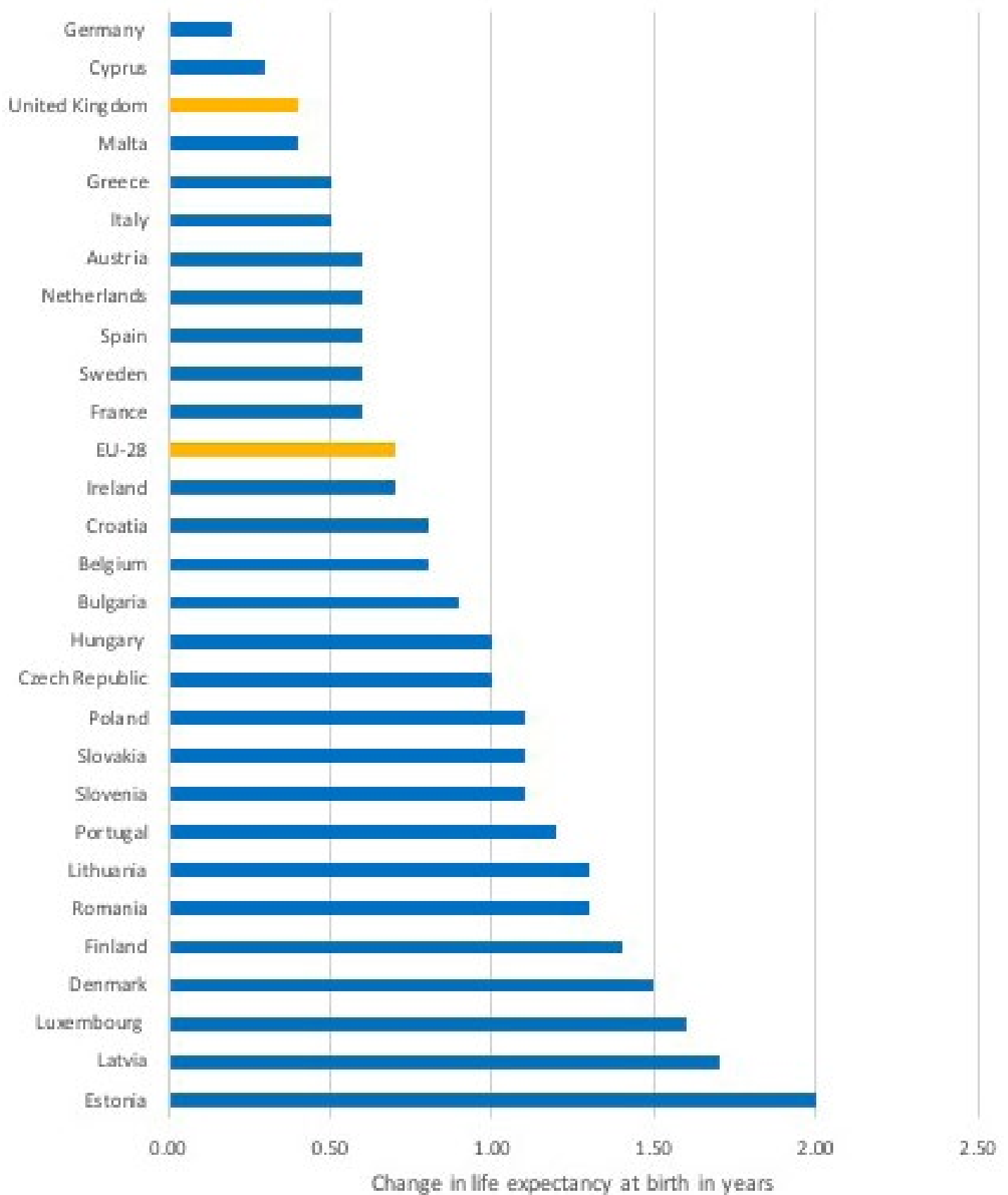
It has been suggested that life expectancy stalling in England and Wales is simply it reaching a natural limit.<sup>10</sup> Data from other countries calls such claims into question.

Using Eurostat data on life expectancy at birth in the EU-28 from 2015, it is clear the UK is performing very poorly.<sup>11</sup> In the short period from 2010 to 2015, the UK fell from 12th in the EU for total life expectancy at birth to 15th. Furthermore, if the changes in life expectancy at birth between 2010 and 2015 are compared, the UK fares even less well. Figure 6.6 shows the UK 3rd from last in life expectancy improvements from 2010 to 2015, and far behind the EU-28 average. It should be noted that both countries performing less well than the UK experienced specific challenges. Germany received well over a million war refugees from Syria in this period and Cyprus suffered an economic crisis in 2012-2013 that was so severe the banks came close to collapse.

For female life expectancy at birth, the UK ranks 17th in the EU-28, well below the average. For males, it ranks 9th. It is very likely that life expectancy in the UK has been improved by the arrival of many young and healthier than average people from the mainland of Europe who are resident in the UK and included in the official mortality statistics. Geographical areas of the UK with fewer such migrants tend to have much higher mortality rates. We do not know to what extent migration might account for the difference between the male and female UK ranking of life expectancy in the EU-28, but it is likely to be an important factor.

A similar pattern can be seen in infant and under-fives mortality. Analysis of WHO and ONS data show that the UK fell down the European child mortality rankings from 7th in 1990 to 19th in 2015, now behind Lithuania and Croatia.<sup>12</sup> For under-fives mortality, the UK fell from 9th in 1990 to 19th in 2015. With infant mortality, the UK has made less progress in 25 years than any of the now 28 EU countries, apart from Germany and France, and for under-5s, the UK made the least progress except for Malta. The infant mortality trend in Scotland may be better than the UK average.

Figure 6.6 Change in life expectancy at birth in years, total population, EU-28 between 2010 and 2015



Source Eurostat; authors' own calculations

### 1.4 Conclusion

The UK has fallen down the rankings significantly for infant and under-fives mortality, as well as for life expectancy at birth. In the most recent two years ONS has reported statistically significant increases in infant mortality across England for all infants. This overall deterioration was preceded by data from 2010 onwards showing that infant mortality was even then rising for babies born to the poorest of mothers in England. Life expectancy at older ages in England and Wales has fallen for some, and there is no sign of these trends reversing.

In the next section, given where we are now in 2018, we consider where we can expect to be in 2040 unless things change greatly.

## 02 Where do we expect to be in 2040?

The simple answer is that we do not know. Population projections are always accompanied with many caveats because of uncertainty about the three things that determine them, births, deaths, and net migration. As we showed in the previous section, the slowing of the improvement in life expectancy after 2010 has already led the ONS to reduce its estimates of future improvements. In due course, if the reasons for these recent trends are fully understood, and especially whether they relate to factors that are transient or sustained, than it will be possible to have more confidence in predictions but, as was noted, there are still many unanswered questions.

There is even greater uncertainty about net migration. The UK's decision to leave the European Union will have a major impact on migration from the remaining 27 Member States (EU27).<sup>13,14</sup> The numbers of migrants from these countries has already fallen sharply. As many have been young adults, this is likely to impact on the birth rate. There is also likely to be an impact on the resident population of older British residents. Loss of existing rights may lead some who have retired to Southern Europe to return, while numbers moving abroad in future is likely to be much less than before. Given, at least at the time of writing, the lack of any clarity, it is impossible to predict what the net effect will be but, overall, it seems likely to accelerate the ageing of the population in the UK while reducing the workforce available to care for the greater than expected number of older people.

With these major caveats, we now use the ONS projections from mid-2016 to examine how the population might look if current trends continue. To illustrate the uncertainty, we also show the mid-2014 projections, which as noted have since been revised.

**Table 6.2 Estimated and projected population in millions of the UK and constituent countries, mid-2016 to mid-2041**

	2016	2021	2026	2031	2036	2041
UK	65.6	67.6	69.2	70.6	71.8	72.9
England	55.3	57.0	58.5	59.8	60.9	62.0
Wales	3.1	3.2	3.2	3.2	3.3	3.3
Scotland	5.4	5.5	5.6	5.6	5.7	5.7
Northern Ireland	1.9	1.9	1.9	2.0	2.0	2.0

Source ONS data, 2016

**Table 6.3 Summary of changes to longer-term assumptions in UK projections, 2014-based and 2016-based**

	2014-based	2016-based	Percentage change
Net annual long-term international migration (after mid-2022)	185,000	165,000	-10.8%
Long-term average number of children per woman	1.89	1.84	-2.6%
Life expectancy at birth, males, mid-2041 (years)	84.3	83.4	-1.1%
Life expectancy at birth, females, mid-2041 (years)	87.1	86.2	-1.0%

Source ONS data, 2016; percentage change authors' calculations

### 2.1 Population size

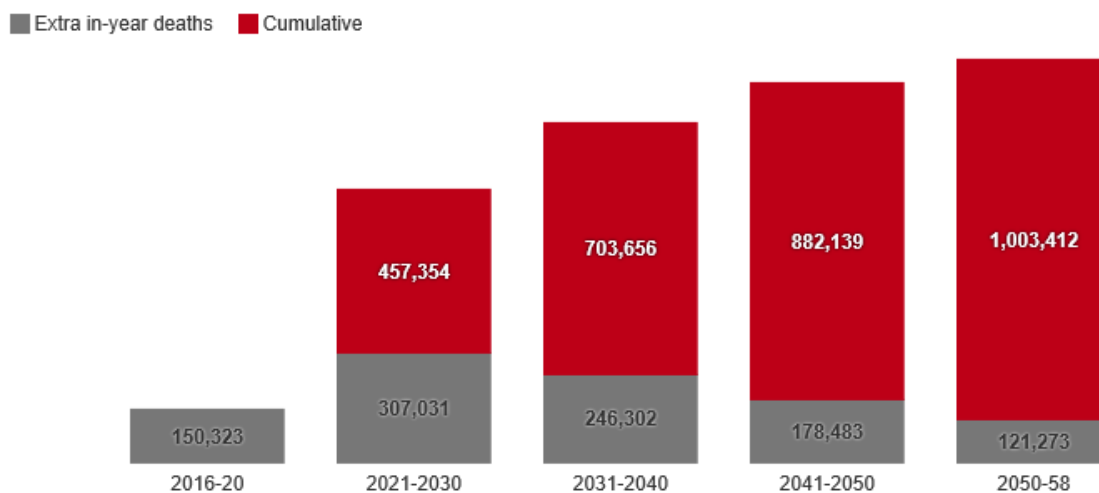
Of the UK nations, England is projected to grow the most quickly, with an increase from 55.3 million in mid-2016 to 62.0 million in mid-2041 – an increase of 12.1%. The percentage increases in the other three nations are somewhat smaller, at between five and six per cent (Table 6.2).<sup>1</sup>

Importantly, these revised estimates do take account, to the extent possible, of the developments discussed above. Thus, the projected UK projected population in mid-2041 is 2.0 million than in the 2014 projections. Table 6.3 shows that all three of the contributors to population numbers have been revised. Thus, net migration is predicted to be just over 10% less while the fertility rate is predicted to fall too, but only slightly. However, the ONS now predicts life expectancy at birth in 2041 for both males and females to be almost a year less that was predicted in 2014. As the ONS notes, the revision is in part due to an 'assumption of a slower rate of increase in life expectancy'.<sup>1</sup>

### 2.2 More deaths

What do these figures mean in practice? A more detailed inspection of the ONS estimates reveal that the new situation, captured in the 2016 revision, will be associated with over one million extra deaths by 2058.<sup>15</sup> Figure 6.7 compares the mid-2014 and mid-2016 ONS projections, calculating the 'extra in-year deaths' and 'cumulative' deaths.<sup>15</sup> If revisions introduced over just two years make such a difference to projections, it is almost impossible to say what the population will look like in over 20 years, given the scope for a wide and diverse range of potential government policies, as well as events beyond the control of governments, all of which could have significant impacts.

**Figure 6.7** Extra deaths and cumulative deaths comparing the mid-2014 and mid-2016 ONS projections



Source ONS data; Dorling D; Gietel-Basten S. *Life expectancy in Britain has fallen so much that a million years of life could disappear by 2058 – why? 2017 [updated 29 November 2017; cited 2018 13 July].*

**Figure 6.8** Age structure of the UK population, mid-2016 and (projected) mid-2041



Source ONS

### 2.3 Older population

What seems certain is that the age structure of the population is likely to change in ways that could not be predicted even a few years ago. Figure 6.8 shows the ONS population pyramid comparing the age structure in mid-2016 with the predicted age structure mid-2041.

In England, the percentage of those aged 60-74 years in mid-2041 is predicted to increase to 16.4%, from 15.1% in mid-2016.<sup>16</sup> The percentage aged 75 years and over is projected to increase from 8.1% in mid-2016 to 13.3% in mid-2041. Figure 6.9 shows the changing percentages in each age group over time. The 30-44 year age group includes the median throughout the period, but by 2040 the median age is almost 44.<sup>16</sup>

### 2.4 Changes to working age population

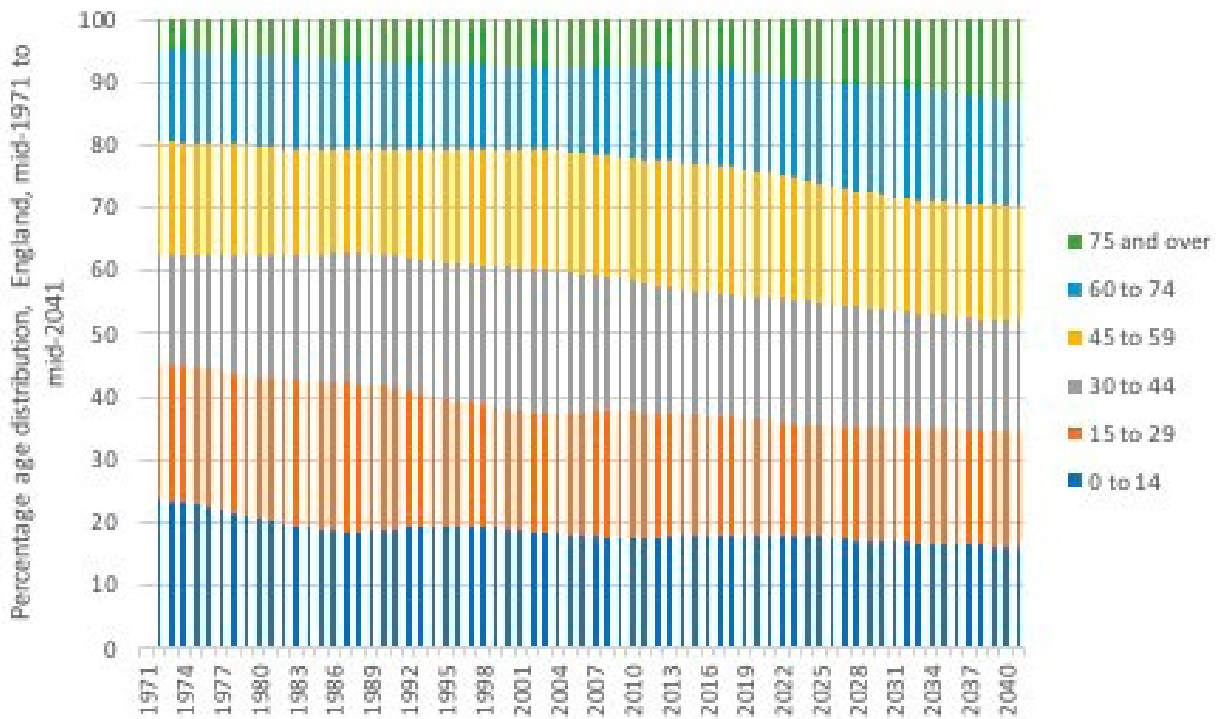
With the increase in population numbers at older ages comes a change in the number of those at different stages in life, and of particular importance, those of working and pension ages. These projections take into account the planned increase of State Pension Age to 67 years by 2028, for both sexes.<sup>17</sup> Figure 6.10 compares the figures for mid-2016 and (projected) mid-2041. There is a 31% increase in those of pensionable age, compared to just an 8% increase in the working age population.

The gender make-up of the UK is also changing. In mid-2016 it was estimated that the population was divided, 50.7% female and 49.3% male; by mid-2041 it is predicted to be 50.3% to 49.7%. This may in part be explained by the stalling and worsening seen in life expectancy, which have disproportionately affected women. However, although a majority of births are always male, during times of high inequality and austerity a slightly higher than usual proportion of babies born in the UK have been female.

### 2.5 Conclusion

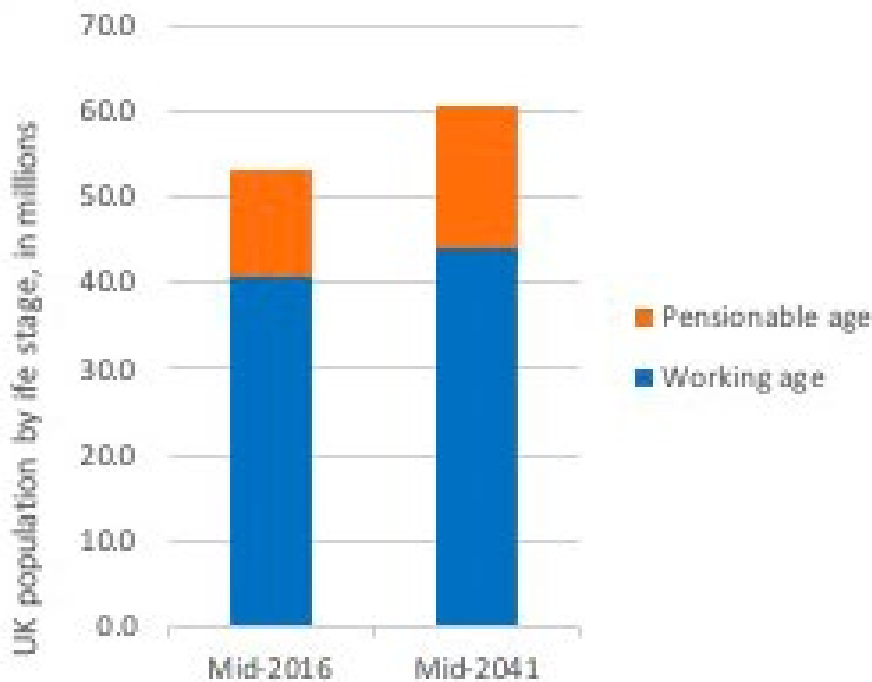
Considering the demographic drivers of migration, births, and deaths, there are clear emerging threats to the population. It is likely there will be a larger, older population, without a substantial increase in the working population. Increasing the birth rate would not alter this very much. Life expectancy could deteriorate further.<sup>17</sup> These predictions are not destiny. They can be used, analysed, and interventions made to improve what has been estimated. How this could be done is considered in the final section. All across Europe the population is aging rapidly, and especially in the countries with the most successful social policies where the old live for the longest. Europe is fortunate to be located near to regions with very large and very young populations.

Figure 6.9 Percentage age distribution, England, mid-1971 to (projected) mid-2041, by age group



Source ONS data; authors' chart

Figure 6.10 UK population by working age and pension age, mid-2016 and (projected) mid-2041



Source ONS data; authors' calculations.



## 03 What could be achieved in 2040?

The authors of this chapter believe that the outlook for 2040 does not currently look bright. An ageing and not especially healthy older population, with a relatively low share of the population of working age, stagnating or even worsening life expectancy, and the unknown impacts of leaving the European Union, all pose challenges to the overall health of the population. However, identifying these challenges provides an opportunity to respond to them. There are three main areas where action could be taken to improve the current position: migration, funding of health and social care, and a focus on 'healthy ageing'. These will be considered in turn.

### 3.1 Migration

The authors of this chapter believe that the recent decrease in immigration, and reduced access to healthcare by migrants living in the UK, both pose a threat to population health, as will be outlined below.

Migrants are generally young, healthy individuals, a phenomenon known as 'the healthy migrant effect'.<sup>18</sup> Data from Eurostat from 2008-2014 on the age distribution of foreign country citizen immigrants to the UK (net) show the largest group is between 20 and 24 years, and the vast majority under 40 years.<sup>19</sup> In fact, the inflow of healthy migrants is one of the reasons the UK has not seen a greater slowdown in life expectancy. The only age group in 2015 not to see mortality rates rise was that aged 25-29 – which also benefited from an inflow of 60,000 migrants of those ages.<sup>20</sup> As outlined above, by 2040 the ratio of pensioners to working age population will greatly increase. Migration can remedy this with young, healthy migrants to the UK increasing the working age population, providing a much needed workforce.

The health and social care system is especially in need of migrants, who make up 13% of the total workforce.<sup>21</sup> EU migrants comprise up to 10% of NHS doctors, and 5% of NHS nurses.<sup>22</sup> Yet, government policies to reduce net migration, with schemes such as 'Earn, Learn and Return', which 'bring qualified professionals to this country for a fixed period, to enhance their knowledge and skills and contribute to our health service before returning home' limit the long-term contribution they can make to the NHS.<sup>21</sup> Record numbers of GPs are leaving the profession, along with nurses, midwives, district nurses and learning disability nurses. Without migration, the NHS may struggle to function. Adult social care is a vital part of the system, particularly with an ageing population. 18% of the adult social care (ASC) workforce were born overseas, and ASC has a required growth from 14% to 31% needed by 2030.<sup>21</sup> Without migration, it is hard to see how this could be achieved. While migration cannot be a solution in the long term as fertility is falling rapidly worldwide, for the next two decades it may be essential for the UK.

Access to healthcare for migrants has changed significantly in recent years. Despite being widely disputed, belief in the existence of large scale 'health tourism' persists. In reality, it is estimated to cost the NHS approximately 0.3% of the annual budget,<sup>23</sup> and data collected over 10 years by Doctors of the World UK, who run a clinic for migrants in London, show patients had on average been in the UK for 6 years before even trying to access healthcare, with less than 1% citing health as their reason for migration.<sup>24</sup> Yet a focus on 'health tourism' led to new legislation in 2017: those not immediately able to prove their eligibility for NHS care must now pay the whole cost upfront (at 150% of the tariff), or be refused healthcare.<sup>25</sup> The regulations are complex, time-consuming, and poorly understood, resulting in many cases of patients being wrongly refused urgent healthcare, such as chemotherapy and cardiac surgery.<sup>26</sup> Furthermore, evidence collected by the Department of Health and Social Care on pilot schemes show it has not been successful; eighteen hospitals carried out identification checks over two months, with staff asking patients to show two forms of ID to prove eligibility for NHS care. 8,894 patients were checked, and 50 were identified as 'not eligible' – 0.6%.<sup>27</sup> There is no estimate of the cost of the staff time spent on this, or the deterrent effect this will have had on those unable to promptly provide two forms of identification, such as the elderly, or those who are homeless.

Deterring some individuals from accessing healthcare threatens the health of the whole population.<sup>28</sup> It is well known that timely, preventative care, whether for non-communicable diseases likely hypertension and diabetes, or antenatal care for pregnant women, is more cost-effective and efficient than those cases presenting as an emergency later on. It saves the NHS money to ensure equitable access to healthcare. Although migrants carry a low burden of infectious diseases, leaving those who have infections untreated poses a further threat to all, e.g. tuberculosis.

### 3.2 Funding health and social care

Recent funding for the NHS, and social care, has failed to keep pace with demand. As we have noted above, although still controversial, there are good reasons to believe that there may be a relationship between austerity and the observed slowing of improvements in life expectancy at birth and the increases in death rates in older people.<sup>2</sup> These reasons have been set out in a series of studies.<sup>4,28-33</sup> However, others reject this argument, citing alternative explanations such as unknown infectious agents,<sup>34</sup> cold weather, and influenza.<sup>35,36</sup> Others have noted the complexity involved in interpreting short-term trends and urged caution in inferring causality from an observed association.<sup>37,38</sup> Despite this, no other plausible cause is forthcoming for the sudden deterioration of the health of people in the UK since 2010/11. This needs to be said clearly while still acknowledging the difficulties of proving causality.<sup>39</sup> There is a need to undertake more detailed examinations of what has been happening in other industrialised countries that have, as noted above, not experienced a slowdown in improvement in life expectancy to anything like the same extent, looking particularly at those that have made different political and funding decisions.

We need to understand these issues in order to inform policy and planning, and a number of pertinent reports have been recently published.<sup>39-46</sup> Even if suggestions that influenza has played a part in the increases in deaths in early 2015 and 2018 were accepted, there would be questions about why the spikes in mortality were so exceptional and whether the NHS would be able to cope with a future pandemic, such as those that occurred in 1951 and 1968.

### 3.3 Healthy ageing

The evidence presented earlier in this chapter highlights the importance of measures that can reverse the declining life expectancy at older ages. If, as is at least plausible, some of the recent changes can be attributed to austerity, it follows that the most effective measures are likely to be those which restore the services needed by older people. Unfortunately, it seems likely the situation will get worse before it becomes better, given the severe funding squeeze on local authorities, some of which are now implementing policies that would provide the bare legal minimum of social services.

Beyond that, there are a number of measures that could be taken to promote healthy ageing.<sup>47</sup> Several factors predict whether someone is likely to age successfully.<sup>48</sup> They include entering old age with a low level of risk factors for chronic conditions. This points to the need for measures that reduce smoking and obesity, and to a greater extent than is often recognised, the hidden burden of problem drinking among those who are middle-aged. Other factors include engagement, with loneliness increasingly recognised as a major risk factor in its own right, and confidence. Growing numbers of older people are socially isolated, a situation exacerbated by the loss of community facilities, including libraries, as well as by the fragmentation of family structures, with their younger relatives often moving far away in search of employment.

Looking further into the future, it is likely that those who comprise the older generation by 2040 could face a much more precarious situation than their counterparts today.<sup>49</sup> Many fewer will benefit from defined benefit occupational pensions. The state pension in the United Kingdom is among the least generous of any industrialised country. As a consequence, many pensioners are dependent on top ups, such as pension credits. A particular concern is that many fewer people will enter retirement owning their own homes. Although they may have managed to pay what are, in international terms, often very high rents, they will struggle to do so with small pensions.

The challenges facing the ageing population in the UK over the next 20 years are immense, and go far beyond what can be covered in this chapter. In several important respects, they are greater in magnitude than in other comparable countries. However, as exemplified by the continuing but so far inconclusive debate about paying for social care, there has been an inability to grasp the issues and take the necessary measures, in marked contrast to countries such as Germany, Japan, and South Korea that have implemented long-term-care insurance schemes.<sup>50</sup>

## 04 Authors' suggestions for policy makers

### 3.4 Conclusion

Demography is not destiny.<sup>15</sup> If the UK is to move forward, protecting population health, it must understand why the changes outlined above have occurred. A first step in projecting the future is to understand the present. Reflecting on the demography provides key opportunities to improve the health of the population by 2040, and change the current trajectory. There is no need for the current very troubling ONS projections to become reality – unless we ignore the warning they give us.

- A first step is to undertake a comprehensive inquiry into the reasons for the slow down and, in some places, reversal in the previous steady improvement in life expectancy. In the medium term we need to learn from other countries.
- Set a target to spend a similar proportion of GDP on health and social care as that in other countries of North West Europe. The UK has the lowest overall levels of public spending in all of this part of Europe and the lowest life expectancy. This is a medium term solution.
- Making housing more affordable makes it easier for health and care staff to live in areas that are otherwise too expensive.
- Quantify the contribution of international migration to England to health, through the health and social care workforce, and through increasing the healthy, working age population.

## Box 6.1 What can generational analysis tell us about public health in 2040?

Text kindly supplied by Michael Clemence and Hannah Shrimpton, Ipsos MORI Social Research Institute

While demographic projections can tell us what the population might look like in 2040, they keep us in the dark about the behaviours this population might exhibit, and the health choices they might make. This is where generational analysis – looking at how attitudes shift among cohorts defined by the years of their birth – can help to shed some light.

Ipsos MORI has explored what generational analysis can tell us for the two youngest generations in Britain – Millennials<sup>i</sup> (those born between 1980 and 1995) and Generation Z<sup>ii</sup> (born 1996 onwards). Here we provide a summary of the evidence generational analysis of Health Survey for England data can furnish on the future direction of public health in three core areas – smoking, drinking and obesity.

Any discussion of generational effects must be careful to distinguish between those views and behaviours which are related to a person's *lifestage* – a behaviour that has always been more common among younger people – from those that are due to their *cohort*. The latter are specific to the circumstances of a generation's upbringing; most importantly for predicting future behaviour these are also more likely to stay with them as they age.

### Smoking

The long-term data presents a well-known good news story: the number of people smoking is in decline. However, different generations are kicking the habit at different rates and those Millennials who do smoke appear to be doing so for longer. When we compare Millennials in 2013 with members of Generation X (those born 1966 – 1979) in 1999 – years where the average age of these generations matches at 26 – we see different trajectories. The trend for Millennials has been shallower than for Gen X; in fact, between 2009 and 2014 the proportion of Millennial smokers has stayed broadly level.

<sup>i</sup> <https://www.ipsos.com/ipsos-mori/en-uk/millennial-myths-and-realities>  
<sup>ii</sup> <https://www.ipsos.com/ipsos-mori/en-uk/generation-z-beyond-binary-new-insights-next-generation>

### Drinking

Regular alcohol consumption is facing a generational decline in England. Every generation has drunk less regularly than the one before it, with only six per cent of Millennials drinking alcohol on five or more days a week, half the proportion we saw among Generation X at an equivalent point (13%).

Looking further forward, we find more evidence of a permanent shift away from the stereotypical 'binge drinking' culture, with our youngest generation hitting teenage life with a very different attitude and behaviour to drinking. For example, in 2000, nearly three quarters of teenage Millennials (then aged 13-15) had tried an alcoholic drink at least once – fast forward to 2016 and the figure for 13-15 year olds (Generation Z) is just 36%.

### Obesity

While smoking and drinking may be in decline, our analysis presents a worrying generational trend for obesity: generation on generation, adults are less likely to be a healthy weight. Already, Millennials are distinguished as the first generation where less than half are at a healthy weight in their twenties. Combine this with the fact that the likelihood of being overweight is highly correlated with rising age and we can expect a continued rise in obesity levels from now to 2040 and beyond.

And although childhood obesity isn't growing – after rising during the nineties the prevalence of obesity among secondary school children now is the same as in 2003 (36%) – there is evidence that the odds are already against Generation Z maintaining a healthy weight in adulthood. A longitudinal analysis of UK birth cohort studies suggests that like Millennials, they are two to three times more likely to become obese or overweight compared with older generations in England.<sup>iii</sup>

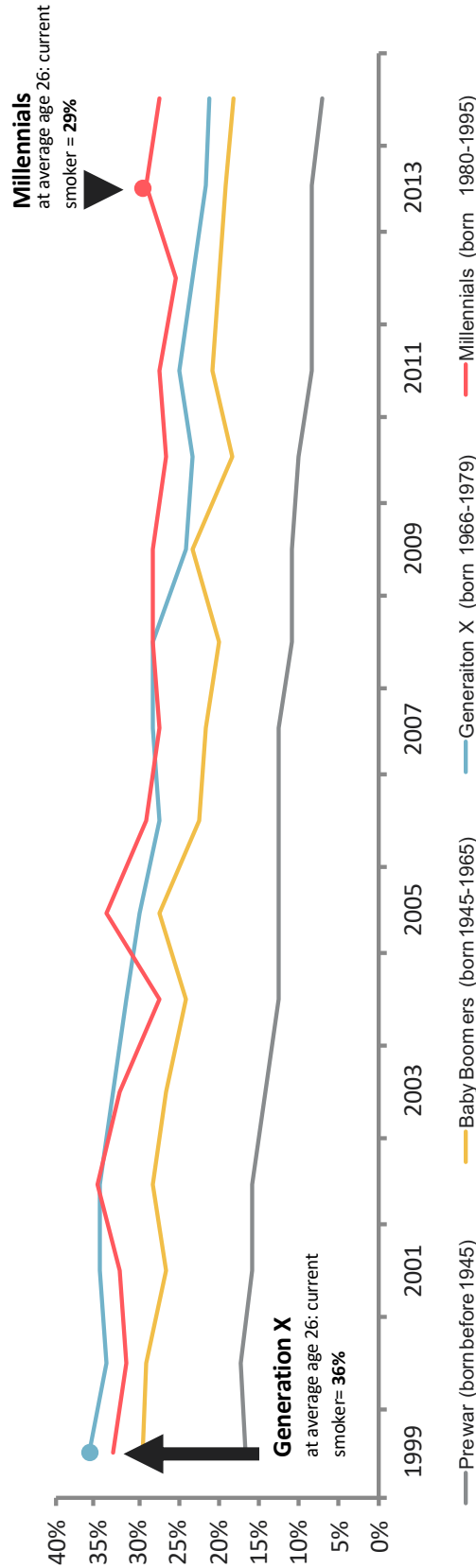
A generational perspective is of course just one part of the picture. The strongest indicators of obesity in children are socioeconomic, not generational. In England in 2016, a third (32%) of children aged 2-15 in the lowest household income quintile were overweight or obese, compared with just 18% of children living in the highest quintile.<sup>iv</sup> But the generational trend can work with socioeconomic factors to widen health inequalities: in an increasingly unhealthy population, it is likely that divides *within* generations are likely to grow.

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<sup>iii</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4437909/>  
<sup>iv</sup> <https://files.digital.nhs.uk/publication/m/c/hse2016-child-health.pdf>

# SMOKING RATES HAVE DECLINED IN THE PAST 15 YEARS, BUT ARE DECREASING AT LOWER RATE AMONG MILLENNIALS - ENGLAND

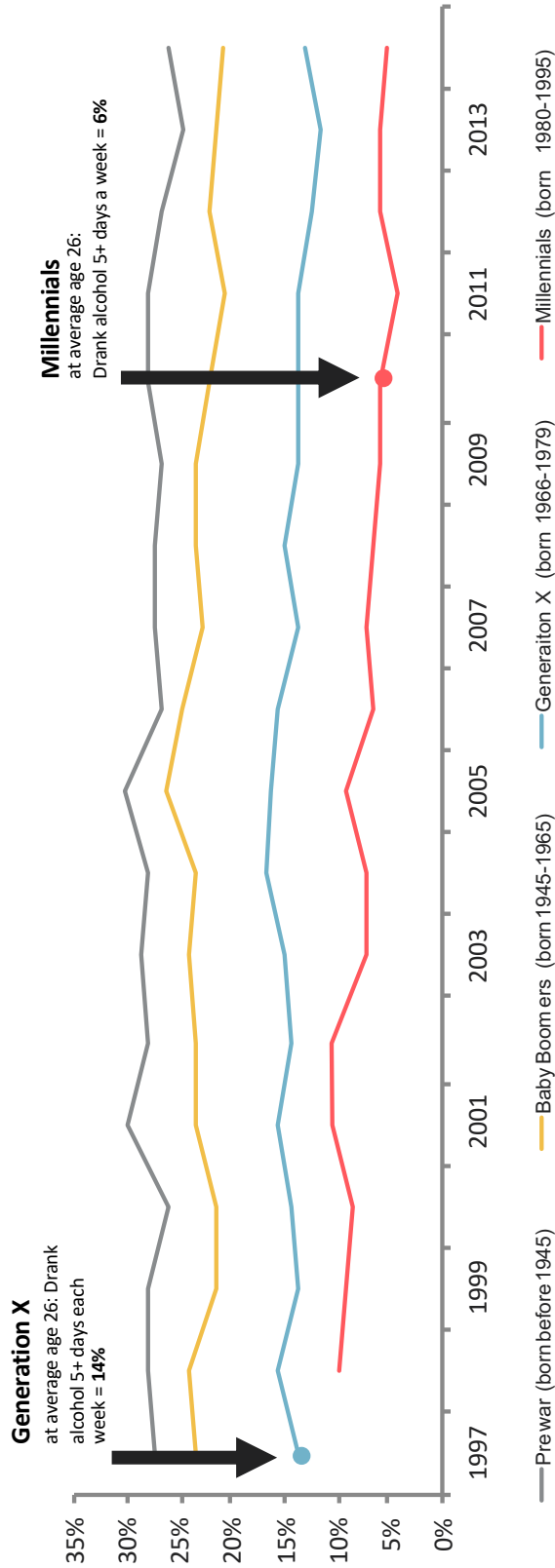
% current smoker (smoke every day/some days)



Source: Ipsos MORI reanalysis of Health Survey for England

# THERE IS A STRICT GENERATIONAL PATTERN TO REGULAR ALCOHOL CONSUMPTION - ENGLAND

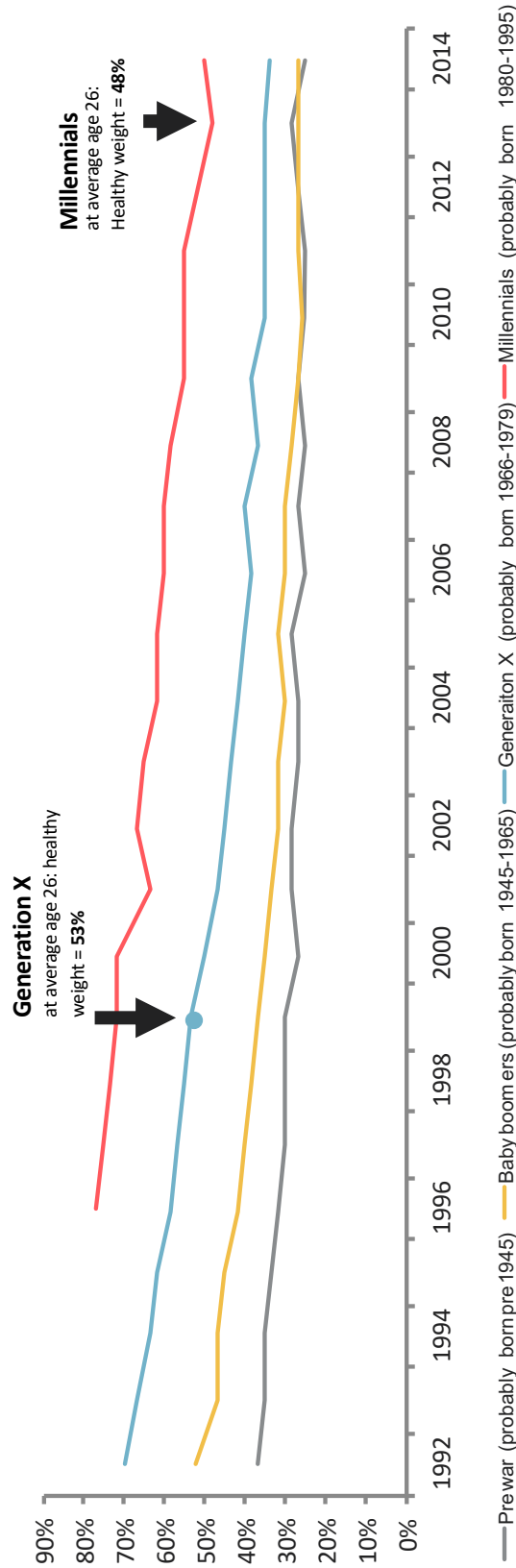
% drank alcohol on 5+ days/week



Source: Ipsos MORI reanalysis of Health Survey for England

# MILLENNIALS ARE THE FIRST YOUNG GENERATION WHERE OVER HALF ARE OVERWEIGHT - ENGLAND

% with a healthy weight (defined as BMI score 18.5-24.9)



Source: Ipsos MORI reanalysis of Health Survey for England

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## Chapter 7

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# Multimorbidity

### Chapter lead

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## 01 Introduction

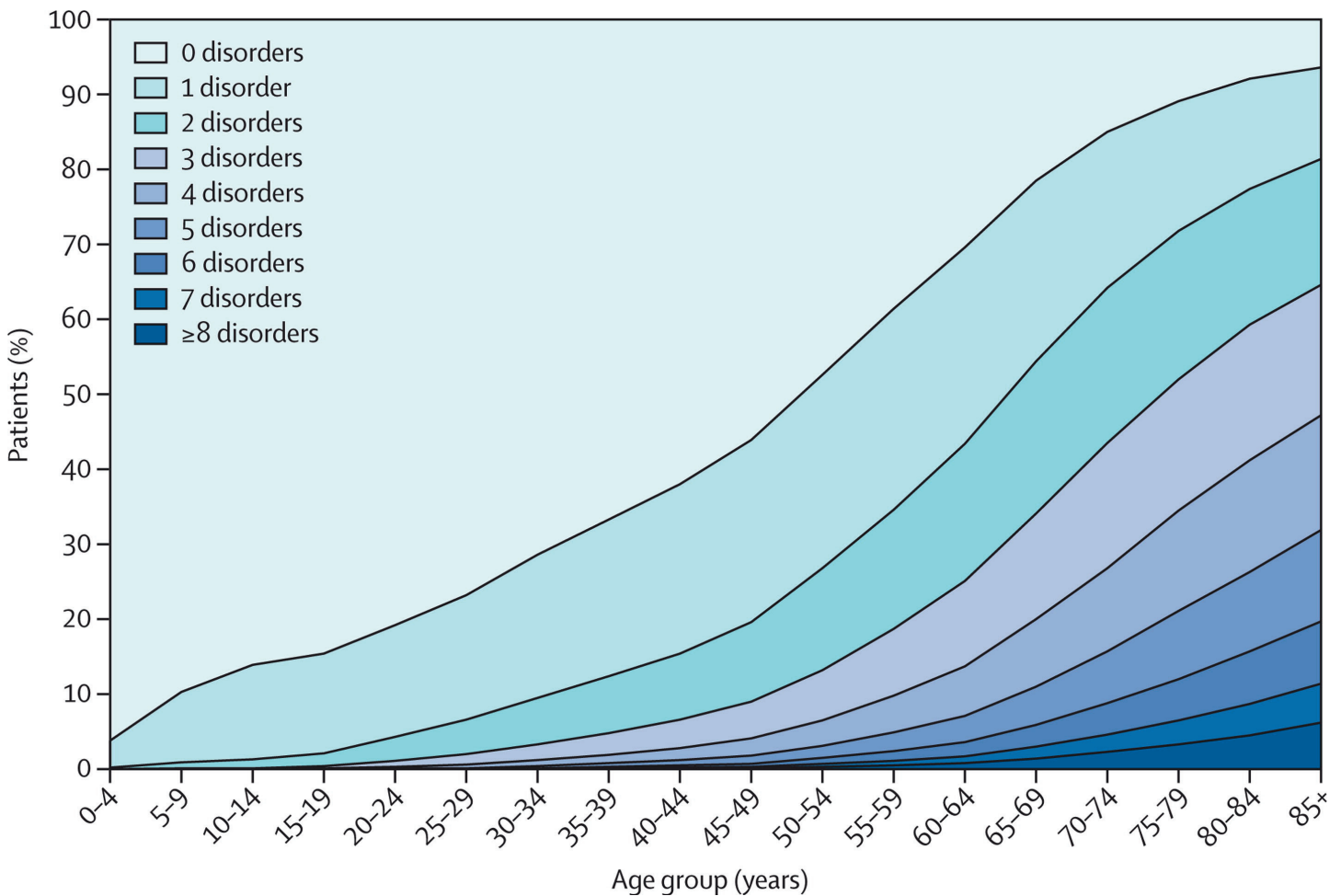
Much of the way we organise health and services, guidelines and science is based around single diseases, but multimorbidity, the co-existence of two or more chronic conditions in an individual, is a large and growing problem for society. It is one of the greatest challenges facing our NHS and wider public health system. Two generalised drivers of multimorbidity everywhere are relative poverty and old age; it is more prevalent in older people and those with a lower socioeconomic status.

Multimorbidity is associated with a reduction in quality of life, increased use of health services and reduced life expectancy. This presents major challenges for patients, carers and the health and social care system. Much of the problem with multimorbidity is that we treat it as a random assortment of diseases, rather than as predictable clusters of diseases around which clinical services and research should be gathered.

## 02 The scale of the problem

We know multimorbidity is common, affecting around 50 million people across the European Union<sup>1</sup> although estimates of prevalence vary depending on how it is defined and measured. Recent studies have started to quantify the scale of the problem. A large study in Scotland reported that nearly 65% of those aged 65-84 were multimorbid and this increased to 82% of those over 85.<sup>2</sup> Increasing age is also associated with increasing number of disorders. Whilst more prevalent in older people multimorbidity also affects the young, the same study showed multimorbidity in almost 1 in 5 25-64 year olds (see Figure 7.1). This places great pressure on them, their families, and the wider health service.

**Figure 7.1** Number of chronic disorders by age group, Scotland, 2012



Source Barnett et al. 2012

## 03 Rising multimorbidity

It is widely recognised that multimorbidity is increasing, both in absolute terms and relative to single morbidity. The population of older people is increasing, in large part due to advances in medical interventions at a younger age. Globally, the number of people aged 60 or above is expected to more than double by 2050.<sup>3</sup> The Office for National Statistics (ONS) projects that in the United Kingdom (UK) the population aged 85, in whom multimorbidity is the norm, will almost double over the next 20 years from around 1.7 million to almost 3.7 million.

For those aged 75-84 the rise will be from 4.1 to 6.3 million. Longitudinal data on multimorbidity are few but there is general agreement that the problem will grow alongside our aging population. A recent study projects that by 2035 the proportion of people with four or more conditions will almost double from 9.8% to 17% of the population.<sup>4</sup>

Whilst shifting demography leading to an increase in the number of older people explains some of the projected increase in multimorbidity it is not the only factor. Risk factors, such as obesity, diabetes, unhealthy diet, lack of physical activity and smoking are known to increase the risk of several chronic conditions and they also inevitably increase the risk of suffering from more than one. Many risk factors for NCDs including smoking, illicit drug use, and high blood pressure have declined over the past decades whilst some risk factor trends have been less favourable. Rates of obesity, a key risk factor for morbidity, have increased from 15% of adults in 1993 to 26% in 2016.<sup>5</sup> When overweight adults (BMI of  $\geq 25$  kg/m<sup>2</sup>) are included in addition to those obese, these figures increase to 53% of adults in 1993 compared to 61% in 2016. One study examining the role of obesity in chronic disease clustering found that it was associated with double the odds of multimorbidity.<sup>6</sup> In England, the number of people with diabetes, for which obesity is a major risk factor, is expected to increase in the next two decades from 3.9 million people in 2017 to 4.9 million in 2035.<sup>7</sup>

Approximately one third of patients with multimorbidity has a mental health condition<sup>8</sup> and the prevalence of common mental health disorders has increased since 1993.<sup>1</sup> The risk factors go both ways; chronic physical ill health can lead to mental health issues (such as depression), whilst those with significant mental health issues tend to have premature physical health problems. In 2014, it is estimated that 18.9% of adults aged 16 to 64 years in England had at least one common mental health disorder.<sup>7</sup> Some physical and mental health conditions commonly cluster. Those with both a physical and mental health condition commonly have a poorer quality of life and reduced life expectancy. The division between services treating mental and physical health commonly places patients suffering both at a heightened risk of disjointed and poor-quality care.

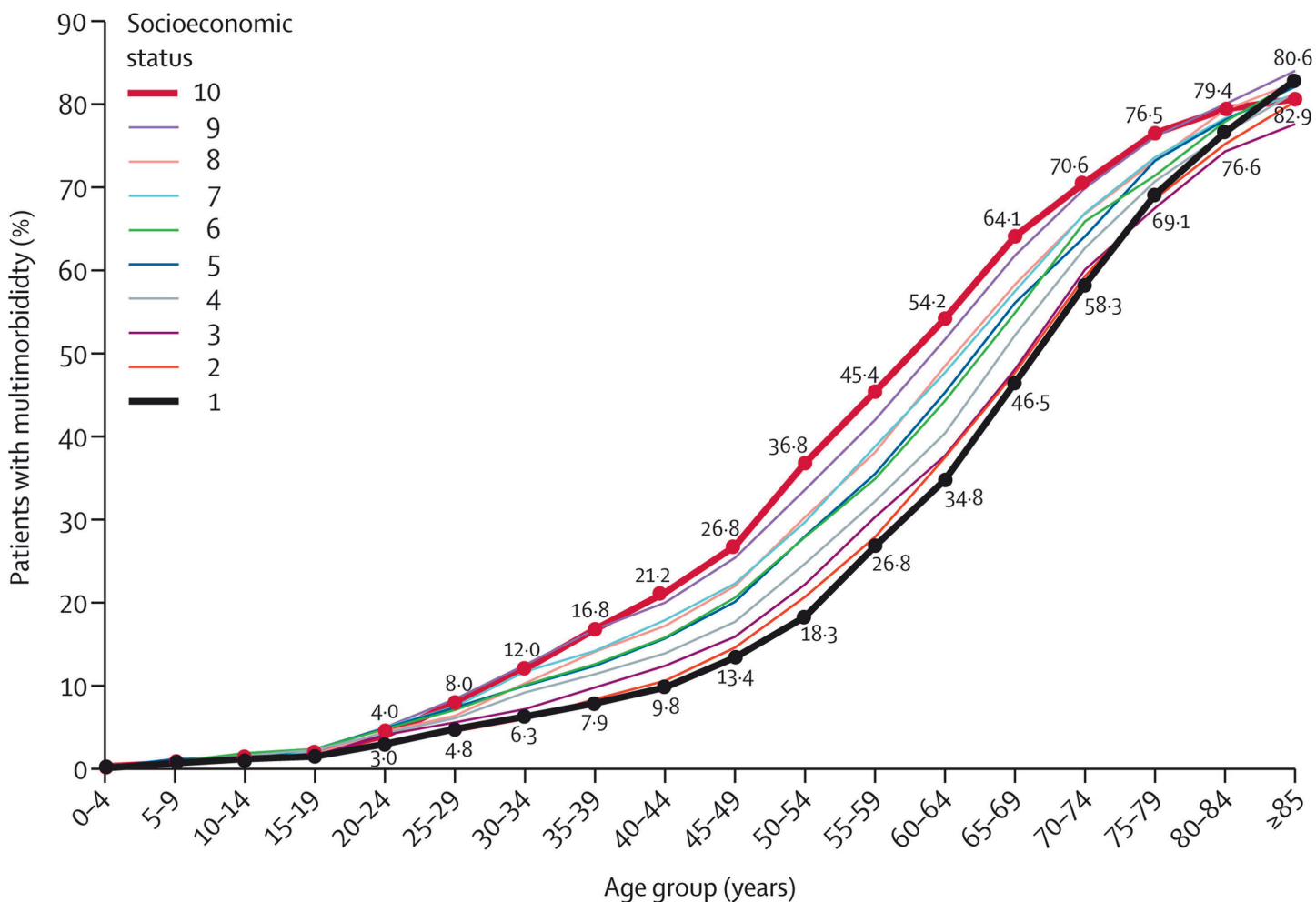
## 04 High-risk groups and inequalities

The association between age and multimorbidity is well recognised and patterns of multimorbidity are becoming increasingly apparent in relation to socioeconomic status, gender and health related behaviours such as smoking and nutrition.

People from the most deprived areas are more likely to be multimorbid. A retrospective cohort study in the UK showed that prevalence of multimorbidity was higher in those with lower socioeconomic status, 30% of those in the quintile of greatest deprivation were multimorbid as opposed to 25.8% of the most affluent quintile<sup>8</sup> (Figure 7.2). The same study showed multimorbidity was higher in females (30%) compared to males (24.4%).

Approximately a third of the gap in life expectancy in deprived areas results from heart disease, lung cancer and lower respiratory conditions. The leading risk factors for these conditions are smoking and obesity, both drivers of several diseases and therefore multimorbidity.<sup>1</sup> Whilst the prevalence of smoking has declined from 19.9% to 14.9% over the past seven years, people in the most deprived areas are still more likely to smoke than people in the least.<sup>1</sup> The 2016 Health Survey for England demonstrated that for women there is a strong social gradient when it comes to obesity, with 38% of women in the most deprived areas classed as obese compared to 20% of women in the most affluent areas.<sup>1</sup> The proportion of multimorbidity inequality attributable to modifiable behaviours such as smoking and alcohol abuse is not yet clear. Mental health disorders comprise a greater proportion of multimorbidity in women, younger patients and those with a lower socioeconomic status<sup>7</sup>, with some studies showing that the most deprived are almost twice as likely to have a mental health disorder compared to the most affluent.<sup>8</sup>

Figure 7.2 Prevalence of multimorbidity by age and socioeconomic status, Scotland, 2012



Source Barnett et al. 2012

## 05 Key challenges and research priorities

### 5.1 Patient care is often built around their individual conditions, we need a holistic approach

The impact of multimorbidity spans across the full range of health services, from primary to end of life care, and it is becoming increasingly apparent that a higher proportion, and sometimes the majority of GP appointments, hospital admissions and prescriptions now involve patients with multimorbidity.<sup>7</sup> Over the past few decades the steady increase in medical specialisation, combined with single disease guidelines from organisations such as the National Institute for Health and Care Excellence (NICE), has been part of a highly successful solution for treating those with a single medical condition. To address the rising tide of multimorbidity we need a more integrated approach.

Scientific organisation also tends to be single-disease focused; the much better recent vertical integration from bench to bedside around specific diseases often works against horizontal integration addressing the needs of those with several conditions. Research groups, promotion panels, grant-giving bodies, journal editors and specialist clinics all tend to handle multimorbidity and the science of multimorbidity badly. To compound this, those with multiple morbidities are often systematically excluded from many studies as they might complicate interpretation, and those with dementia may be excluded because of concerns about informed consent. To address this, we need changes both to the intellectual model we use to consider multimorbidity and probably to our clinical and scientific structures.

One major intellectual barrier is that many people think of multimorbidity as if it were a random assortment of diseases, when it is in fact a non-random series of predictable clusters of conditions.

### 5.2 Identify and map disease clusters

Some clusters around risk factors are so strong they are already well known. For example, it is widely understood that chronic obstructive airways disease, ischaemic heart disease and peripheral artery disease cluster around smoking, or retinal disease, peripheral neuropathy and heart disease cluster around diabetes. Some clusters occur more commonly in different regions or ethnic groups. More prevalent conditions within clusters include hypertension, depression or anxiety, chronic pain and osteoarthritis.<sup>10</sup> Whilst there is some knowledge of common clusters, progress identifying others is limited by the fragmented and scarce existing evidence base and lack of methodological research in this area.

Breaking down what is termed multimorbidity into widely recognised clusters of disease would make both clinical, public health and scientific progress considerably easier. The pattern recognition tools machine learning allows, and the large datasets available (although often not integrated) in the NHS mean this is possible now in a way it has not been previously. Identifying clusters of ill health would allow a search for the common genetic, behavioural and

environmental risk factors which drive them. With a better understanding of clusters we can also begin to organise clinical services and guidelines around common or particularly serious clusters rather than expecting individuals to go to multiple specialist clinics where at any moment only one of their many problems is being considered, be on several simultaneous NICE guidelines, and have the subsequent polypharmacy with multiple drugs whose combined effect is not known. Identifying people with the first disease in a known cluster may allow secondary prevention to delay or halt the subsequent diseases.

### 5.3 If we want to tackle multimorbidity, we need to go to where it is common

The impact of both age-driven and poverty-driven multimorbidity is not evenly spread geographically. Urban areas such as London or Manchester import youth (typically aged around 18 or 21) and then people tend to move out from the time they start a family onwards. As a result, cities maintain a young demographic structure whilst many semirural and rural areas are ageing, and therefore acquiring multimorbidity, substantially faster than the average numbers would imply. This is going to provide a serious challenge to current delivery models of medical and social care. As the age support ratio changes, current structures are difficult to scale up to the degree needed outside urban areas and will need to be rethought. Continuing to treat multimorbid clusters in multiple single-disease clinics will compound the impact of concentrating age in parts of non-urban Britain on local NHS services.

For the more applied, clinical and public health end of the research spectrum there is a strong scientific need for research to be conducted in and with the populations most affected. Research activity needs to go to the populations that need it, and the National Institute for Health Research (NIHR) encourages the best researchers, wherever they are based, to undertake research in the areas of the country with greatest health needs. For multimorbidity, this will usually not be university towns, and need to include rural and deprived areas.

### 5.4 Research by definition is forward looking; there is wide consensus multimorbidity is a major future agenda

When NIHR went out to the academic community to predict future trends and areas of research that were not progressing rapidly, multimorbidity was widely cited. In parallel the Academy of Medical Sciences (AMS) released a report, 'Improving the health of the public by 2040', in which multimorbidity featured strongly.<sup>1</sup> A subsequent AMS report, specifically on multimorbidity 'Multimorbidity: a priority for global health research', crystallised current views around research needed in this area.<sup>2</sup> Previous calls by NIHR and other funders for multimorbidity research have been disappointing, with few high quality proposals. Structural barriers to undertaking good research include the way most university and NHS research units are organised around single or similar diseases (e.g. cardiovascular disease). It is clear that a collective, concerted effort of major research funders is required with a shift in the approach to funding and the type of work supported to achieve significant progress.

In July 2018 the NIHR and MRC jointly launched a call for research projects into disease clustering in multimorbidity, particularly encouraging applications from cross-disciplinary and cross-institutional teams whose combined efforts could tackle the complexity of multimorbidity at all levels. This call marks the start of a shared longer-term substantial commitment amongst major research funders to galvanise research into multimorbidity.

## 06 Conclusion

The future of medicine will increasingly be one of multimorbidity in older people, and multimorbidity in younger people is already a major driver of NHS activity. This is tractable if we identify and respond to clusters of ill health rather than seeing them as a random assortment of conditions. Since multimorbidity is the future direction of medicine, we have no option but to support the best physician scientists to prevent and manage it. Doing so will require changes in the way we think scientifically, organisationally, clinically and possibly philosophically.



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# *Special section – Mental health disorder*

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## Mental disorder and inequalities

### Mental health disorders are common

Mental health disorders are common and costly: Mental health disorders represent the largest single cause of disability in the UK, with an associated cost to the economy estimated at £105 billion a year and accounts for 23% of NHS activity.<sup>1</sup> The Adult Psychiatric Morbidity Survey<sup>2</sup> shows that one adult in six adults has a common mental disorder (CMD). CMDs are non-psychotic disorders, including different types of depression and anxiety, which affect physical, social and occupational functioning.

All types of CMDs are more common in adults of working age, compared to retirement age, though one in five older people living in the community and 40% of older people living in care homes will experience depression.

Rates of CMDs have been steadily increasing, particularly for women; anxiety is most common in young women (16-24) who present with symptoms nearly three times more commonly than men of the same age group. Since 2007, there has also been an increase in CMDs in midlife (55 to 64) for men and women.

The prevalence of psychotic disorders (such as schizophrenia and affective psychosis) remains relatively stable (0.4% in 2007, 0.7% in 2014), with higher rates (Figures 7.3 and 7.4) amongst black men and those living on their own.<sup>2</sup>

In 2017 the age-standardised suicide rate was 10.1 deaths per 100,000 population, which is one of the lowest rates observed since the suicide data series began in 1981. Suicide is more common in males in all age groups. Over a similar time period, non-fatal self-harm has increased in young people, with over 200,000 hospital attendances per year in England.<sup>3,4,5</sup> High-risk groups for suicide, as identified by the cross-Government National Suicide Prevention Strategy for England, include young and middle-aged men, individuals interacting with mental health services or the criminal justice system, and those with a history of self-harm, as approximately 50% of people who have died by suicide have a history of self-harm.<sup>5</sup>

### Mental health, life course and family

Most mental health problems develop in childhood and 1 in 8 children and young people (age 5 to 19) have at least one diagnosable mental health condition.<sup>6</sup> By the age of 14, half of all mental health disorders have been established, increasing to 75% by age 24.<sup>7</sup> Poor mental health for parents is associated with negative effects upon children's physical and emotional development, behaviour and overall wellbeing.<sup>8</sup> Approximately 10% of women and 6% of men are parents with mental health disorders, with the majority suffering with CMDs.<sup>9</sup> There is a strong association with lone parenthood, though this appears to be related to lone parents' relative socio-economic disadvantage.<sup>9</sup> Parents with mental health disorders, particularly lone parents, are identified as one of four groups (alongside people from ethnic minorities, young men and adults with complex needs) facing particular barriers in getting their mental health and social needs addressed.<sup>10</sup> Specific to mothers, one in five suffer from a mental health problem during pregnancy or in the first year after childbirth and suicide is the second leading cause of maternal death.<sup>11</sup>

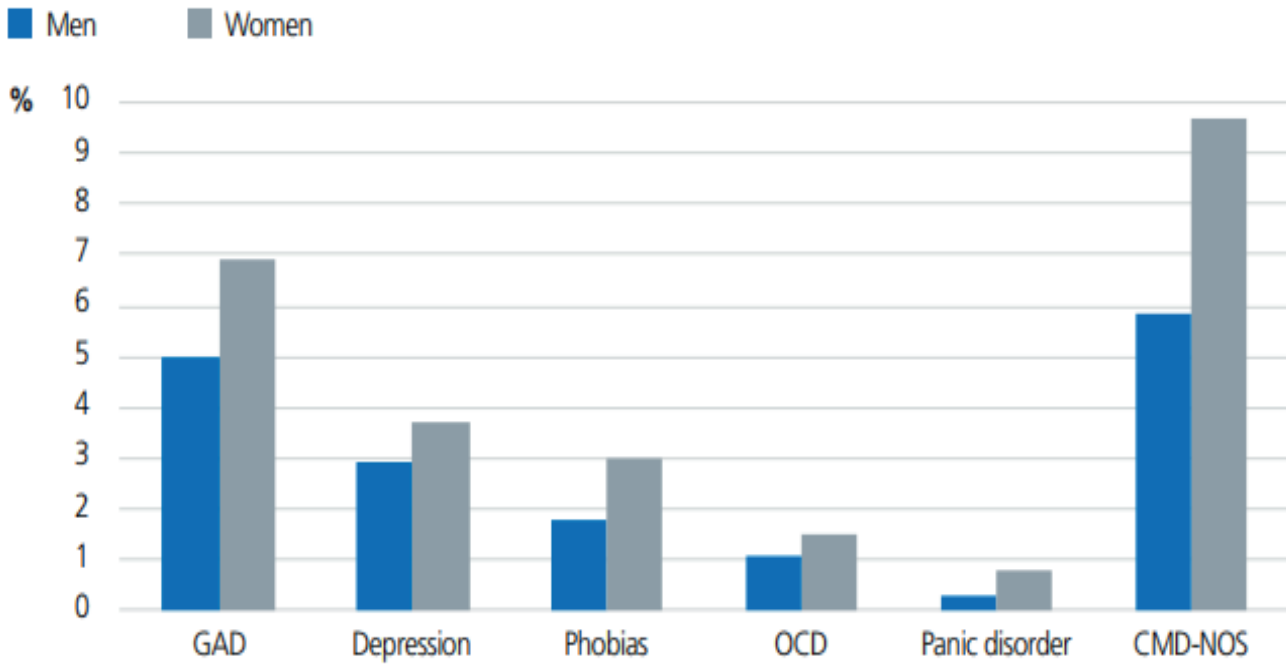
### Inequalities and mental health disorders

Mental health disorders are associated with economic and social disadvantage. There is a bidirectional association between poverty and mental health with each being associated with an increased risk of the other.<sup>11</sup>

The South East London Community Health study, SELCOH,<sup>12</sup> a local psychiatric and physical morbidity survey of adults in South London, found that socio-economically disadvantaged individuals had poorer physical and mental health, such as common mental disorders compared to those with higher income and/or more education. In vulnerable populations such as the homeless, CMDs and psychosis are approximately 2 and 15 times higher than the general population.<sup>13</sup> Similarly, Ford et al.<sup>14</sup> showed that rates of psychiatric morbidity for children living in disadvantaged households are double that of the general population, increasing to four to five times higher for children looked after by local authorities.

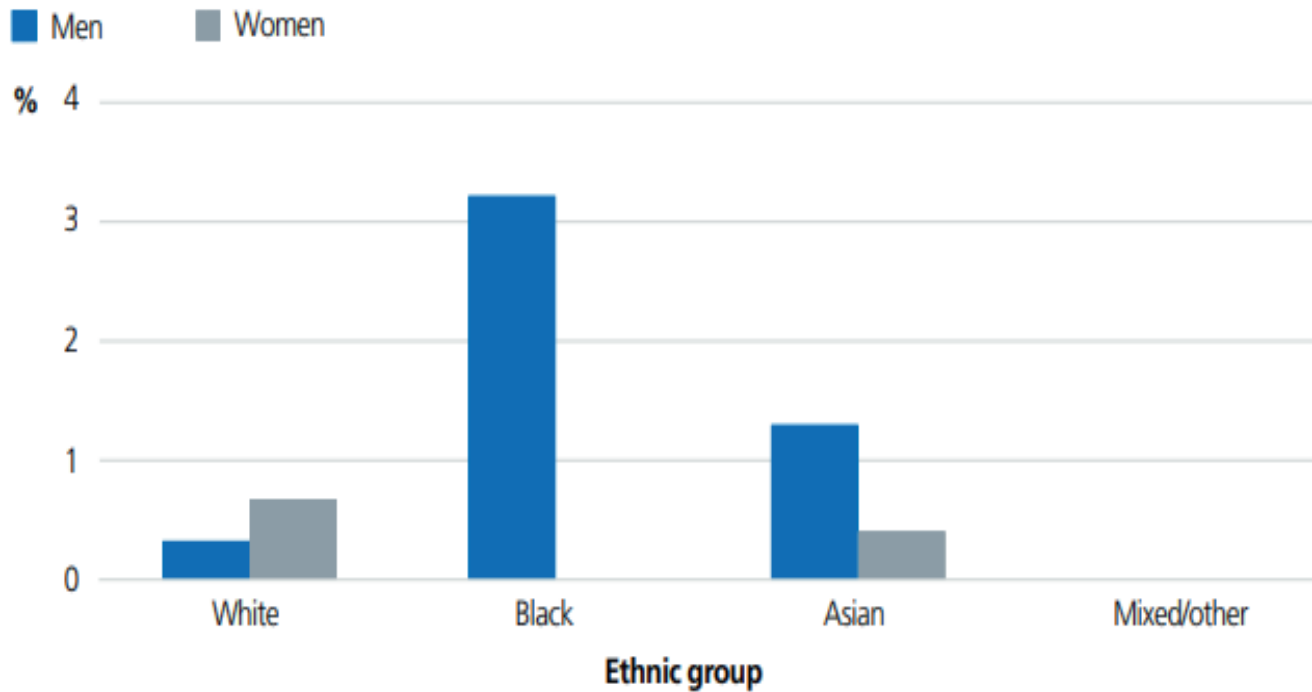
Mental health disorders including suicide, depression and self-harm are also more common in lesbian, gay, bisexual and transgender (LGBT) individuals with depression, anxiety, alcohol and substance misuse 50% more common than non-LGBT individuals.<sup>15</sup>

Figure 7.3 Prevalence of common mental health disorder by gender



Source adapted from Adult Psychiatric Morbidity Survey data from 2007 and 2014 (combined)

Figure 7.4 Prevalence of psychotic disorders by ethnic group and gender



Source adapted from Adult Psychiatric Morbidity Survey data from 2007 and 2014 (combined)

### Inequalities in access to mental health services

Access to mental health services varies by age, ethnicity and socioeconomic status. Data from The Adult Psychiatric Morbidity Survey<sup>2</sup> shows demographic inequalities in the use of treatment and services by people with CMDs. Those most likely to access treatment were female, White British, and middle-aged (35-54). Those in employment were less likely to receive treatment than those who were economically inactive, however people with CMDs living in lower income households were more likely to have unmet treatment requests (used as a proxy measure for need).<sup>2</sup>

The Increasing Access to Psychological Therapy (IAPT) Programme has extended access to psychological therapies but concerns remain about patterns of inequity. When comparing participants in the South-East London Community Health study<sup>16</sup> with those accessing a local IAPT service or being referred by a primary care physician, disparities in access were evident. These differences were less significant in patients who self-referred suggesting that the self-referral pathway to IAPT could be important in addressing inequitable access.

There are significant differences in the pattern of use of compulsory treatments for mental health disorders: higher rates of detention under the Mental Health Act are found for people from Black Caribbean, Black African and mixed Black ethnicity, as noted in the interim report of the independent review of the Mental Health Act.<sup>17</sup> Patients who are Black Caribbean, particularly men, are also over-represented in other compulsory treatment groups including those that are re-admitted under the Mental Health Act, those who come in contact with mental health services via the police, those admitted to secure hospitals and those on Community Treatment Orders.<sup>17</sup>

### Co-morbidity of mental and physical illness

Inequalities in life expectancy for people with mental health disorders have been well established, with a mortality rate that is 2.2 times higher than the general population and a reduction of 15 to 20 years in life expectancy for people with bipolar disorder or schizophrenia.<sup>18</sup> These differences are primarily accounted for by “natural” causes of death, including cardiovascular and metabolic conditions.<sup>18</sup> Several ‘gaps’ in parity esteem between mental and physical care have been highlighted including inequalities in screening, dental, medical and surgical care and inequalities in assessing and monitoring comorbid physical ill health.<sup>19</sup>

Many factors, including background, lifestyle, economic disadvantage, behavioural risk factors (especially smoking), and difficulties accessing and adhering to medical treatments, contribute to premature mortality in patients with severe mental illness.<sup>20</sup>

Conversely, the presence of a mental health disorder alongside long-term physical health conditions is a “particularly common and pernicious form of multi-morbidity”.<sup>21</sup> Specific associations have been identified for cardiovascular disease and depression, diabetes and depression and chronic musculoskeletal disorders and depression. Evidence suggests that at least 30% of people with a long-term condition also have a mental health problem.<sup>22</sup>

## Mental health disorder and stigma

Attitudes towards people with mental health disorders have improved over time,<sup>23</sup> however negative attitudes still exist particularly towards certain diagnoses, which are perceived as ‘dangerous and unpredictable.’<sup>24</sup> Nearly 9 out of 10 people with mental health disorders report that the experience of stigma has had a negative effect on their lives, sometimes describing the experience as more damaging than the illness itself.<sup>25</sup>

A survey conducted by Mind<sup>26</sup> to better understand the experience of stigma by people in contact with mental health services showed the following about the respondents:

- 34% said they had been dismissed or forced to resign from jobs
- 69% of people had been put off applying for jobs for fear of unfair treatment
- 47% had been abused or harassed in public, and 14% had been physically attacked
- 26% were forced to move home because of harassment
- 24% of parents said their children had been teased or bullied, or that they were afraid it would happen
- 25% of people had been turned down by insurance or finance companies
- 50% felt unfairly treated by general health care services.

Mental health related stigma has a detrimental impact on help-seeking behaviour.<sup>27</sup> Ethnic minorities, young men and those in military and health professions appear disproportionately deterred from help-seeking by stigma.<sup>28</sup> In addition, there is increasing evidence of stigmatising attitudes and behaviours by health and mental professionals towards people with mental health disorders contributing to poorer outcomes (for example for people with severe mental illness) and negative experience of care (for examples for people who frequently self-harm).<sup>28</sup>

## The future

The risk of developing mental health disorders, as well as their impact and life course, are determined by a complex interaction between biological, psychological and social factors. Therefore, mental ill health is associated with and embedded within a society’s broader social and economic context. Addressing the complex issues of mental health and inequality will need system-wide changes and the willingness to move towards what has been called ‘triple integration’<sup>29</sup> – integration of health and social care, primary and specialist care, and physical and mental health care.

At population level many of the issues of relevance in public health (equality, diversity and the social determinants) are also relevant to public mental health. The efforts towards promotion of mental health and emotional wellbeing, prevention of future mental health disorders and support towards recovery, whilst aided by relevant research and emerging supportive policy, have been hampered by the climate of austerity affecting public services. Such approaches include adopting a proportionate universalism approach, a life-course approach that accounts for foundations of good mental health in infancy and reducing stigma.<sup>30</sup>

Current models of service delivery should expand to acknowledge the links between physical and mental health, the central role of social context and the importance of taking into account the impact of poverty, social exclusion and discrimination across the life span. Strength-based approaches in service delivery are paramount and necessitate a competent and engaged healthcare workforce that challenges mental health related stigma and stereotyping and promotes a recovery-based approach with patients, thereby helping them to challenge internalised stigma.

Finally, it is crucial to adopt a life course developmental approach to the design and delivery of mental health services. This may bring renewed focus on mental health promotion, prevention and early interventions that address the mental health needs of children and adolescents.

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## Chapter 8

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# Changing behaviour for a healthier population

### Chapter lead

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## 01 Introduction

There have been notable improvements in the health of people in England in recent years. For example, life expectancy has increased continuously since 1980, and was 83 years for women and 79 years for men in 2016.<sup>1</sup> Similarly, healthy life expectancy (the number of years lived in good health) has increased since 2000. However, progress on these measures masks two significant and persistent challenges for the health of the population in England: many of those additional years of life are lived in poor health by many people, and both life and healthy life expectancy are unequally distributed. For example, on average, those in the poorest communities die 7.4 (women) and 9.3 (men) years sooner than those in affluent communities, who in turn enjoy 18 more years of life in good health. Importantly, inequalities in health between the most and least socioeconomically deprived communities have also worsened over the past 15 years.

The largest contributing causes of premature deaths in the UK in 2016 were ischaemic heart disease, lung cancers, cerebrovascular disease and lung disease, specifically chronic obstructive pulmonary disease (COPD).<sup>2</sup> While each of these conditions has multiple interacting risk factors, it is estimated that changing four sets of behaviour – smoking, unhealthy diet, harmful consumption of alcohol and insufficient physical activity – could prevent up to 80% of new cases of heart disease, stroke and type 2 diabetes<sup>3</sup> and 40% of cancer incidence.<sup>4</sup> Achieving widespread changes in these behaviours would help to ensure the precious asset of a healthy population for benefit of the economy and society, as well as reducing current growth in the proportion of NHS and social care budgets that treatment and management of their associated diseases requires. In addition to the four behaviours that are the focus of this chapter, many others also contribute to physical and mental health, including gambling, sexual relations, sleep, sun exposure and recreational drug use. The principles for changing behaviour discussed here will also apply to these behaviours.

Historically, informing and educating people about the harmful consequences of smoking tobacco, eating unhealthily, drinking harmfully and moving too little has been core to many strategies aimed at changing their behaviour. Interventions commonly used have included providing non-personalised risk information through mass media campaigns and more recently providing individuals with personalised risk information based on a range of biological markers. However,

such approaches often have limited impact on health at a population level: while they can increase awareness of harms associated with engaging in unhealthy behaviours – and this is of course important – their impact on behaviour itself is often insufficient to achieve the changes needed across the whole population to prevent leading causes of ill health and death.<sup>5-10</sup> Importantly, such information-based approaches delivered with greater intensity can increase health inequalities because, when they do have effects, these are disproportionately realised in higher socioeconomic groups.<sup>11-13</sup>

Consequently, the burden of ill health and premature deaths attributable to smoking, unhealthy diet, harmful alcohol consumption and insufficient physical activity will remain an intractable public health challenge without effective interventions delivered at a population level. For example, with over half of the population in England now overweight or obese,<sup>14</sup> we have passed the stage when a strategy focused on changing the behaviour of individuals at high risk of disease would stand any chance of reversing this epidemic of preventable disease. Improving health and reducing inequalities between more and less socio-economically deprived communities requires interventions that make minimal demands on individuals and have a sustained impact across the whole population.<sup>12</sup>

While we do of course exercise choice in how we behave, much of our behaviour is also strongly shaped by environments – often without our awareness.<sup>15</sup> Cues that shape much of our behaviour abound in the physical, economic, digital, social and commercial environments that we inhabit.<sup>16</sup> See Box 8.1 for a description of a possible ‘normal’ day in England. Environments are also interrelated in ways that make them difficult to change, and that disproportionately impact the health of people living the poorest communities.<sup>17</sup> For example, numerous fast food restaurants, takeaways, off licences and other alcohol outlets, tobacconists and gambling outlets are often found on the same street (so called ‘toxic high streets’),<sup>18,19</sup> many unhealthy foods are more profitable for manufacturers and retailers than healthier foods and therefore more likely to be heavily promoted through advertising in print and digital media and on the high street,<sup>20</sup> and a lack of safe infrastructure to support active travel in urban environments often places limits on physical activity.<sup>21</sup>

## Box 8.1 An ordinary day for many people in England?

Upon waking we check our phones and social media accounts, interacting with a steady stream of targeted advertising promoting tasty snacks, local takeaways and 'coffee outlets near me'. During the morning routine, we see and hear more commercials on television and radio promoting sugary and alcoholic drinks. If there is time, we grab a bowl of breakfast cereal that, without our awareness, contains a substantial proportion of our recommended daily intake of sugar. We head out of the house, perhaps pausing to buy a large coffee and a cheap bar of chocolate that seems like a good deal when we are offered it at the cash register. We commute to work in cars, buses or trains, all the time being exposed to more advertising on our phones and on passing billboards. We are deterred from walking or cycling to work by the lack of safe routes.

At work, we spend most of the day sitting at a computer, in meetings or on the phone. We step out at lunchtime to buy a 'meal deal' that takes us well over the recommended 600 calories for lunch, returning to eat it at our desk. Mid-afternoon we pass a vending machine at work and treat ourselves to that chocolate bar that we have been craving. On the way home, we stop at a supermarket where we are forced to navigate stacks of cut-price beer and wine at the entrance, numerous multi-buy offers on crisps and snacks, and run the gauntlet of sweets and chocolate on the way to the checkout. On the way out, we queue for fuel where we are bombarded with further offers of discounted snack food and chocolate at the fuel pump and in the kiosk.

On the route home, we pass about thirty takeaways, many with multi-buy or meal-deal offers. When we arrive home, we eat a supermarket 'ready meal' for two and drink beer or wine while watching sport on television, seeing over one hundred adverts for takeaway food, beer and opportunities for online gambling during the breaks, on the players' shirts and on pitch-side displays. We are prompted to take a punt on the outcome of the match (available at tempting odds). At half time, we light up a cigarette and grab another beer. After the game, we watch television late into the evening, intermittently snacking on crisps and chocolate. We finish off the pack of beer or bottle of wine before eventually going to bed, setting the alarm for 6 hours time to start all over again.

As our understanding of the science underpinning health-related behaviours improves, there is an unparalleled opportunity to reduce the burden of preventable ill health and deaths in England that are attributable to the leading behavioural risk factors. We need to find and implement effective interventions that are most likely to improve population health and reduce health inequalities when implemented at scale, namely those that seek to alter the environmental factors that exert the greatest influence on our behaviours, and focusing in particular on tobacco, diet, alcohol and physical inactivity.

The most robust evidence shows that some of the largest effects come from changing economic environments by increasing prices – mainly through taxes – for tobacco and alcohol, with growing evidence that sugar taxes reduce consumption of sugary drinks.<sup>22</sup> Promising interventions in physical environments include reducing the availability and proximity of unhealthier foods, for example by removing unhealthy foods from supermarket checkouts to reduce impulse purchases of confectionery<sup>23</sup>, reducing portion and package sizes<sup>24</sup> and increasing the proportion of healthier foods available.<sup>25</sup> Similarly, a promising intervention in digital environments is to limit marketing of unhealthy foods to children. Making such changes in the environments we inhabit has other benefits across wider society – including shifting commercial behaviour and societal norms – thereby helping to reduce the harms to health and costs to the healthcare system of unhealthy products and to provide a level playing field for commercial competitors.

In this chapter, we identify ways that society, led by strong collaborations between government and partners in the public, private and civil society sectors, can change the environments we inhabit in order to change behaviours, prevent the major causes of premature illness and death, and radically improve health and life chances for all in England. For example, we look at when it is helpful for government to intervene to change economic environments in order to stimulate behaviour change, such as through regulation of the commercial sector and by using taxes and subsidies, and to change aspects of our physical and digital environments to make healthier behaviours the easier behaviours for everyone. We examine how changes in many aspects of the complex, interrelated environments that we inhabit could lead to a step-change in prevention and population health in England, enabling everyone to live longer in good health. By providing leadership and focusing collective efforts on effective ways of changing environments in order to change health-related behaviours, policy-makers have a unique opportunity to make England a world leader in prevention, securing major improvement to health for all and in dramatically reducing health inequalities by 2040.

## 02 Leading behavioural risks and trends

Together, the leading behavioural risk factors of tobacco smoking, unhealthy diet, harmful consumption of alcohol and insufficient physical activity accounted for about 35% of all deaths in England in 2017.<sup>26</sup> Among these, smoking and dietary behaviour are attributable for the largest burden, each accounting for around 15% of all deaths.<sup>26</sup> Improving health in England requires not only changing these behaviours but changing them most in areas of high socioeconomic deprivation where they are most common. To achieve significant changes in population behaviours will require concerted efforts to change the physical, economic, digital, social and commercial environments that promote unhealthy behaviours. Furthermore, achieving the required improvements in these environments will demand a new approach to policy-making, combined with changes to approaches taken in the commercial sector. In this section, we outline recent data and trends concerning the four, key health-related behaviours, summarising the challenges they present for population health, and highlight some of the changes in environments that would enable healthier behaviours.

Smoking tobacco is associated with illness and premature deaths from a range of conditions including cancer, chronic respiratory diseases, ischaemic heart disease and common infections, and accounted for about 15% of all deaths in England in 2017.<sup>26</sup> In 2016/17 there were about 484,700 hospital admissions and 77,900 deaths (in 2016 only) attributable to smoking.<sup>27</sup> Between 1993 and 2016 there was a steady decline in the proportion of current smokers in England, from 28% to 20% among men and from 26% to 16% among women.<sup>28</sup> In 2017, the overall proportion of smokers in the adult population was 14.9% – about 6 million people.<sup>29</sup>

Despite this progress, rates of smoking are four times higher amongst the most deprived compared with the least socioeconomically deprived groups (see Figure 8.1), accounting for about half of the difference in life expectancy between the richest and poorest people in England.<sup>28</sup> In the most deprived areas of England, 27.2% of adults were smokers in 2016 (down from 32.7% in 2012) compared with just 7.9% of adults in least deprived areas (down from 10% in 2012).<sup>30</sup> Importantly, diseases associated with smoking, including lung cancer and chronic obstructive pulmonary diseases are also more common among deprived populations, and therefore may represent important sentinel indicators for reducing health inequalities through changing smoking behaviour at population level.

### 2.1 Smoking

#### Box 8.2 Smoking behaviour and policy responses in England

##### *The costs of smoking to the NHS, social care and wider economy*

- The cost of smoking to the NHS was an estimated £2.6 billion in 2015, including a cost of £1.1 billion to primary care.<sup>i</sup>
- In 2015/16, there were approximately 520,000 smoking-attributable hospital admissions among people aged over 35 in England; around 25% of hospital inpatient beds were occupied by smokers.<sup>i</sup>
- Smoking-related health conditions may add an additional £760 million per year in costs for adult home care services.<sup>ii</sup>
- The costs of smoking to employers through sickness absence and productivity losses are estimated to be £5.3 billion annually.<sup>iii</sup>
- The costs to wider society through smoking-attributable deaths and economic inactivity associated with ill health are estimated to be £4.1 billion annually.<sup>iii</sup>

##### *Key issue: smoking in pregnancy*

- The Tobacco Control Plan for England includes a target to reduce the prevalence of smoking in pregnancy in England to 6% or less by 2022.<sup>iii</sup>
- In 2017/18 in England, 10.8% of pregnant women smoked at the time of delivery.<sup>iv</sup>
- There is wide geographical variation reflecting deprivation with, for example, 26% of women in Blackpool smoking at delivery compared with 2% in Central London.<sup>iv</sup>

##### *Government policy*

- For England, the government published 'Towards a smoke-free generation: a tobacco control plan for England' which outlined a plan to reduce smoking in England, with the aim of creating a 'smoke-free generation'.<sup>iii</sup>
- Key national targets are to reduce smoking among adults to 12% and among 15-year olds from 8% to 3% by 2022.<sup>iii</sup>

The plan includes a general commitment to 'reduce the inequality gap in smoking prevalence between those in routine and manual occupations and the general population', without specifying how much the gap should be reduced by, and by when.

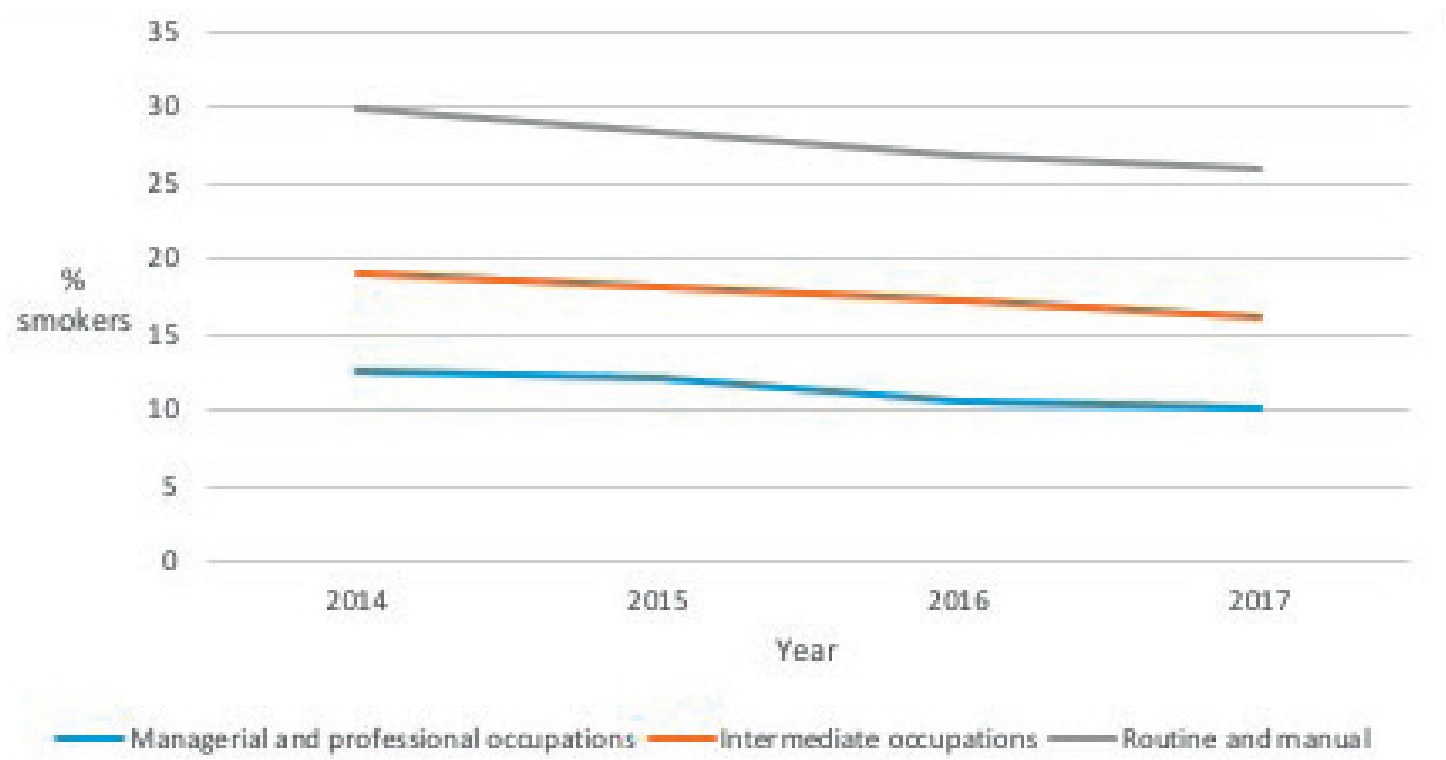
##### *References*

- <sup>i</sup> Public Health England, 2017
- <sup>ii</sup> Action on Smoking and Health, 2017
- <sup>iii</sup> Department of Health, 2017
- <sup>iv</sup> NHS Digital, 2018

## Smoking inequalities – a note on policy

- The tobacco control plan for England set targets to reduce smoking among adults and 15 year olds by 2022.<sup>31</sup> However, there is no accompanying target to reduce inequalities in smoking.
- The plan includes a general commitment to ‘reduce the inequality gap in smoking prevalence between those in routine and manual occupations and the general population’, without specifying how much the gap should be reduced by, and by when.
- In addition to continuing to focus on reducing the overall proportion of smokers in England, specifying targets for the reduction of smoking inequalities in England may incentivise collective action to tackle the environmental influences on smoking behaviour that drive persistent inequalities, including public availability of smoking spaces and tobacco prices.

**Figure 8.1 Smoking prevalence by socioeconomic status, 2014 – 2017**



Source Office for National Statistics, 2018

## 2.2 Unhealthy diet

**Box 8.3 Unhealthy diet and policy responses in England**

- Unhealthy diet is a risk factor for a range of health problems which impact on the NHS and wider economy, including obesity and type 2 diabetes.
- In 2016/17 there were about 617,000 hospital admissions where obesity was a factor (an increase of 18% on 2015/16)<sup>i</sup>
- The NHS spent about £6.1 billion on overweight and obesity-related ill health in 2014/15<sup>ii</sup>
- Obesity has a significant adverse impact on productivity and economic development. The overall cost of obesity to wider society is estimated to be £27 billion annually.<sup>ii</sup>
- The UK-wide NHS costs attributable to overweight and obesity are projected to reach £9.7 billion by 2050, with wider costs to society estimated to reach £49.9 billion per year.<sup>ii</sup>
- 18% of hospital beds are occupied by a person with diabetes (about 1 in 6)<sup>iii</sup> and an estimated 25% of care home residents have diabetes.<sup>iv</sup>

**Key issue: food environments as a driver of obesity in England**

- The food environments we are exposed to strongly influence our dietary behaviour, including excess intake of energy, which is a key driver of obesity among children and adults in England.
- An important factor in excess energy intake is the oversupply of calories in the population through the commercial food system; alongside physical activity, research shows that increases in average population body weight are largely attributable to increases in food supply; the more food is available, the more people consume (particularly in high income countries).<sup>v</sup>
- In this way, environmental influences on energy intake such as the total energy supplied by the commercial food system represent important targets for public policies to tackle obesity through curbing excess energy consumption at a population level.

**Government policy**

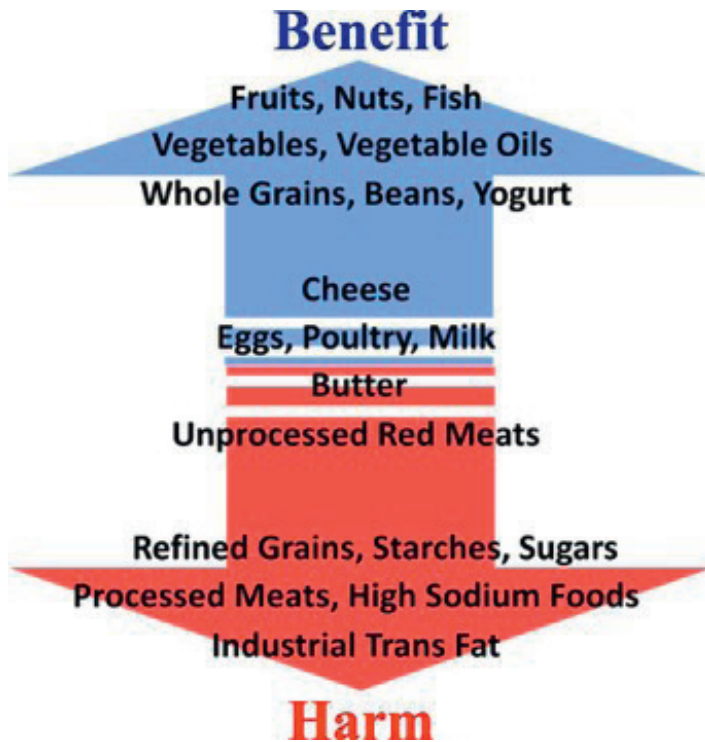
- In England, Government has set an objective through the Childhood Obesity Plan to halve rates of childhood obesity by 2030.<sup>vi</sup>
- Although the plan includes a commitment to 'significantly reduce the gap in childhood obesity between those from the most and least deprived areas by 2030', there is no specified target to reduce inequalities in obesity among children.

Currently, there are no government targets either for reduction of obesity among adults or to reduce inequalities in obesity between adults in more and less deprived areas.

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- vi Department of Health and Social Care. (2018). Childhood obesity: a plan for action. Chapter 2. London: Department of Health and Social Care.

**Figure 8.2 Summary of current evidence of health effect of different food groups upon cardiometabolic health**



Source Mozaffarian, *Circulation*, 2016

Dietary behaviours are among the leading causes of death and accounted for almost 15% of all deaths in England in 2017.<sup>26</sup> Diets high in processed foods and low on raw ingredients, such as fresh fruits, vegetables and whole grains, are associated with a range of conditions that contribute to excess illness and deaths, including obesity, type 2 diabetes, cardiovascular diseases and cancers.

On average, diets in England do not comply with current guidelines for a healthy diet. This is because they tend to contain too much sugar (especially from sugary drinks), too many foods high in refined carbohydrates and unhealthy fats, too much salt, and insufficient fibre. A particular problem is that our diets also tend to be too high in energy relative to what we need (see Box 8.4).<sup>32</sup> It is widely recommended that a man needs about 2,500 calories/day and a woman about 2,000 calories/day, but our requirements differ according to age and other factors, including how active we are. Thus, variation in excess weight across the population and the growing proportion of adults who are obese indicate a broader imbalance between overall energy intake and energy expenditure in the population and represent a complex public health challenge.

In common with other risk factors for ill health, both dietary behaviours and their consequences (e.g. obesity in the case of excess energy intake) are strongly socially patterned (see Box 8.5).

Alcohol accounts for a significant proportion of deaths from liver disease, accidents and suicide including 2.6% of all deaths in England in 2017.<sup>26</sup> In 2016/17, there were 337,000 hospital admissions primarily due to alcohol consumption and about 5,500 alcohol-specific deaths, 4% higher than in 2015 and an increase of 11% on 2006.<sup>33</sup>

Overall, alcohol consumption has declined in England in recent years. For example:

- Fewer adults report consuming alcohol in the previous week: down from 65% in 2007 to 58% in 2018.<sup>33</sup>
- More 16-24 year olds report consuming no alcohol: up from 19% in 2005 to 23% in 2017.<sup>34</sup>

However, a significant proportion of adults still drink above the Chief Medical Officer's recommended levels (see Box 8.6) and harmful drinking remains a problem among particular demographic and socioeconomic groups. For example, in the most recent (2017) Drinking Habits Amongst Adults in Great Britain survey,<sup>34</sup> young people aged 16 to 24 years were less likely to drink than other age groups; however when they did drink, consumption on their heaviest drinking day tended to be higher than all other age groups and they were more likely to binge on alcohol.<sup>34</sup>

It is clear that declines in overall consumption mask patterns of harmful consumption (see Figure 8.3). In particular, there are marked socioeconomic differences in consumption and related harms (see Figure 8.4). Although people living in socio-economically deprived communities drink less on average than those living elsewhere, they experience substantially greater alcohol-related morbidity and mortality – the so-called 'alcohol harm paradox'<sup>35</sup> (see Box 8.7).



## Box 8.4 Patterns of unhealthy dietary behaviours in England

Dietary behaviour in England is characterised by unbalanced intake of a range of nutrients and foods – too much intake of some that are harmful to health, and not enough of others that are beneficial to health. Results from the National Diet and Nutrition Survey demonstrate that, on average, the UK population consumes too many calories, too much sugar and red/processed meat, and not enough fruit and vegetables.

### Too much energy

- In addition to insufficient levels of physical activity, excess energy intake is a key driver of obesity.
- In the UK, both adults and children take in more energy than they need.<sup>i</sup>
- Among overweight and obese children, boys consume about 140-500 excess kcals per day and girls consume about 160-290 excess kcals per day, depending on age. On average, adults consume about 195 excess kcals per day, and overweight and obese adults consume about 320 excess kcals per day.<sup>i</sup>

### Too much sugar

- Consuming too many foods and drinks high in sugar is associated with a range of chronic diseases and is a key risk factor for obesity and its associated health problems.
- On average, sugar consumption is more than double the government recommendation of sugar providing no more than 5% of daily total energy intake, among all age groups. For example, sugar makes up 14.1% of the daily energy intake of 11 to 18-year-olds.

### Too much red and processed meat

- Overconsumption of red and processed meat is linked with increased risk of developing cancer, particularly bowel cancer.
- On average, men exceed the recommended intake of red and processed meat of no more than 70g per day, while women meet the recommended intake.

### Not enough fruits and vegetables

- Fruit and vegetables are natural sources of nutrients (including dietary fibre, minerals and vitamins) that reduce the risk of a range of health problems including cardiovascular disease and some cancers.
- Only 31% of adults and 8% of children aged 11-18 years meet the recommended intake of 5 fruit or vegetables per day.

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<sup>i</sup> Public Health England. (2018). Calorie reduction: The scope and ambition for action. London: Public Health England

## Box 8.5 The social patterning and widening inequalities of childhood obesity in England

Like other behavioural risk factors, unhealthy diet and its consequences (including excess weight and obesity) are strongly socially patterned. The differences in prevalence of obesity among children in the most and least deprived areas in England are particularly marked.<sup>i</sup>

- Children in England are among the most overweight in Europe: 24% of children start primary school overweight or obese, rising to 33% by the time they leave primary school.
- Importantly, the distribution of obesity among children is strongly related to deprivation.
- Among reception year children in 2017/18, data from the National Child Measurement Programme showed that 12.8% of children living in the most deprived areas were obese compared to 5.7% in the least deprived areas.
- Among the same children, prevalence of severe obesity was almost four times higher in the most deprived areas (3.8%) than the least deprived areas (1%).
- Among year 6 children in 2017/18, 26.8% of children living in the most deprived areas were obese compared to 11.7% in the least deprived areas.
- The inequality gap in childhood obesity has also increased substantially over time and continues to grow.
- Among reception year children between 2006/07 and 2017/18, the difference in obesity prevalence among children attending schools in the most and least deprived areas increased from 4.5 to 6.0 percentage points.

Among year 6 children over the same period, the difference between the most and least deprived areas increased from 8.5 to 13.5 percentage points.

#### References

<sup>i</sup> NHS Digital. (2018). Statistics on Obesity, Physical Activity and Diet England: 2018. London: NHS Digital.

## 2.3 Harmful alcohol consumption

### Box 8.6 Harmful drinking and policy responses in England

#### *The costs of alcohol to the NHS, social care and wider economy*

- The cost of alcohol to the NHS is an estimated £3.5 billion annually.<sup>i</sup>
- In 2016/17, there were an estimated 337,000 admissions to NHS hospitals that were primarily related to alcohol consumption.<sup>ii</sup>
- The costs of alcohol to wider society include about £11 billion in alcohol-related crime and £7 billion in lost productivity, including through unemployment and ill health.<sup>i</sup>
- An estimated 167,000 working years were lost to alcohol in 2015, equating to 16% of all working years lost in England that year.<sup>ii</sup>
- Public Health England estimates the annual cost of health, social and economic alcohol-related harm to be between 1.3% and 2.7% of annual GDP.<sup>iii</sup>

#### *Key issue: binge drinking*

- A significant proportion of adults in England drink at levels associated with increased risk of harm.
- In 2016, 31% of men and 16% of women reported drinking more than 14 units of alcohol a week.<sup>ii</sup>
- In the most recent Drinking Habits Amongst Adults in Great Britain (2017) survey<sup>iv</sup>, 28.7% of men and 25.6% of women exceeded 8 and 6 units respectively (thresholds for 'binge drinking') on their heaviest drinking day.

#### *Government policy*

- The government in England does not currently have an alcohol policy, although one is being developed.
- Public Health England is expected to be commissioned to undertake a review of the evidence for minimum unit pricing in England, following its introduction in Scotland in 2018.<sup>v</sup>
- The National Institute for Health Research (NIHR) has commissioned an evaluation of MUP in Scotland. This may be viewed online at <https://www.journalslibrary.nihr.ac.uk/programmes/phr/11300540/#/summary-of-research>.

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- v Scottish Government. (2018, April). Guidance on the Implementation of Minimum Pricing for Alcohol. Retrieved from <https://www.gov.scot/Publications/2018/04/6136/1>

### Box 8.7 The alcohol harm paradox

From Bellis M, et al. (2016). The alcohol harm paradox: using a national survey to explore how alcohol may disproportionately impact health in deprived individuals. *BMC Public Health*, 16:11.

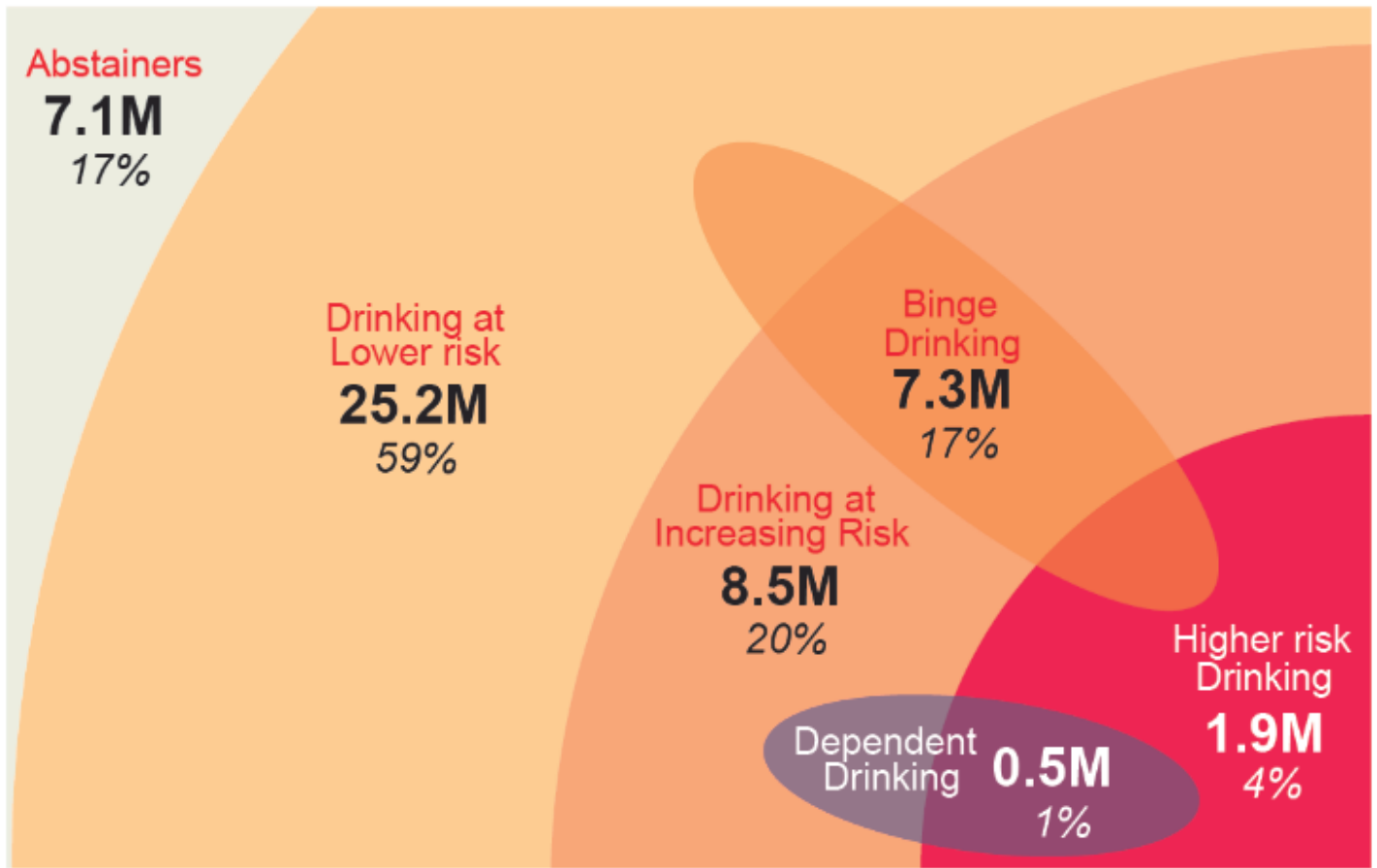
People living in deprived communities experience more alcohol-related morbidity and mortality than people living in less deprived communities, despite drinking less overall.

Drinkers in deprived communities are more likely than affluent drinkers to drink alcohol as part of a range of unhealthy behaviours and risk factors, including smoking, unhealthy diet and insufficient physical activity; as a result, their drinking patterns are likely to be disproportionately harmful to health.

#### *References*

Bellis M, et al. (2016). The alcohol harm paradox: using a national survey to explore how alcohol may disproportionately impact health in deprived individuals. *BMC Public Health*, 16:11.

Figure 8.3 The distribution of drinkers in England, 2014<sup>[i]</sup> from Public Health England's 2016 report on the public health burden of alcohol



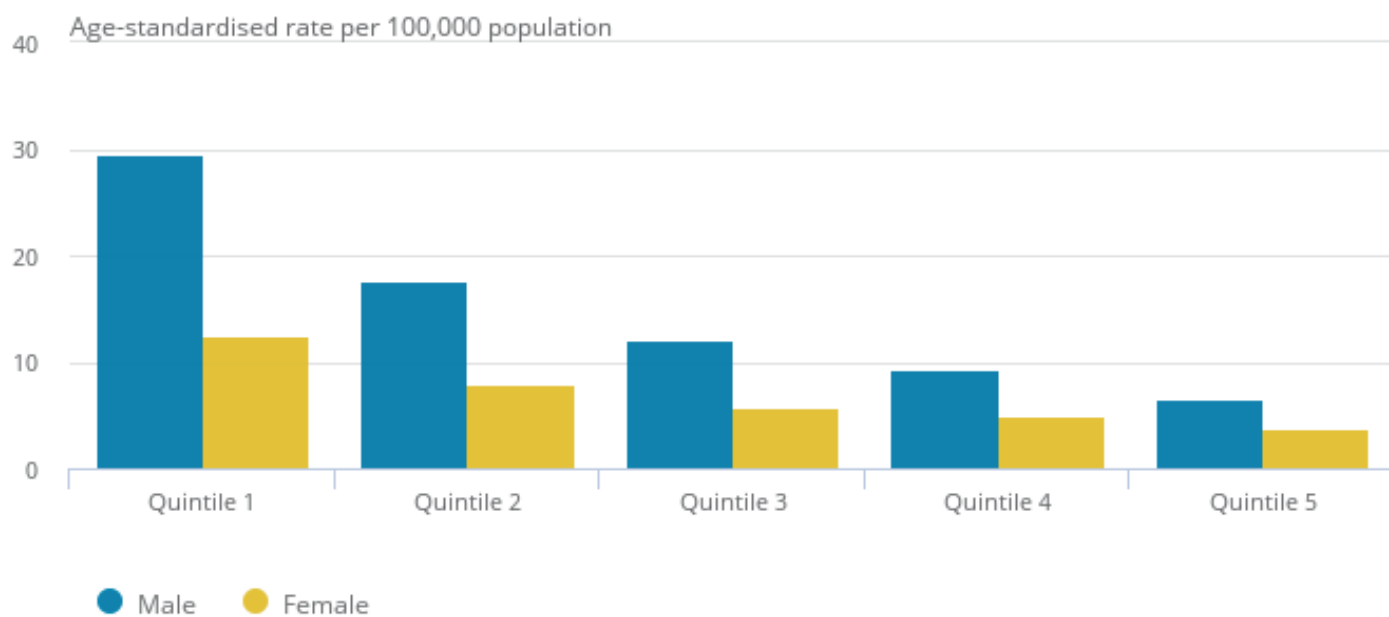
[i] Lower risk defined as  $\leq 14$  units; Increasing risk defined as  $> 14$  and  $\leq 50$  units for men and  $> 14$  and  $\leq 35$  units for women; Higher risk defined as  $> 50$  units for men and  $> 35$  units for women; Binge drinking defined as 8+/6+ units on heaviest drinking day in previous week for men and women respectively; Dependent drinking derived from the Adult Psychiatric Morbidity Survey

Source: Public Health England, *The Public Health Burden of Alcohol and the Effectiveness and Cost-Effectiveness of Alcohol Control Policies An evidence review*, 2016

## Minimum unit pricing – note on policy

- There is strong evidence that harms from alcohol increase as consumption increases, and that as alcohol becomes more affordable, consumption increases.
- Minimum unit pricing (MUP) sets a price below which a unit of alcohol cannot be legally sold and there is a large body of international evidence that suggests it is an effective intervention to reduce alcohol consumption.<sup>36</sup>
- MUP has the greatest impact on drinkers of low cost, high strength alcohol, who account for most harmful drinking in England.<sup>36</sup>
- Introduction of MUP in England would alter the commercial environment of alcohol sales and stand a good chance of reducing harmful drinking among the heaviest drinkers and reducing health inequalities related to harmful alcohol consumption in England.

**Figure 8.4 Age-standardised rates of alcohol-specific deaths by deprivation quintile, England 2016**



**Note**

Quintile 1 = most socioeconomically deprived

Source ONS 2017

## 2.4 Insufficient physical activity

### Box 8.8 Insufficient physical activity and policy responses in England

#### *The costs of insufficient physical activity to the NHS, social care and wider economy*

- Insufficient physical activity accounted for about 2.4% of all deaths in England in 2017.<sup>i</sup>
- Physical inactivity is estimated to cost the UK economy £7.4 billion annually, including about £1 billion to the NHS.<sup>ii</sup>
- Physical inactivity is also a key risk factor for type 2 diabetes, which accounts for about £9 billion of the NHS budget; 80% of these costs are due to complications of the disease.<sup>iii</sup>

#### *Key issue: levels of walking and cycling*

- While meeting the recommended level of activity is often thought of as requiring participation in sports or active recreation, the easiest way for most people to build physical activity into their lives is through active travel in the form of walking or cycling.<sup>iv</sup>
- Between 2005 and 2015, average walking trips decreased by 19% in England, from around 4.7 trips per week to 3.8 trips per week on average. Average distance travelled per person per week also decreased by 8%, from about 3.8 miles to 3.5 miles.<sup>iv</sup>

- However, between 2006 and 2016, people cycled 26% further, from an average 42 miles per year in 2006 to 53 miles per year in 2016, despite cycling trips decreasing by 16% over the same period (the change in trips was not statistically significant).<sup>v</sup>

#### *Government policy*

- The Chief Medical Officer makes evidence-based recommendations for government for levels of physical activity that promote health and wellbeing across the life course.
- The current recommendation for adults is 150 minutes per week of moderate activity, or at least 75 minutes per week of vigorous activity, or an equivalent combination of both in bouts of 10 minutes or more.<sup>v</sup>

#### *References*

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Physical activity has a wide range of health benefits that reduce the risk of a range of chronic diseases, including obesity, type 2 diabetes, cardiovascular disease, some cancers, and mental ill health.<sup>37</sup> The benefits are greatest in response to regular physical activity sustained over a lifetime, ideally meeting (as a minimum) the UK physical activity guidelines.<sup>3</sup>

Notwithstanding the challenges of relying on self-reported data to assess physical activity at a population level (see Box 8.9), the most recent Health Survey for England (2016) showed largely unchanged levels of physical activity between 2012 and 2016<sup>14</sup>:

- 66% of men and 58% of women aged 19 and over reported meeting the aerobic activity recommendation.
- 21% of men and 25% of women were classified as ‘inactive’.
- Activity levels decreased with age: 69% of 16-24-year olds and 72% of 25-34 year-olds reported meeting the aerobic recommendation, falling below 60% for ages 55 and over.

In common with other health-related behaviours, physical activity correlates strongly with socioeconomic status. In 2016, the proportion of adults meeting the national recommendation varied from 50% in the most socioeconomically deprived areas to 68% in the least deprived areas in England<sup>14</sup> (see Figure 8.5). Sedentary behaviour is similarly patterned across the population (see box 8.10); in 2016 34% of adults in the most deprived areas were classified as ‘inactive’, compared to 17% in the least deprived areas.<sup>14</sup>

\* The UK Chief Medical Officers have produced guidance on physical activity levels, for a range of age groups. See <https://www.gov.uk/government/publications/uk-physical-activity-guidelines>

## Box 8.9 The problem with self-reported physical activity tests

Sources of data on physical activity levels that rely on self-reporting of activity by individuals are widely perceived as unreliable due to difficulties in accurately recalling and reporting relevant behaviours. Importantly, data from the Health Survey for England (a key source of data on physical activity) are based on self-reported physical activity, which is associated with over- rather than under-reporting of activity levels. The extent of the inaccuracy is unknown but when self-report and objective measures of physical activity have been compared in population samples the overestimate can be six to eight-fold.<sup>i</sup> Figures based on objective measures of physical activity are far lower than those based on self-report. When accelerometers were used as part of the 2008 Health Survey for England, only 6% of men and 4% of women were found to meet national activity guidelines, compared with 39% and 29% based on self-report. 2008 Health Survey for England.<sup>i</sup>

### Reference

<sup>i</sup> Public Health England. (2010). Adult physical activity data factsheet. London: Public Health England.

## Box 8.10 The social patterning of walking and cycling

Physical activity and inactivity are strongly associated with socioeconomic position and can be described as 'socially patterned'. People in areas of higher deprivation are less likely to walk overall.

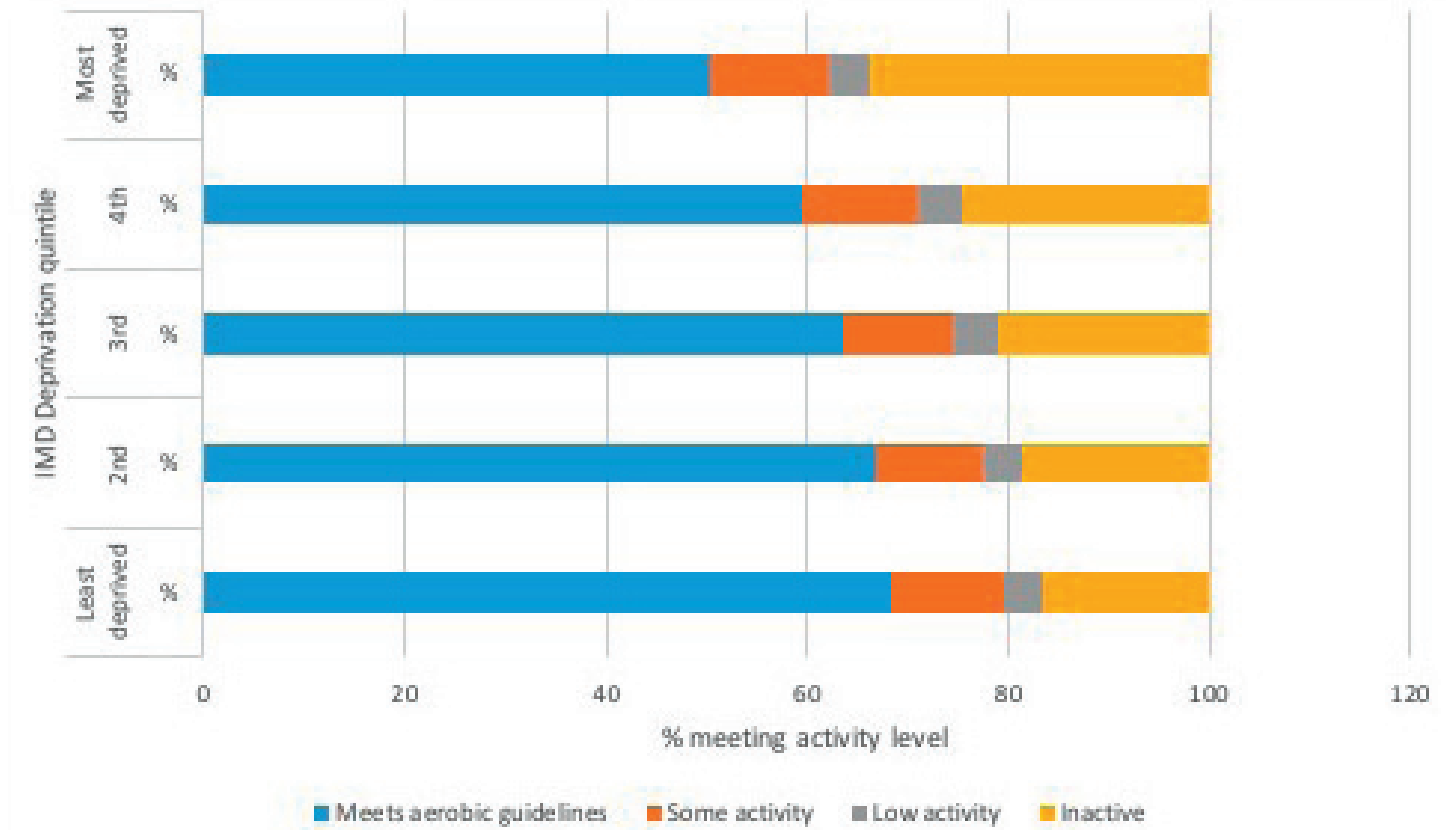
In the most recent statistics on walking and cycling in England, the proportion of adults who walk at least once a week was 64% among the most deprived areas, compared to 71% in the least deprived areas.<sup>i</sup> Similarly, adults in the least deprived areas were more likely (13%) to cycle at least once per week than adults in areas in the most deprived areas (10%).

The same relationship exists for cycling for leisure, experienced by 9% and 6% of people in the most and least deprived areas respectively.<sup>i</sup> Areas of higher deprivation tend to be located in urban areas. Thus, policies and interventions targeted to improve active travel in urban areas may be more likely to ameliorate health inequalities related to walking and cycling.<sup>i</sup>

### Reference

<sup>i</sup> Department for Transport. (2018). Official Statistics: Walking and cycling statistics, England: 2016. London: Department for Transport.

**Figure 8.5** Participation in physical activity by deprivation in England, 2016



Source NHS Digital



## 03 Intervening for largest effects

### 3.1 The lessons of history

The main achievements in public health over the last century provide useful lessons for today's challenges. Tobacco control in high income countries is one of the great public health successes of the 20th century, along with control of infectious diseases, improved car safety, and family planning.<sup>38</sup> Globally however, smoking remains the largest preventable cause of premature death.<sup>39</sup> The recognition of smoking as a cause of lung cancer in the 1950s led to a series of interventions to minimise the harms caused by tobacco. Early on it was recognised that the key driver of smoking was the existence of an industry with highly sophisticated strategies to maximise reach and sales. This prompted efforts to restrict the activities of the industry and to implement interventions that collectively aimed to modify smoking behaviour through changing environments, including:

- Regulation of the product (reducing tar and nicotine content).
- Legislating to restrict the promotion of tobacco by limiting advertising and product placement.
- Legislating to prevent the purchasing of tobacco products.
- Taxation of tobacco products to ensure price continually increases.
- Restricting the places where tobacco can be smoked (e.g. the UK's ban on smoking in indoor public spaces).

These population-level approaches to prevention have been complemented by a range of approaches targeting those at highest risk from smoking – ways to encourage and support individuals to reduce or quit smoking, such as the systematic delivery of education and behavioural counselling, nicotine replacement therapies and new drugs.

It is this combination of both approaches (population and targeted) over nearly 70 years that has achieved a reduction of about two thirds in the prevalence of cigarette smoking in the UK from the peak of the tobacco epidemic in the 1950s, to present levels. So, what lessons can we draw from the history of tobacco control that can guide a strategy to achieve important improvements in population health?

The first lesson is that changing the environments that people inhabit – whether physical, economic, digital, social or commercial – is key to making healthy behaviours more likely by ensuring they require less effort than unhealthy behaviours.<sup>12,15</sup> The second is that population interventions with wide reach that place minimal demands on individuals are more likely to narrow than widen health inequalities.<sup>40</sup> Such interventions are also more efficient and help to ensure the true costs of tackling these societal challenges are borne by the sectors that contribute most to increased risk. Lastly, population interventions can be usefully complemented with more intensive, individual level interventions, which can be effective at achieving sustained behaviour change, regardless of socioeconomic position, among those at high risk.<sup>41-43</sup>

### 3.2 Envisioning an alternative future by 2040

Aware that “it is difficult to predict, especially about the future” we nonetheless sketch out below an aspirational future in which the environments that most affect health have changed to achieve a healthier future for everyone in England by 2040.

## Box 8.11 A better future – Imagining a healthier environment in 2040

### *Environmental influences on smoking behaviour*

Through a combination of high and continued rising taxation on tobacco, banning smoking in all public and private spaces where children are present, less than 1% of the population will smoke and tobacco will be available only to those with a registered addiction – typically those born before 2020. Thanks to a focus on population-level approaches between 2020 and 2040, inequalities in smoking behaviour between socioeconomic groups will narrow dramatically. In particular, smoking during pregnancy will become obsolete among women in the most deprived communities.

### *Environmental influences on dietary behaviour*

The food system will shift from one primarily incentivised by the profitability of food sold to one driven by the healthiness and sustainability of food offered to the public. The economic and commercial environment will be reformed to make it easier for food businesses that prioritise nutritional value and sustainability over profit margins to flourish. Sustainable business growth in the food sector will increasingly require a value-creating and health-enhancing approach to manufacturing, production and sales, with important benefits for the dietary patterns of the whole population, particularly the least well-off.

Prices and marketing of food will no longer favour the most health harming products and larger portion sizes, allowing a more balanced use of promotions to reflect the real value of food products to individuals and society.

The supply of food will be reshaped with a larger proportion of food produced locally, generating a more abundant supply of fresh seasonal produce, significantly reduced consumption of animal protein, and a substantial reduction in the availability of cheap, energy-dense, processed foods. These changes will lead to greater fruit and vegetable consumption, particularly among people in the most socioeconomically deprived communities.

The takeaway market will have radically changed, with high street outlets selling more healthy choices and more appropriate portion sizes, leading to significant reduction in overconsumption of calories. Readily understood information on the nutritional content of all foods and drinks will be widely available on all products, in store and online. Substantially more grocery and takeaway ordering will take place online, offering a wider choice of healthy alternatives, in suitable portion sizes, widely sourced and efficiently delivered. Eating out of home will have increased further, and the range of options for family dining will have widened, enabling greater choice of healthy meals at competitive prices.

The collective impact of these changes to the food system will result in substantial improvements to dietary

patterns in England, with health benefits accruing disproportionately to the most deprived.

### *Environmental influences on alcohol consumption*

Prices and marketing of alcohol will be further reformed to better prevent harmful consumption of alcohol, including underage drinking, and binge drinking. Through a combination of rising taxation on alcohol products, the introduction of minimum unit pricing and better independent regulation to limit exposures to the promotion of alcohol products through digital and social media, alcohol consumption will decline among all socioeconomic groups. The cumulative effect of new measures, combined with curbs on the sale of cheap, high strength alcohol products that contribute most to harmful drinking behaviours, will decrease overall alcohol consumption in the population. Changes to consumption patterns will disproportionately improve the health of people from the most socioeconomically deprived communities and combined with changes to other behaviours will go some way to reversing the ‘alcohol harm paradox’.

### *Environmental influences on physical activity*

The physical environment in urban areas will look very different and travel for both work and leisure will no longer be dominated by the private car. Instead of designing cities around the desires of drivers, planners will focus more broadly on the actual mobility needs of the population. This will marry improved spatial planning to efficient and sustainable low-emission public transport and active travel, leading to social, cultural and economic benefits. Cities will be substantially greener – with more trees and urban green space, and more sustainable policies – both to help reduce air pollution and to mitigate the impacts of climate change on rising temperatures, extreme weather events, and risks of flooding.

The resulting environment will be more conducive to active travel and outdoor leisure both in cities and rural areas and will contribute to restoring people’s connection with nature by making it easier to walk and cycle safely. Workplace environments will also continuously evolve, in ways that are increasingly designed to maximise movement during the working day.

Collectively, these changes in our physical, built and urban environment will dramatically increase average levels of physical activity across the population, including among people from the most socio-economically deprived communities.

All of these improvements will only be sustained and developed further through partnerships built throughout society, requiring the collective leadership of the public, private and voluntary sectors as well as national government.

## 04 Realising the vision

The principles that underlie the vision outlined in Section 03 of this chapter above have been articulated before; this vision is not utopian, but it is both aspirational and achievable with public support and political will. No nation has yet managed to realise these kinds of changes in multiple, overlapping environments simultaneously in the interests of population health. Nevertheless, many aspects of the vision have been achieved in different places in the past, offering evidence that these components could be achieved by 2040.

To take an example, Chapter 2 of the Childhood Obesity Plan<sup>44</sup> contains a set of ground-breaking proposals that, if implemented together, could begin to have substantial impact. They are an important start, but on their own insufficient to lead to the changes needed to reshape physical, economic, digital, social and commercial environments simultaneously in ways that will substantially reduce and not just slow the growth of childhood obesity. Setting aside the political will to make them happen. Much work is needed to identify the mechanisms by which improvements will be secured, to define the parameters of success and to select the best levers for initiating and sustaining changes.

### 4.1 Roles of policy makers, businesses, the scientific community and the public

Policy-makers, businesses and corporations, the scientific community and the public are all stakeholders in the wider health system. Implementing structural interventions to change environments will require collective will, through which societal norms – as well as the behaviours of stakeholders themselves – can be shifted in order to improve population health. This will require greater understanding among policymakers of the underlying determinants of health-related behaviours, and of how businesses, the scientific community, and the public can best act collectively as catalysts for public policies that improve health.

#### **Policy makers**

Policymakers are vital to ensuring that the best available evidence on how to change health-related behaviours is incorporated into public policies designed to improve health (see Box 8.12). To best effect the kind of change that will secure improvements in the leading behavioural causes of ill health, there are two key considerations for policy makers.

First, understanding the complex, adaptive systems within which public health challenges need to be addressed is crucial to determining sustainable solutions. Regarding changing behaviour, as our understanding of the underlying science of decision-making improves, support among scientists for population and systems-based change increases. Consequently, policy approaches should increasingly focus on population-level interventions that prioritise changing the environments that people inhabit that largely determine their behaviours, rather than seeking to engage individuals through health promotion efforts targeting those at high risk.

Incorporating such approaches into the heart of policy making processes in all parts of government and all sectors of the economy – a ‘health in all policies’ approach – is most likely to bring sustainable, large scale success in addressing leading causes of preventable disease.

Second, our vision of how best to improve health outcomes has profound implications for the macroeconomic model within which we currently operate as a nation. Through the promotion of harmful behaviours such as smoking and harmful consumption of alcohol, market economies, and the activities of global as well as national corporations within them can have severe and deleterious effects on population health.

In the pursuit of strategies to improve health that account for the commercial determinants of behaviours, the case for new economic models including trade agreements that put ‘health before profit’ is strong. For example, reforming macroeconomic levers to favour food companies that improve access to foods of high nutritional value whilst restricting access to or disincentivising the production and sale of energy dense and high sugar content products are much more likely to improve population health whilst reducing diet-related

health inequalities than interventions focused on 'the choices individuals make'.

This argument is particularly potent when linked to addressing the challenge of how to increase productivity across the economy as a whole; given what is known about the relationship between workforce health, employment and productivity,<sup>45,46</sup> policies that reduce smoking, improve diet, cut harmful alcohol consumption and increase physical activity are likely to have benefits that accrue beyond the NHS to the economy and wider society. While the case for such change is strong, re-visioning and realising changes to trade and investment as well as macroeconomic factors remains a challenge for policy-makers to achieve step changes in population health.

Second, our vision of how best to improve health outcomes has implications for incentivising and disincentivising those responsible for our health environment. Through the promotion of harmful behaviours such as smoking and harmful consumption of alcohol, the activities of global corporations (as well as national corporations within them) can have severe and deleterious effects on population health.

In the pursuit of strategies to improve health that account for the commercial determinants of behaviours, health (and implications for health), should be considered more widely. For example, reforming fiscal measures that incentivise food companies to improve access to foods of high nutritional value whilst restricting access to, or disincentivising, the production and sale of energy dense and high sugar content products are much more likely to improve population health whilst reducing diet-related health inequalities than interventions focused on 'the choices individuals make'.

Such policies that reduce smoking, improve diet, cut harmful alcohol consumption and increase physical activity are likely to have benefits that accrue beyond the NHS to the economy and wider society.<sup>45,46</sup> While the case for such change is strong, re-visioning and realising changes to the many components that affect health remains a challenge for policymakers.

### Box 8.12 Policy makers' behaviour

Policy-making is a complex behaviour subject to multiple influences of which research findings is just one.<sup>ii</sup> Two influences on the options considered by policy-makers are the way a problem is framed and the likely public acceptability of the policy options. A better understanding of these influences provides the potential for policy makers to design policies aligned more closely to evidence of need and likely effectiveness for changing population behaviour than is currently the case.

#### Problem Framing

The framing of a problem shapes the responses we generate. We often frame or explain behaviour as reflecting individual choice to the neglect of far more influential situational factors, known as the fundamental attribution error or correspondence bias.<sup>iii,iv</sup>

Reflecting this, an international survey of over 300 policy-makers found that 80% of them perceived individuals to be "very responsible" for reducing obesity while only 40% attributed this level of responsibility to governments.<sup>v</sup> Framing obesity as a matter of personal responsibility has no impact on support for policies to tackle it, but framing it as a response to our environments can increase support for policies targeting these environments.<sup>vi</sup>

Influencing public and political discourses to frame unhealthy behaviour as primarily a matter of individual choice and personal responsibility is one of several strategies that form part of "Corporate Political Activity" – efforts to shape government policies to favour industries manufacturing the products that harm health.<sup>vii-x</sup> In contrast, by reframing unhealthy behaviour as primarily a social problem mediated by the multiple unhealthy environments that influence it, policy-makers could play a leading role in promoting more effective societal responses to public health challenges, dramatically improving health and reducing inequalities by 2040.

#### Public Acceptability

Public acceptability of government policies to change behaviour is also a consideration for policy-makers. Unfortunately, the most effective interventions – altering physical, economic and regulatory environments – sometimes tend to be the least acceptable to the public<sup>xi</sup> and in turn, to policy-makers. In addition to being shaped by the way that a policy is framed, public acceptability is shaped by beliefs about policy effectiveness and these beliefs often seem mutable. For example, in a meta-analysis of 36 experiments, support for a range of policies – including policies designed to tackle obesity, climate change and gun control – increased by 4% following the presentation of evidence of effectiveness of those policies, with a similar decline in support seen following the presentation of evidence of ineffectiveness.<sup>xii</sup>

The most effective ways of communicating such evidence awaits more systematic research.<sup>viii</sup> Civil society organisations engaged in health advocacy – in England these include ASH, Obesity Health Alliance and Alcohol Health Alliance and

internationally, the NCD Alliance – are key communicators of this evidence both to the public and to policy-makers. Indeed, it has been suggested that the collective global voice of these organisations could act as a powerful lever to stimulate the political will to successfully challenge companies manufacturing unhealthy commodities, whose actions currently serve as one of the largest obstacles to effective public policies.<sup>xii</sup>

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## **Businesses and corporations**

Our vision has important implications for businesses, corporate responsibility and corporate behaviour. An addition to the persistent and growing social and health inequalities that characterise many western societies, a key characteristic of market economies is the tendency of corporations not to bear the costs of the adverse impacts of their products on population health. In England, externalities of corporate behaviour include the impacts of tobacco, fast food and cheap, high strength alcohol on health, the cost of which is borne by Taxpayers and the public services they fund, particularly the NHS, social care and public health services bear the cost.

Products that are harmful to health – including cigarettes, energy dense, high sugar foods and alcohol – tend to be artificially cheap, because they do not incorporate the costs to society of the damage they cause. Responses to this challenge might include taxing industries that produce harmful products so as to cover could cover a greater share of the costs to currently borne by taxpayers and society, regulating the production and promotion of such products and legislating to restrict their use.

In light of these regulatory challenges, alternative approaches will be required to better protect public health and taxpayers while addressing behavioural risk factors in 2040. Specifically, new ways must be found to deal with externalities of products that harm health to ensure industry bears the full economic cost of those products where appropriate. For example, innovative costing models that include the full cost – to taxpayers, the economy and wider society – of tobacco and alcohol could radically alter the economic environment of consumers, changing behaviour particularly among the most socioeconomically deprived communities. Through spill over benefits for productivity in the wider economy, such measures could also be beneficial to businesses in the medium and long term.

## **Scientific community**

Public health researchers and the broader scientific community have a key role to play in rethinking how studies and the evidence they generate are conceived, funded, conducted and reported to benefit public understanding and influence public policy.

By nature, public health problems are complex and multifactorial. As a result, studies at low risk of bias – for example, tightly controlled randomised trials of population interventions – are often difficult or not possible to conduct. However, complexity in itself is not an argument against being able to identify and address significant contributing factors to public health challenges. For example, there is no perfect evidence on the relation between smoking and lung cancer, and randomised controlled trials are obviously not appropriate. Moreover, not all of the detailed pathways between exposure and outcome are known. Despite this, we have sufficient evidence of the risks from tobacco that is more than adequate to demonstrate the need for action. We know “what works” to reduce those risks and bold policy decisions have enabled us to demonstrate the effectiveness of a range of interventions by evaluating their impacts in the real world.

An important linked challenge is that population health research, as with much of science, rarely proves causation; instead increasing evidence incrementally builds an ever-stronger case that action needs to be taken.<sup>47</sup> Small incremental changes may be easy to implement and easy to evaluate over the short term – as seen with “Test-Learn-Adapt” approaches – but it is also essential to consider the trajectory and impact of actions taken over the long term.<sup>48</sup> For example, the ban on smoking in public places could not have taken place without the decades of actions that changed public and political attitudes towards smoking to make such a ban acceptable. A short-term focus tends to ignore wider system-level drivers of ill health and may fail to achieve the substantive structural changes that are ultimately required.<sup>48,49</sup> See Box 8.13 for an example of system-wide consideration of a public health intervention.

The decision to act on population health is frequently informed by the precautionary principle and the need to take preventive action despite inevitable uncertainties.<sup>50,51</sup> Pragmatic public health decision-making and policy-making therefore – legitimately – relies on assessing and integrating a range of sources of scientific evidence, including from evaluations when available, as well as observational epidemiological data, qualitative data, evidence from epidemiological and economic modelling, and existing theory.<sup>52</sup> This is the approach that was taken in the final judgment on plain packaging of cigarettes, implemented in the UK in 2016, where in reaching his decision, Mr. Justice Green concluded that “...in accordance with internationally accepted best practice the qualitative and quantitative evidence has to be examined as a whole, and in the round.”<sup>53</sup>

As well as scientific evidence, policy-making also takes account of acceptability to a range of stakeholders, wider impacts of any intervention across all sectors, unintended consequences, the balance of costs and benefits, feasibility and political considerations. Better understanding of policy processes and how they are influenced by key stakeholder groups, including civil society groups and commercial interests, will help to identify ways to ensure that the health of the people is at the forefront of future policy making across all sectors.

For their part, public health researchers and the wider scientific community can make valuable contributions to this collective endeavour by better engaging policy-makers in the scientific process and in the development of research questions, as well as communicating clearly the policy implications of their research both to policy-makers and the public (see Box 8.12).

### **Public**

Building on the need for policymakers, corporations and researchers to align their approaches towards a new vision for improving population health by changing our environments, the public also have a central role to play and public support for changes in the environments we inhabit will be vital.

Public acceptability is linked to the effectiveness of interventions and has been instrumental in shifting societal norms. For example, the ban on smoking in public places was introduced when public acceptability reached a threshold for it to become a viable policy, and not smoking in public places has become an accepted social norm in the UK.

As the evidence-base underpinning population-level interventions to improve behaviour evolves, the public may increasingly demand action on other behavioural risk factors. As described in Box 8.12, organisations engaged in health advocacy are key communicators of this evidence. Health advocates’ communications need to be effective in order to compete with counter messages from industries that manufacture products that harm health.<sup>55,55</sup>

## 05 Conclusions

### Box 8.13 A system-wide approach to improving road safety: 'Vision Zero'

A significant example of an effective systems response to a public health problem is the 'Vision Zero' approach to reducing road deaths developed in Sweden.<sup>i</sup> It is based on the ethical imperative that "it can never be ethically acceptable that people are killed or seriously injured when moving within the road transport system." It accepts that it is inevitable that human error will occur within the system, which thus needs to be designed to be tolerant of such faults so that they never lead to death or serious injury.

This approach integrates safety into spatial planning, road engineering, vehicle design, driver training, lighting, regulation, and all other aspects of the transport system. By focusing on the ethical imperative as the underpinning driver of policy it effectively aligns multiple disparate factors. This approach has now been adopted in a number of other countries, and has recently been proposed for London.<sup>ii</sup>

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- i Tingvall, C., & Haworth, N. (1999). Vision Zero – An ethical approach to safety and mobility. Retrieved from Monash University Accident Research Centre: <https://www.monash.edu/muarc/our-publications/papers/visionzero>
- ii TFL. (2018). Vision Zero for London. Retrieved from Transport for London: <https://tfl.gov.uk/corporate/safety-and-security/road-safety/vision-zero-for-london>

The challenges of changing health-related behaviours at the scale needed to improve health across all sections of the population in England are large, but the prize is great. In this chapter, we have explored some of the main trends and determinants of the four health-related behaviours that account for the largest share of risk for chronic diseases in England. We have examined how physical, economic, digital, social and commercial environments play a significant role in driving these behaviours, and envisioned ways in which these environments might be changed to improve population health. We have identified some key approaches to achieving this vision, including: regulating the commercial sector, including more effective regulation of marketing and advertising; using taxes and subsidies to reduce the supply and demand for unhealthier products, increasing the supply and demand for healthier products, and changing our physical and digital environments to make healthier behaviour an easier option for everyone.

A step change is needed to slow the growth of preventable chronic disease by 2040, requiring our approach to be more radical, coordinated and intensive than in the past. It will require a shared ambition and – with appropriate safeguarding – strong engagement between government and partners in three key sectors – public, private and civil society. In this way, through the collective leadership of committed partners to change the environments that govern our behaviours, England could become a world leader in the use of public policy to improve health and reduce health inequalities.



### Box 8.14 Minimally invasive transcatheter technology for heart valve disease

*Text kindly supplied by A. Vecchi, S. Niederer, R. Rajani, S. Redwood, and B. Prendergast of the Department of Cardiology, St Thomas' Hospital, London*

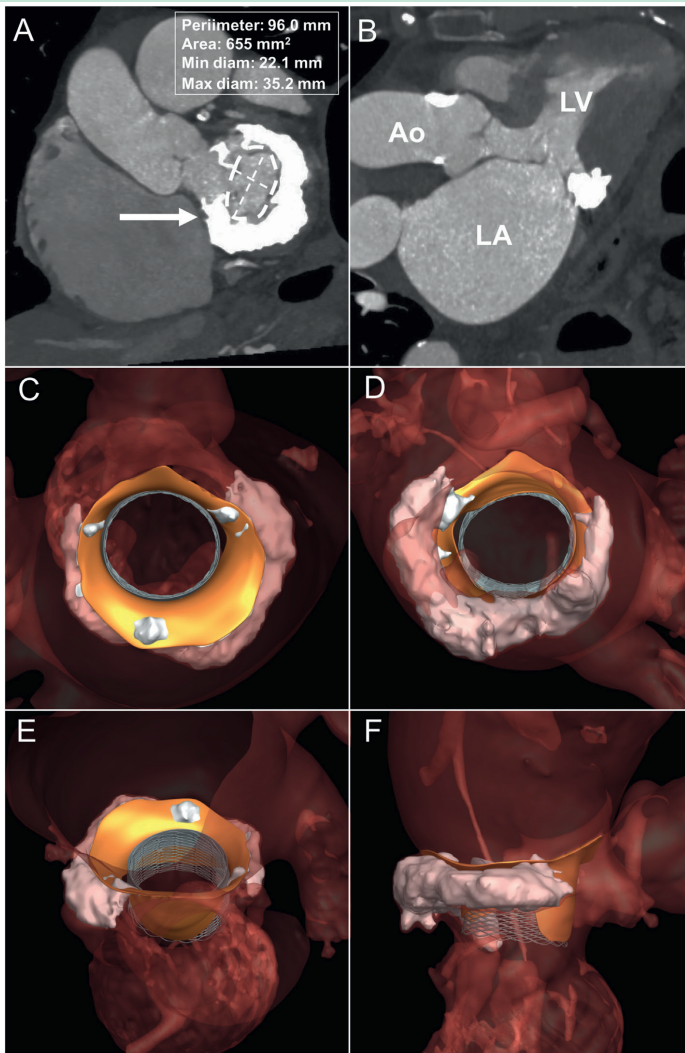
One million individuals in the UK aged 65 and over are affected by heart valve disease. Given the rapidly ageing population, the prevalence of clinically significant disease is projected to double, or even triple, by 2050. These forecasts carry serious implications for healthcare providers, who will be addressing the needs of a growing cohort of patients who are too old and frail for open surgery.

Aortic stenosis and mitral regurgitation are the most frequent heart valve conditions – both carry adverse prognosis and there are no effective medical therapies. Transcatheter aortic valve implantation (TAVI) is already established as an alternative to conventional surgery for inoperable, high- and intermediate-risk patients, and the outcomes of trials in low-risk cohorts will be presented in early 2019. Within 5 years, it is likely that TAVI will be the default treatment for the majority of patients with aortic stenosis.

Based upon this paradigm shift, attention is now firmly focused on transcatheter mitral valve replacement (TMVR), requiring bioengineering solutions to address the unique challenges posed by the heterogeneity and complexity of mitral valve anatomy and physiology, and its interaction with the left ventricle. Specific concerns include difficulty in anchoring the device to the deformed mitral annulus (with risk of valve migration or paravalvular leak), and potential for left ventricular outflow tract obstruction by the implanted valve (with risk of refractory heart failure and late mortality). Robust and consistent evaluation techniques are required to assess which patients will benefit from TMVR and which type of device is best suited for specific anatomical patterns.

Pre- and peri-procedural imaging are key to the success of both TAVI and TMVR, with contrast-enhanced cardiac computed tomography (CT) and echocardiography playing a crucial role in the evaluation of patient suitability and procedural planning. Previous experiences with TAVI and the new challenges of TMVR have generated interest in the use of computed simulations to predict the effects of different devices on patient-specific pathophysiology and the risk of procedural complications. The combination of state-of-the-art imaging with computer-assisted design (to model the mechanical behaviour of the device, Figure A) and advanced computational techniques (to simulate ventricular hemodynamics, Figure B), allows tailored prediction of the ventricular response to device implantation (and its haemodynamic impact), and the degree of outflow obstruction in individual patients. Over the next decade, these new technologies hold major potential to augment early feasibility trials of new transcatheter valves and improve the quantity and quality of life of a growing cohort of patients.

**Figure A**



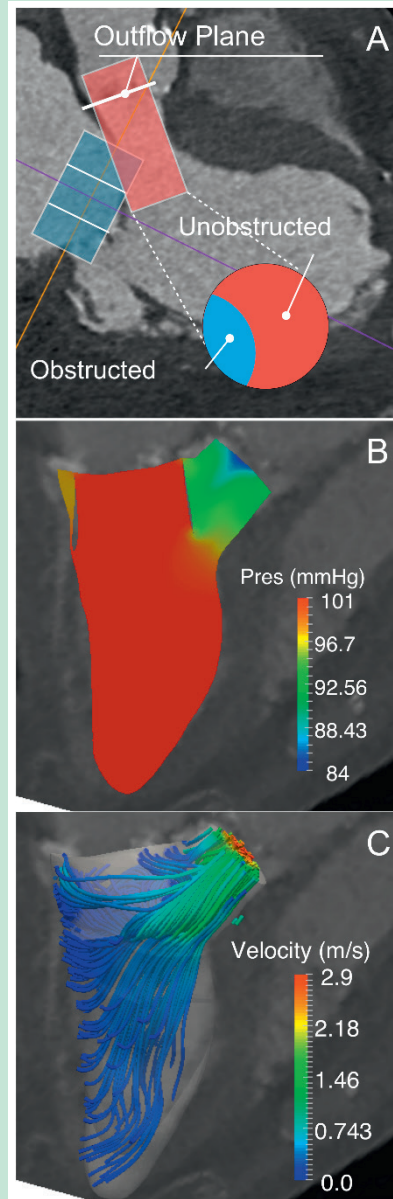
**Note**

A-B: Annular sizing and assessment of native mitral valve positioning relative to the left ventricular outflow tract using multi-slice CT.

C-F: Virtual implantation of a transcatheter mitral valve device using computer-assisted design into a personalised model of the left ventricle, which includes chordae, sub-valve apparatus, and annular calcification. Post-implant device position viewed from the left atrium (C) and the left ventricle (D), and predicted appearance of the left ventricular outflow tract after deployment (E). Three-chamber view of the valve in the annulus (F).

Source Karadi J et al. *Journal of Cardiovascular Computer Tomography*, 2018

**Figure B**



**Note**

A: Geometrical evaluation of the extent of left ventricular outflow tract obstruction using CT angiograms obtained by perpendicular projection of outflow tract cross-section.

B-C: Computed simulation of the ventricular hemodynamic response to TMVR, demonstrating intraventricular pressure gradients (B), and blood flow dynamics visualized by streamlines coloured according to velocity magnitude (C).

Source De Vecchi A et al. *Nature Science Reports*, 2018

## 06 Authors' suggestions for policy makers

We outline below five principles based on evidence and ethics for maximising the benefits to population health through changing behaviours.

### ***Seek the most appropriate evidence available to inform public policy***

- To best answer questions relating to the effectiveness of public policy to change behaviour, use evidence that, as far as possible, accounts for contextual factors that moderate the effectiveness of population level interventions and their implementation.
- Seek the most robust evidence available, as appropriate to the policy question; when judging the relative merits of population level approaches, seek balanced evidence on a range of factors, including evidence of:
  - Acceptability
  - Need
  - Effectiveness
  - Equity and differential impacts on different groups
  - Value for money

### ***Avoid interventions that have little or no impact on behaviour across populations***

- Providing information can raise awareness – which is of value – but generally does not change behaviour at the scale needed to improve population health.
- Interventions targeting people at high risk can be effective for targeting specific groups defined by their risk status (e.g. smokers, those already overweight or obese), for whom the benefits can be worthwhile, but are unlikely to achieve change at a population level, and risk widening inequalities.

### ***Establish guidelines for interactions with organisations with competing interests***

- Establish clear guidelines that could systematically inform decisions about collaborations and partnerships with organisations and industries that have interests that harm health.

### ***Implement interventions that have the potential to change behaviour to significantly improve population health when applied at scale***

- Intervene in physical, economic, digital, social and commercial environments to make engaging in healthier behaviours easier for all.
- Focus on influencing the social, commercial and other structural determinants of unhealthy behaviours.
- Emphasise the importance of population interventions that do not place significant demands on individuals for them to work (so called 'low-agency' interventions), such as environmental restructuring or regulatory policies.
- Ensure interventions reach the whole population irrespective of baseline risk, including vulnerable groups and people in the most socioeconomically deprived communities.
- Ensure policy interventions to change environments are subject to rigorous and independent evaluation in order to generate learning about their effectiveness in changing behaviours and improving health, including through secondary effects and unintended consequences

### ***Forge and foster strong collaborating partnerships***

- Engage partners and organisations in the public, private sectors and civil society sectors that have demonstrable commitment to improving population health and reducing health inequalities, including – but not limited to – policy-makers, health advocacy organisations, businesses, researchers and the public.

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## Chapter 9

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# Health inequalities – a challenge to current health policy

### Chapter lead

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**Authors' note**

Much of the material in this chapter is based on a paper by Bennett et al.<sup>1</sup>

## 01 Current status of health inequalities in England

### 1.1 Inequalities in life expectancy and healthy life expectancy

In 2016 life expectancy at birth in England was 83.1 years for females and 79.5 years for males, and 83.2 and 79.7 years in the UK as a whole.<sup>2,3</sup> In the same year, the highest achieved life expectancy of any country was 87.1 years for women in Japan and 81.2 years for men in Switzerland,<sup>3</sup> demonstrating that life expectancy in the UK is well below the global best-performing country and that significant improvements can be achieved with better social, economic, environmental and health system policy choices.

The national average however masks the stark inequalities within the country. In 2016, life expectancy at birth ranged from 78.8 years in the most deprived 10% of Lower Super Output Areas (LSOAs)<sup>4</sup> to 86.7 years in the most affluent 10% for females; for men the range was from 74.0 years to 83.8 years (Figure 9.1).<sup>4</sup> The 7.9-year gap in female life expectancy between the most affluent and most deprived 10% of LSOAs is about the same as the difference between UK as a whole and Libya or Azerbaijan, and the 9.7-year gap in male life expectancy is about the same as the difference between UK as a whole and Guatemala or Azerbaijan.<sup>4</sup>

The life expectancy gaps between the least and most deprived LSOAs are about the same as those between the extreme local authority district life expectancies.<sup>4,5</sup> For example, the gap between the local authorities with the highest life expectancy (Kensington and Chelsea, and Camden) and lowest life expectancy (Manchester and Blackpool) was 7.4 years for females.<sup>5</sup> For males, the gap between the local authorities with the highest life expectancy (East Dorset and Kensington) and lowest life expectancy (Blackpool and Manchester) was 9.5 years.<sup>5</sup>

Healthy life expectancy (HLE) at birth in 2014-2016 was consistently lower in more deprived communities.<sup>6</sup> HLE in men ranged from 51.9 years in the most deprived 10% of LSOAs to 70.4 years in the least affluent 10%. The gap was even larger in women, 51.8 years in the most deprived 10% compared to 70.7 years in the least deprived 10%. As a result, a child born in the most deprived areas would have 18 fewer years in good health than one born in the most affluent areas. And only people living in the four least deprived deciles of LSOAs could expect to reach retirement age in good health.

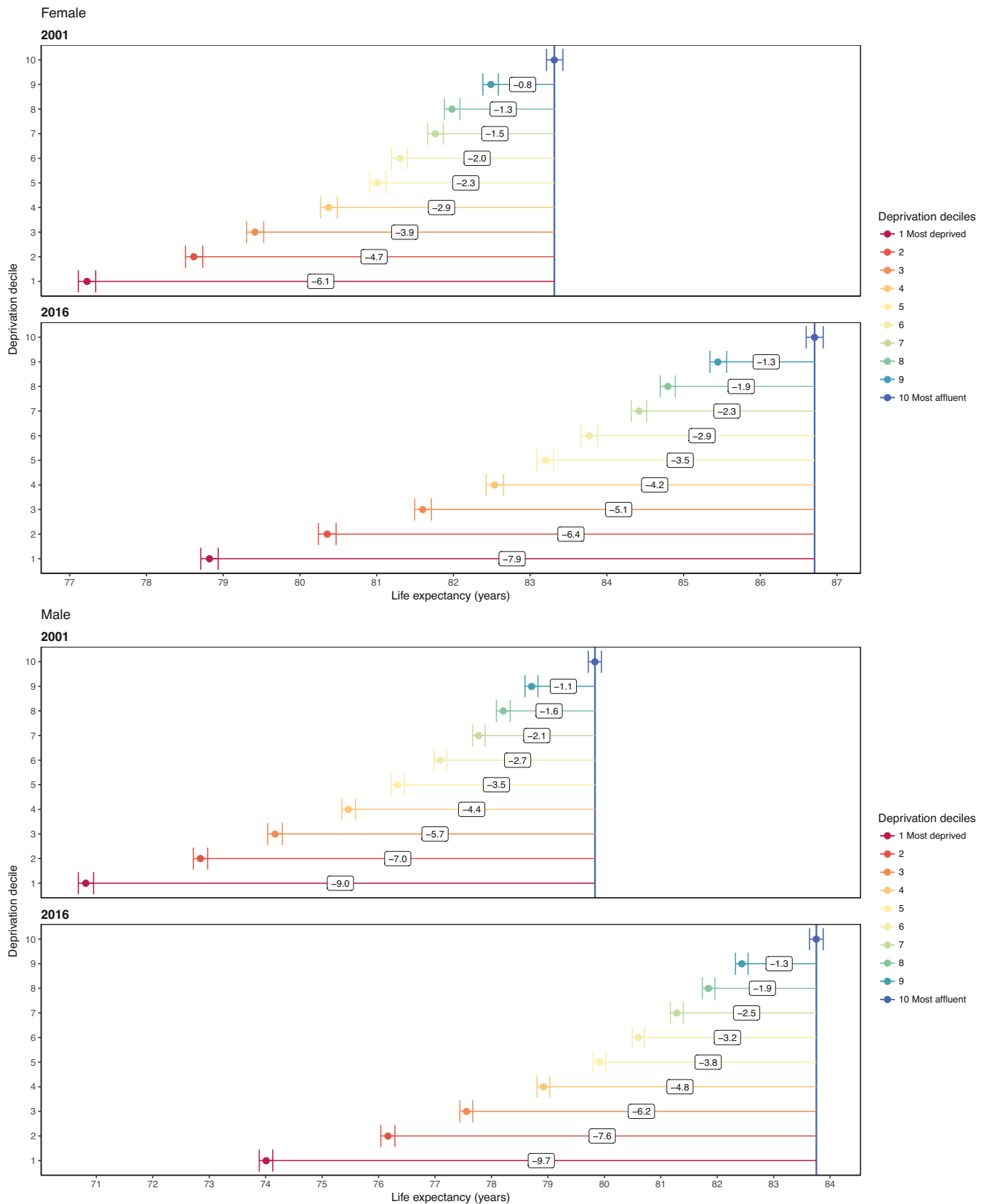
### 1.2 Inequalities in deaths from specific diseases

Figure 9.3 shows age-standardised death rates from different diseases and injury clusters with clinical and public health relevance by decile of IMD from 2001 to 2016. Death rates from every disease and injury and at every age were higher in the most deprived LSOAs than in the most affluent ones in 2016.<sup>7</sup> The absolute inequality (i.e. difference) between the most and least deprived groups in 2016 was larger for diseases with higher death rates, i.e. ischaemic heart disease (IHD), respiratory diseases, lung cancer and dementias. Relative inequality (i.e. ratio) was largest for lung cancer, diabetes and respiratory diseases, ranging from 2.5 to 3.3 in the two sexes; it was smallest for prostate, breast and haematological cancers, with relative inequalities of 1.1.

The diseases and injuries that contributed the most to life expectancy inequalities for both sexes were under-five (mostly neonatal) deaths (0.3 and 0.4 years of the 7.9 and 9.7 years gap for females and males, respectively), lung and digestive cancers (together contributing 1.2 and 1.4 years for females and males, respectively), respiratory diseases (1.6 and 1.5 years for females and males, respectively), IHD (0.8 and 1.5 years for females and males, respectively), and dementias (0.5 and 0.3 years for females and males, respectively, mostly above 70 years of age) (Figure 9.4).<sup>7</sup> Injuries contributed to 0.2 years of the life expectancy gap between the most affluent and most deprived deciles in females, and 0.6 years in males.

\* Deprivation groups refer to deciles of Index of Multiple Deprivation (IMD). The most deprived LSOAs were mostly in urban areas, especially those in the north, north-east and west-midlands (e.g., Birmingham, Bradford, Leeds, Liverpool, Manchester and Newcastle). They were more likely to be classified as urban conurbations (59%) than the most affluent LSOAs (23%), which were mostly in smaller cities and towns (58%).

**Figure 9.1** Life expectancy at birth, by decile of deprivation, and sex, in England, in 2001 and 2016



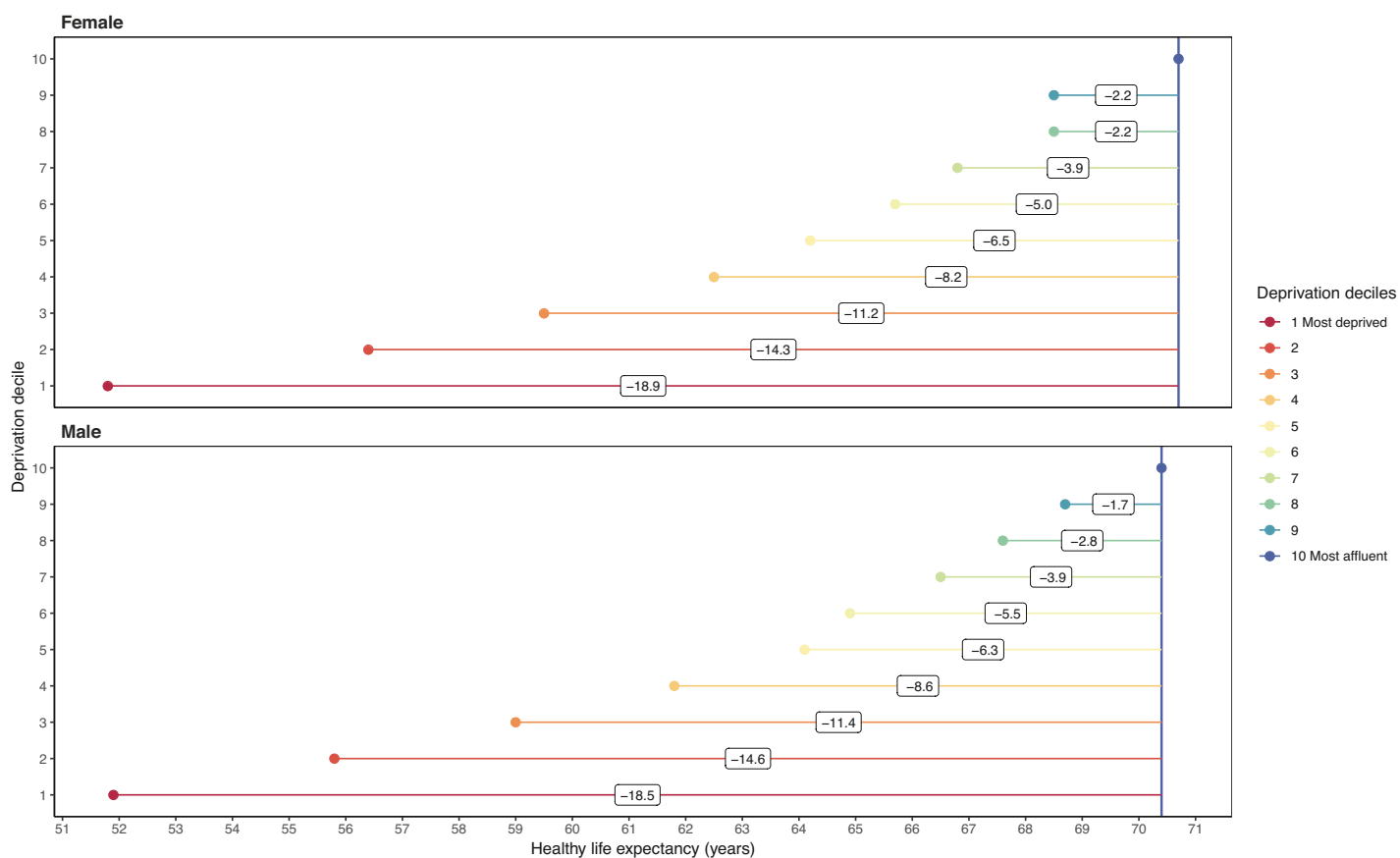
Note

Point estimates of life expectancy for each estimate are shown, with credible intervals indicated by vertical bars. The numbers show the difference between life expectancy for each decile compared with that of the most affluent group, with credible intervals in brackets.

Source Bennett et al., *The Lancet*, 2018



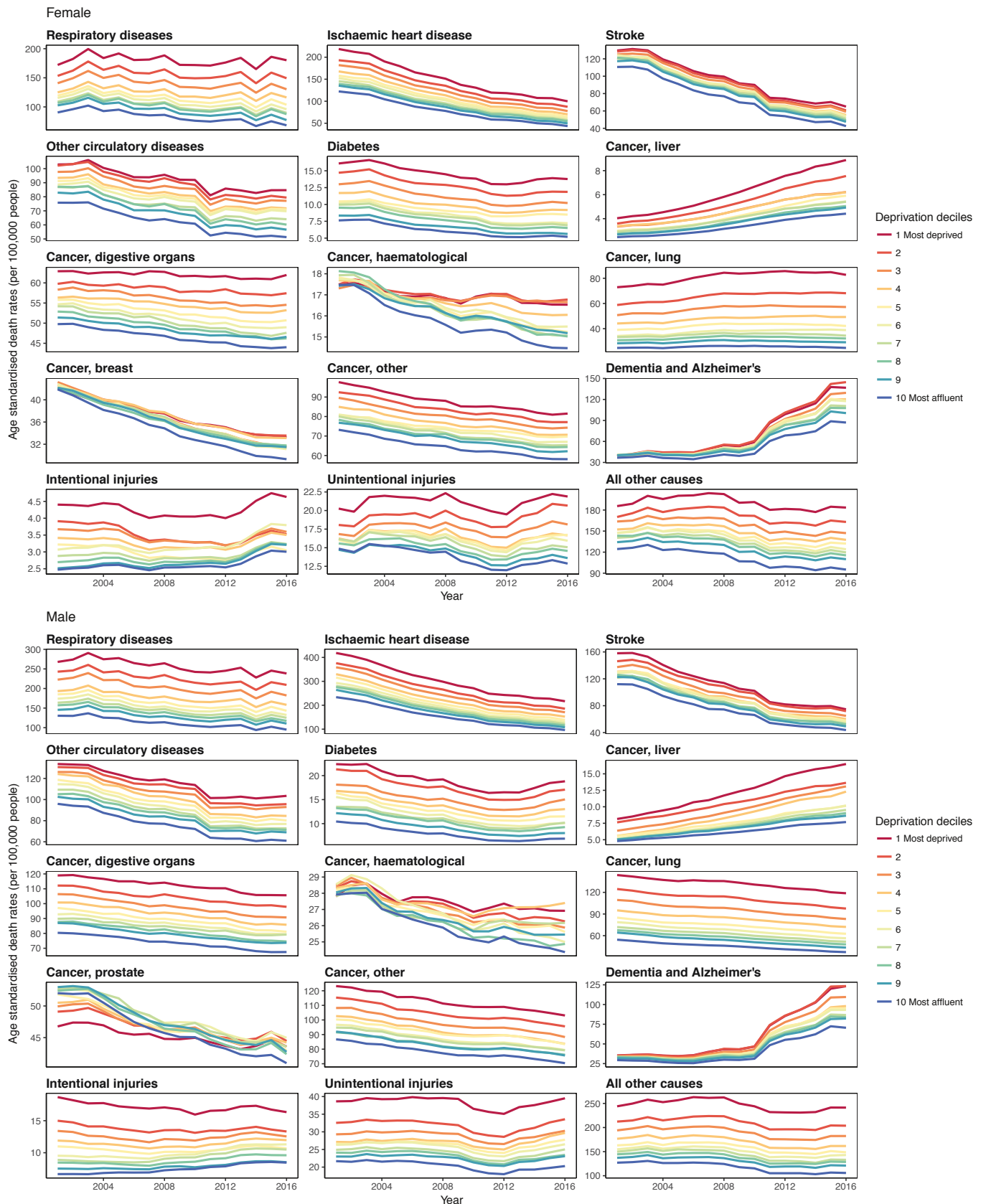
**Figure 9.2 Healthy life expectancy at birth, by decile of deprivation, in England and Wales, in 2014-16**



**Note**  
The numbers show the gap between healthy life expectancy for each decile compared with that of the most affluent group.

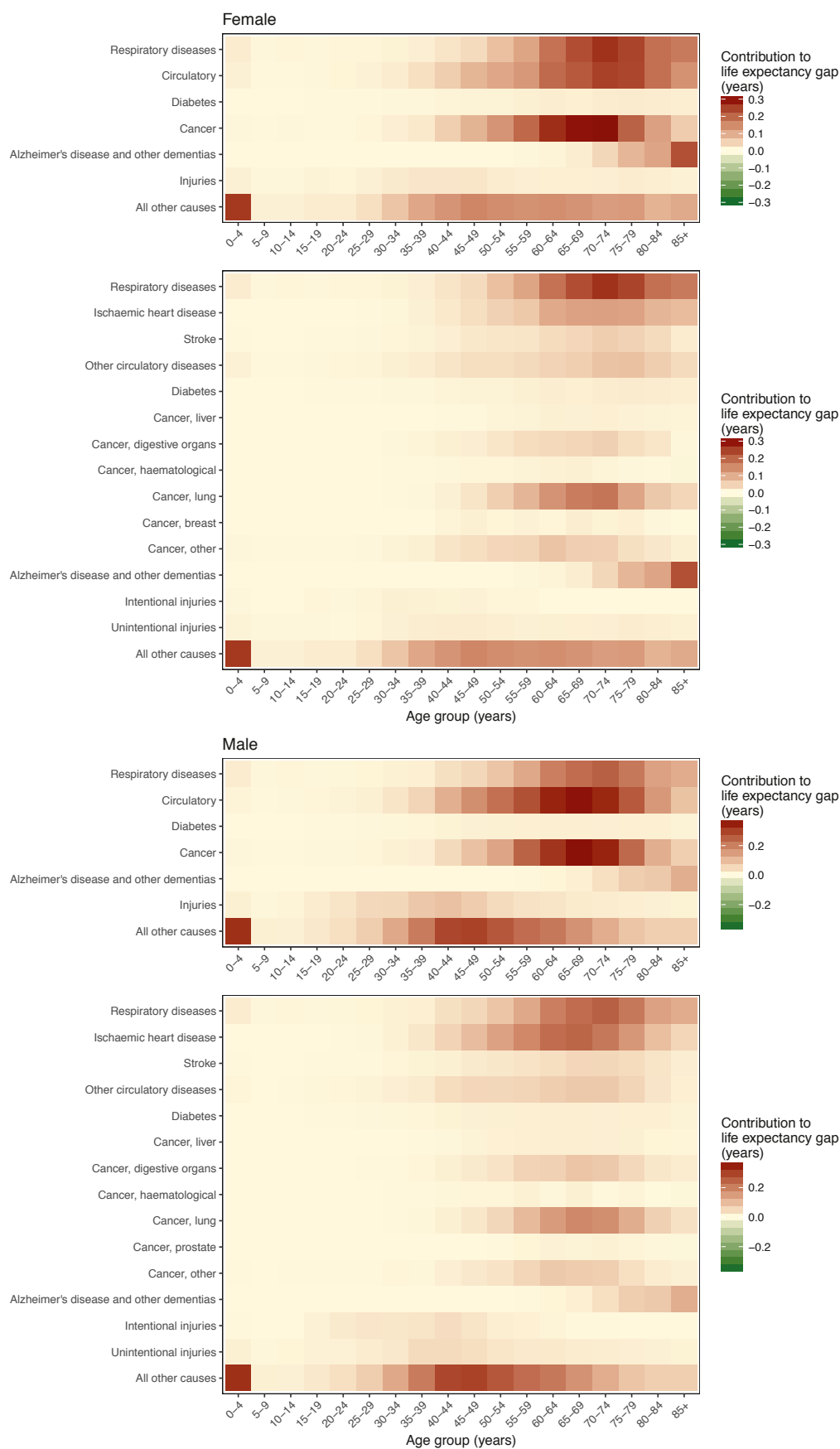
**Source** Office for National Statistics statistical bulletin. *Health state life expectancies by national deprivation deciles, England and Wales: 2014 to 2016.*

**Figure 9.3 Trends in age-standardised death rates, by underlying cause of death, and decile of deprivation, in England, from 2001 to 2016**



Source Bennett et al., *The Lancet*, 2018

**Figure 9.4 Contributions of deaths from diseases and injuries, at different ages, to life expectancy inequalities, between the most affluent and most deprived deciles, in England, in 2016**



Source Bennett et al., *The Lancet*, 2018

## 1.3 Inequalities in children's health

Inequalities affect children's health and development throughout their life course. Through the Sustainable Development Goals countries have committed to creating the conditions for children to survive and thrive. The Royal College of Paediatrics and Child Health's (RCPCH) State of Child Health Report found that the UK was not the European leader in any of the 25 indicators for child health.<sup>7</sup> A recent report by Nuffield Trust found that many UK child health outcomes fared poorly in comparison with other high income countries. Infant survival in England is among the lowest in EU15+ countries.<sup>8</sup> UK infant mortality has now risen over the past two years,<sup>9</sup> following on from a trend of slowing annual gains.

Within this context, inequalities in total infant, perinatal, neonatal, and post-neonatal mortality manifest between rich and poor, and between North and South of England.<sup>10,11</sup> Infant mortality is around two per 1,000 live births for the most affluent, but more than triple that among the most deprived groups in the UK.<sup>9,10</sup> About 70% of UK infant deaths were in the neonatal period, closely related to prematurity and low birthweight, which are strongly associated with poverty.<sup>12-14</sup>

Beyond mortality, infants, children and adolescents in poor families and communities have higher rates of common infections, asthma, serious injury, and mental health conditions.<sup>7,11</sup> In 2015/16, the most deprived children and young people were approximately 60-70% more likely to go to A&E than the least deprived.<sup>15</sup> Over this same period, emergency admissions to hospital increased by approximately 10%, and again the most deprived children were 2-3 times more likely to be admitted.<sup>15</sup>

Not only do poor children have higher rates of disease and death, they also have poorer developmental outcomes, which in turn affects their health, education and wellbeing throughout their life, creating a vicious circle of poverty. Children from low-income families perform more poorly than better-off children on a variety of tests at the age of two years.<sup>16,17</sup> Data from the Millennium Cohort Survey shows that by the time they are five years old, children from the poorest quintile are nearly a year behind in language acquisition (vocabulary) compared with their peers from middle income families.<sup>18</sup>

## 02 How inequalities have changed over time

### 2.1 Rising life expectancy inequalities

Life expectancy has increased steadily in England for decades, although the rate of increase has decelerated since around 2010.<sup>5,19</sup> In 1981, life expectancy at birth was 77.0 years for females and 71.1 years for males. By 2001, these had risen to 80.6 years for females and 75.9 years for males, and by 2016 to 83.1 years and 79.5 years, respectively.

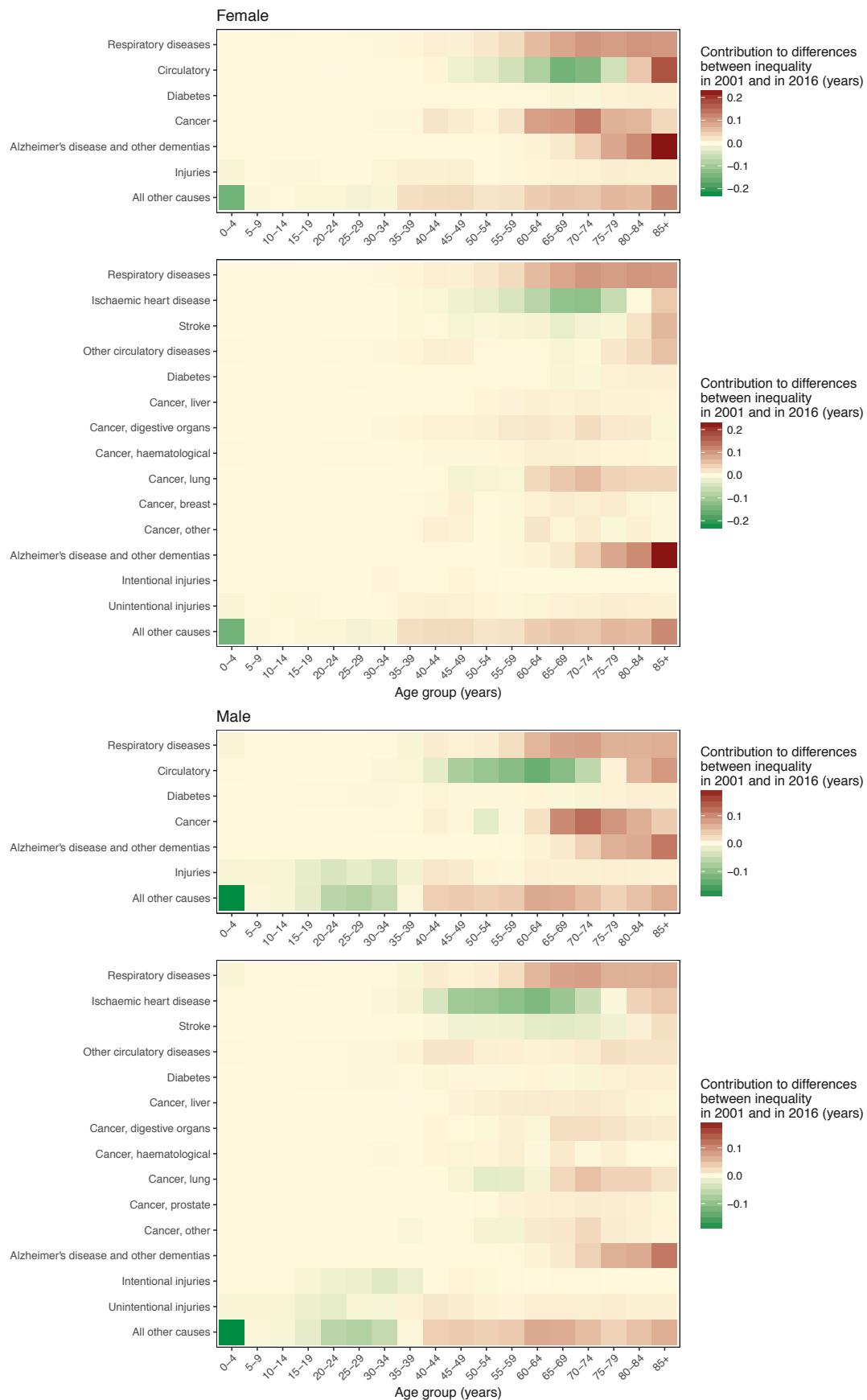
The rise in life expectancy in England since 1982 was accompanied with rising inequality across local authorities.<sup>5</sup> From 2001 to 2016, where consistent data by the decile of IMD are available, life expectancy increased in every deprivation decile, but the gains were smaller in deprived LSOAs than in affluent ones. As a result, the life expectancy gap between the most affluent and most deprived deciles increased from 6.1 years (5.9-6.2) in 2001 to 7.9 years (7.7-8.1) in 2016 in females, and from 9.0 years (8.8-9.2) to 9.7 years (9.6-9.9) in males (Figure 9.1). Notably, since 2010, the rise in female life expectancy in the two most deprived deciles has virtually stalled (increasing by 0.07 years and 0.13 years, respectively, from 2010 to 2016) but has continued in the least deprived deciles with increases of up to 0.80 years in the more affluent deciles.

### 2.2 Changing contributions of diseases to life expectancy inequalities

From 2001 to 2016, age-standardised death rates from most diseases declined, except for liver cancer and dementias, which increased in every deprivation decile (Figure 9.3). Death rates from both intentional and unintentional injuries also increased after 2010. Over the sixteen years of analysis, absolute inequalities between the most and least deprived deciles increased for all diseases except IHD, intentional injuries and a cluster of “other cancers” in both sexes and stroke, lung cancer and digestive organ cancer for men.

The contribution of deaths in children under five years of age to life expectancy inequalities declined from 2001 to 2016, from 0.5 to 0.3 years for females and from 0.6 to 0.4 years for males (Figure 9.5). There were also large declines in the contributions of IHD and to a lesser extent stroke for both sexes, and intentional injuries for men. The contributions of respiratory diseases, cancers and dementias to the life expectancy gap between the affluent and deprived groups increased. The cancers whose contributions increased the most were liver and other digestive cancers for both sexes and lung cancer for women. For men, the contributions of lung cancer to life expectancy inequalities fell below 65 years of age but increased in older ages, resulting in a net increase of ~0.1 years.

**Figure 9.5** Change in the contributions of deaths from diseases and injuries, at different ages, to life expectancy inequalities, between the most affluent and most deprived deciles, from 2001 to 2016



Source Bennett et al., *The Lancet*, 2018

## 03 Why health inequalities are rising and how to reverse the rise

To envision how to achieve a healthier and more equal society England by 2040, it helps to understand how current inequalities in health have developed, and what policies might lead us to a better future for all.

### 3.1 The social and economic determinants of health inequalities

Meaningful, secure employment and poverty are key determinants of health status that contribute to and can worsen health inequalities. Social policies in the 1970s and 1980s combined a trend towards much faster wage growth for highly educated workers than for less educated ones in many developed countries,<sup>20</sup> reduced job security and increased income inequality, contributing to rising health inequalities in subsequent decades.<sup>21</sup> Between the early 1990s and the 2007/2008 financial crisis, income inequality across most of the income distribution in the UK fell, driven by more inclusive growth, falling worklessness, redistribution to poor families and rising pensioner incomes.<sup>22</sup>

While income inequality continues to decline across much of the income distribution in the UK,<sup>22</sup> working poverty has emerged as a prominent issue due to a combination of higher employment and poor pay growth, especially in the self-employed who on average have lower earnings than employees.<sup>23</sup> This combination has contributed to 1.5 million people experiencing destitution<sup>24</sup> and a substantial rise in child poverty because families with children (and especially those with lone parents) are particularly affected by the benefits cuts.<sup>24,25</sup> As a result, there has been a significant increase in the number of families relying on food banks.<sup>26</sup>

Beyond cuts in welfare spending, which increase demand for social and health services by impoverished families, the Coalition and Conservative governments also reduced spending, including local government budgets.<sup>27</sup> Sources of social support for children and families living in poverty have closed, including children's centres.<sup>28</sup> 84% of local authorities report financial pressures as being the main cause of recent changes in services.

As a result of reductions to working-age benefit entitlements and earnings growth benefiting middle income households, relative poverty has been projected to rise between now and the early 2020s, particularly for families with children.<sup>29</sup>

Increases in working-age welfare spending could halt or reverse projected increases in poverty and increased spending on unprotected public services will especially shield low income households from some of the adverse health impacts of poverty. The financing of such spending, through higher taxes and/or public debt, has been discussed in economics literature.<sup>30</sup>

### 3.2 Behavioural risks and early childhood environment

Smoking, alcohol use, and poor nutrition, which all have substantial social inequalities,<sup>31-35</sup> are important causes of some of the diseases with the largest contributions to life expectancy inequalities including cardiovascular diseases (CVDs), lung and liver cancers and respiratory diseases. Some public health efforts addressing these risk factors may have inadvertently worsened inequalities even if in some cases, such as smoking, they have helped reduce mortality for all social groups, including the most deprived. In particular, hidden behind a decline in aggregate smoking prevalence, social inequalities in smoking have increased,<sup>36-38</sup> especially during pregnancy where more than a tenfold difference exists among English local authorities.<sup>39</sup> Significant reductions in local authority smoking cessation budgets, and in some cases decommissioning of smoking cessation services by local authorities, risks worsening these inequalities as those most at-need will no longer have access to support. Similarly, inequalities in obesity in childhood and adolescence have risen over time with obesity declining slightly in the best-off children, while it continues to rise in deprived areas.<sup>40,41</sup>

The role of behavioural risk factors in mortality inequalities is widely acknowledged. However, achieving substantial reductions in smoking and alcohol use and improvements in diet in an equitable manner requires a shift that embraces health equity as integral to the planning and implementing public health policies and programmes. In particular, fiscal and regulatory measures have consistently been more effective at achieving behaviour change and reducing inequalities than voluntary approaches.<sup>42,43</sup> For example, the Soft Drinks Industry Levy resulted in about half of beverages, with higher consumption in deprived groups, reducing their sugar content before the levy was even implemented.<sup>44</sup> In contrast, the Public Health England voluntary sugar reformulation programme for foods commonly consumed by children achieved an only 2% reduction after one year, not even meeting the programme's own modest 5% target.<sup>44</sup>

To meaningfully address persistent inequalities in diet and health behaviours, the UK should embrace effective fiscal and regulatory policies for alcohol, and foods rich in sugar, salt and trans fats,<sup>45</sup> with strong monitoring and enforcement. Finally, and importantly, the cost of healthy foods, and especially fresh fruits and vegetables, has increased in the UK and other high income countries<sup>46</sup> relative to unhealthy processed foods.

The gap in infant mortality is affected by inequalities in smoking during pregnancy, age at conception and maternity care.<sup>47</sup> Pleasingly, England has reduced the number of teenage conceptions by 60% since 1998,<sup>48</sup> although the UK still has the highest proportion of births among women under 20 years old in the EU.<sup>49</sup> Beyond mortality, a large body of evidence, including randomised trials, show that

it is possible to leverage early childhood interventions to improve health and developmental outcomes for children with disadvantageous socioeconomic conditions.<sup>50-53</sup> Given the importance of social and economic determinants of child health and development, it is unlikely that isolated interventions targeting parenting and the early years home environment alone can overcome gaps in health and development between rich and poor groups. Rather, such interventions should accompany policies that improve the structural and social conditions of the health environment.



### 3.3 Health and social care

The House of Commons Health Committee stated nearly a decade ago that “the NHS has the capacity to tackle health inequalities by providing excellent services targeted at, and accessible to those who need them”,<sup>54</sup> reiterated recently in a report on new models of care.<sup>55</sup> For example, equitable treatment of acute coronary events and secondary prevention in survivors<sup>56</sup> are likely to have contributed to declining absolute inequalities in IHD mortality (however and worryingly, the gap in non-urgent angioplasty has recently risen, with patients from the most deprived quintile waiting 20% longer than those from the least deprived in 2016 compared to 10% in 2008).<sup>57</sup> The potential of universal high-quality health care to reduce health inequalities is undermined by unequal provision and de facto utilisation of health care, leading to worse survival in deprived groups compared to affluent ones. For example, cancer patients from deprived areas of the UK have a later diagnosis and worse survival compared to their affluent counterparts.<sup>58,59</sup>

A fair and effective health service should respond proportionately to need by segmenting and targeting its services to ensure equitable access and uptake of services across the entire population. Three components of health and social care are particularly relevant for reducing inequalities under the principle of proportionate universalism: access to healthcare; health promotion and disease prevention through risk prediction and early diagnosis; and strengthening integrated health and social care.

Universal access is a pillar of the NHS. However, in practice services are not equally accessible due to patterns of provision and uptake. Earlier efforts to reduce inequalities in provision had some success, for example in redressing physician numbers in deprived areas.<sup>60</sup> Today however, health and social care is more stretched than ever before, owing to a prolonged period of below-average annual funding increases since 2010 (1% for health compared to long term average of 3.9%). The funding squeeze, a growing and ageing population, and workforce shortages have prolonged wait times, from primary tertiary care, and especially in deprived areas.<sup>57,61</sup> Recent changes to junior doctors’ contracts used targeted enhanced recruitment schemes to incentivise clinicians into careers such as primary care, but consideration could be given to expanding to incentivise primary care physicians to work in areas with the highest unmet need.

Prevention and screening programmes can effectively identify asymptomatic people at increased risk of adverse health outcomes, and allow for prevention of diseases with large contribution to life expectancy inequalities. Screening, such as the NHS Health Check, while beneficial for all social groups, risks worsening inequalities if it differentially benefits more affluent groups, which is likely if their implementation is not incentivised to identify those segments of the population most at-risk and encourage uptake.<sup>62</sup> For example, abdominal

aortic aneurysms (AAA) are more common in the most deprived, yet uptake of screening, which aims to identify and treat those with asymptomatic AAAs, in this group is almost half of that in the least deprived.

Making screening, early detection and disease prevention more equitable is partly related to healthcare access and utilisation, discussed above. Novel point-of-care technologies, such as those for cancer detection<sup>63,64</sup> and arrhythmias<sup>65</sup> have the potential to move screening and early detection from clinic and laboratory to home and communities at highest risk of disease at a much earlier stage. However, if health inequalities are not at the forefront of policy makers’ and commissioners’ minds, such technologies risk exacerbating existing inequalities through a two-tier system of access and outcomes.

Unequal utilisation of services according to need is complex and multi-faceted. Some contributing reasons include resources not matching local need, limited availability of services outside working hours, limited control over one’s work, and social and cultural barriers to health-seeking all contribute. Incentivising more flexible access to care, including accessible hours and more accessible service locations in relation to residence and work could help increase healthcare utilisation for the most vulnerable segments of the population. This could be additionally supported by an expansion of employers’ responsibilities from protection of health, safety and welfare to active promotion of good physical and mental health, through prevention and care. Beyond traditional face-to-face forms of service provision, emerging technologies, such as mobile, digitally delivered primary care could facilitate appointments that do not inhibit working patterns, reduce waiting time for initial consults, and subsequent triage to specialist care. However, like diagnostics such technologies should be designed and rolled out to avoid worsening inequalities, for example by leaving a care gap for complex patients with multiple morbidities.

Finally, better and more equitable health outcomes in early childhood and older ages and for other vulnerable groups requires enhancement and integration of health and social care (for the elderly and adults with multiple conditions) or education (for children and adolescents). This form of integration is not only hindered but also set back by the cuts to local authority budgets over the past eight years,<sup>66,67</sup> resulting in worse outcomes compared to those able to pay for better care.<sup>68,69</sup> A variety of programmes are implementing new models of integrated care. One smaller scale initiative is the Children and Young People’s Health Partnership (CYPHP) in Lambeth and Southwark, South London. This partnership is working to improve access to care, equity and quality of care, integrating physical and mental healthcare, prevention and health care, and joining up health and school sectors. CYPHP is being evaluated using a pragmatic cluster randomised controlled trial and early results<sup>70</sup> indicate more equitable access to care.

## 04 An equitable future

England currently faces a “perfect storm” of obstacles to addressing health inequalities (stagnation in social and economic policy, public health policy and health and social care determinants of health). These are leading to rising inequalities. However, these inequalities are not inevitable and can be overcome through sustained and coordinated action across these determinants.

In particular, a positive tide may be emerging, driven by two phenomena that could create a more equitable England by 2040: First, after decades of being treated as secondary to aggregate improvements in the economy and health, inequalities are being acknowledged and promising policy discussion in the UK and other high-income countries. Pressured by the public, civil society organisations and philanthropists, political parties, while differing massively in their ideology and responses, are acknowledging inequalities as a key social challenge and promising policy responses.

Second, and in a more subtle movement, many English cities, where the majority of England’s population live, are starting to develop and implement strategies to address inequalities especially those related to health.<sup>71</sup> The concentrations of knowledge and innovation, economic activity, healthcare, education and other public services in cities endows them with the potential to deliver substantial improvements to the health and wellbeing of their residents.<sup>72</sup>

To improve the health of the poorest fastest, we must identify the most effective strategies for improving the health of deprived populations under the principle of “proportionate universalism”,<sup>73,74</sup> which targets and allocates resources at those most at risk to reduce inequalities.

## 05 Authors’ suggestions for policy

The UK Government should adopt a ‘Equity in all policies’ approach such that the potential effects of any policy upon inequities are considered in advance.

The Department for Health and Social Care should strengthen the Healthy Start Programme with a view to provide extra support to families experiencing food poverty.

The commissioning of health and social care should be integrated at national and local level, with services delivered locally with resources proportionate to local health and social care need.

NHS Digital should ensure that implementation of emerging technologies in healthcare has an associated target to ensure health inequities are reduced.

### Box 9.1 Socio-economic inequalities in 5-year cancer survival: avoidable premature deaths among patients diagnosed in England in 2010

*Text and analyses by Aimilia Exarchakou, Camille Maringe, Libby Ellis and Michel P. Coleman, from the London School of Hygiene and Tropical Medicine*

For most cancers in England, survival up to 5 years after diagnosis varies between population groups defined by their level of socioeconomic deprivation, even after correction for the higher risk of death from other causes than the cancer among more deprived groups.<sup>i,ii,iii</sup>

Socio-economic inequalities in cancer survival have a substantial impact on public health, because many of the cancer-related deaths would be avoidable if survival among the more deprived groups were as high as among the most affluent patients.

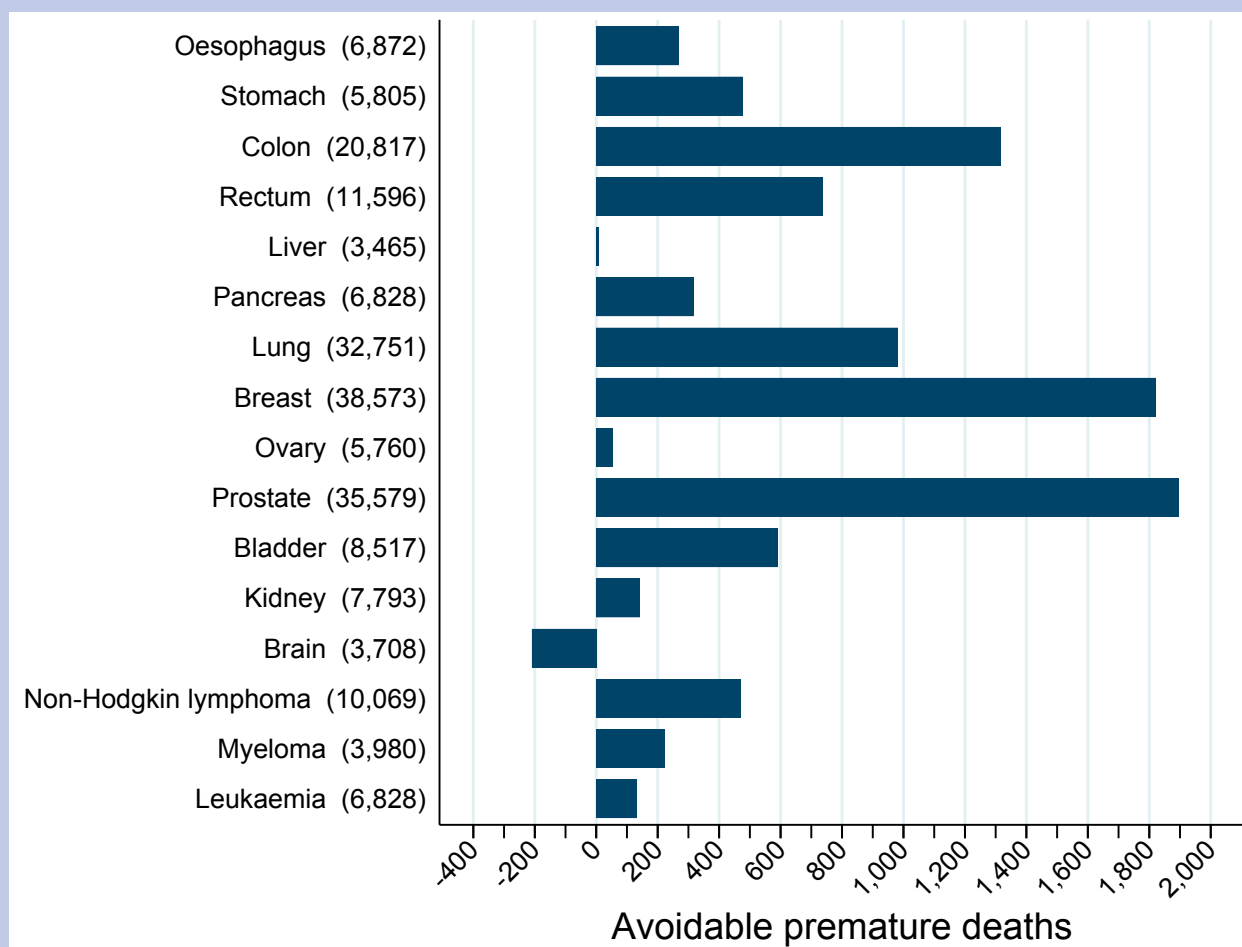
Among the 238,000 adults (15-99 years) who were diagnosed with one of 24 common cancers in England in 2010, about 10,000 (10%) of the 98,700 cancer-related

deaths within 5 years would have been avoidable if 5-year survival had been the same in all socioeconomic groups. The most important contributors to this total were cancers of the colon, lung, breast and prostate.

Cancer survival can be improved by earlier diagnosis and access to optimal treatment and, for cancers of the breast, colon, rectum, cervix, by higher compliance with national screening programmes. These factors explain part of the socioeconomic inequalities in survival.<sup>iv</sup>

We conclude that more can still be done to ensure equal access to prompt diagnosis and optimal treatment for cancer patients in all deprivation groups in England.

**Figure A** Avoidable premature deaths within 5 years of diagnosis, among cancer patients diagnosed in England in 2010, if all patients had had the 5-year survival seen in the highest socio-economic group (selected cancers)



*Note* The number of patients diagnosed in 2010 is shown in brackets

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## Chapter 10

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# Machine learning for individualised medicine

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# 01 Machine learning in healthcare: challenges and opportunities

In 2015, Eric Topol<sup>1</sup> presented persuasive evidence and arguments that current advances in medical technology – and further advances that are likely to come in the very near future (including wearable devices, faster and cheaper means of genomic sequencing) – will enormously increase the amount of data that is available for individual patients. But as Topol points out, if we wish to use this data to predict, prevent and treat illness – especially chronic illness – data will not be enough: “we want answers, not just data.” In particular, we need predictive power. And as Topol also points out, “such predictive power must rely on machine learning.”

By machine learning (ML) we mean the process by which computer systems can learn directly from data, examples and experience, rather than being taught on the basis of pre-determined rules.<sup>2</sup> The purpose of this chapter is to illustrate some of the progress ML has already made in healthcare and to suggest some of the progress it might make – and ought to make – in the near future. The view presented here is deliberately optimistic; for ML to have a chance to achieve this potential – as we believe it does – there must first be a vision of what is possible. Topol has discussed at length the potential of accumulating more data; our focus here is on extracting more information from that data.

It is important to keep in mind that the medical domain has many stakeholders: patients, nurses, physicians, administrators and policy-makers, as well as clinics and hospitals. We believe that ML can make a revolution in healthcare – but it will not do so by replacing any of these stakeholders, but rather by enabling and empowering them to improve the entire path of healthcare – from prevention, to diagnosis, to prognosis, to treatment, with the ultimate aim of enabling “individualised medicine”, while maintaining or even reducing costs. In particular, ML will support and complement, rather than substitute for, the judgment of medical personnel, and will also inform patients and administrators. Put differently: the purpose of ML in the medical domain is to provide intelligence – especially actionable intelligence – and decision support to all the stakeholders.

Currently a lot of the technology that has been developed by ML (and by digital medicine) has been driven by opportunities seen by the technological community, rather than by the need to provide information that matters, that is actionable,

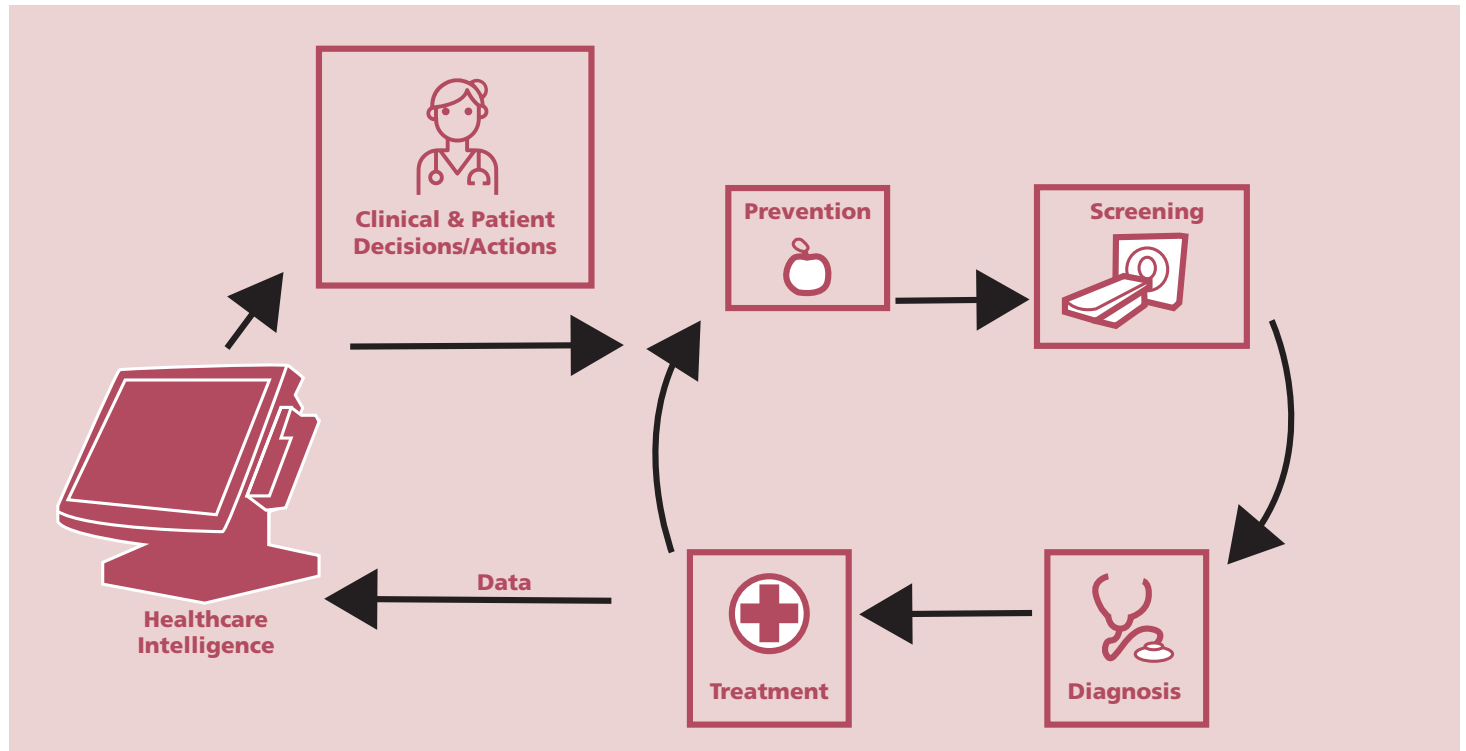
and that will actually improve healthcare. This must change: the development of ML for healthcare must be pulled by the healthcare stakeholders (from patients to policy-makers) and not just pushed by the technological community. The ML community and the medical community and stakeholders must work more as partners: the design and assembly of these building blocks must be guided by the needs of the users and supported by ML development. To accomplish this, ML must accomplish at least two things. The first is to provide building blocks – methods and algorithms – that the users can assemble for their own particular needs. The second is to make these methods and algorithms sufficiently transparent and understandable, and validated in a wide variety of contexts, that they earn the trust of the users.

It may be appropriate to begin by briefly discussing just one of the challenges that we believe ML can help to meet: the rising incidence and cost of cancer. Approximately 360,000 people in the United Kingdom are diagnosed with cancer each year and approximately 160,000 people die of the disease. The NHS currently spends approximately £6.7 billion per annum treating cancer patients. Moreover, as the average age of the population increases over the next three decades, the incidence of cancer is projected to rise – and the cost of treatment is projected to rise even faster. According to the statistics fact sheet issued by Macmillan Cancer Support<sup>3</sup>, “there are an estimated 2.5 million people living with cancer in the UK in 2015, rising to 4 million by 2030. The number of people living with cancer in the UK in 2015 has increased by almost half a million people in the last five years.” Given these numbers, it is clear that treating an increasing population of patients with current methods will rapidly become financially challenging. Similar problems exist globally: “the economic impact of cancer is significant and is increasing. The total annual economic cost of cancer in 2010 was estimated at approximately US\$1.16 trillion”.<sup>4</sup>

Although this challenge is daunting, it represents an opportunity for ML to provide better tools for the medical community to prevent, detect and treat cancer – and at a sustainable cost. Similar challenges and opportunities exist for many other diseases and throughout medicine. Especially important examples include the multitude of morbidities for which the aging population of the United Kingdom is increasingly at risk. It is to these challenges and opportunities that this chapter is addressed.

\* We distinguish Machine Learning from the broader discipline of Artificial Intelligence, which refers to any system that can perform “intelligent” tasks – including systems that act entirely on the basis of pre-determined rules.

**Figure 10.1** Machine learning in healthcare



Source *Mihaela van der Schaar*

Human beings are good at understanding and drawing conclusions from information gathered from a limited collection of data sources over a short period of time. They are less adept at understanding and drawing conclusions from information gathered from a broad collection of diverse data sources over a long period of time – although such information may in fact have significant impact on all aspects of decision-making. In the medical domain, this is particularly true because more and more data is becoming available from a wider and wider variety of sources (imaging, genomics, vital signs and lab tests collected over time, etc.). Extracting intelligence from this data is necessary to advance to new and improved levels of prognosis, diagnosis and treatment. This is especially important in dealing with complex diseases such as Alzheimer's, cancer, cardiovascular disease, cystic fibrosis, diabetes, etc. which exhibit complex phenotypes and require sophisticated analysis of data – many features, not just a few – which is difficult for humans but easier for machines (computers).

There is already too much data for human beings to keep track of and make use of. This is one of the reasons that clinical risk scoring methods tend to use only a subset of the features that are recorded: treating clinicians simply cannot keep track of and make use of the hundreds or even thousands of features that may actually be available. And the amount of data is growing exponentially quickly; not just the data in electronic health records (which is now recorded for a majority of patients in developed countries) but also genomic data, proteomic data, etc. Although some of this data (e.g. the genomic data) is fixed, some of it changes rapidly – and

it is not just the current data that is important but also the history/trajectory of the data. Moreover, as guidelines are changing, different information is being collected. Static clinical methods have a hard time adjusting to these changes. ML methods can do much better because they can be continually re-trained to incorporate these changes and adapt to them.

Progress toward understanding, preventing and treating such diseases will require developing new methods that break the barriers between ML, statistics and mathematics, and using these new methods to discover new links, causes and causal relationships among clinical data, genetic data, metabolic data, environmental data, social data etc. and their implications on the risk, incidence and trajectory of disease.

In what follows, we discuss some of what ML has accomplished and can accomplish in a wide variety of areas. We begin by discussing risk scoring because it pervades every aspect of medical care.

## 02 Risk scoring

Evaluation of risk is essential in many medical domains because it informs every aspect of patient care, including prevention of a disease/condition and prognosis and treatment after the onset. Before the onset of a disease/condition, patients thought to be at high risk may be screened more often and more thoroughly, and are more likely to receive prophylactic interventions and/or treatment. After the onset of a disease/condition the course of treatment will often be different for patients having different levels of risk. Evaluation of risk also plays a particular role in operational settings where triage is key.

Currently, most evaluation of risk is not done systematically, or on the basis of any formal model, and hence does not integrate the wealth of information available about the patient. Even in areas in which the evaluation of risk is done on the basis of a formal model that produces specific risk scores, it is usually done on the basis of a linear model, such as a Cox proportional hazards model, and using a relatively small number of hand-picked features, often chosen either by clinical judgments or by simplistic variable selection methods. ML-based methods provide two kinds of gains over such models. The first is an informational gain: ML-based methods are able to handle many more features. This is especially important because different features often make different contributions to risk for different classes of patients, and it is becoming even more important as more kinds of data are becoming available – hence there are more features to be taken into account. The second is a modelling gain: ML-based methods are able to make better use of the same features by better capturing the potentially complex interactions between features. These gains allow ML-based methods to issue more accurate predictions, and hence better treatment guidance, for the patient at hand. Because ML methods provide both informational gains and modelling gains, the improvement in predictive accuracy of ML-based models over existing clinical models has been, and is likely to remain, largest for settings (diseases) in which many features are potentially important – especially if different features are important for different kinds of patients – and in which features interact in complicated ways that are not captured by linear models such as the Cox proportional hazards model.

An additional advantage of ML-based models is that – in part because they are capable of using many features – they make it possible to discover the importance of features and of interactions among features that were not previously understood to be important. For example, the work of Alaa and van der Schaar revealed an unexpectedly important role for oxygenation – in addition to FEV1 (forced expiratory volume) – in predicting the decline of patients suffering from Cystic Fibrosis.<sup>4</sup>

A number of challenges need to be overcome to enable large-scale deployment and use of ML-based risk-scoring methods. Some of these challenges, and the progress that is being made to meet the challenges, are outlined here.

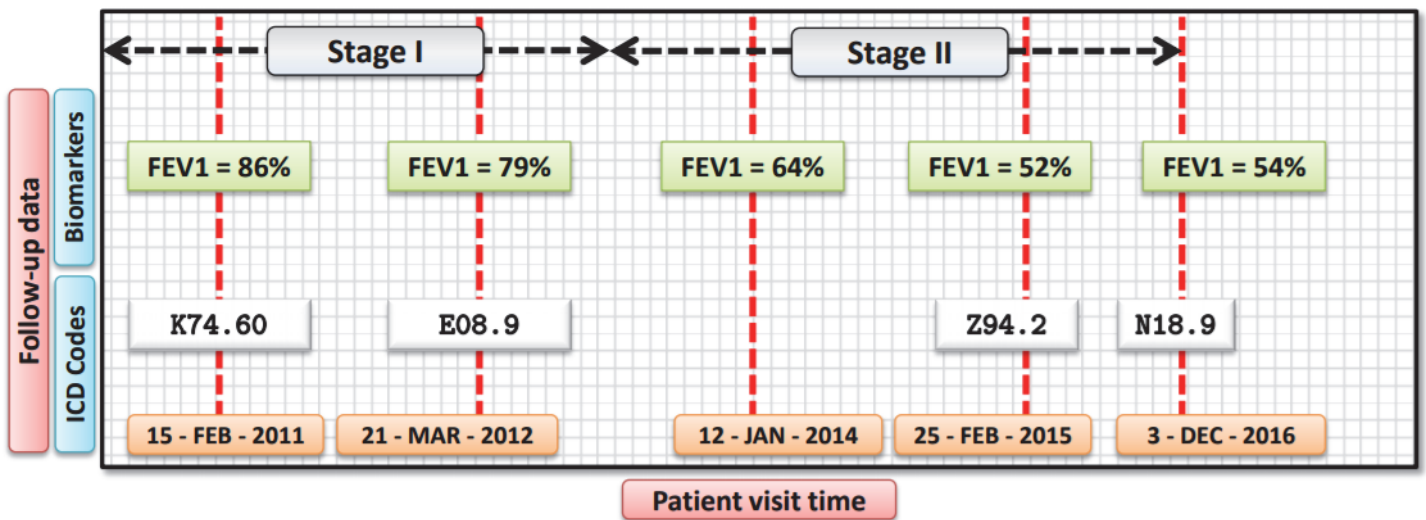
### 2.1 Longitudinal trajectories and multiple states/stages of disease

The most important challenge is the universal problem that there are multiple states/stages of conditions/diseases and the true state and the true probability of transition from one state to another cannot be observed directly. Instead it must be inferred from information that can be observed directly, such as symptoms, measurements, tests, images, etc. Figure 10.2 illustrates the problem: the patient transitioned from Stage I to Stage II – indicated by a large drop in FEV1 – between visits. Moreover, it is important to make use of what can be learned implicitly from the absence of information in the electronic health record of a patient. ML has made great progress in recent years on learning trajectories of risk and disease – and deriving risk and prognostic predictions – from the information available in the patient records.<sup>5</sup> ML has also made substantial progress in the development of new methods for understanding disease from longitudinal data, including the number of states needed to provide an accurate representation of the disease, how to infer the current state, what triggers the transition from one state to another, etc. – all on the basis of the available information. The progress that has already been made, and the progress that will be made in the future, can play a key role in understanding and preventing disease as well as in triaging patients.

## 2.2 ML Know-how

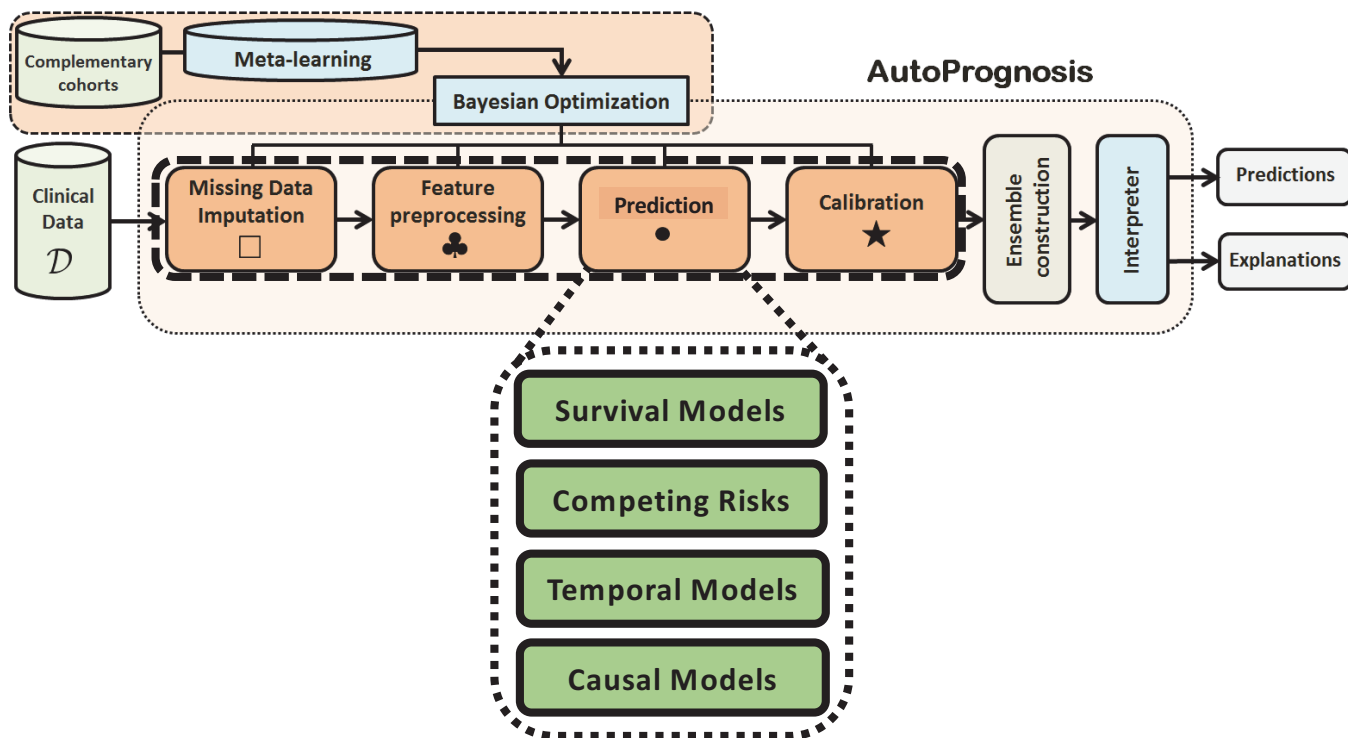
One of the barriers to the use of ML-based methods has been that they have required a great deal of technical knowledge of ML to choose and tune the particular predictive model to be used. However, the development of automated methods such as AutoPrognosis<sup>9</sup> is now making it possible for clinical researchers who have little or no technical knowledge of ML to apply state-of-the-art ML-methods. These automated methods use ML itself to both choose and tune the ML-model(s) – more generally, the entire pipelines of models – to be used. Figure 10.3 provides a diagram of such a pipeline.

**Figure 10.2** An example of the risk and disease trajectory for a patient



Source: Mihaela van der Schaar and Ahmed Alaa

Figure 10.3 AutoPrognosis – Automatic Machine Learning for Healthcare



Source Ahmed Alaa, Mihaela van der Schaar, "AutoPrognosis: Automated Clinical Prognostic Modelling via Bayesian Optimization with Structured Kernel Learning," ICML, 2018

## 2.3 Changing Practice

One of the challenges facing all predictive models is that medical practice is constantly changing – and often the population of patients is changing as well. For example, the management and care of patients who have had heart failure and are potential candidates for a heart transplant has changed dramatically over the past decades as surgical procedures and assistive technologies have improved. ML-based predictive models such as the one developed by Yoon, Zame and van der Schaar can more easily adapt to these changes than traditional clinical models, both because they can incorporate more features and because they are more readily re-trained to incorporate new data.<sup>7,8</sup>

## 2.4 Interpretability

In order to be integrated into clinical practice in truly useful way, it is not enough that models be accurate – they must also be understandable to the users. This requires that the models have a high degree of transparency and that the predictions of the models should be interpretable to the users, who will be accountable for the decisions made on the basis of these predictions. Many widely-used clinical models have these properties – but many ML models do not. Rather they are “black-boxes” whose workings are rather opaque and whose predictions are not readily interpretable. This has posed a barrier to clinical acceptance of ML models – even when the data has shown that ML models provide more accurate predictions.

Interpretability is important for the adoption of ML methods in clinical practice. In order to be adopted, it is not sufficient that a new model predicts better than an older model; it is also necessary to understand why. Does the new model make better use of features that are already known to have clinical relevance (e.g., by better capturing the interactions between features)? Does the new model make use of features that were not previously known to have clinical relevance, but whose clinical relevance can now be understood? Does the new model identify subpopulations for whom certain features – or the interactions between certain features – play a different role than in the general population? The absence of satisfactory answers to these and other similar questions may lead to dismissing a new model on the grounds that its predictive success is simply coincidental (e.g. specific to a particular dataset).

There are (at least) three approaches to the challenge of interpretability. The first is to focus on refining existing ML models that are (relatively) transparent and whose predictions are already interpretable. Classification and Regression Trees have these properties. The second is to create new models with these same properties; this is part of the motivation for the creation of a new generation of ML models such as Trees of Predictors.<sup>7,8</sup> The third is to provide methods for interpreting existing ML models; this has prompted a substantial recent body of work.<sup>9,10</sup>

An important aspect of all of this is that much recent work has pointed to a trade-off between transparency/interpretability and accuracy. This is a trade-off that the ML community can identify – but it is up to the medical community to decide how to make the trade-off. Clinicians who will be accountable for the decisions made on the basis the model they use might (quite reasonably) emphasize transparency and ease of interpretation in their choice of which model to use. Thus, it is important that the users of the models be involved in the process of creation and evaluation.

## 2.5 Leveraging Multiple Datasets

Modern ML methods often require large amounts of data in order to learn the large number of parameters that define them efficiently; this may be because the model itself is complex and/or because the dimensions of the input data are large. Acquiring large datasets can be difficult. Moreover, it is often important to learn a model that performs well on a specific, potentially small, sub-population. Learning such models can be difficult because data from a particular hospital is often limited, so it is important to leverage data from other hospitals, while keeping in mind that different hospitals may collect different data, may serve different populations with different incidences of disease, and may treat patients differently. Hence, simply importing data from other hospitals may therefore lead to biased and inaccurate prediction. ML-based methods are capable of learning to translate from one clinical setting (dataset) to another, thereby effectively enlarging the dataset from a single hospital and enabling the creation of better predictive models.<sup>11</sup>

## 2.6 Multi morbidities

Some patients suffer from – or are at risk for – multiple diseases/conditions; these risks significantly increase as the patient ages. In order to monitor and treat such patients, it is important to predict which disease/condition is likely to occur sooner and which is likely to occur later and how the risks for various diseases/conditions are changing over time. This poses problems for models that consider each risk separately (e.g. the cause-specific Cox model) and often leads these models to make very poor predictions; what is necessary is to treat the multiple competing risks in a holistic fashion. ML-based methods have done much better by learning representations of factors that are shared between the diseases/conditions and hence produce joint predictions of the risks of the various diseases/conditions.<sup>12</sup>

Most of the work, however, that has been done on multiple morbidities has focused on the setting in which patients might develop any of several diseases, but will actually develop only one. For example: a patient might be at risk of death from both cancer and cardiovascular disease – but will die only of one. However, it is often the case that a patient may develop first one condition – e.g. diabetes – that does not result in death but that affects the risk of developing a second condition – e.g. cardiovascular disease.

This latter setting is especially important because more preventive care is potentially possible. Initial work in this area<sup>12,13,14</sup> suggests that ML may have enormous promise in dealing with this problem.

As should be clear from this discussion, ML has enormous potential in the domain of risk-scoring. It is important to keep in mind that the potential of ML in the domain of risk-scoring is not only informing medical personnel but also informing patients themselves. Individualised information about risk factors, current and predicted health state, preventive measures and treatment plans can be provided to patients and embedded into apps and wearable devices, which can track the health state and risks of the patient over time, and empower patients to make informed healthy choices, adopt better lifestyles and better adhere to plans for screening, monitoring and treatment so that disease is prevented or treated effectively at early stages. This can lead to a new equilibrium in which patients are more involved in their own healthcare.

### 03 Imaging and diagnosis

Medical imaging and diagnosis is perhaps the area in which ML has had the greatest success so far.<sup>15</sup> Some of this success (especially the success that has come from deep learning) is very widely known, and has been trumpeted in the popular press. ML has demonstrated its ability to provide more accurate and definitive interpretation of images, especially in the areas of radiology, ophthalmology<sup>16\*</sup>, pathology<sup>17-19</sup> and dermatology.<sup>20,21</sup> These methods can be incorporated into decision support systems that can aid physicians by offering second opinions, flagging concerning areas in images and determining abnormal tissue or lesions. The progress in ML in these areas has exploited the enormous body of existing data (millions of photographic images), the ability to easily generate additional data, and the exploitation of a great deal of prior knowledge and understanding of the structure of the data.

Although these achievements are impressive, much more is possible. A particularly promising new application of ML to medical imaging is in digital mammography. Improved accuracy of digital mammography could have a profound impact on breast cancer screening programs by reducing manpower requirements, reducing costs and distinguishing patients who are at greater risk from patients who are at lesser risk. This need for better risk prediction is already recognised and steps toward an adaptive approach to screening are already being undertaken. For example, women with “dense breasts” are often directed to supplemental screening modalities such as ultrasound, contrast enhanced and/or 3-dimensional mammography or MRI scanning. However, “dense breasts” is a very coarse – and often subjective – classification; ML can more objectively identify which of these expensive and resource-intensive technologies should be used for which women – and when.

ML can also play an important role in the interpretation of ordinary mammograms. Properly trained and validated ML algorithms could be used to assist radiologists in a number of ways. Most obviously, ML algorithms can identify some images that are not problematical and do not need to be examined further, thus providing the radiologist with more time to examine those images that are problematical. Perhaps less obviously, ML algorithms work with the radiologist in examining images that are problematical – e.g. identifying areas that appear suspicious. The ultimate aim is to use ML to streamline the reading process, allowing radiologists to focus on more difficult cases and improve diagnostic accuracy. By answering and understanding what ML methods – especially deep learning methods – are good at, we can take the next step to integrating them into an operational clinical setting by instilling confidence through interpretability and understanding.

More generally, ML can improve breast cancer screening and detection by better stratifying patients into risk groups, and determining which groups would benefit most from different screening regimes. These various regimes might be differentiated by the time at which screening begins, the frequency of screening, the particular imaging modality/modalities (mammogram, 3-D mammogram, ultrasound, MRI with/without contrast, etc.) to be used at each screening opportunity, etc. The initial assignment of a patient to a particular risk group (and hence to a particular screening regime) should be based on the attributes of the patient, including demographics, lifestyle, family history and genetic information, but the assignment should change as new information is provided by screening that has already taken place. The information provided by this more individualised screening process will help to provide support for clinicians in deciding when a biopsy is needed, and perhaps what steps to take after the results of a biopsy are known. See Figure 10.4 for an overview of what the process could look like, and for some steps along the way.<sup>22</sup>

More generally, leveraging digital pathology and advanced radiological imaging and integrating these with ML can increase the efficiency, speed and accuracy of detection, diagnosis and monitoring for many diseases.

\* See Chapter 12 of this report for a case study of AI in ophthalmology (Moorfields-DeepMind Collaboration, 2016-2018)



## 04 Screening

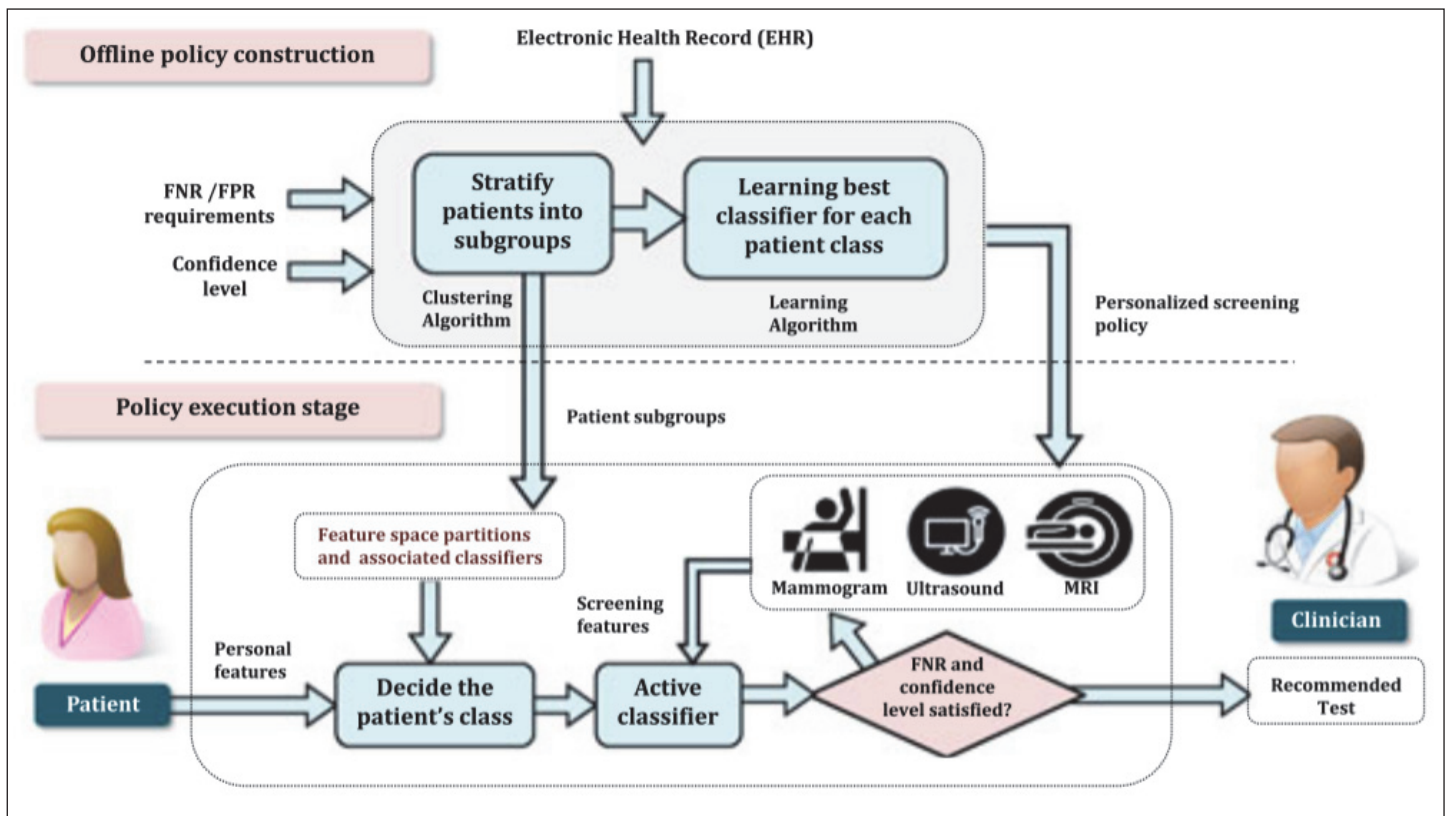
For most diseases, the current guidelines prescribe a one-size-fits-all screening program: a particular screening procedure (which may involve imaging, but also many other tests) is carried out at fixed intervals for every patient in the relevant population. However, for many diseases, the actual risk faced by a patient varies widely across patients, and for the same patient, may vary widely over time. Hence patients whose actual risk is low are screened too often – which is wasteful of societal resources and unnecessarily costly/invasive for the patient – while patients whose actual risk is high are not screened often enough, so that detection of disease is delayed. It is therefore important to tailor screening policies to the particular patient.

For a few diseases, such as breast and colon cancer, current United Kingdom screening policies do take into account genetic markers for the disease, family and personal history of the disease, and the findings of previous screenings. However, even for such diseases, current policies group patients into very large bins and follow a single procedure within each bin. We have already mentioned that ML has the potential to greatly improve digital mammography, but this is only a part of its potential to improve breast cancer screening. ML also has the potential to integrate a wide variety of patient features with the patient’s history, to

create individualised screening policies that are better for the patient while also making better use of expensive and scarce resources. Moreover, even after initial screening has revealed the presence of a condition/disease, treatment and follow-up are typically either one-size-fits-all or very ad-hoc – depending on the experience and judgment of the treating clinician and perhaps the insistence of the patient – despite the fact that actual risk varies widely across patients.

It is important to keep in mind that the recommendations of such a policy will sometimes be “screen more often” or “use more accurate – but perhaps more invasive or more expensive – screening procedures”. They will also sometimes be exactly the opposite, because many patients who are low risk do not need to be screened as often and do not need costly or invasive screening procedures. Less frequent screening of patients at low risk frees up scarce resources to provide more frequent screening for patients at high risk. In addition, ML has the potential to learn the value of screening and of screening over time for the particular patient at hand. And it is not only the timing of screening that should be individualised to a particular patient: ML can learn the value of information – and the value of information over time – and hence learn that some patients require a particular method of screening or follow-up while others do not.

**Figure 10.4 Building an individualised screening policy**



Source Ahmed Alaa, Kenneth Moon, William Hsu and Mihaela van der Schaar, 2016

## 05 Individualised treatment effects

Choosing the best treatment for a particular patient requires estimating the effects of a variety of treatments for that particular patient – not only some average over the large population of patients. To accomplish this, we need to understand individualised treatment effects and not just average treatment effects. Unfortunately, this is beyond the state of the art of current medical knowledge.

Clinical trials are – and will remain – the gold standard for understanding the efficacy of new medications and treatments. However clinical trials, by their very nature, have important limitations. They have strict criteria for entrance that often exclude elderly patients and patients with multiple morbidities (which often represent a large fraction of the patients who will actually receive the medication or treatment), and they are often limited by ethical considerations. Moreover, the guidelines developed on the basis of clinical trials are based on the average effects found in the trial, although it is often the case that a given medication or treatment may have very different effects for some particular subpopulations than for the population as a whole. Clinical trials often provide a lot of information about average treatment effects but much less about individualised treatment effects.

Recent advances in ML have shown that ML is capable of learning individualised treatment effects by beginning where clinical trials leave off – learning from observational data: the data captured in clinical practice. Learning individualised treatment effects from observational data is an extremely challenging problem because the data is biased (clinicians choose which patients should receive the drug/treatment rather than randomising), counterfactuals (what the outcome would have been if a treated patient had not been treated or conversely if a non-treated patient had been treated) are not observed, and both the decisions and the outcomes may be affected by hidden confounders (not recorded in the observational data). Moreover, because counterfactuals are not observed, predictive models cannot be tested out of sample.

However, recent work in ML has made promising progress on this problem. Stefan Wager and Susan Athey have adapted a standard ML-method (Random Forest) in order to produce predictions that come with statistically valid confidence intervals.<sup>23</sup> Ahmed Alaa and Mihaela van der Schaar have developed general guidelines for the design of ML algorithms for estimating individualised treatment effects by characterising the fundamental limits of what can be achieved and establishing conditions under which these fundamental limits can be realised.<sup>24</sup> Their theoretical analysis reveals, among other things, that the relative importance of the different aspects of observational data vary with the sample size. Selection bias is the most important bottleneck to performance in small-sample regimes, while the modelling of the control and treated outcomes is the most important

bottleneck to performance in large-sample regimes. Building on these findings – and others that result from the theoretical analysis<sup>24,25</sup> – they develop practical ML-algorithms that outperform previous methods.

The impact of accurate prediction of individualised treatment effects is hard to overestimate because it provides a basis for the choice of treatment according to the features of the particular patient at hand. This leads to improved outcomes for patients – who receive the best treatment – and for improved use of resources, not wasting scarce resources on patients who will receive little or no additional benefit from them. One potent example comes from the realm of cardiac transplantation: how much would a patient who has experienced heart failure benefit from a mechanical assist device (e.g., an LVAD), either as a bridge therapy or as a destination therapy? A second example comes from the realm of chemotherapy: when one regimen of chemotherapy has achieved all that it can, what – if any – further regimen should be tried next?

While ML methods suggest that substantial progress has been made in understanding individualised treatment effects on the basis of observational data, the progress so far has serious limitations. Most importantly, the findings of ML with regard to individualised treatment effects need to be validated in clinical practice. One obvious way to do this is to use the predictions of ML to design further clinical trials, perhaps focusing on subpopulations for which the effect of a particular treatment seems different from the effect on the population as a whole.

## 06 Monitoring and early warning systems

Many hospitalised patients suffer sudden, unexpected and life-threatening deterioration such as septic shock or cardiac arrest, and the death rate from these events is very high (as much as 75%). However, many of these events could have been prevented, and many other patients who did experience these events could have been saved, if earlier warning – even a few hours – had been given. Unfortunately, the existing early warning systems that are widely used in hospitals have not proved adequate: they miss many events and issue many false alarms – which strains the resources of hospitals and leads to alarm fatigue among care-givers.

Providing accurate early warnings – both in and out of the hospital – is a challenging problem for many reasons, of which we mention only a few. The most important reason is the universal problem that the true state of the patient cannot be observed directly but must be inferred from what can be observed directly. Such inference requires integrating data of many kinds from many sources: demographic information, laboratory tests, vital signs, imaging, etc. Moreover, since observations cannot be made constantly, the possibility that the patient's state has changed in between observations must be taken into account. And the probability that a patient will deteriorate in the near future depends not only on the patient's current state but also on the past history – in particular, on the time the patient has been in the current state.

Despite these difficulties, ML methods have made real progress. Saria et al have developed ML methods that provide predictions of septic shock that are more accurate and more timely than those provided by commonly-used clinical models.<sup>26</sup> Van der Schaar et al have developed ML methods that provide predictions of cardiac arrest in hospital that are more accurate and more timely than those provided by commonly-used clinical models.<sup>27-29</sup> The methods used in these two examples are very different, in part because they address very different kinds of sudden deterioration in hospital. But there are many kinds of sudden deterioration in hospital, and creating a predictive model for each one would present an insuperable task. Here again, the idea of Auto-Prognosis<sup>5</sup> – to make ML itself create the model – has enormous potential.

Outside the hospital, a variety of sensors of many different types, including wearables, are becoming widely available for use by consumers. These sensors can already track activities, motions, food intake, body temperature, heart rate, blood pressure; in the very near future they will also be able to track blood chemistry and many other things. These sensors can enhance care in (at least) three ways:

- By collecting information that can be used by the treating clinicians (especially in tracking patients' behaviour and progress).
- By collecting information that can be used by the patient to monitor, track, follow progress.
- By providing feedback to the patients including warnings, reminders and suggestions for adherence to medication, exercise and treatment regimes.

ML will play a vital role in this by creating systems that can: integrate the data; make predictions about the patients' health, behaviour, adherence to medications and therapy, etc.; provide feedback about the patients' progress; offer recommendations including alternative regimes of diet and exercise; and alert the patient and medical personnel when further consultation is needed. Such systems can also empower and encourage patients to take a more active role in their own healthcare by providing them with feedback about the (positive or negative) effects of their own actions and behaviours. They can also increase the efficiency of the patient/clinician relationship by keeping both informed about the necessary level of interaction. Is a visit necessary? Should the physician provide feedback about progress (or the lack of it)? Should the physician suggest changes in behaviour? in medication? in treatment?

An important aspect of the feedback loop that remote monitoring (especially wearables) enables is that the clinician may become more involved with the patient – even though the patient may make many fewer visits to the clinician.

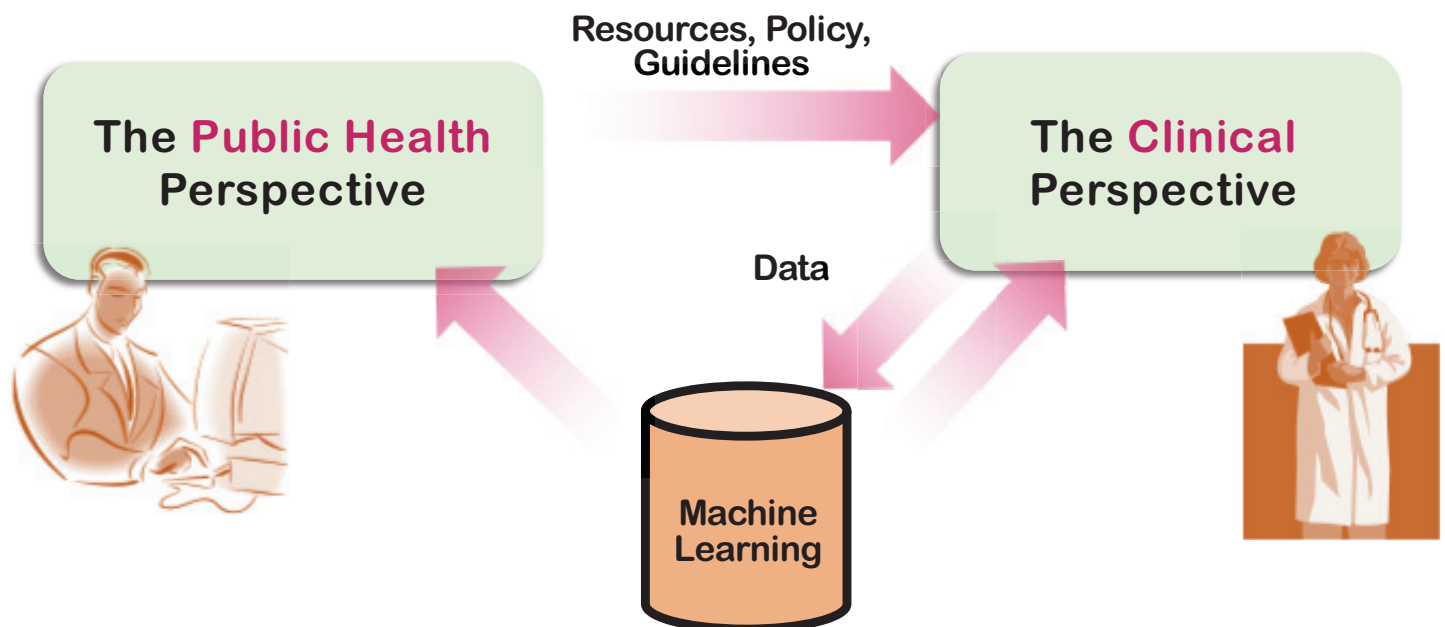
## 07 The electronic health records of the future

We have discussed many ways in which ML can improve health care, but one of the most important ways is by creating a system that integrates all of these. This might be thought of as the electronic health records of the future – but since it will not only record data but also process and integrate information and provide forecasts and recommendations, it might better be thought of as a Learning Engine for Healthcare (LEH).<sup>1</sup> In addition to all the information currently recorded in electronic health records, the LEH will produce a holistic view of risk – and the trajectory of risk – for many diseases to which the current patient might be at risk, and select and display those that are requested (by the clinician or patient) and those that are most pertinent, even if not specifically requested. This

should be contrasted with current electronic health records, which can compute only risks for a few diseases, and display only those which are specifically requested. The distinction is important because many patients may actually be at risk for diseases that are not suspected (by the clinician or patient). By anticipating risks, the LEH becomes a tool by which the clinician and patient can actively prevent future disease (through lifestyle modification, prophylactic treatment, etc.).

Because the LEH can continuously learn from observational data that is recorded in the EHR and information that is provided by patient wearables or apps, the LEH can continually update the intelligence provided to the user, leading to a cycle of improvement in all stages of care – from prevention to screening to diagnosis to treatment.

**Figure 10.5 ML informs both the public health perspective and the clinical perspective**



Source: Mihaela van der Schaar and Ahmed Alaa

\* See Oon International Award and Lecture in Preventative Medicine 2018 for some more details about the Learning Engines for Healthcare and their capabilities ([https://www.youtube.com/watch?v=2MdvYoN6\\_20](https://www.youtube.com/watch?v=2MdvYoN6_20))

## 08 Public health

With the availability of more diverse data, such as the data that is now becoming available in UK Biobank, wearables, social media and a plethora of apps that track exercise, nutrition and vital signs, ML can unravel a variety of determinants of health; not only clinical factors but also social, environmental, nutritional and behavioural factors. This provides the potential to identify and to personalise the determinants of health (risk factors) that go beyond well-known clinical markers. (For example, it is already well-known that high cholesterol is generally associated with higher risk of cardiovascular disease, but ML methods are being developed that can assess the extent of this risk and suggest appropriate counter-measures – which may be very different for different individuals.) To do this, there are many challenges that need to be addressed and which ML has been shown capable of addressing. The first is that the number of risk factors – which now include environmental, social and behaviour factors – is vast, and hence selecting those relatively few factors that really matter and how those factors interact requires new methodology. The second is that different factors matter for different people so it is essential to discover those factors that matter for each individual. The third is that different factors matter at different times, both at different ages and at different stages of disease. The fourth is that the factors that matter for a given disease may be different when the patient suffers from – or is at risk for – another disease. Thus, a holistic view is a necessity. ML provides the methodology to address all these challenges.

This can have significant impact on public health, by enabling a shift from providing a one-size-fits-all view of one disease at a time to a more personalised and holistic view.

## 09 Communication and interaction

It has been estimated that as much as 50% or more of physicians' time is spent simply entering data.<sup>30</sup> The data obtained in this way is invaluable, and its accessibility in electronic health records makes it extremely usable. However, because the data is collected by human beings, the collection of the data and its entry into the electronic health record are prone to error and very time-consuming. Natural language processing (NLP) has enormous potential to reduce the time for data entry and the probability of error. (Natural language processing (NLP) is a subfield of AI and ML concerned with the programming of computers to process, analyse, understand and interpret language data. Challenges in NLP involve speech recognition, language understanding and interpretation, and generation of language for clinical notes and reports, etc.<sup>31</sup>). This has the potential to be transformative because it will reduce the time spend on data entry and free up valuable time for actual interaction with patients. It also has the potential to increase the amount of data that is routinely collected and entered into the record while reducing the number of entry errors.

A second and perhaps less obvious use of NLP is in the analysis of text of many kinds, including clinical notes, imaging reports, etc., and in integrating this text with other sources of information as an additional set of patient features, or an additional set of labels, or as a way to enable semi-supervised learning. Raw text is difficult for ML methods to use, but the additional information in this text may prove extremely important in facilitating and enhancing the performance of ML-based methods in order to improve prognosis, diagnosis and treatment.

A third application of NLP is in the development of chatbots, which may prove useful in a variety of settings, including preliminary triaging in NHS 111 services and patient support of all kinds including mental health, adherence to medication therapy and treatment, reminders, etc.

Another important aspect of communication is the contextual interaction taking place among the participants in the treatment and support of each particular patient. The treatment of complex diseases such as cancer typically involves many clinicians across many sub-specialties in addition to the GP, the patient support network and the patient. Rapid and accurate communication among all these participants is essential for the best treatment. This is yet another area in which ML can be of enormous value by automatically creating networks of expertise and support, based on the state of the patient, that will identify information that needs to be solicited and shared and by providing the means in which that information can be shared in ways that are easily understood – and, when appropriate – acted on by the various participants. (For an example of this see Tekin, Atan and van der Schaar.<sup>32</sup>) This may require the integration of many areas of ML including multi-agent learning, contextual learning, natural language processing and others.

## 10 Operations management in healthcare

It is currently estimated that a very large fraction – perhaps as much as 50% – of US healthcare spending constitutes waste, and that this waste largely arises in a few categories: failures of care coordination, failures in execution of care processes, administrative complexities, pricing failures, overtreatment, and fraud/abuse. ML can significantly reduce this waste by streamlining the operation of the entire system of providing healthcare, thereby reducing costs and improving outcomes. For example, in the domain of care coordination, ML can advise medical personnel, staff, administrators and patients with whom an appointment should be made (nurse, general practitioner, specialist) for a specific patient with a specific history and current symptoms, when this appointment should occur, how much time should be scheduled for this appointment, and where this appointment should occur – in a clinic or remotely by telephone or videoconference. ML can also be tremendously useful in identifying and reducing fraud/abuse. (It has already been used to identify credit card fraud).<sup>33</sup>

Another way in which ML can also be enormously useful is in streamlining the delivery of care in the complex ecosystem of hospitals, for example by improving the triaging of patients at many stages. In the emergency department of a hospital, ML can help personnel to decide in which order patients need to be seen/treated: which patients must be seen/treated immediately and which patients can wait – and for how long – and which tests need to be performed to make these triaging decisions. ML can also play a crucial role in estimating the current disease state of the patient and determining when a patient requires immediate hospitalisation and surgery or can wait safely at home and be monitored remotely, thereby reducing the stress on the system and on the patient.

## 11 Education

ML can play an important role in training both medical students and practicing clinicians in a personalised way, in both traditional clinical areas and in non-traditional areas such as statistics and data science, including ML. Personalised education/training is especially important for practicing clinicians, who must constantly upgrade their knowledge and skills, but have no time to attend formal classes and may have very individual needs and different backgrounds/skills. Personalised education/training will accelerate the ability of clinicians to absorb new technology, the ability to re-train in new areas and especially the ability of clinicians to think more holistically about the patient in front of them. ML can help clinicians to learn about new medical advances and techniques and also about new ML-enabled decision support systems (as described above). ML-enabled personalised education is an active area of research<sup>34</sup> but personalisation to the special requirements of clinical and medical personnel poses special problems and will require additional work.<sup>35</sup>

# 12 The way forward

As we have noted in the beginning, we believe that ML can make a revolution in healthcare – but by empowering medical personnel (clinicians and researchers) rather than replacing them. Hence medical personnel should embrace what ML can do – rather than fear it – and should fully participate in – even lead/direct – the development of ML for healthcare. This is a positive message – and also a call to action for medical personnel, especially young personnel, to join – indeed drive – the revolution.

One of the reasons that medical personnel must be actively involved in this revolution is that the application of ML to medicine will require a different approach than has been taken in the application of ML in other areas. ML has been enormously successful in domains – such as game-playing<sup>36</sup> and autonomous vehicles – in which we have good models, in which the interactions (among players/entities and with the environment) are governed by “rules” (of the game, of physics, or of law) that can be clearly specified, in which data is plentiful or can be readily generated, and in which, whenever a decision – a particular move or sequence of moves, for instance – has led to failure/loss, it has always been possible to go back and try a different decision to see if the alternative would have done better.

Medicine presents a much more complex domain because we do not have good models, the interactions are governed by “rules” that we do not always understand – indeed, discovering the “rules” that govern disease and the human body is perhaps the most difficult task – and data is limited and fixed – we must learn from the patients we actually see rather than (hypothetical) patients we would like to see in order to gain more information. Moreover, in medicine, it is not possible to go back and undo a particular decision (surgery or treatment); in medicine we do not have, and cannot generate, counterfactuals. Despite this, ML for medicine has made substantial progress – and it promises to make much more.

Of course, the application of ML to medicine is really in its adolescence. New models need to be developed and validated, and their impact on efficacy, safety, quality and cost of healthcare needs to be properly assessed. Moreover, the opacity and complexity of many ML algorithms presents a barrier to their adoption. Widespread adoption of ML methods will require better understanding of existing algorithms and development of new algorithms that are more transparent and more easily interpreted. And throughout, attention must be paid to the central theme that ML algorithms and recommendations must go hand-in-hand with human judgment and actions; the combination of humans and machines will prove much more powerful than either alone. This is an extensive and ambitious agenda – but an important one.

We believe that the NHS provides a particularly fertile environment for the development and integration of ML into healthcare because it is a single party provider with a unified healthcare network that can promote rapid dissemination of innovations to an entire population. Close working relationships among NHS Trusts and allied academic institutions, provides the United Kingdom with the opportunity to lead the world in the transformation of healthcare through ML.

## 13 Authors' suggestions for policy

- Electronic Health Records are currently used only for the collection and storage of data – but their potential value as a resource goes far beyond this; they should be made more open and accessible. This will enable the extraction of actionable intelligence on behalf of the patients.
- Risk and treatment should move away from the current view that looks at a single risk at one moment in time to a view that looks at multiple competing risks over time. This will enable a holistic view of patients and patient care.
- Screening/monitoring policies should be personalised to the patient at hand – rather than based on one-size-fits-all clinical guidelines. This will lead to better use of resources, improved outcomes for patients and reduced costs.
- Learning individualised treatment effects on the basis of observational data should be used to complement learning on the basis of clinical trials. This will enable better matching of drugs/treatments to specific patients.
- ML should be integrated with Operations Research to improve triaging, queuing and work-flow planning. This will lead to better use of resources, improved outcomes for patients and reduced cost.



### Box 10.1 A fictional narrative of big data and cardiometabolic disease personal prevention in 2040

*Text kindly supplied by Mihaela van der Schaar, University of Cambridge and Jonathan Pearson-Stuttard, Imperial College London*

Jim is 52 years old and lives with his wife and 2 teenage children in Newcastle upon-Tyne, England. Jim rises early ahead of a big day at work. Years ago, he used to pick up breakfast on his way to work, but now he doesn't need to. Jim upgraded his fridge to an 'intelligent fridge'; it re-stocks automatically, and does so according to Jim and his family's preferences, and the national guidelines for healthy dietary patterns.

Jim noticed his yoghurt was tasty, but different, this morning. He remembers his Electronic Health Engine (EHE) told him yesterday that his blood sugar is a little high, classed as 'pre-diabetes', and his food shop was modified by his artificial intelligence (AI) dietician and intelligent fridge. Jim enquires about the yoghurt – "Yes, this yoghurt has less sugar", Jim's smart speaker informs him.

Jim leaves home and walks to the bus stop; he is reminded by his (EHE) that this helps keep him healthy, but most importantly, helps him stay fit enough to keep up with his daughter, Jennie, when they play football together on Saturdays.

As Jim boards the bus, his (EHE) reminds him he's got a video consultation with a doctor once he arrives at work, in 20 minutes. Jim's (EHE) integrates all health and health-related data about Jim including social demographic data, food and alcohol consumption, physical activity, clinical measurements and his genome. Jim's (EHE) noticed his blood pressure, measured by his wearable health device, had been high consistently for past few weeks so it took 24-hour ambulatory measurements yesterday ahead of his video consultation today.

Jim's (EHE) scans all food and drink barcodes to update his risk trajectory and provide personal advice. This morning, his (EHE) advised against the packet of crisps Jim was going to buy this morning, offering lower-salt alternatives that are 'better for Jim'.

Jim has his video consultation before beginning his shift. He understands his recent dietary changes have helped a little and he should continue with them, but he would also benefit from beginning an anti-hypertensive drug. Jim's (EHE) information is available to his clinician via cloud computing, providing information regarding the most effective drug and dosage for Jim given his genome. Jim and his doctor agree to have another video call in one week to review Jim's blood pressure and new medication.

*NB Throughout this scenario, Jim and his family have given their permission for data about them to be used in selected circumstances.*

## Box 10.2 Vision for Machine Learning in Cystic Fibrosis

*Text kindly supplied by Oli Raynor and Mihaela van der Schaar*

In Cystic Fibrosis (CF), patients have to continuously make life-changing decisions, and sometimes 'life and death' decisions, on the basis of data and evidence about the 'average' person with CF. But we know the 'average' person with CF does not exist. The disease affects people in very different ways. So, population-based evidence is of limited practical value to individuals trying to make medical decisions, manage and plan their lives, and understand their future.

At the same time, people with CF face a gruelling daily burden of self-administered treatment (typically 2-3 hours a day of pills, nebulisers, inhalers, injections, airway clearance and exercise) and there are no days off. There have been major advances in treatment but each new treatment adds to the existing regimen. It is hard to know whether a particular treatment is necessary for an individual at a given time. Are new treatments helping? Are old treatments still necessary?

People with CF also have to go to the clinic every three months for routine appointments, even when well. Cross-infection risks between people with CF mean they are advised not to meet in person – the time when it is hardest to follow this advice is when they attend hospital. This model of care is based on a one size fits all approach.

Machine learning has potential to enable a more personalised model of care based on more individualised characteristics and predictions of health trajectory. Decisions about whether a clinic visit is necessary could be informed by patient-generated health data gathered and recorded on digital devices. In fact, machine learning approaches might even suggest when an individual is about to have an exacerbation and proactively suggest some clinical action. When a new treatment is started, data helps people with CF, and their CF teams, understand whether the treatment is working and, if so, whether other treatments are still necessary.

With the benefit of machine learning, CF could be a less disruptive force in people's lives; they could know whether their treatments are effective or not and they could avoid cross-infection risks by cutting down unnecessary time in the clinic. More generally, people with CF will have the information they need to manage, and make better informed decisions about, their healthcare, their lives and their futures. The burden of treatment could lessen, both as a result of removing unnecessary treatment components and by the willpower-conserving impact of knowing whether specific treatments are really helping or not. As we all know, it is easier to do something unpleasant or inconvenient if you know it is going to help you.

A model of care like this could also help demonstrate the economic case for the high-priced disease-modifying therapies that typically target specific genotypes within the population of people with CF. It could lighten the load on the CF healthcare system as the population of people with CF grows due to better survival.

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## Chapter 11

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# Emerging technologies – population scale impacts

### Chapter lead

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## 01 Introduction

A range of personal, social, economic and environmental factors influence health status as health determinants. The United States (US) Department of Human Health and Health Services' Office of Disease Prevention and Health Promotion broadly groups health determinants into policymaking, social factors, health services, individual behaviour and biological and genetics.<sup>1</sup> The interrelationship among these factors drive individual and population health.

There are unfolding technological mega-trends that have the potential to significantly affect population health factors in the coming decades. Specifically, around health services, individual behaviour, biology and genetics there are ongoing inflection points that are likely to radically alter health determinants related to them. This presents both challenges and opportunities to improve population health. We want to examine some of these technological trends with highest potential to affect health determinants by 2040, so that they can be considered in planning and policy making.

We are now living in an age of unparalleled scientific breakthroughs. Breakthroughs due to significant progress in individual scientific fields are increasingly accompanied by breakthroughs due to megatrends, which arise from the convergence of knowledge across fields. Megatrends that are converging include computational power, the emergence of big data sciences, the emergence of artificial intelligence, breakthroughs in micro-fluidics, and material sciences for new bio-sensing, wearables, ubiquitous connectivity etc. These breakthroughs and megatrends can have significant, positive impacts on the health of the population including through revolutions in neuroscience, regenerative medicine, personalised medicine, drug discovery,

## 02 Trends in population health

Data in population health suggest a series of trends that are likely to drive significant requirements for evolving health care delivery. Over the medium term, population life expectancy in the United Kingdom (UK) continues to outperform expected numbers, suggesting that people overall will live longer and necessitate shifts into healthcare delivery models that will be appropriate for an ageing population.

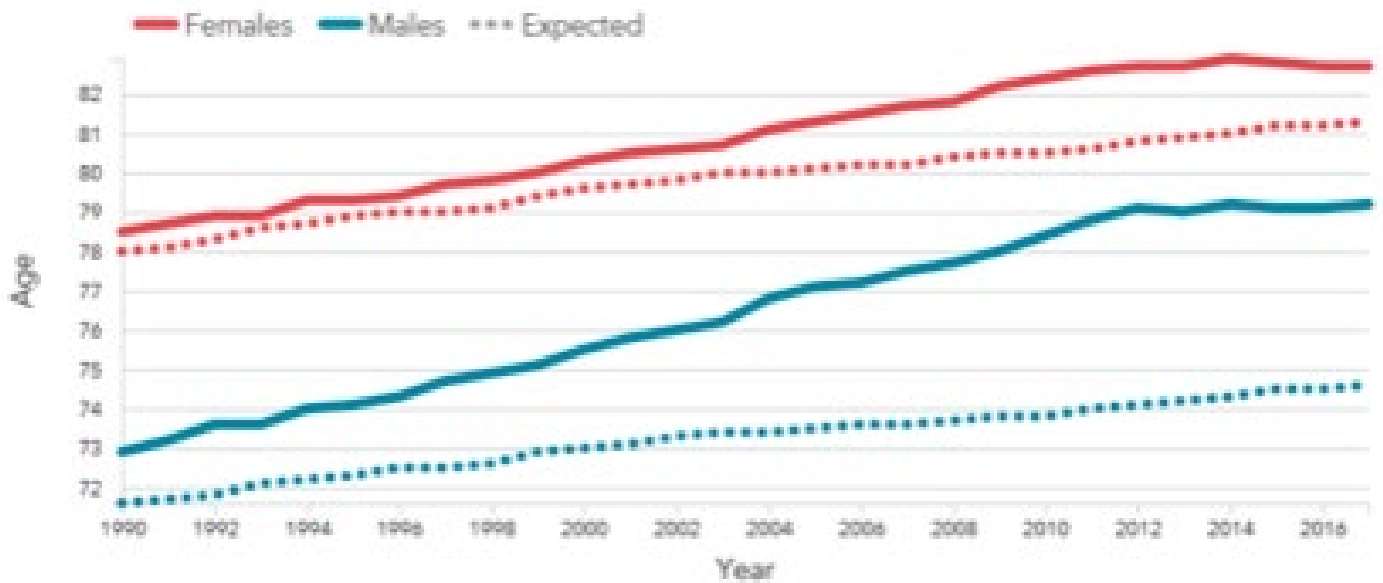
The impact of an ageing population is evolving the disease burden as well as the population scale of morbidity and mortality. This suggests an evolution in healthcare delivery is needed and technology has a role in it. Evidence of this can already be seen in the evolution of the burden of disease for the UK. While this data is for the UK overall, England is a significant contributor to these trends, and is substantially represented in this data. While ischemic and heart disease continue to be the leading cause of mortality, as a per cent change in the 2007-2017 period its burden shrunk by 13.4%, (Figure 11.2). In the same period, Alzheimer's disease became the second leading cause of death and grew by 31.3%.

When looking at the trends associated with death and disability we similarly see significant increases on disability-adjusted life-years growth from Alzheimer's disease, back and neck pain, sense organ disease, depression, migraine and COPD. We see reductions in ischemic heart disease and cardiovascular disease, likely due to the emphasis in prevention and the impact of improved treatments in those diseases.

From the perspective of driving health determinants, alcohol and drug abuse exhibit growth in the top ten risk factors, while most other risk factors are exhibiting negative rates. This is evidence of the continuing progress of public health interventions.<sup>2</sup>

The growing, ageing population will significantly increase the disease burden. This is likely to become increasingly difficult to manage if we continue to rely on secondary and tertiary care, without triaging patients effectively in primary care and/or improving access to routine care outside of the healthcare system.

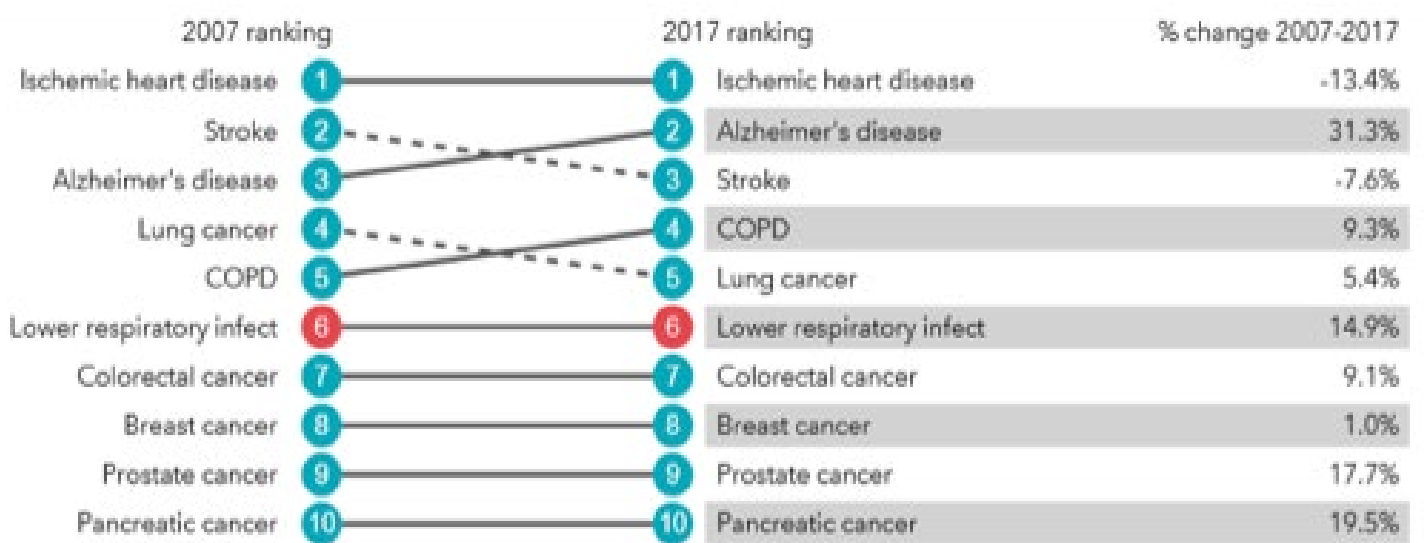
**Figure 11.1** Life expectancy in the United Kingdom, 1990-2017



	Expected		Observed	
	1990	2017	1990	2017
<b>Females</b>	78.0	81.3	78.5	82.7
<b>Males</b>	71.6	74.6	72.9	79.2

Source Institute for Health Metrics and Evaluation, available online <http://www.healthdata.org/united-kingdom>

**Figure 11.2** Top 10 causes of death (all ages) in 2017 in the United Kingdom and per cent change, 2007-2017



Source Institute for Health Metrics and Evaluation, available online <http://www.healthdata.org/united-kingdom>

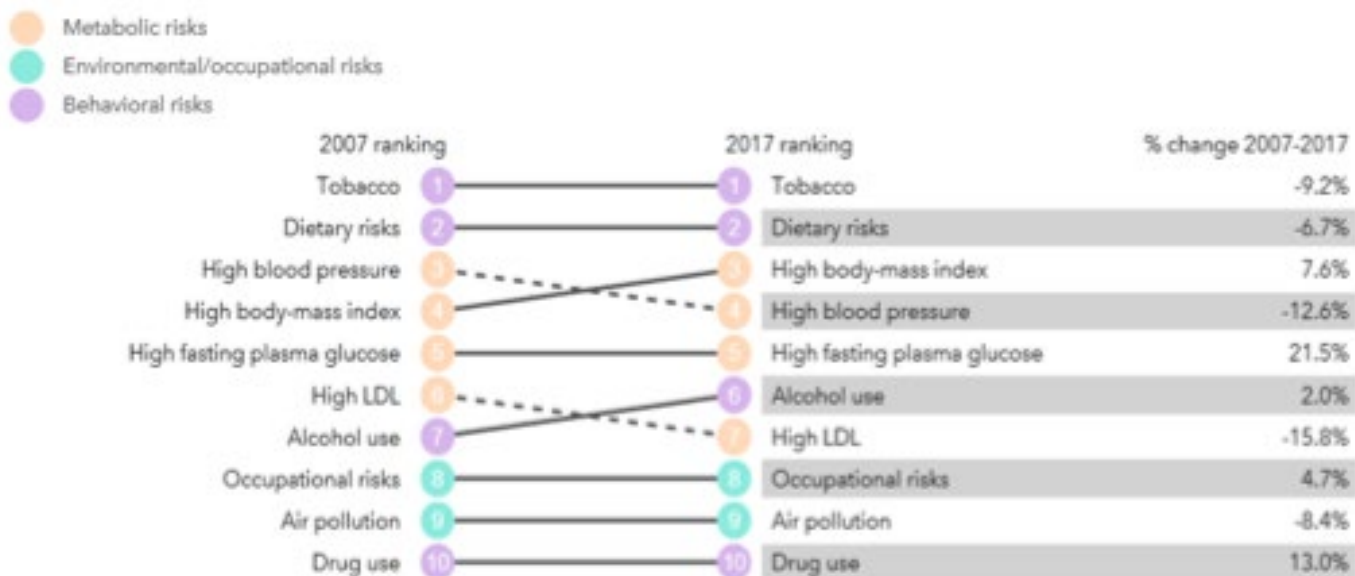
**Figure 11.3 Top 10 causes of disability-adjusted life years (DALY) in 2017 in the United Kingdom and per cent changes, 2007-2017**



Source Institute for Health Metrics and Evaluation, available online <http://www.healthdata.org/united-kingdom>

**Figure 11.4 Top 10 risks contributing to DALYs in 2016 in the United Kingdom and per cent change, 2007-2017**

## What risk factors drive the most death and disability combined?



Source Institute for Health Metrics and Evaluation, available online <http://www.healthdata.org/united-kingdom>



## 03 Reinventing Primary Care

Technology is likely to be a critical enabler for change in the role of primary care so that clinical decisions and treatments can be offered at the lowest level of care, without compromising effectiveness and quality of outcomes.

Digital transformation is likely to play a key role in a 2040 scenario of health delivery. The care that patients receive – and the methods in which hospitals deliver care – has been dramatically transformed with the introduction of advanced technologies and the increasing availability of data. Systems of record like electronic medical records (EMRs) have laid the foundation for intelligent healthcare. Applying advanced analytics to massive amounts of data from internal and external sources like clinical analytics and environmental systems can help health organisations glean deeper insights. These systems of insight are the next evolution of digital transformation. With better access to the right data at the right time, you can reduce operating costs, improve the quality of care, increase the involvement of consumers in the care process, and optimise provider satisfaction.<sup>3</sup>

Unstructured data is the information that resides outside of organized databases such as electronic health records and laboratory reports. If we become capable of tapping the potential of that data, we could make patient care more efficient and cost-effective than ever before.<sup>4</sup>

Utilising a combination of clinical analytics and operational analytics, unstructured data can be combined with emerging technologies to use the data and analytics to improve clinical treatment processes and outcomes. Clinicians could for example, pull insights from data to help identify at-risk patients and deliver optimal treatments. Sophisticated analytics engines enhanced through machine learning and AI can provide evidence that can inform actions.

Operational analytics focuses on the use of data and analytics to improve the efficiency or effectiveness of systems used to provide and manage care processes. By using AI, for example, healthcare teams can predict operational issues and track safety metrics, monitor equipment health, maintain the integrity of the supply chain, and identify fraud.<sup>5</sup>

Although not yet widespread, some AI-powered, consumer-operated diagnostic and monitoring devices are already on the market, including, as an example, a smartphone device that captures digital images of the ear canal and sends them to a physician for diagnosis of possible infection. Smartphones from leading manufacturers are also incorporating built-in heart rate monitors. And some pioneering companies are offering online services they say can evaluate digital photos of rashes, moles, and skin conditions and then connect consumers with physicians for consultation.

Some harbingers of AI's future applications dramatically expand these capabilities.

Self-serve, consumer-friendly diagnostic tools could replace the routine work of primary care physicians, freeing them up for more complex patient care. Care providers would just have to confirm the results indicated by a patient's device and follow up with treatment plans, negating the need for an office visit. According to a 2015 clinician survey, 42% of US doctors say they are willing to prescribe medications based on the results of consumer-operated diagnostic technologies. Widespread use of these technologies could mean big cost savings. Researchers developing a strep throat test for consumer use estimate that the device has the potential to eliminate 780,000 doctor visits in the US a year, resulting in \$94 million in savings annually.<sup>4</sup>

By 2040 the most significant trend expected to emerge is predictive care guidance, which will use analytical solutions to search through large amounts of data from sources like EMRs, smart medical devices, patient and population demographics, and the public domain to find hidden patterns and trends and predict outcomes for individual patients. Most predictive care guidance relies on AI learning models that become more precise when additional data and cases are introduced.

Predictive analytics is akin to a data-driven crystal ball, taking analytics to the next level, beyond descriptive or diagnostic methods that look backwards on what happened and why. Predictive care guidance enables clinicians to determine the likelihood of disease and helps with determining diagnoses and predicting future wellness or illness. Predictive care guidance can improve the quality of healthcare and reduce the costs of care. It provides clinicians with answers they're seeking for individual patients, with a focus on increasing the accuracy of diagnoses.

The availability of predictive analytics and guidance are likely to empower clinicians in primary care to make valid clinical decisions that previously were the purview of specialist settings. They are also likely to improve the epidemiology of disease and plan public health responses.

Some examples of outcomes that could use analytical models to connect symptoms to treatments are:

- Clinical pathway prediction - assess and predict which treatment option will likely produce the best outcome for a patient.
- Drug effectiveness - predict which drug will produce the best outcome for a patient.
- Disease progression prediction - predict the likely path and progression of a disease.
- Behaviour changes - technology enabled personal tools are already driving significant improvements in non-communicable diseases behaviour changes at the patient level.

Implications also exist for commissioners and providers of health services. These tools could also improve:

- Health risk prediction - predict the likelihood that a patient presenting a certain set of symptoms is at risk for an adverse health event.
- Predictive risk scoring - assess which patients might be at risk for readmissions and hospital-acquired infections.

Some of these tools are finding their way in clinical practice already. As an example, an artificial intelligence tool launched by Ochsner Health System in the US analyses thousands of data points to predict which patients will deteriorate soon. Built with a machine learning platform, the tool triggers alerts to prompt Ochsner's care teams to intervene and proactively treat patients and prevent emergency situations. During a 90-day pilot with the tool, Ochsner was able to reduce the hospital's typical number of codes (cardiac or respiratory arrests) by 44%. In addition to sending pre-code alerts, this predictive model can predict any patient deterioration that needs attention, based on lab values, vital signs, and other data.<sup>3</sup>

## 04 Population health and precision medicine

Population health strives to influence the delivery of care to a group of individuals that have similar healthcare needs, as opposed to focusing on evaluating and treating medical conditions one patient at a time. Combined with improvements in diagnostics and the correct data analytics, population health approaches are likely to be disruptive in key clinical delivery areas such as the following examples.

### **Integrated care**

Health care will become integrated care – coordinated treatment across care team members, including clinicians, social workers, physical therapists, and behavioural health care professionals. Analytics can help identify and measure the effectiveness of care across all care settings.

### **Specialty care**

Use data to determine the best ways to manage health needs and outcomes for entire populations of people suffering from chronic conditions as well as effectively segment population subgroups for which one treatment has greater outcomes.

### **Patient engagement**

Empower patients to more effectively manage their own health and participate in the decision-making process to improve outcomes. Population health also has the potential to affect commissions and providers of health services.

### **Self-care management**

Use patient data to improve patients' understanding of their role in their wellness, help them stay healthier, and reduce the cost per service.

### **Cost management**

Manage the health of populations by creating better outcomes at an efficient cost by the addition of new technologies. Several critical technology trends are occurring because of the evolution of diagnostics. Artificial intelligence is one aspect of this evolution. Other aspects of this revolution relate to genetic and genomic applications, as well as emerging applications of metabolomics and epigenetics. All these sciences are in rapid evolution and several new capabilities are likely to dramatically affect clinical practice.<sup>5</sup>

This is starting to happen already. As an example, scientists and physicians at Johns Hopkins Medicine in the US are gathering huge amounts of data from medical care, genomics, and wearable devices to predict disease progression and pinpoint individual treatments. They're examining individual diseases by looking deeply into their subgroups. Because patients in the same disease subgroups are likely to have the same biological conditions and show the same response to treatments, researchers can use this information to discover mechanisms that drive specific diseases. The team is conducting data investigations of patients treated for prostate cancer, multiple sclerosis, cardiac arrhythmias, amyotrophic lateral sclerosis, and more – to improve diagnoses, prevention tactics, and cures.<sup>3</sup>

### **Point of care diagnostics**

In the diagnostic space, rapid, point-of-care, or even at-home tests with high predictive value, are emerging. New biomarkers that can predict not only specific conditions, but also "severity" of conditions are also emerging. An example of this is quantitative data on Ang-2 and sTREM-1 as biomarkers of severity from all cause fevers, which are now being developed into rapid tests for triage applications.<sup>5</sup>

Additionally, the continuing decrease of the cost of sequencing and the availability of low cost, automated and multiplexed nucleic acid amplification techniques (NAAT) are likely to drive advanced testing to the point of care. Recently CRISPR techniques have shown potentials for diagnostic applications and the space of molecular testing is undergoing dramatic evolution. It is safe to forecast that we are heading towards an age of simple blood tests that can be performed at point-of-care that can identify markers of diseases for virtually all targets. This will have a dramatic effect on clinical care, triage and outcomes, and to the extent that these tests require no specialist interpretation or delivery they are also likely to affect the cost of care.<sup>6</sup>

While central laboratories will still play a leading role for high throughput assays, as well as reference methods, the ability for the point-of-care and primary care to rapidly assess a patient, triage the patient to secondary and tertiary care if needed, could increase the effectiveness of primary care while reducing cost.

### **Host response measurements**

Additionally, the availability of these type of tests as well as novel microbiological assays such as digital culture assays will enable the ability to monitor treatment response at point-of-care as well as manage drug resistance. This will have significant impact on health outcomes as increasingly there is evidence that a "one-size-fits-all" approach to treatment is not effective. Near real time host response, drug susceptibility and precision treatments promise to be transformational for infective disease management, such as lower respiratory infections, sepsis and inflammatory diseases at the center of significant mortality. Novel treatments relating to immunology, such as new onco-immunological treatments will also benefit from rapid measurement of immune responses. By 2040 we expect this to be the face of personalised medicine, where genetic markers of diseases, accurate binning of patients to treatment groups and customised treatments are combined under monitored individual responses using these techniques. Most of this should be available at the point of care.

## 05 Image intelligence

Medical image intelligence is the embedding of analytical capabilities into images to augment or improve diagnostic and treatment planning processes. Medical images represent one of the largest categories of unstructured data used in healthcare. Specialists (including radiologists, oncologists, ophthalmologists, and others) are trained to evaluate medical images to assess medical conditions, make diagnoses, and deliver treatments based on their reading of these images. Analytics technologies can increase the effectiveness of these efforts. The quality of the automated analytics will increase access to medical imaging interpretation at the lowest level of the healthcare system and relegate human interpretation to very complex and specialised assessments. Increasingly the use of techniques like deep learning and machine learning are not only automating interpretation but also discovering new clinical correlations. For the first time the 'machine' can teach the 'humans' new medicine as it identifies biomarkers in the image data that correlate well with disease.

Examples are recent results around cervical cancer diagnosis, where machine learning applications applied to cervical imaging via colposcopy are showing significantly improved predictive value over human interpretation. Large clinical data sets following women over many years with clinical outcomes correlated with visual colposcopy where used as a training set for a new machine learning algorithm is capable of using an ordinary camera-phone. This is capable of taking an ordinary cervical image and identify pre-cancerous lesions significantly better than ordinary colposcopy as well as better than cytology.<sup>7</sup> The example of the cervical application illustrates a case where machine learning could be discovering new correlations, which is now advancing medicine by identifying novel biomarkers of diseases.

These techniques are also promising to extend the capabilities of certain modalities beyond the conventionally assumed role. An example is ultrasound. Ultrasound is becoming increasingly inexpensive, portable and rapidly converging to smartphone form factors. It is further attractive among modalities as it is not based on ionising radiation. Ultrasound however has traditionally not been thought of as useful for certain types of assays, for example, lung pathology.

In recent results, scientists at the Global Good Fund, the Intellectual Ventures Laboratory and the Oregon Health and Sciences University, have shown that machine learning techniques applied to lung ultrasound imaging have better predictive value in lung pathology, including pneumonia diagnosis, than the standard of care Xrays.<sup>8</sup> By 2040 it is envisioned that smartphone imaging modalities with artificial intelligence applications and transducers for ultrasound might be as common a tool for physicians as today's stethoscope.

## 06 Continuous monitoring

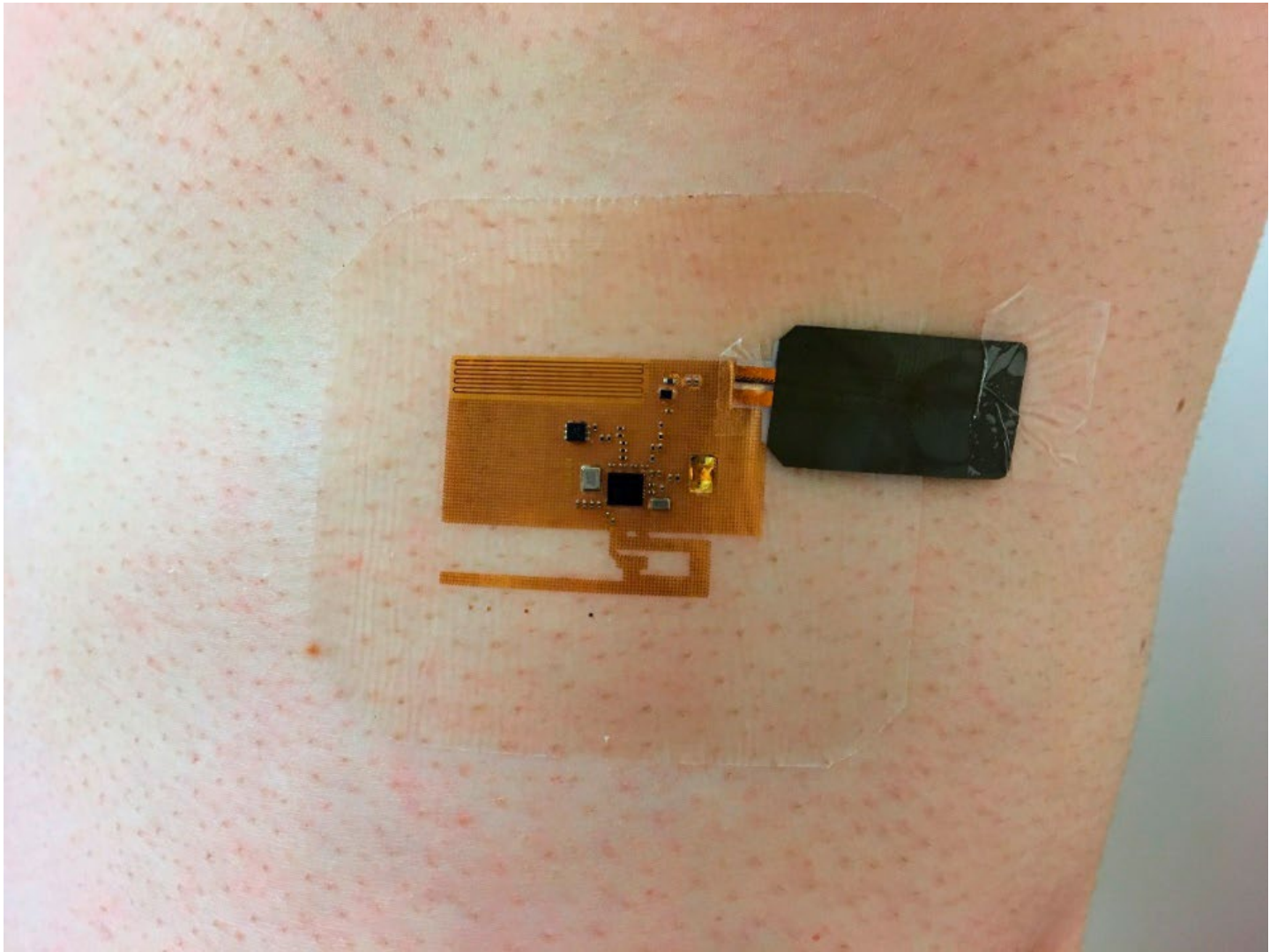
Wearable technology combined with novel bio-sensors promises to unleash new capabilities for continuous monitoring. This could be transformational in enabling chronic disease management outside of traditional clinical settings. Devices that can monitor patients on a continuous basis and can provide real time analytics on trends are likely to have high value on treatment response, compliance and predictive value of outcomes. New health determinants are likely to be discovered when such analytics are able to be applied to population scale data sets.

Since patients with chronic conditions consume more than 75% of healthcare spending this has the potential for dramatic cost reductions while maintaining or improving health outcome. Two significant capabilities are converging to bring about this technology-based revolution. Material sciences have progressed in the area of bio-sensing where electronic devices applied to novel materials, membrane and microfluidics devices can make sensors that can measure a variety of signals in continuous mode. Electrical signals such as electrocardiograms are already a reality inside wearable consumer products such as smart watches. But increasingly 'lab-on-chip' on flexible patches are converging with bio-sensors capable of molecular scale volatile and other chemistry analysis. One can envision real-time glucose monitoring through sweat, pathogen detection through breath analysis and similar modalities.

Novel biosensors of this type have been built on inexpensive, band-aid like patches such as those prototyped by at the University of California in San Diego, where complex circuitry is embedded on flexible, breathable wearable patches at a cost that makes the whole system disposable.

Data streams from such systems represent ideal data sets, when combined with outcomes to provide analytical inference through machine learning. This area might be the way new medical discoveries are made by 2040. Patterns in physiological responses, measured continuously and over long terms analysed by machine learning algorithms might become better indicators of drug efficacy than traditional analytical techniques. They might also aid discovery of new treatments.

**Figure 11.5** Image of wearable patch, suitable for extended human use



## Note

- a) Image shown is of an intelligent, disposable, wearable patch with complex circuitry and power module, suitable for skin contact and extended human use
- b) Examples of possible applications could be sensors to provide continuous monitoring in connection with premature births (paediatric NIC on a chip); cardiovascular continuous monitoring combined with oxygen saturation; continuous monitoring for blood glucose.

Source *Courtesy of Todd Coleman's Laboratory, University of California San Diego, Department of Bioengineering*

### 07 Driving behaviour change for non-communicable diseases

The use of wearable and mobile technology has already been shown to affect patient behaviour. In a variety of low-resource countries, the use of mobile alerts and reminders with pregnant mothers, has for example, significantly improved prenatal and maternal health outcomes. Most significantly evidence exists that repeated reminders have the potential to increase significantly compliance and treatment adherence across the spectrum of non-communicable diseases (NCDs).

With the emergence of continuous monitoring, feedback directly to the patient for behaviour change in near real time shows the potential to alter not only treatment but also prevention. We can envision that by 2040 a plethora of consumer technology will incorporate behaviour changing feedbacks to drive patient-centric improved behaviour. This could be a strategic component of prevention and treatment for the future, with the potential to keep patients at home and out of clinics.

An interesting question is raised, in the ownership of such data. If every patient contributes to data sets that can be mined for new medical discovery, what should the patient's privacy rights be and should the patient be compensated for contributing to such discovery? What are the roles of government in both facilitating access to such data and maintaining data privacy? By 2040 these issues could lead to a transformation of how medical services are paid for, where patients might "contribute" their data as a form of payment for treatments.

### 08 Personalised treatments

We will not attempt to review here all the advancements associated with therapeutic technologies which are likely to revolutionise care in the future. We will limit to suggest that advances in personalised therapies enabled by the genomic revolution are likely to enable highly targeted therapies and even the ability to "edit" disease genes prior to disease emergence with technologies such CRISPR. Key drivers will be the continuing decrease of the cost of sequencing, expected to drop below \$100 in the not-too distant future.

New ethical questions are emerging on how to regulate genetic editing capabilities, and an urgent question of the right policy environment to enable the medical potential of these technologies within an ethical environment. Another likely driver of therapeutic revolution is the use of immunology to target disease. Cancer immunology is promising in stimulating the body immune system to seek and destroy a cancer.

An example is CAR-T therapy, or chimeric antigen receptor therapy, is an immunological treatment that uses the body's own immune system to destroy cancerous cells. Normally, a person's T-cells are responsible for detecting noncancerous "intruders," such as viruses and bacteria.

This kind of technology promises to unleash an era of not only more effective treatments to diseases like cancers but event to possibility of creating a sort of "cancer vaccine" in the future.

## 09 In-silico medicine

Integrated data-driven healthcare delivery, patient centric and precision medicine all require rethinking of the healthcare delivery models. High speed of technology evolution also requires increasingly deliberate delivery of resources at a time when those resources are increasingly scarce, due in part to the population health trends discussed earlier.

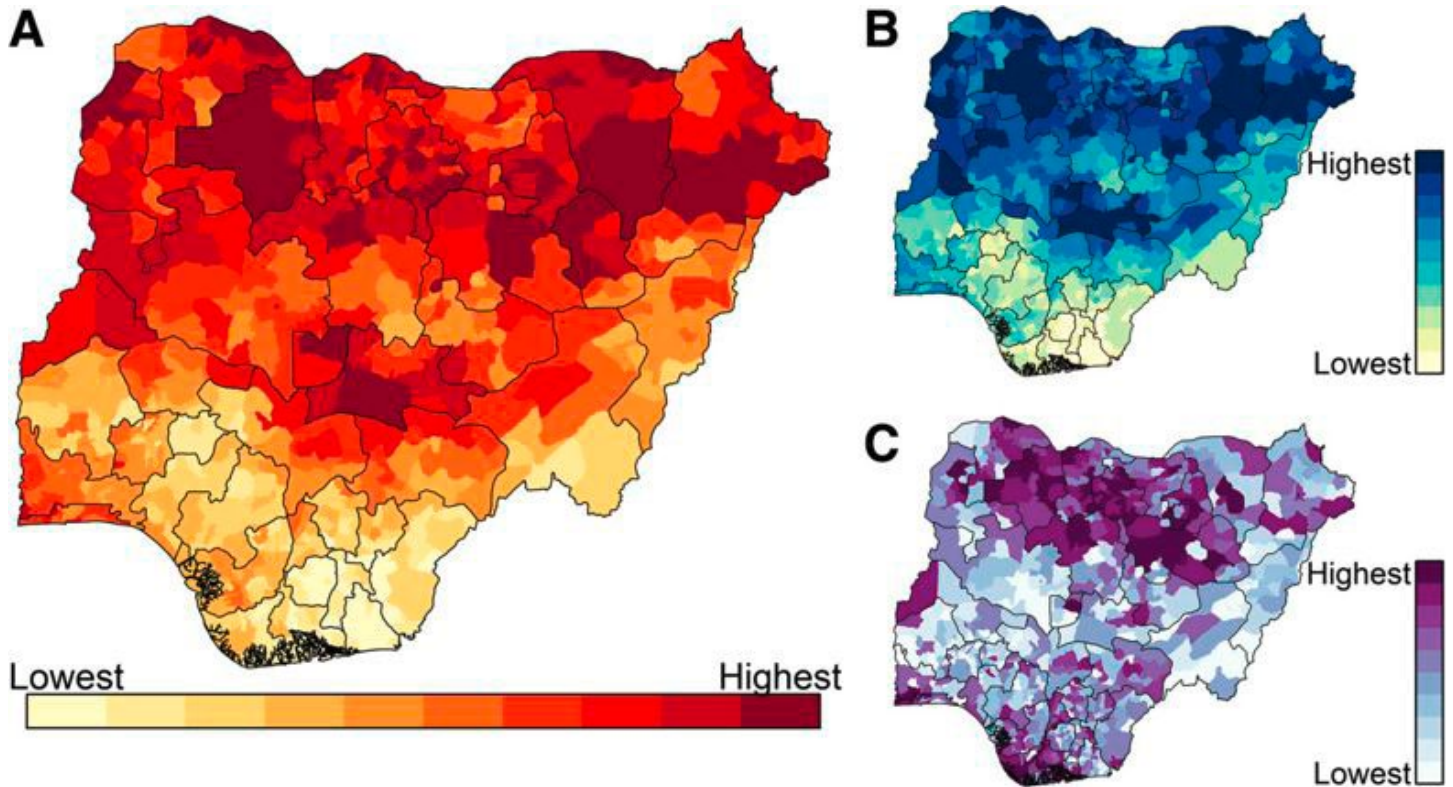
Increasingly predictive models can be used to test public health interventions in-silico. The availability of rich data sets from the trends discussed before should make it possible for the healthcare system to develop risk-mapping at the sub-national level, model epidemiology and have predictive models that enable policy makers and provides to optimise care for individual populations.

These techniques are already in use in the context of infective disease eradication programs globally. The Institute of Disease Modeling, a unit of the Global Good Fund in the US, for example has developed massive agent-based models of populations in target countries and has demonstrated the ability to create predictive risk maps for disease outbreaks up to six months in advance, with excellent predictive value. These techniques are being used to guide the eradication of polio, as an example.

Some of these techniques can also be used to supplement sparse or incomplete data sets. Agent-based simulation provides a window on disease whose prevalence might be highly heterogeneous, as in the case of polio where the campaign is nearing elimination. This makes these techniques also very applicable to public health risks in advanced countries where population epidemiology and disease risk might be equally heterogeneous. The ability to produce these types of risk maps on a periodic update basis provide insight on the effectiveness of intervention on a population scale. In the examples for Nigeria and Pakistan these risk mapping exercises are being produced semi-annually to support their respective public health policy plans (see Figures 11.7 and 11.8).

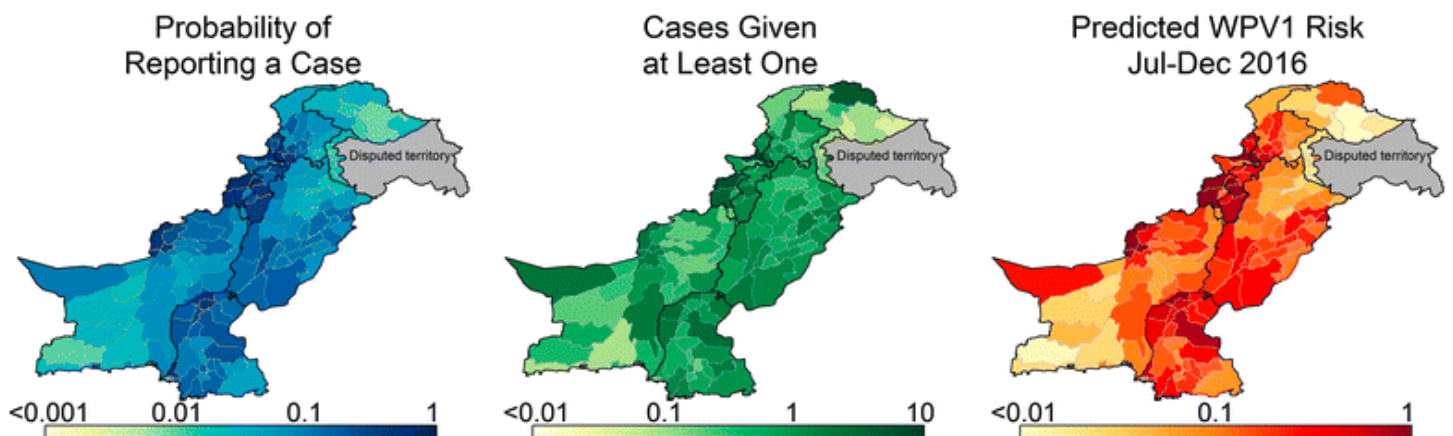
The notion of simulating, in-silico, an intervention prior to implementation can also be applied to discovery of new drugs. Increasingly these kinds of stochastic simulations are being combined with machine learning and mechanistic models to study molecular targets or optimise targets for optimal binding efficiency or other outcomes. By 2040 it is likely that data and simulation-driven drug discovery and optimisation will be a reality.

Figure 11.6 Polio risk maps for Nigeria



Source Global Good Fund and the Institute for Disease Modeling (Upfill-Brown AM et al., 2014. Predictive spatial risk model of poliovirus to aid prioritization and hasten eradication in Nigeria.)

Figure 11.7 Polio risk maps for Pakistan



Source Global Good Fund and the Institute for Disease Modeling. (Mercer LD et al., 2017. Spatial model for risk prediction and sub-national prioritization to aid poliovirus eradication in Pakistan.)



## 10 Author's suggestions for policy makers

Based on the trends discussed here, the author makes the following policy recommendations.

### ***Routine use of algorithms for decision support***

Innovation today is focused on using algorithms to make decisions. Complex algorithms are increasingly able to diagnose patients more accurately than clinicians. Even simple models built on large data sets can transform clinical practice. This can also apply to the efficiency of hospitals and primary care facilities.

### ***Evolution to precision medicine***

Today most treatments decisions follow standardised guidelines based on clinical trials. However, participants in clinical trials tend to differ from treatment populations in the real world, which can limit the predictive power of the published evidence. The policy environment needs to facilitate the emergence of precision treatments based on genetic data.

### ***The rapid evolution of technology will challenge the regulatory and ethical environment***

The role of government will be to introduce agility in the regulatory environment, considering the implications of learning systems and precision medicine. It will be essential for policy makers to understand the scientific and technological trends in which their regulatory system operates. It is advised that technical advisory boards help inform the policy environment.

### ***Data will become a national asset***

It is essential that the policy environments facilitate the emergence of large data which is usable in discovery and clinical practice, at the population scale. This might be more important in emerging data-driven and artificial intelligence medicine than algorithmic evolution. Policy makers should think about their ability to manage such large data sets as a "national asset" of both strategic and financial value. It might very well be that countries which can manage these data driven population scale data sets will be at the centre of tomorrow's innovation in medicine.

### ***Data will democratise medicine***

The individual citizen will be the "owner" of his data. However this data is only valuable when aggregated at the population scale and linked to outcomes. Government and Citizens need to develop a grand partnership in incentivising individuals to participate in the development of national data sets. New business models for healthcare delivery trading data for care might emerge. This might represent an evolution of universal care coverage and other reimbursements schemes might evolve. Policy makers should be at the forefront of these trends.

### ***Health care should emphasise improved primary care***

Technology is supporting an evolution of care out of secondary and tertiary specialized care and into primary and even at-home care for a majority of patients. This is because new technologies are creating the ability for point of care to offer high quality care at equal or even superior than acute care settings for many conditions. Triaging patients to bring only those that need the more acute or specialised care will become critical to maintain high quality while providing cost-efficient care in the future.

### Box 11.1 Personalised DNA-based dietary guidelines to nudge the public to better health

*Text kindly supplied by Chris Toumazou, Caroline Golden and Philip J. Kitson of DnaNudge and Imperial College London, Maria Karvela of DnaNudge*

*Please note – this is one example of such technology and should not be read as an endorsement by the Chief Medical Officer*

DnaNudge technology takes the power of the information encoded in an individual's DNA and puts it in their hands. Using lab-on-chip technology, DnaNudge can look for variations in a person's genetic code, known as single nucleotide polymorphisms (SNPs), using a swab of saliva from the inside of their cheek. Using a Nudgebox, DNA from the saliva is extracted, amplified and analysed to determine the presence of SNPs linked to metabolic traits. The Nudgebox works with the camera of the user's smart phone to read the genetic results in as little as 30 minutes. The genetic results are combined with proprietary algorithms that integrate the latest nutrigenetic research, national dietary guidelines, and the nutritional information of thousands of food products, to provide the user with personalised, DNA-based dietary guidelines. Via a genetic report, users can learn about their predisposition to metabolic traits such as sugar sensitivity.

Users are able to scan food products to find out if they are recommended for them according to their DNA using a simple traffic light system; green for recommended, red for not recommended. This can be performed using the camera on their smart phone in the barcode scanning function of the DnaNudge app, or using the DnaBand, a quick, point-of-decision technology that has been integrated into a wearable. If they scan a 'red' product e.g. a chocolate bar, they will be recommended alternative chocolate bars that are more suited to their DNA. Using NudgeShare, users can incorporate the recommendations of family members and through a simple scan, they can determine if the food product is good for the family, and if not, which alternative food products would be best for everyone as a whole.

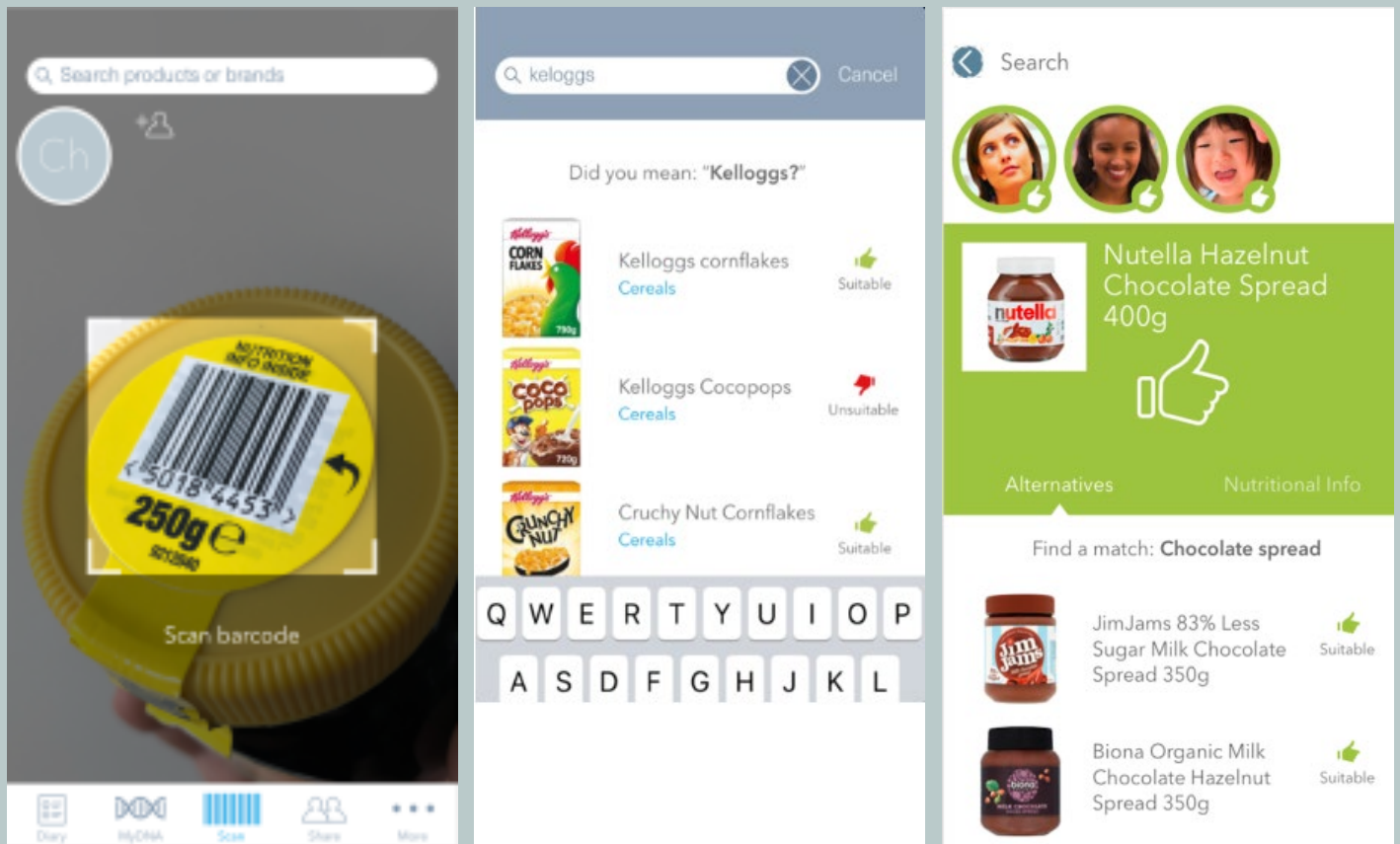
The technology is focused on primary prevention, improving health before ill health. By educating individuals about their body, and providing dietary nudges that are tailored to them, DnaNudge technology empowers the individual to make informed decisions quickly, easily, and for all members of

the family. DnaNudge is keen to engage the whole family in becoming more informed about what a healthy diet is for them. By using NudgeMatch, users can create a social network using the technology. Users can decide which genetic traits they want to find a match for, and with a simply click of the band, they can find their match. This technique can be used for social accountability, where finding a genetic match of someone healthier can provide inspiration to make better food choices. Through social networking and DNA traits, people can start connecting and comparing lifestyle options as well as genetics. It brings children into the technology by gamifying how many greens they can get before they can "unlock" the genetic traits of their favourite footballer or tennis player, and see if they match. By having the motivation to get "greens", children will have the desire to know more about what makes a product green, and can encourage their parents to buy less "reds". Through education and nudging, DnaNudge can help shift public health in a positive direction.

DnaNudge technology is also targeting secondary prevention in healthcare. It is collaborating with Imperial College London to conduct a clinical trial to examine how this technology can improve glucose regulation in pre-diabetic individuals. The effect of DNA-based dietary guidelines is being compared against standard care for individuals with impaired glucose regulation. A third arm of the trial is determining if the intervention can be delivered effectively through the DnaNudge App. If effective, this will be a low-cost, scalable intervention to arrest progression to type 2 diabetes. Moreover, it will circumvent the screening issue common to many national diabetes prevention programs. People will no longer need to self-identify as pre-diabetic to receive the benefits, as the App is targeted at improving overall health. Thus, the technology can provide secondary prevention to individuals who have impaired glucose regulation, and primary prevention to the general public.

## Box 11.1 continued

Figure A Features of the DnaNudge app



### Note

- (i) Users can shop using their personalised app by scanning the barcodes of food products.
- (ii) The product will then appear green or red indicating that it is recommended for them or not.
- (iii) NudgeShare enables users to see whether the product is recommended for their friends and family.

### Box 11.2 Cartridge Based API Synthesis

*Text kindly supplied by Leroy Cronin and Philip J. Kitson, School of Chemistry, University of Glasgow*

*Please note - this is one example of such technology and should not be read as an endorsement by the Chief Medical Officer.*

The manufacture of active pharmaceutical ingredients (APIs) is vital for modern healthcare, yet critical drugs are regularly manufactured for a finite period in a limited number of sites. The manufacture of chemical products, whether they be bulk, fine or specialty chemicals, such as APIs, is currently based on a model whereby a central plant is exclusively designed for the manufacture of the product, or range of products, sold by that particular company, these large scale plants are often at the mercy of complicated and global supply chains of raw materials, the failure of which at any point will reduce or halt the capacity of the plant to produce materials and deliver them effectively. Also, when a given complex intermediate or API goes out of production, the plants are often repurposed and the manufacturing capacity is lost.

The reinstatement of the process would require, in the best case, substantial capital investment to reconfigure a chemical plant for its synthesis.

To alleviate this issue, we are developing a concept whereby the large-scale manufacturing process of complex fine chemicals, such as APIs are augmented by distributed, point-of-use manufacturing in self-contained cartridges, requiring limited user interaction to produce the desired products on demand. We are developing a methodology for the translation of bench-scale synthesis procedures into a step-by-step workflow which can be used to create digital designs for custom reactionware that can be fabricated using 3D printing technologies. This methodology, allows for the distribution of simple chemical precursors and solvents rather than the complex products themselves.

Also, the translation of these synthetic approaches into a digitally defined format, where the reactor design and, eventually, an automated synthesis procedure are encoded, will allow the digitization of chemical products into a very low cost manufacturing format. This could allow large numbers of discontinued APIs to be made available as they can be brought back into production on a small scale by the fabrication and use of the appropriate cartridges. In our recent publications we have demonstrated this approach in the synthesis of the anti-convulsant medication ( $\pm$ )-baclofen.

**Figure A Image of a 3-D printing mechanism**



*Source Leroy Cronin and Philip J. Kitson, University of Glasgow*

## Box 11.3 Next generation Brain Computer Interfaces

*Text kindly supplied by Dr Jinendra Ekanayake, Wellcome Trust Centre for Surgical Sciences/NHNN and Dr Timothy Constandinou, Reader in Neural Microsystems and Deputy Director of the Centre for Bio-inspired Technology at Imperial College London*

Brain computer interfaces (BCI) aim to replace, restore or enhance the normal pathway of brain-directed neural signals as a means of controlling bodily functions. By directly implanting an electronic device onto neural tissue, neuronal activity can be extracted from a target brain region and converted into a command signal. This can be used to enslave a prosthetic device, or as a trigger to reactivate damaged brain regions. The current state-of-the-art typically requires bulky, wired implants with poor cosmetic profiles, powered by a single use, surgically implanted battery. The devices themselves record or stimulate at a comparatively crude resolution applied to macroscopic areas of brain or spinal cord.

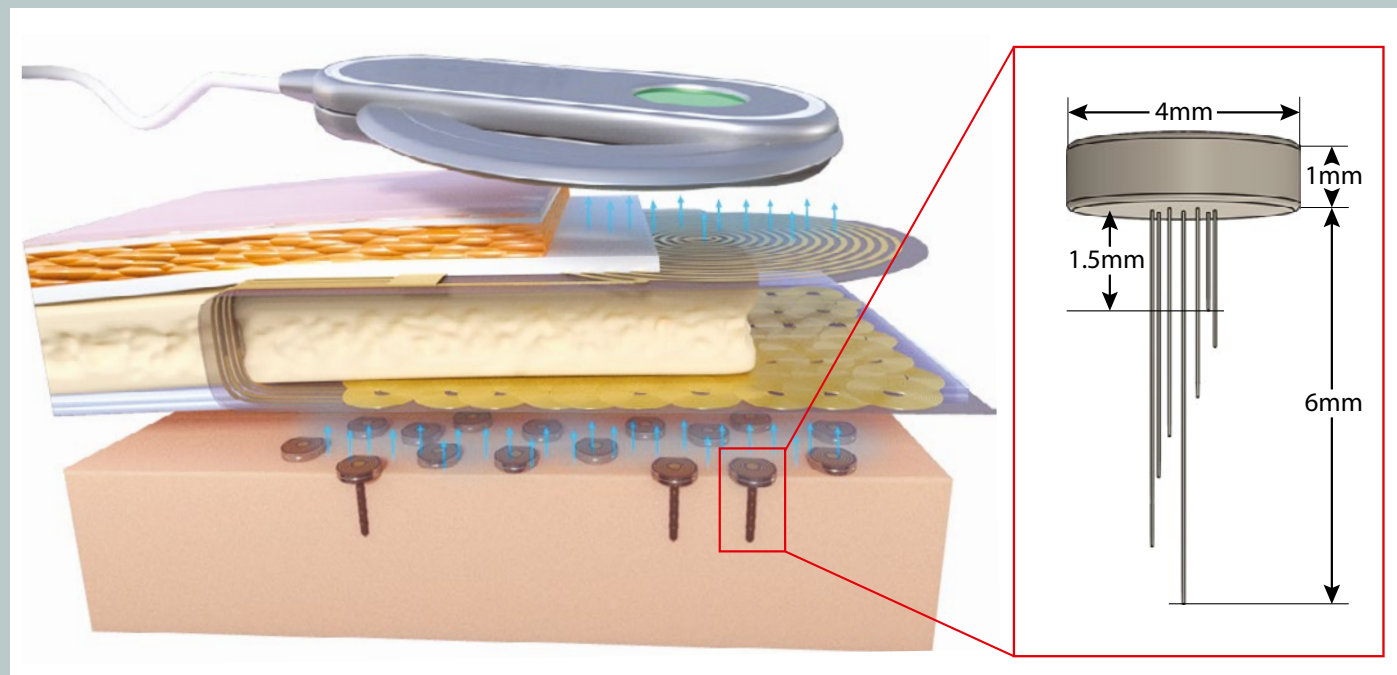
The trajectory of implantable BCI is geared towards wireless miniaturisation, improvement in signal quality by selectively interfacing with nervous tissue on the sub-mm scale, and distribution across multiple cortical and subcortical sites. The ENGINI platform (Empowering Next Generation Implantable Neural Interfaces) combines a family of innovations that address these key challenges.<sup>1</sup>

It has 3 components: 1) multiple mm-scale subdural implants for intracortical recording; 2) a customised skull substitute with an embedded transponder and; 3) an external battery transponder (Figure A). Each implant, comparable to Neural Drawing Pins, contains a fully integrated wireless recording system that is capable of power management, signal amplification and data telemetry. The micropackage utilises ultra-low power instrumentation and hermetically sealing to ensure stability with chronic use. The probes span cortical layers (Figure B), providing access to granular information at the level of neural microcircuits between cortical layers.<sup>2</sup> The aim will be to provide both 'read-out' and 'write-in' capabilities for recording and modulating neural activity.

By interfacing with distributed brain regions across multiple layers, complex dynamical networks of brain activity can be observed. This will be essential for understanding and re-producing human behaviour from brain activity using BCIs. Multi-receiver transducer architectures for multiple implants, as outlined here, can be paired with machine learning algorithms to enable analysis of multiple distributed recording and stimulation sites, simultaneously. This approach can be leveraged for neurological disorders that typically affect multiple brain areas, enabling treatment at the scale of neuronal cell bodies, with the promise of inducing highly focused neural plasticity with paired wireless electrical stimulation and biologics.

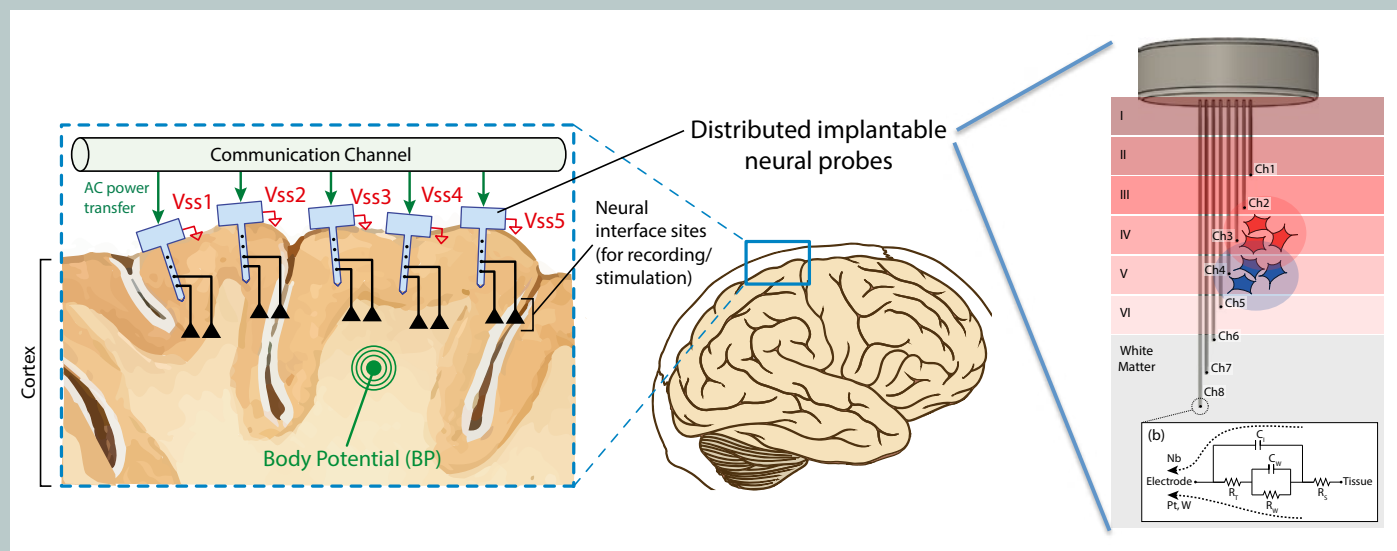
Comparable approaches, currently in early stages of development, include Neurograins<sup>3</sup> (Brown University, USA) (Figure C) and Neural dust<sup>4</sup> (UC Berkeley, USA), which utilise implants the size of grains of salt. Tissue action potentials are read by showering the implants with radiofrequency or ultrasound waves, which also provides power. The resulting 'back-scatter' is read wirelessly and externally.

**Figure A** ENGINI platform concept showing 3 tier architecture for wireless power/data transfer. A single probe is shown with dimensions



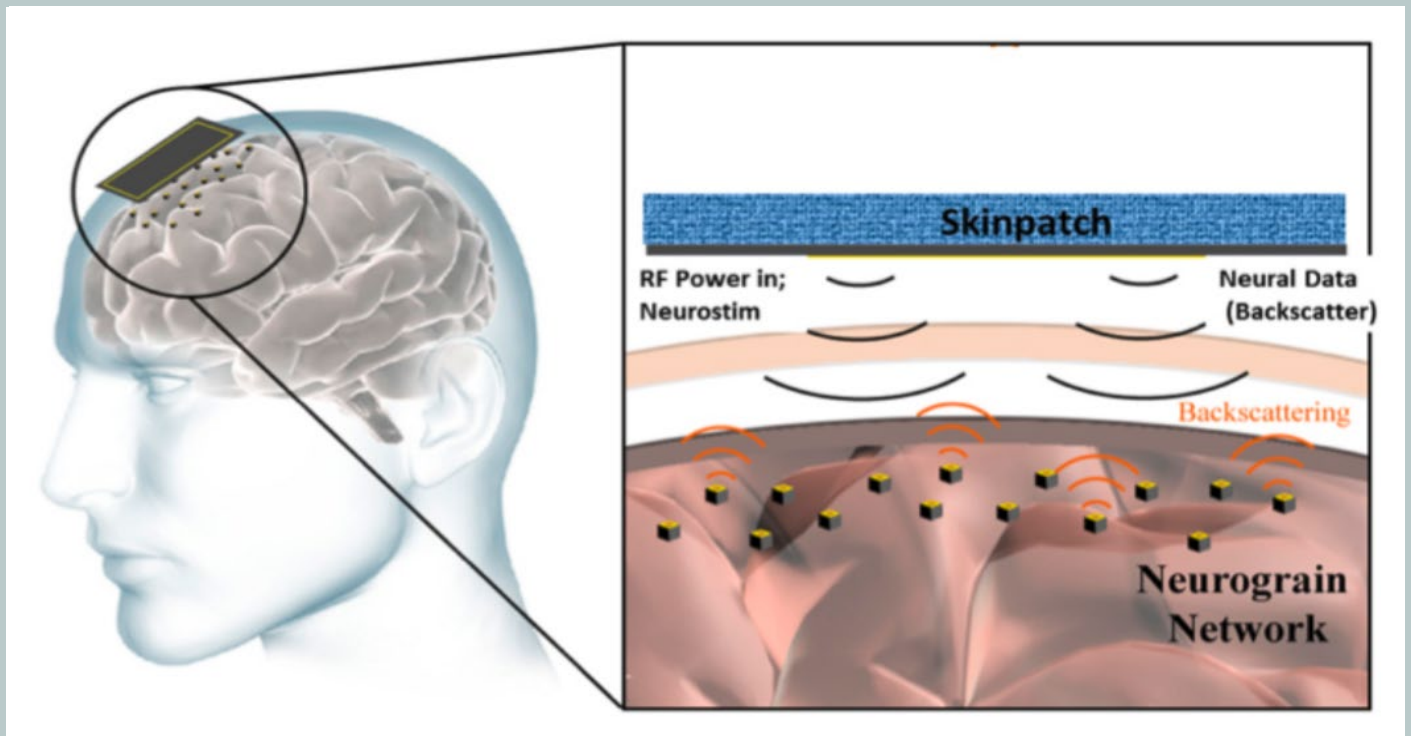
Source Imperial College London

**Figure B** Single cortical implant spanning the neocortical layers (II-VI), and distributed across the cortical surface



Source Imperial College London

**Figure C** Schematic of the 'Neurograins' system, which intends to establish a 'cortical intranet' of multiple implants



Source *Imperial College London*

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## Chapter 12

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# Emerging technologies in healthcare

### Chapter lead

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## 01 Introduction

Artificial intelligence could help take us one step closer to a range of other advanced technologies being developed in medicine. As a technology whose potential lies in getting the right information to the right clinician at the right time in the right form they can be used to improve care. Artificial intelligence could allow clinicians to get a much more precise grasp of patients' specific treatment needs and accelerate the rollout of information-intensive technologies, such as biopharmaceuticals, personalised medicine, genomics, the identification of applications for stem cells, and the development of new drugs.

However, the productive and sustainable use of artificial intelligence in healthcare will require policymakers to overcome a number of challenges to wider implementation relating to the availability and quality of data; data governance and compensation; public confidence; the digital readiness of the health service and its staff; and longer-term questions about liability and ethics.

Artificial intelligence (AI)<sup>1</sup> is not the only example of the advanced technologies that will define healthcare by 2040, but AI will likely be the development that enables and enhances many of the other developments in advanced technologies over the coming decades.

The promise of AI has waxed and waned since the 1950s as research approaches and resources have fluctuated. However, the field has been undergoing a consistent renaissance over the last decade, driven by a combination of increasing computing power, the availability of large datasets, and new techniques inspired by advances in theoretical understanding.

AI is a term with multiple meanings, which can confuse efforts to understand its uses. 'General AI' refers to research into whether generalist human intelligence can be replicated or augmented in machine form. These efforts are in their infancy. 'Narrow AI' involves the application of highly complex, probabilistic algorithms to a narrow range of purposes, such as picking out signs of disease in a medical scan. This constitutes the vast bulk of current research into AI today.

Most of what should be called 'AI systems' today are a narrow subset of machine learning algorithms known as deep learning. Simply put, deep learning involves constructing a hierarchy of mathematical models, known as neural networks, which process input data as a huge series of interlinked, probabilistic calculations. As these systems are exposed to input data to produce a specific kind of output, the way the system interprets input data changes. This is what is meant when researchers talk of "training" a machine learning system.

Progress in the field continues apace. Where two years ago machines were making great strides in game-playing, consistently beating world champions at the extremely

complex game of Go,<sup>1</sup> AI is now starting to make an impact in real-world settings. Google parent Alphabet's autonomous driving unit Waymo became the first company to declare over 8 million miles of self-driving in July 2018,<sup>2</sup> and University of Iowa Health Care became the first hospital in the United States to deploy an artificially intelligent diagnostic device in direct clinical care in June 2018.<sup>3</sup>

AI excites researchers because it can handle vast quantities of complex data with an enormous range of variables, known as "high dimensionality data," to produce inferences and recommendations that are easily tractable by humans and other machines. Put simply, where traditional computing involves handling relatively simple operations, such as  $1+1=2$ , or displaying graphics on a screen, AI systems try to answer highly complex, probabilistic questions, such as: "How likely is it that the lesion in this medical scan is cancerous?" Such systems can assess huge amounts of information, such as a patient's medical record or weather patterns, producing a clear recommendation for a clinician or climatologist.

Currently, AI systems are most fruitfully applied to problems whose boundaries can be relatively clearly defined, such as identifying signs of cancer on a medical scan, or playing a board game. There are many such problems in medicine that AI promises to transform, and many studies demonstrate that it can achieve 'expert level' or 'better-than-expert-level' performance in a number of practical applications.<sup>4-9</sup>

Most of these early applications involve using deep learning to analyse medical images and digital pathology according to a restricted classification system – the likeliest early areas of mainstream AI applications in healthcare. However, by 2040, AI systems that analyse a patient's test results, medical scans and data from wearables and connected devices in the home will give clinicians a much more thorough understanding of a patient's condition, allowing clinicians to deliver personalised, precise diagnoses and treatments, often preventively.

AI will also integrate with new approaches in precision medicine, biopharmaceuticals and medical genetics to begin to offer systematically personalised healthcare. The ability of an AI system to synthesise disparate information alongside a vast library of prior medical cases far beyond the memory of any one human clinician will also mean AI systems can free human experts from the time-consuming work of medical analysis and information gathering, instead allowing them to focus on the personal elements of patient care. Widespread adoption of AI systems, if carefully considered and thoughtfully deployed, should lead to a more human, precise and attentive healthcare system that allows clinicians to focus on the needs of the individual, and can contribute to better shared decision-making.

AI will likely have reached a point of sophistication by 2040 that it should help make health systems more sustainable.

\* By AI, we mean the use of deep learning algorithms that are trained to perform specific tasks by extracting patterns and information from a set of data, without humans programming how to achieve this.

Because AI systems can analyse vast amounts of information, they offer a way to handle the increasingly complex medical requirements of ageing populations: helping ensure that expensive medical interventions and treatments are used in a much more targeted fashion, before patients become seriously unwell.

Getting there, however, will involve new approaches to research design that are centred around patients and clinicians, to ensure AI addresses genuine clinical need. And, as with any novel proof-of-concept technology, independent clinical trials must be conducted and appropriate regulatory systems and processes put in place to ensure that the medical use of AI is evidence-based. This will help ensure their effectiveness and improve public confidence that these technologies can be sufficiently and safely deployed.

In addition, AI raises a number of unique challenges that must be confronted before it can be widely deployed in healthcare systems.

Firstly, deep learning requires large amounts of highly detailed medical information to function safely and effectively. To ensure there is public confidence in AI-assisted healthcare, the use of this technology must not undermine the confidentiality of patient information, and nor can it infringe on patients' rights to know how and why their data is being processed.

Secondly, due consideration also needs to be given to real-world medical data, without which the training and validation of machine learning models would, in many cases, be impossible. As the Department of Health and Social Care's draft code of conduct into the use of AI in healthcare (published September 2018) makes clear,<sup>10</sup> financial benefits derived from the development and use of these technologies should be equitably distributed, so taxpayer-funded healthcare systems receive a fair return for the data they make available. And if machine learning systems are trained on datasets that do not fully represent the patient populations whose treatment resulting algorithms are intended to support, we risk incorporating bias that has the potential to distort, rather than improve, healthcare outcomes.

Thirdly, the health service must be digitally ready. AI cannot be easily integrated into a system that predominantly relies on pagers, paper lists and fax machines, so modern digital technologies will be an important stepping stone before we can realise the full potential of AI-enabled healthcare.

Finally, over the long term, it is possible that highly sophisticated AI systems could replace the judgement of qualified medical professionals. If that happens, and AI systems begin taking decisions of legal (and moral) consequence, such as providing a medical diagnosis, then this will raise new questions of liability, ethics, and compensation that require due consideration in an appropriate regulatory framework.

Ultimately, the NHS is in a good position to take advantage of the potential of new technologies. The UK has spearheaded many advances in healthcare over the decades, such as the invention of the CT scanner, and so has a long track record of technological innovation. The NHS also boasts world-leading hospitals and clinicians, supported by a strong regulatory and research governance regime that encourages responsible innovation. That means there is real potential for the UK and the NHS to be a pioneer in the thoughtful, careful and effective clinical deployment of advanced technologies in healthcare.

### 02 The present landscape

To understand how advanced technologies could improve healthcare, it is important to assess the current state of healthcare provision. Four points stand out for our purposes.

Firstly, the ageing population means care is generally becoming more complex. Patients who live longer are more likely to develop multiple comorbidities, the interplay of which presents harder challenges for caregivers to solve. For example, providing fluids is often an important part of treatment for a patient with renal failure, but this can exacerbate forms of heart failure. The more comorbidities, the harder a patient's case often becomes to treat.

Secondly, the continued development of new therapies means there are now more treatment options than there were 20 years ago, further complicating treatment plans.

Thirdly, the NHS, like other health systems, lags behind other industries when it comes to the use of digital technologies. Studies show that there are significant potential benefits to be realised from the greater use of smartphone technologies by clinicians.<sup>11,12</sup> International surveys suggest that clinicians are spending an excessive amount of time doing administrative work,<sup>13</sup> while there is evidence that clinicians who use digital documentation support software spend more time interacting with patients than those who do not, which could suggest potential improvements in efficiency.<sup>14</sup>

Fourthly, across the NHS, patients receive different standards of care depending on the availability of clinical expertise at local health services, with variations in care pathways

common, exacerbated by varying provision of social and community care. Increasing efforts to standardise pathways nationally to improve patient outcomes, such as the introduction of a nationally mandated algorithm for acute kidney injury in 2014<sup>15</sup> and an updated national early warning score in 2017,<sup>16</sup> are helping to identify acutely ill patients at an earlier opportunity, but are not, alone, a 'silver bullet'.

Currently, one in ten NHS patients suffers some form of avoidable harm in hospital,<sup>17,18</sup> often because early warning signs about a deterioration in their condition are not picked up on in time.<sup>19</sup> In addition, the patient experience is often characterised by delays: delays in admission to hospital, delays of progression through the emergency department, delays in getting treatment from a specialist, and delays in the discharge of patients to social and post-hospital care.

Too often, the promise of better technology for the NHS has led to increased costs without significant improvements in outcomes. Current efforts in AI research aim to change this picture in small ways. A recent study at MIT suggests machine learning could help predict whether high-risk breast lesions on mammograms are in fact truly cancerous, potentially reducing the number of unnecessary surgeries by 30%.<sup>20</sup> Similarly, Chen et al.<sup>21</sup> discuss a system that can predict how stroke patients will respond to treatment, helping clinicians devise better care plans. Studies such as these suggest a potential way to square the circle of improving outcomes while reducing costs: increasing the effectiveness of treatment through more targeted, precise interventions.

## 03 The potential of 2040

AI could be the single biggest feature unlocking the full potential of other promising advanced technologies being developed in medicine, such as biopharmaceuticals, personalised medicine, genomics, the identification of applications for stem cells, and the development of new drugs. This is because each of these developments, and others like them, are primarily about using data and technology to achieve a much more precise grasp of potential treatment needs, both at the patient and population level. AI is all about getting the right information to the right clinician at the right time and in the right form that they can act on it to deliver improved clinical interventions, so it could accelerate the clinical applicability and rollout of such technologies in medical care.

### 3.1 Areas of application

AI systems outlined in the academic literature have a wide range of potential applications in detection and diagnosis, fewer potential applications in monitoring disease, and currently the fewest potential uses in treatment. While some researchers and organisations are exploring the identification of new treatment targets and molecules (such as BenevolentAI, which aims to synthesise scientific breakthroughs to assist with drug development<sup>22</sup>), most current work focuses on clinical decision support.

More ambitious future efforts on diagnostics will therefore focus on replacing, rather than augmenting, some elements of clinical decision making. An early example is the IDx-DR system, approved for use in live clinical care by the US Food and Drug Administration in April 2018,<sup>23</sup> which aims to improve diagnosis of blinding eye diseases in the community before a referral for treatment. The system thus still primarily serves a triage function, allowing appropriate escalation for urgent cases to human specialists. Crucially, however, those triage decisions are not confirmed by a human clinician.

In the future, autonomous diagnostic systems will compare incoming patient cases with an immense repository of historic cases, outcomes and established best practice. By automating the process of information-gathering that currently defines much of a clinician's work, such systems could therefore allow clinicians to redirect their time on human tasks while also improving the quality of decisions made about patient care.

Over the long term, AI could also help facilitate the establishment of a truly preventive healthcare system. Because AI systems can synthesise high dimensionality data, they can potentially draw out inferences from data that human clinicians might miss or not think to explore. This offers the possibility of pushing disease prevention further upstream into the field of prediction by making better use of more data to improve care. Acute care and deterioration will be the likely initial areas of focus, as AI's advanced data analytics and predictive inferences improve existing efforts at

the algorithmic standardisation of care, such as the National Early Warning Score and the AKI algorithm, to help stop the progression of diseases such as cancer, renal failure, sepsis and pneumonia before damage sets in.<sup>9\*</sup>

Wider risk factors are currently considered in some algorithmic approaches, but it will take the development of effective AI before they can reach their full potential. For example, the QRISK cardiovascular disease risk calculator<sup>24</sup> is an improvement on earlier tools because it includes a wider range of risk factors, such as social deprivation, family history and other demographic and social determinants. However, the algorithm's rules are 'hand-drawn' in advance, which leads to an inflexible algorithm whose rules have to be hand-coded and that is hard to update.

AI could have two distinct advantages over such systems. Firstly, AI systems can self-improve over time as they gain experience through exposure to more data. Secondly, AI can tease out signals among high-dimensional data that humans would not and could not programme a computer to spot. AI can identify unexpected inferences between speech patterns on emergency calls to better triage potential cases of out-of-hospital cardiac arrest.<sup>24</sup> This is one of AI's biggest areas of potential: generating new knowledge from existing data.

This means AI could improve on existing algorithms, such as QRISK, to tease out potential signals of disease from a wider range of data, including behavioural risk factor data and information about wider social determinants, that existing algorithms cannot incorporate without manual programming. By making a wider range of data tractable and making connections humans would not otherwise incorporate, AI can help make sharper predictions about future health that clinicians can act on to target prevention resources more effectively.

We have already noted how AI could make medical treatments more precise by reducing the number of unnecessary procedures and false diagnoses. Genetic medicine promises much the same result. Its advocates argue that future medicine will take into account each person's unique variation on the human genome to determine their susceptibility and responses to disease and treatment. Armed with an understanding of a patient's genome, clinicians can use a wider range of variables to produce a more detailed classification of patients into more fine-grained subpopulations for diagnosis and treatment.

\* See Rajpurkar et al. (2017) for an early proof-of-concept applying AI to pneumonia care.

Personal genetic data thus has a particularly high dimensionality – it represents the unique genetic code of an individual encompassing over three billion pieces of information.<sup>13</sup> So AI will help realise the potential of precision genetic medicine, reducing high-dimensional data to inferences and recommendations that clinicians can review and use to plan precise preventive or therapeutic interventions.

AI is likely to have a similar enabling effect on other high dimensional domains, such as drug discovery and evaluation, the development of biopharmaceuticals, the identification of applications for stem cells, and other moves towards precision medicine. In each case, the advanced technology could build a fuller clinical picture of individual patients' treatment needs to improve outcomes and reduce costs.

AI may also begin to play a role in therapeutics, particularly outside of acute care. For example, the growth of digital mental health consultations could be combined with advances in natural language processing to help improve understanding and enhance interactions between patients and therapists. As natural language processing grows in sophistication, it could replace human therapists, potentially eliminating geographic disparities in access to mental health services. One potential area of application is avatar therapy: Craig et al.<sup>25</sup> describe a system whereby patients with schizophrenia engage in face-to-face discussion with a digital avatar representing their auditory hallucinations, which can help reduce symptoms when used in conjunction with usual treatment.

Finally, AI could help to transform clinicians' working lives. Poissant et al.<sup>26</sup> suggest that many electronic health record (EHR) systems consistently fail in their goal of reducing documentation time; some clinicians may in fact spend more time managing EHRs than caring for patients.<sup>13</sup> The use of electronic health records (EHR) is contributing to clinicians' stress,<sup>27</sup> and the American Agency for Healthcare Research and Quality argues that the use of EHR systems is contributing to burnout.<sup>28</sup> However, more accurate and real-time voice-to-text transcription will help improve healthcare logistics and back office functions by automating prescriptions, automatically writing chart notes, radiology and pathology reports, and ordering tests. The automation of information retrieval and analysis will offer clinicians more time to care, making medical jobs more enjoyable and less stressful. In turn, that could help improve staff retention rates.

### 3.2 The potential impact of advanced technologies on health

Over the next few years, immediate applications of AI are likely to lead to a reduction in the number of unnecessary medical procedures and more timely prioritised medical interventions for patients whose condition is deteriorating. Novel use cases will proliferate beyond the medical imaging cases that are currently best documented in the literature: recent developments, for example, include the use of an AI system to analyse emergency calls, thus helping responders better prioritise cases of out-of-hospital cardiac arrest.<sup>24</sup>

However, medical imaging will continue to be a consistent early application for AI because of its potential to streamline the detection, diagnosis and monitoring of disease, lightening radiology workloads for clinicians so they can focus on priority patient cases. It is also expected to contribute to other areas: evidence suggests robot-assisted surgery could also both improve patient outcomes and reduce costs, with AI systems analysing data from pre-operative scans and medical records to guide surgeons in real time. One recent study recorded reductions in both postoperative surgical complications and patients' length of stay, suggesting potential improvements.<sup>29</sup>

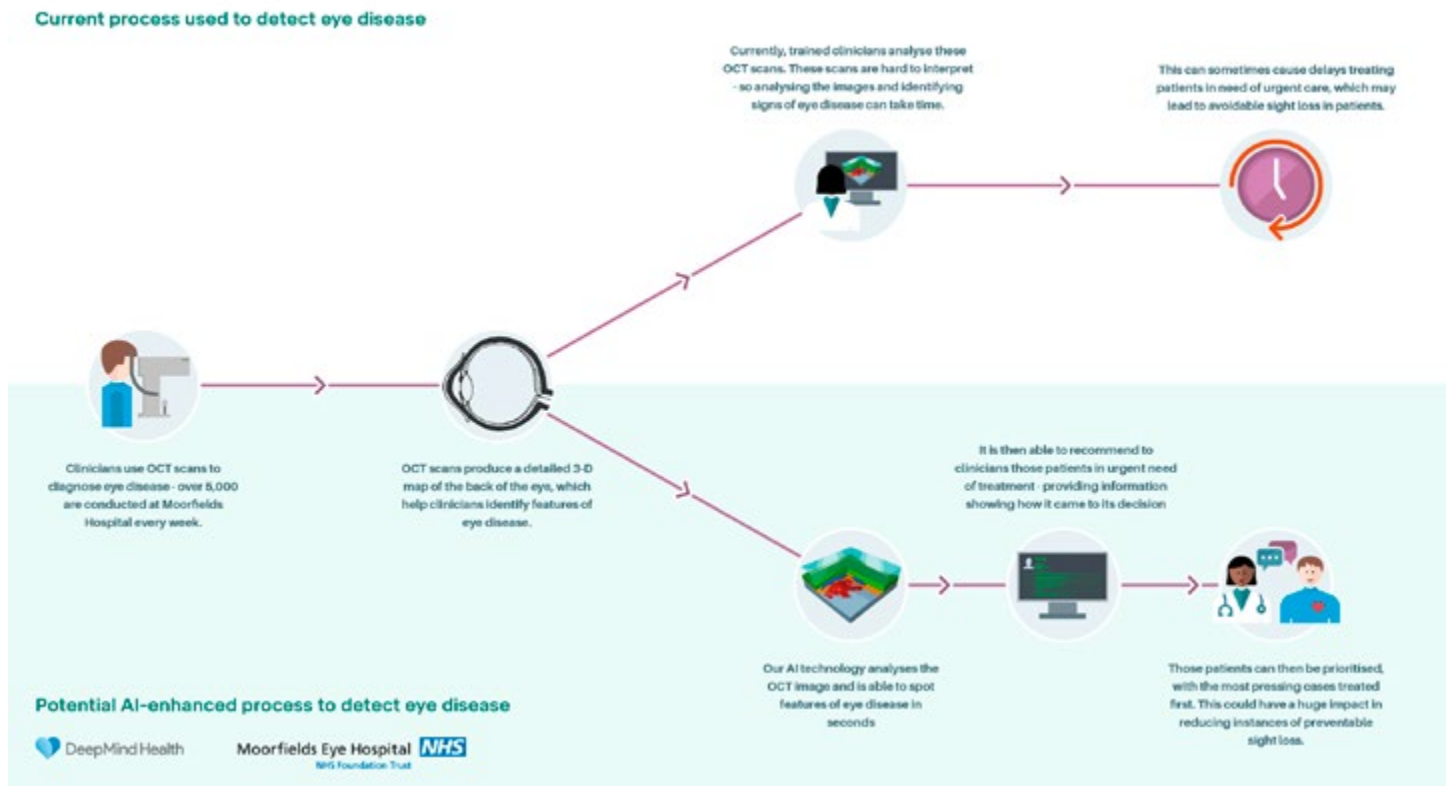
AI's impact on care pathways is likely to be more complicated. The introduction of AI-enabled precision medicine could obviate the need for rigid care pathways, with AI providing a greater understanding of a patient's response to preventive and therapeutic treatments to support more flexible, evidence-based patient journeys through the care system.

AI could also help reduce regional disparities in healthcare outcomes. DeepMind's recent work with Moorfields Eye Hospital suggests one way this could be implemented in practice: De Fauw et al.<sup>30</sup> describe a novel proof-of-concept system that can analyse optical coherence tomography scans and recommend the correct treatment referral for over 50 eye diseases at expert-level accuracy (Figure 12.1) Such a system could triage patients presenting with symptoms at the community level, generalising gold-standard initial assessments across the healthcare system irrespective of local human clinical expertise. This could ensure patients receive prompt treatment, helping reduce geographical inequalities and save sight.

Similar systems could be used for other conditions where speedy diagnosis is key, such as cancer and heart disease. AI systems could thus reduce geographic disparities by helping best-in-class standardisation of initial review for a range of diseases, helping ensure more equitable outcomes across the health service.

\* Strictly speaking, there are over three billion base pairs on a human genome. See He et al. (2017)

Figure 12.1



Source DeepMind, 2018

## 04 Realising the potential for 2040

### 4.1 Challenges to implementation

There are a number of challenges to wider implementation that the NHS must overcome to reach the full potential of advanced technologies.

Firstly, there is a pressing need for better quality research data. Without it, the use of low-quality data to train AI systems will lead to low-quality algorithms. As part of this, we must ensure that datasets are representative of the patient populations whose care they will be used to help, to reduce the likelihoods that machines entrench or exacerbate unequal outcomes. It also means ensuring that patients' right to opt out is respected while ensuring that opt-outs do not make datasets unrepresentative.

How this data is accessed is also important: only fair, transparent and productive access for research will ensure the development of effective advanced technologies. Making data publicly available, to fast track research, is not likely to be sufficient at meeting information governance standards, and will likely erode public confidence. Instead, a brokerage system that ensures only approved individuals and organisations can use data for clearly defined purposes, safeguarded and policed by appropriate regulators, is more appropriate. A good example is the National Institute for Health Research's proposed AI BioResource,<sup>\*</sup> which has the potential to encourage innovation while protecting patient privacy and preventing data misuse through a robust governance framework. This should also include appropriate penalties for those who attempt to reidentify patients, as well as due consideration of the risks from using datasets together, (since a combination of datasets used together can make reidentification possible in a way that using datasets in isolation does not.) Protections for data used in AI research should also include:

- Technical controls to ensure appropriate data security, such as encryption, installing software updates and technology to identify system intruders.
- Authentication mechanisms to prevent unauthorised access to data, such as two-factor authentication against an approved list of individuals with access rights.
- Information governance training for all employees and contractors with access to data.

Secondly, the NHS needs to become much more digitally mature. Some early progress can be made without this – early real-world uses of AI that allow radiologists to better analyse medical images will plug into existing picture archiving and communications systems on premises.<sup>\*\*</sup> However, many future applications of AI are likely to require a smartphone, wearables or another digital device as an interface between the AI system and the clinician, such as app-based voice-to-text transcription,

or the predictive analysis of medical records, test results and genomic information to recommend treatment plans. These 'intermediary' digital technologies delivering AI-supported care require basic digital infrastructures, such as fast, reliable and secure WiFi, and open-sourced digital design standards to ensure these systems can integrate seamlessly both within hospitals and between primary and secondary care. In the same vein, fully digital healthcare records will be crucial if AI algorithms are to ensure consistently higher standards of care across the health system, particularly when triaging patients at the community level.

Thirdly, public understanding of and approval for new technologies, the use of data and how they improve care are required to ensure patient and public confidence. The authors of this chapter believe that companies designing AI should play an important role in this, explaining first-hand how their technologies work and how they protect patients' rights. We must acknowledge that healthy individuals, patients with disease and healthcare professionals may all have different and valid perspectives on the use of AI technologies.

This will help ensure that advanced technologies do not exacerbate inequalities in health outcomes: the crowdsourcing of data through patient-facing apps shows that many patients are eager to record and harness their data to make it work for them. However, we must ensure that a lack of awareness of the potential of advanced technologies does not prevent less digitally-aware groups from playing a greater role in their own healthcare. This work may thus be a more complicated undertaking than other programmes, given the extent to which science fiction narratives have dominated public discourse about AI.

Fourthly, we must ensure that AI decisions are intelligible to the medical professionals who will decide treatment plans. For example, many AI systems do not provide easy insight into how they reached their recommendations. Such 'black box' systems will likely not be acceptable in medical care – if a clinician is to trust an algorithm's recommendation that a patient's breast lesion is not cancerous, she will want to scrutinise how the algorithm reached its decision to have confidence in its recommendation. However, it should also be noted that the mechanisms of clinicians' own decision-making processes are a black box with many biases – and, as before, we need to ensure that these biases do not creep into the AI systems we design. It is also possible, though unlikely, that we may consider the black box a price worth paying, as we do in some other areas: isoflurane, the most commonly used general anaesthetic, sits on the World Health Organization's list of essential medicines, but the exact way it acts on the body to cause anaesthesia is still not properly understood.

\* The National Institute for Health Research (NIHR) BioResource was established to further clinical research within the UK - researchers are able to select volunteers for studies based on their genetic make-up or on other characteristics, such as markers in their blood cells. For more information see <https://bioresource.nihr.ac.uk/>

\*\* Examples include Zebra Medical (<https://www.zebra-med.com/>) and Arterys (<https://www.arterys.com/>)



## 05 Authors' suggestions for policy makers

Finally, AI-backed medical interventions must also be evidence-based, ideally fully referenced and published so that data limitations and biases in development are understood by users. Retrospective cross-validation with multi-centre trials that are agnostic to the impact of specific equipment and patient populations is a likely gold-standard, though may not be achievable in all circumstances. If so, healthcare regulators should also consider mandating that AI systems only be used on populations matching the inclusion criteria of the dataset against which the system's performance is quantified. And finally, prospective safety studies are likely to precede independent clinical trials of effectiveness – again, these should ideally be registered publicly, to mirror the lessons learned from harmful publication bias in the drug industry.

The NHS could expand and bring together its investment in ready research datasets that are geared towards solving pressing healthcare challenges, developing on early efforts, such as the OPTIMAM mammography database hosted at the Royal Surrey County Hospital in partnership with Cancer Research UK. Ready research datasets will facilitate an acceleration in medical research. They will also obviate the need for third-party researchers to invest time and resources into dataset preparation – in turn, this may result in the NHS being better equipped to negotiate appropriate contractual provisions. The NHS could explore bringing together the various research bodies working on digital healthcare advances, such as the regional digital innovation hubs and Health Data Research UK, into a single unified digital research strategy, to encourage uniform data management standards for AI research.

- The NHS should continue to prioritise its efforts to digitise patient records, to ensure that the digital foundations for equitable access to advanced technologies are in place. This should include NHS-wide bring-your-own-device policies for clinicians, and a national approach to ensuring fast, secure and reliable WiFi is provided across hospitals and community care.
- Advanced technologies in healthcare are all-purpose innovations that require multidisciplinary expertise across healthcare, mathematics, technology and design. The authors of this chapter believe the NHS should invest in skills training in preparation for the widespread use of AI technologies, encompassing a basic level of workforce digital literacy training and new career pathways where health professionals can learn computer science skills (and vice-versa) to create a new cadre of digitally trained healthcare leaders. For that reason, we endorse the recommendation in the interim Topol Review<sup>31</sup> that the Government create new qualifications and professional groups, such as clinical data scientists, medical software engineers and digital medicine specialists.
- Regulatory agencies need to develop effective, ethical and timely approval and monitoring processes for not only the current generation of AI technologies, but future innovations like adaptive algorithms and general-purpose AI. The United Kingdom can lead in the ethical application of effective AI to health, but this requires regulatory frameworks that not only command public confidence, but also are effective and efficient.
- Since AI is a self-improving technology whose effectiveness can depend on access to data, the NHS must encourage an open and interoperable ecosystem to ensure that first-mover advantages in AI are not entrenched, distorting competition. For example, NHS Digital could host open-source FHIR toolkits to make it easier for new advanced technologies to integrate with systems from existing providers.

### Box 12.1 Forward Health - overcoming the disconnect (an app to join up Healthcare)

*Text kindly supplied by Lydia Yarlott and Barney Gilbert of Forward Health.*

*Please note - this is one example of such technology and should not be read as an endorsement by the Chief Medical Officer.*

Forward is a smartphone app which healthcare staff download by choice on their own devices, and which instantly connects them to other users across the NHS. By enabling these connections Forward is changing the way patients move along care pathways. Modern healthcare is increasingly complex and has multidisciplinary, cross-specialty teams at its core. Clinical staff are dealing with a higher volume and turnover of patients than ever before, yet healthcare communication tools have failed to keep up with the pace of change, resulting in failure to coordinate care and silos of information, in a system that cannot afford such inefficiencies. Forward offers an agile, robust solution to these problems, and is an example of a simple, easily implemented technology that represents modern changes in the way healthcare is delivered.

The repercussions of facilitating good communication securely are many and varied, and involve not only time saving and efficiency gains, but improvements in patient satisfaction and outcomes resulting from instant transfer of information, facilitation of rapid, ongoing MDT discussion, and the avoidance of delays when advice and referral can be expedited. Movement of a patient between sites which operate different record keeping systems is currently a challenge – Forward offers a solution which streamlines this process and keeps the patient at the centre of the journey from one NHS organisation to another.

Forward have developed NHS partnerships locally, through referrals and recommendations from clinical champions on the frontlines to an organisation's management (usually in the form of a Chief Information Officer). This model borrows from that of tools like Slack and Dropbox in the corporate sector. It is successful in ensuring buy-in from those who matter most: the clinicians actually using the technology. Clinicians themselves are leading the dissemination process; at Leeds Teaching Hospitals NHS Trust, where a third of clinical staff have chosen to use Forward for clinical communication, organic use cases are varied and evolving. For example, referrals to Dermatology from A and E are now being coordinated on Forward. Previously, patients would be required to reattend for an outpatient appointment when an immediate opinion from a specialist was unavailable – now, this opinion can be sought instantly and remotely, expediting diagnosis and reducing unnecessary follow up. This use case demonstrates how early diagnosis and prevention can be achieved with better transfer of information – connecting GPs directly with hospital specialists could prevent readmission, whilst a patient with a chronic condition in the community could be opportunistically discussed in a

flexible, “virtual” MDT, preventing secondary complications and improving quality of care. In a system which lacks breathing room, tools that enable convenient, reactive opinion seeking and remote connection will be vital in the route to better preventative care.

In the future, tools like Forward may be essential for centralising data. Artificial intelligence technologies now have the ability to learn from population health data and make predictions for individuals, but the ability to deploy these tools relies on freeing information from silos currently embedded in the NHS' digital architecture. Personalised healthcare, a cornerstone of preventative care, is within our grasp, and has the potential to lead to a healthier ageing population with fewer demands on services, but key infrastructures need to develop prior to realising this vision – primarily, the accessibility and flow of information.

Disparate systems in healthcare mean that new technologies must have three core features in common: a) they must be easily adoptable, and adaptable, throughout different types of health facilities and for different health professionals; b) they must seek to improve the accessibility of data they process by design (open APIs and interoperability); c) they must be built with the end user in mind – the clinician, and ultimately, the patient. Only once this is achieved will we be in a position to deploy powerful technologies to bring about a data revolution, transforming the way we think about health at a population and individual level.

**Figure A** Image – using the Forward app



Source Forward Health, 2018.

**Box 12.2 Artificial Intelligence in Ophthalmology - the Moorfields-DeepMind Collaboration**

*Text kindly supplied by Professor Sir Peng Tee Khaw, and Pearse Keane of Moorfields Eye Hospital, London*

*Please note - this is one example of such technology and should not be read as an endorsement by the Chief Medical Officer.*

The UK is a world leader in ophthalmology,<sup>1</sup> and has driven many high-tech advances in areas such as microsurgery (with artificial lens insertion during cataract surgery), medical lasers (including the use of excimer lasers to correct refractive error), and regenerative medicine (with stem cell and gene therapies for both corneal and retinal disease).

Despite these achievements, ophthalmology faces substantial pressure for continued innovation, both in the UK and worldwide. Nearly 10% of all NHS hospital outpatient appointments each year are for eye care (equating to nearly 10 million appointments), a figure second only to orthopaedics.<sup>2</sup> Fortunately, recent breakthroughs in AI – in particular a technique called “deep learning” – offer the potential to address this capacity challenge.

Deep learning uses artificial neural networks as a computational model to discover intricate structure in large, high dimensional datasets.<sup>3</sup> Since 2012, deep learning has brought seismic changes to the technology industry, with major breakthroughs in areas as diverse as speech recognition, natural language translation, robotics, and even self-driving cars.<sup>4</sup> Deep learning may be particularly well suited to the classification of medical images for the purposes of screening, triage, diagnosis, and long-term monitoring.<sup>5</sup>

In July 2016, Moorfields Eye Hospital NHS Foundation Trust announced a long-term, formal collaboration with DeepMind. This collaboration has involved the application of deep learning to >1 million retinal optical coherence tomography (OCT) scans with the aim of automating the diagnosis of retinal diseases such as age-related macular degeneration (AMD) and diabetic retinopathy. To facilitate the sharing of NHS data with an industry partner, robust ethical and governance frameworks have been established. The research involves OCT scans from which all patient identifiable information has been removed

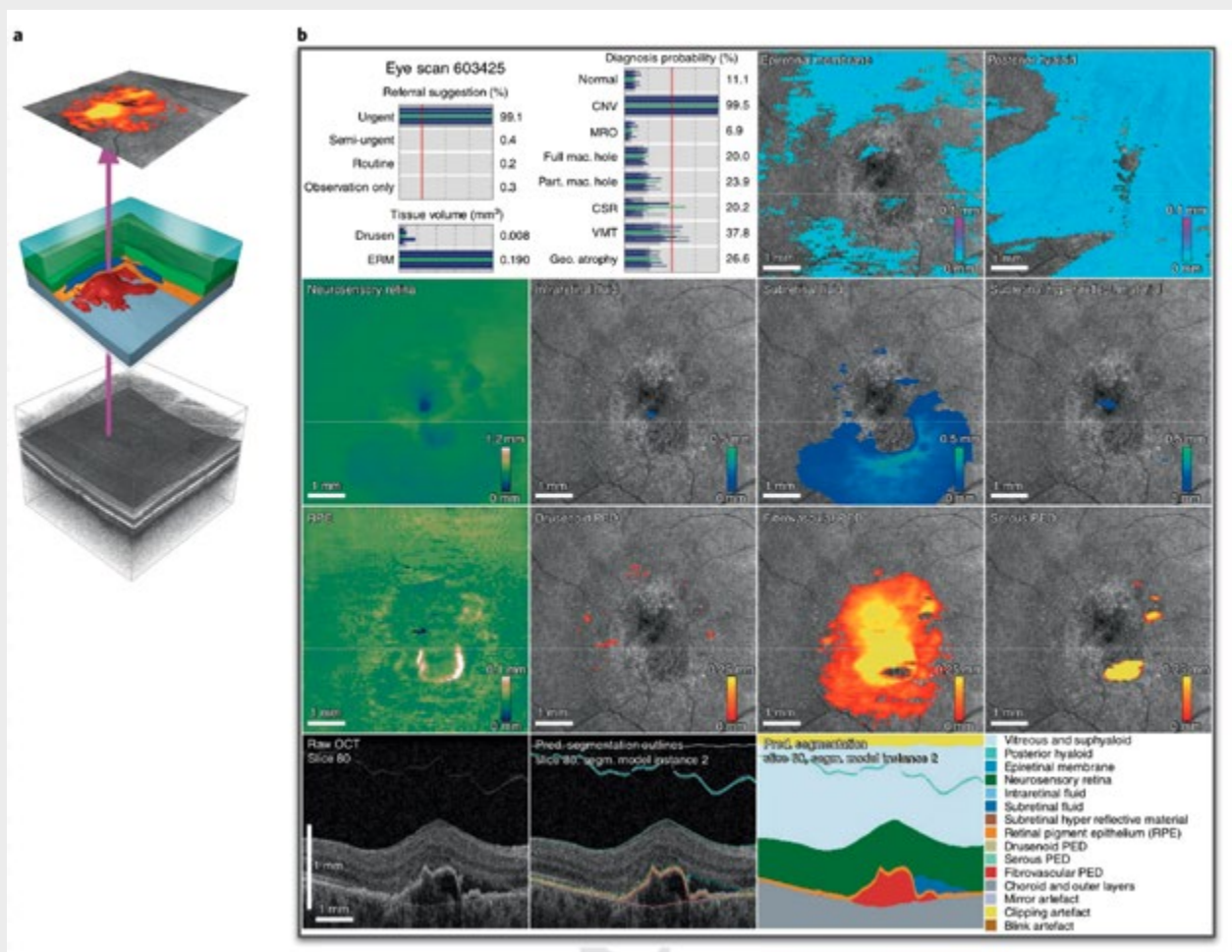
– the de-identification process is validated, certified and audited by the Moorfields Information Governance (IG) department. The research is retrospective in nature (ie, does not involve any changes in patient care) and has received ethical approval from the NHS Health Research Authority (HRA) (reference 16/EE/0253)).

This process has also been accompanied by a programme of patient and public engagement, including: 1) a section of the Moorfields NHS website dedicated to the collaboration with frequently asked questions (FAQs),<sup>6</sup> 2) publication of the study protocol in an open source peer-reviewed scientific journal from the outset,<sup>7</sup> 3) support from the major eye disease charities, including the Macular Society, Royal National Institute for the Blind (RNIB), and Fight for Sight UK, 4) multiple patient focus groups and engagement events, and 5) a series of >80 lectures to the clinical and research communities, as well as members of the public.

Through engagement with bodies such as the NHS HRA policy team, the Wellcome Trust “Understanding Patient Data” group,<sup>8</sup> and others, it is hoped that this experience from this collaboration can be both shared more widely across medical specialties and improved upon.

Moorfields and DeepMind have now successfully developed an AI algorithm that can assess more than 50 different conditions on a retinal OCT scan and then make a referral decision with an accuracy on par with world leading consultant ophthalmologists. Unlike other approaches, the algorithm is not a “black-box” – it provides insights into its decision making process by highlighting disease features on each OCT scan (Figure A). The results of this work have been published in the leading journal, *Nature Medicine*, online in August 2018 and will feature on the cover in the print version due to its impact. This story has been covered on the front page of several British national newspapers and was covered by the BBC and other international media outlets.<sup>9</sup>

Figure A Image of an intermediate tissue representation that highlights specific disease features



Source: de Fauw et al. Nature Medicine, 2018.

Efforts are currently underway to plan further validation of the algorithm in multi-centre, prospective clinical trials, and to achieve the appropriate regulatory approvals so that it can be used routinely in real-world patient care. In the short term, this algorithm will be used in rapid access OCT clinics in the hospital eye services. However, with the increasing adoption of OCT in high street optometrists,<sup>10</sup> and perhaps, even in the general practice or the home,<sup>11</sup> it is likely to be used much more widely in the future in a preventative role. This algorithm holds the prospect of significantly increasing accessibility, quality and capacity in the NHS in the future.

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### Box 12.3 Advanced imaging prospects for surgical and clinical interventions

Text kindly supplied by Ekanayake J<sup>1</sup>, Ourselin S<sup>3</sup>, Price C<sup>2</sup>, Hawkes D<sup>1</sup>

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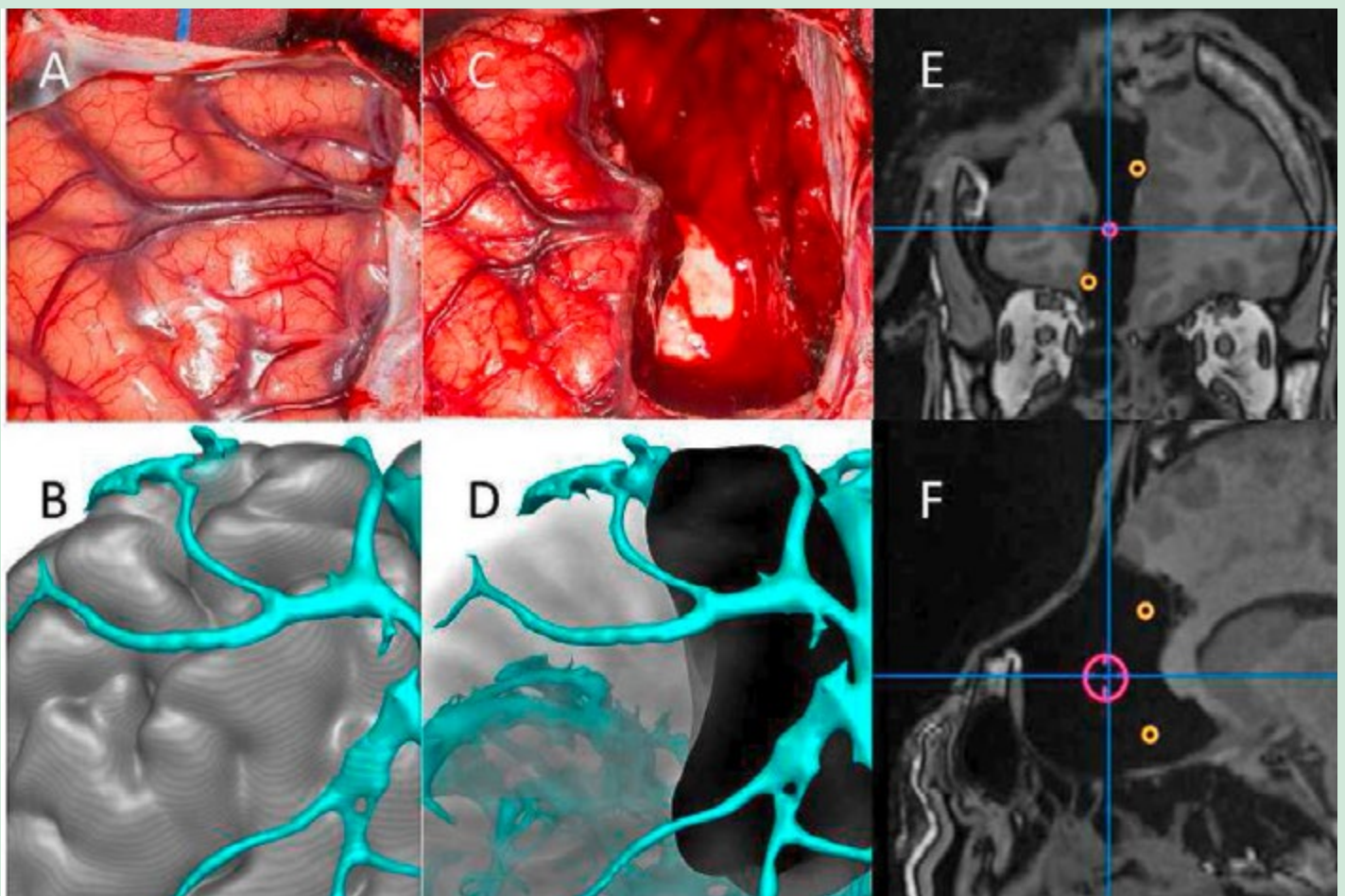
Surgical navigation systems exist to enable anatomically precise surgery to be performed for the maximal removal of pathology and the preservation of healthy tissue. At best, this is currently achieved using static, three-dimensional representation on a viewing screen, of the anatomy and pathology at the macroscopic scale (Figure A).

Functional imaging data can provide a further overlay, presently delivering a relatively gross localisation of where some tissue functional output resides in relation to the

operative field-of-view. Emergent technical advances offer incremental gains for the clinician. These include machine learning and deep learning approaches to enable rapid, automated delineation of pathological tissue, and augmented reality visualisation to allow image representation in a real-world interactive workspace.

Nonetheless, a critical mass of biologically motivated approaches and engineering innovations are poised to result in a series of transformative changes for imaging applications in surgical and clinical practice.

**Figure A**



#### Note

A and C Pre and post-resection of view of epileptogenic lesion.

B and D Detailed model of gyral and vascular anatomy based on CT and MR imaging, pre and post resection.

E and F Intraoperative MR imaging post-resection.

Primary region of seizure generation indicated by purple circle.

Source Ourselin et al.

### *Examples of biologically motivated approaches and engineering innovations*

#### **1) 'Molecular' functional MRI (mfMRI) and molecular maps of disease**

An alternative to traditional functional magnetic resonance imaging (fMRI), mfMRI enables visualisation of genetic and chemical 'labels' at a molecular and cellular scale<sup>2</sup>. Specific examples of these labels in development include calcium-sensor nanoparticles, and metalloprotein markers. By combining this with ultrahigh field (14 Tesla), ultrafast MR imaging, and optimisation of signal-to-noise using approaches such as 'compressed sensing', mfMRI could provide imaging maps of diseased cellular architecture, with precision on the micron scale.

#### **2) Multi-task maps of function**

In function critical regions of the body such as the brain, high field MRI at 7T, combined with multi-task assessments of complex behaviours such as language, will enable the production of highly detailed topographical functional maps. This can then be incorporated into the surgical plan. Prior to surgery, an informed discussion with the patient as a partner can be undertaken. Based on the location of the pathology and the type of function in the vicinity of the pathology, the patient and the surgeon can

determine the degree and type of functions they might be prepared to preserve or lose in order to ensure maximal removal of disease, and optimal life expectancy.<sup>3</sup>

#### **3) Predictive physiological modelling**

Multimodal imaging data sets will be used to produce patient-specific predictions of the outcome of surgery. This would include computational modelling of tissue resection margins, tissue distortion, healing and inflammation in response to surgery, and the physical processes produced by subsequent interventions such as radiotherapy.<sup>1</sup> This will inform a less reactive, and a more considered approach to the surgical management of patients.

#### **4) Augmented Reality and real-time surgical instrument tracking**

True AR assisted surgery will entail the surgeon and the surgical team working in an immersive environment in which the internal anatomy and target pathology will be projected onto the patient. A genuine 'heads-up', 'hands free' experience will exist, with the surgeon being able to see his own hands in the operating field at all times, and surgical instruments will be tracked in realtime in the AR view.

### Box 12.4 BD (Becton, Dickinson and Company) – Advancing point of care diagnostics

*Text kindly supplied by Patrick R. Murray, Vice President, Scientific Affairs, BD Diagnostic Systems  
Please note - this is one example of such technology and should not be read as an endorsement by the Chief Medical Officer.*

Influenza is a seasonal viral infection that frequently occurs when other respiratory pathogens (e.g., group A Streptococcus, respiratory syncytial virus, coronavirus, metapneumovirus) are circulating in the community. Specific diagnostic tests are required to differentiate influenza virus from the other pathogens, guide antiviral therapy, and avoid inappropriate antibacterial therapy. Additionally, for an optimum response to antiviral therapy, it should be administered within 48 hours of the onset of symptoms, so the timeliness of diagnosis is critical.<sup>1</sup>

Prolonged delays in transportation of specimens to centralized testing sites, laboratory workflow practices, and inefficient communication of test results compromise the value of influenza diagnosis in centralized test facilities. For these reasons, testing has is moving from central laboratories to hospital acute care units and laboratories in physician offices, retail clinics and pharmacies. Historically, rapid influenza point-of-care (POC) tests were not reliable for patient management; however, newer digital immunoassays such as the BD Veritor™ Flu A+B and nucleic acid amplification tests have better analytical performance<sup>1,2</sup> and can be performed reliably in primary healthcare settings.<sup>3,4</sup>

Kidd et al (2017) assessed the impact of performing BD Veritor™ Flu A+B tests in pediatric and adult acute care units in the Hampshire Hospitals NHS Foundation Trusts.<sup>5</sup> The authors reported 30% of the requested tests were outside the laboratory operating hours, so the POC tests significantly reduced the turnaround time for results for these patients. Compared with the PCR tests performed in the central laboratory, the BD Veritor™ test reduced TAT from 6 – 14 hours to 10 – 15 minutes, with a five-fold reduction in test cost.

Mese et al (2016) compared the BD Veritor™ Flu A+B test performed in nine physician offices in Istanbul with the influenza PCR test performed in the Istanbul University Influenza Reference Laboratory.<sup>3</sup> The BD Veritor™ test was highly accurate, and use of the rapid POC test resulted in a significant reduction in turnaround time, an increased rate of appropriate antiviral treatment and decreased rate of inappropriate antibiotic use, and it facilitated informed physician-patient discussions about influenza virus infections.

Rapid POC tests are particularly useful when performed in retail clinics and pharmacies.<sup>1,6</sup> Patients have the opportunity for prompt diagnosis and specific treatment for influenza with antivirals or symptomatic relief for other viral infections. Papastergiou et al (2016) collected nasal swabs in two Toronto pharmacies from patients with symptoms suggestive of influenza and tested the sample with the BD Veritor™ Flu A+B assay.<sup>4</sup> Patients who screened positive for influenza were reported to their physicians and antiviral therapy was provided. Symptomatic relief was provided for patients with negative test results. Community pharmacy-based influenza screening facilitated prompt treatment for patients and decreased the burden on the healthcare system by eliminating the need for all patients with suspected influenza to seek medical care in physician offices or hospitals.

Retail clinics and pharmacies offering digital immunoassays or nucleic acid amplification tests for streptococcal pharyngitis may further reduce the use of unnecessary antibacterial therapy by distinguishing between patients with bacteria or viral pharyngitis.<sup>7,8</sup> One further value of POC tests performed in retail clinics or pharmacies is access to care can be improved for patients who may not have a primary care physician or may seek care outside traditional office hours. Ultimately, with the exception of performing diagnostic tests in the patient's home, rapid POC tests with good analytical performance performed in neighborhood pharmacies and retail clinics provide rapid, accessible, convenient care for ill patients without compromising quality or medical oversight.

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## Box 12.5 BD (Becton, Dickinson and Company) – Advancing infection prevention and control practices globally

*Text kindly supplied by Adam Zerda, Director, AMR Strategy and Development, BD*

*Please note - this is one example of such technology and should not be read as an endorsement by the Chief Medical Officer.*

Since the first uses of penicillin in the early 1940's for treatment of bacterial infections, antimicrobial drugs have become a mainstay of modern medical practice. Today, the increasing prevalence of antimicrobial resistance threatens to return the world to the pre-antibiotic era, when patients routinely died from common infections, and the limited pipeline of new antimicrobials makes it imperative to extend the life of existing drugs for as long as possible.

Healthcare facilities are ripe breeding grounds for bacteria and other infectious organisms that may be resistant to drug treatment. The European Center for Disease Prevention and Control (ECDC) estimates that in Europe alone, approximately four million patients each year acquire Healthcare Associated Infections (HAIs), and approximately 37,000 die as a result. Multidrug resistant bacteria cause a large proportion of these mortalities, with published resistance rates<sup>1</sup> ranging from 7.3% for vancomycin resistance in *Enterococcus* spp. isolates, to 29.9% for oxacillin resistance (MRSA) in *S. aureus* isolates. Preventing spread of infection in healthcare environments is therefore essential to reduce these deaths and to preserve the viability of existing antimicrobials by limiting unnecessary use.

Fortunately, HAIs are preventable when effective infection prevention and control practices are implemented. BD (Becton, Dickinson and Company), a 121 year old manufacturer and global supplier of medical devices and life science systems, is committed to helping healthcare facilities advance these practices. BD offers in-depth infection prevention and control training programs for medical procedures that are most likely to cause HAIs, and a broad range of medical devices that support compliance to best practices.

Further, BD is collaborating with governments and professional societies to develop and deploy these programs by assessing clinician performance, training practitioners and monitoring improvements in surgical, urinary and vascular care; towards the goal of advancing infection prevention and control practices globally.

### Blood Stream Infections (BSIs) and Vascular Access Complications

Peripheral vascular access is a routine procedure that is conducted worldwide. It is estimated that 60-90% of hospital inpatients will require an IV catheter.<sup>2</sup> However, routine does not mean low risk, as 35-50% of peripheral catheters have to be removed prematurely due to catheter related complications such as dislodgement, occlusion, phlebitis, infiltration, extravasation or infections.<sup>2,3</sup> These complications impact the standard patient care and outcomes. In Europe, evidence-based guidelines developed for the prevention of catheter-related complications ensure clinicians follow the best clinical practices to reduce complications and ensure effective patient care.

BD Vascular Access Management is an integrated approach to vascular access preparation, placement, care and maintenance built around clinical best practices. It includes best-in-class tools, technologies and services for every step of the vascular access process, paired with clinical practice assessments, evidence-based recommendations and training and education programs. Where the elements of BD Vascular Access Management have been implemented, the results have been strong, including 40% reduction in CLABSI rates,<sup>4</sup> 32% reduction in complications,<sup>5</sup> 15 point increase in patient satisfaction scores,<sup>6</sup> and 33% reduction in costs.<sup>7</sup>

### Surgical Site Infections (SSIs)

According to the ECDC, SSIs are associated with longer post-operative hospital stays, may necessitate additional surgical procedures, may require intensive care, and result in higher attributable morbidity and mortality.<sup>8</sup>

BD developed the Power in Prevention program to help hospitals standardize processes and promote high-quality outcomes in surgery. Led by a team of clinicians and product experts, this program uses a comprehensive quantitative process to identify potential risks for infections and provides evidence-based infection control strategies for specific areas of quality improvement in skin preparation, hair removal, surgical instrument care and handling and hand-hygiene. Health facilities participating in the BD Power in Prevention program achieved tangible results including a 50% increase in compliance to manufacturers' directions for skin preparation as well as a 20% reduction in practice variability.



## Catheter Associated Urinary Tract Infections (CAUTIs)

The urinary tract is considered one of the most important sources of HAI. The presence of a urinary catheter is a major risk factor, associated with up to 80% of health-care associated UTIs.<sup>9</sup>

To aid with compliance to aseptic catheter insertion and maintenance practices, BD provides kits containing essential items required for a catheterization procedure. These kits are designed to support efforts to reduce CAUTIs through encouraging best practice and standardizing the care pathway. Nottingham University Hospital NHS Trust, which introduced the BD catheterization tray in 2014, experienced an 80% reduction in CAUTIs<sup>10</sup> between 2014 and 2016. When combined with appropriate staff training and continuing evaluation initiatives such as BD's Zero In program, these solutions support a standardization of care which may contribute to reductions in CAUTIs.

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## Chapter 13

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# Data, technology, trust and fairness

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## 01 Introduction

We live in a data-driven society; there has been an explosion in the amount of data generated and retained by individuals, governments, companies and other institutions and organisations. It has been estimated that by the year 2020, about 1.7 megabytes of new information will be created every second for every human being on the planet, meaning that the total amount of digital data in existence will grow to around 44,000,000,000,000 gigabytes.<sup>1</sup> The discipline of data analytics has emerged to extract value from and identify patterns in this data – this has proven to be extremely commercially lucrative. In the commercial world, the business models of today’s technology giants are dependent on the analysis and monetisation of data provided by their users. A virtuous cycle thus exists wherein data analytics are used to develop and deliver an increased range of services via the Internet, leading to rising numbers of consumers opting to access these services online, leading to increases in the amount of data collected and analysed, leading to further service optimisation, and so on. Online retail is now a \$2.29 trillion global industry, and US subscribers to Netflix surpassed traditional cable TV viewers for the first time in 2017.<sup>2,3,4</sup> The trend for many businesses is to go digital and move online. A similar set of trends can be seen in the public sector where digitisation and data-driven approaches are viewed as offering the potential for better quality, more efficient, effectively targeted services.

Healthcare is no exception in terms of data generation. The volume of healthcare data is rising by 48% annually, to reach 2.3 billion gigabytes by 2020 according to some estimates, and is increasing in complexity and longevity.<sup>5,6</sup> However, unlike in other sectors, the majority of healthcare data is currently unstructured or not machine-readable, severely limiting its use in the development of digital health tools.<sup>7</sup>

This may be one reason why, thus far, the rate of medical data generation has not been matched by an increase in healthcare services being delivered via digital tools, but this may now be changing. Healthcare is becoming more digitised and consumer-oriented. In the United Kingdom, the trend towards digitisation has resulted in almost 100% coverage of electronic health records (EHR) in primary care.<sup>8</sup> Newer initiatives such as the 100,000 Genomes project are continuing with this momentum.<sup>9</sup> The number of Americans using technology to access, store, and transmit health records doubled between 2013 and 2015.<sup>10</sup> A survey of 12,000 people in 12 countries across Europe, the Middle East and Africa conducted by the consultancy PwC showed that 54% were “willing to engage with artificial intelligence and robots for their healthcare needs”, as compared to 38% who were unwilling.<sup>11</sup> Research by Future Advocacy suggests that the UK public is willing to allow the use of artificial intelligence in disease diagnostics, but is less keen on AI taking on other tasks performed by doctors and nurses, such as suggesting treatments or breaking bad news.<sup>12</sup>

The widespread use of data-driven technologies such as artificial intelligence in healthcare will present a series of important challenges to healthcare practitioners, policymakers, and patients. The successful and appropriate utilisation of such tools in the development of improved health services and better care requires these challenges to be analysed and effectively addressed. In this chapter, we focus on five main domains: data (including public attitudes towards its collection and use to develop AI and related technologies), relationships with technology, trust in technology, transparency, and the potential role of regulation.

## 02 Data: collection, storage, ownership, and use for the development of AI tools in health

### 2.1 Public attitudes towards data use and misuse in the United Kingdom

As more decisions that impact across all aspects of people's lives are driven by their personal data, there is growing public awareness and concern about how these data are collected, used, and shared. These concerns are feeding into calls that have been growing for several years for greater regulation of personal data handling by commercial entities, much of which is done using AI. The European Union is leading on this worldwide, with the General Data Protection Regulation (GDPR) having come into force in May 2018. The GDPR concerns itself with a wider swathe of data types than has previously been the case with data protection legislation. According to the GDPR, 'personal data' that falls under its scope is "any information relating to an identified or identifiable natural person ('data subject')".<sup>13</sup> Clearly, many forms of data can be considered sensitive, where their abuse or misuse could result in harm to the individual concerned. Health data – or at least some forms of it – provides an important example of a form of data considered by many to be sensitive. Despite its potential value, the use of health data beyond the direct care of individual patients has been controversial in the UK. Bodies such as the National Data Guardian, the Information Commissioner's Office and the Wellcome Trust's Understanding Patient Data initiative have led the way in gauging the public's attitude to health/medical data and its uses, and the Nuffield Council on Bioethics has also published a Working Group Report on these issues.<sup>13</sup>

Key issues identified by these projects include:

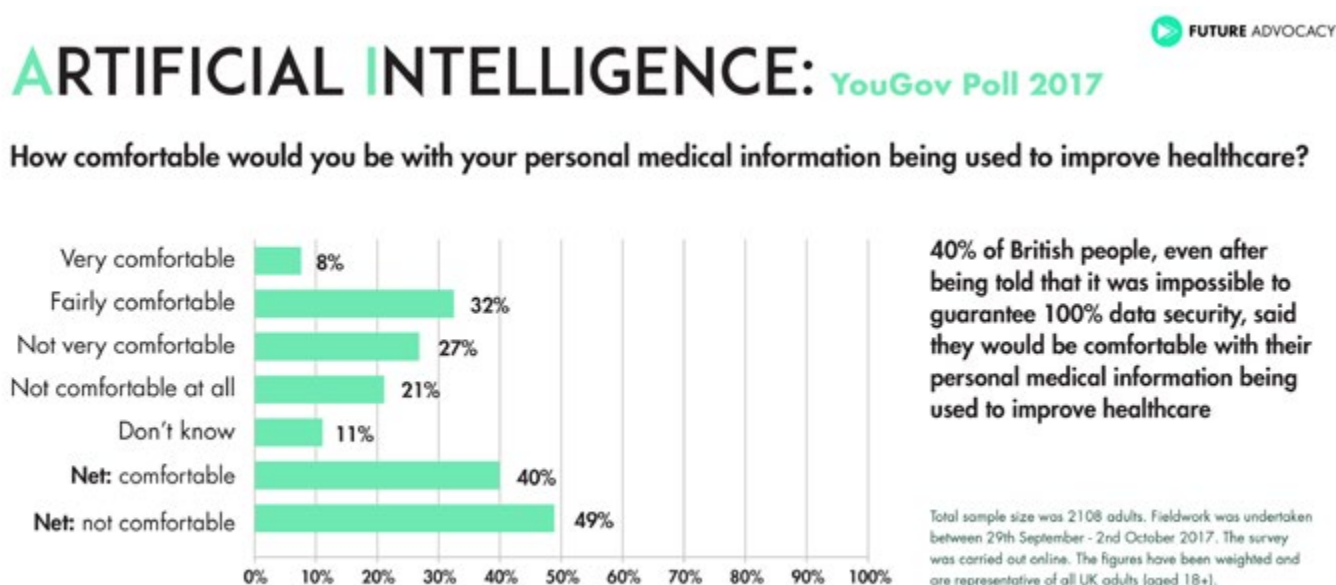
- There is a lack of public understanding of how patient data is used and there is an appetite both on the part of patients and of healthcare practitioners to be educated about this.
- People seek transparency about the type of data shared, who it is used by and for what purpose, as well as data security.
- There is a strong desire for data users to be held accountable for any data misuse, for example by receiving a large fine and, in the worst imaginable cases, a prison sentence.
- There is a recognition that the use of data (e.g. genetic data) offers both the potential for large benefits in the public interest and risks. Against this background there is greater support for uses that are clearly in the public interest, even where these include commercial partners.

Future Advocacy's survey on this issue found that a relative majority (49%) of UK adults surveyed would not be comfortable for their medical data to be used to develop algorithms that could improve healthcare, but a significant proportion (40%) were comfortable with this, even after it was explained that data security could not be 100% guaranteed (Figure 13.1).<sup>\*\*</sup>

\* An "identifiable natural person" is "one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person". More information is found at Information Commissioner's Office, "Guide to the General Data Protection Regulation (GDPR): Key Definitions", available at <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/key-definitions/>

\*\* YouGov poll 2017: all figures, unless otherwise stated, are from YouGov Plc. Total sample size was 2108 adults. Fieldwork was undertaken between 29th September to 2nd October 2017. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+).

**Figure 13.1 Results of Future Advocacy survey of public attitudes towards artificial intelligence in health (conducted by YouGov)**



#### Note

A weighted, representative sample of UK adults was asked how comfortable they are with their data being used to develop medical algorithms.

Source: Future Advocacy, 2017

## 2.2 The limitations of consent and governance and the need for social protections

The sheer size of the healthcare datasets that are required to train and test AI algorithms, combined with the fact that not all future uses of the data and the algorithms are foreseeable, raises another challenge. Currently, much of medical research and clinical practice proceeds on the basis of the valid consent of the participant or patient to a clearly specified set of activities.<sup>14</sup> The very large, varied, and changing datasets required for AI and other data-driven activities make the achievement of specific consent impractical – it may be impossible (or unrealistic given limited resources) to get specific informed consent from each and every patient whose data is in a particular training dataset for each and every activity. Similarly, as AI excels at finding patterns and correlations in data that may not be obvious on human analysis, it is impossible to state, at the point of collection, exactly how an algorithm will use a particular data point from a particular person in future, and whether this will be important for the algorithm as a whole. Taken together with the fact that such research is likely to be in the interests of current and future patients, these considerations mean that approaches to the ensuring of ethical uses of such

data that do not depend upon 'specific' consent are going to be required. These approaches are likely to comprise a combination of (i) appropriate models of data governance, (ii) a complementary set of social protections to ensure that those who do give their consent are not harmed or discriminated against and that there is equitable access to resulting health services, and (iii) the broad consent of patients to the use of their data subject to (i) and (ii). The National Data Opt-Out programme, launched in May 2018 by NHS Digital, may provide one such framework. Under this programme, patients and the public who decide they do not want their personally identifiable data to be used for planning and research purposes (i.e. do not give their broad consent) can set their national data opt-out choice online or via a 'non-digital alternative'.<sup>14</sup>

\* Examples include the General Medical Council's 'Consent to Research' guidelines ([https://www.gmc-uk.org/guidance/ethical\\_guidance/5993.asp](https://www.gmc-uk.org/guidance/ethical_guidance/5993.asp)) and the Medical Research Council's 'Guidance on Patient Consent' (<https://www.mrc.ac.uk/research/policies-and-guidance-for-researchers/guidance-on-patient-consent/>)



### 2.3 The need for a social contract

In the context of a discussion about the uses of genomic and other health data, the Chief Medical Officer's report of 2016 ('Generation Genome')<sup>15</sup> called for a rethinking of the 'social contract' for medical practice and research in the UK. This would require the NHS to set out a mutually acceptable statement of what expectations patients can reasonably have of the uses of their data. It would also require the setting out of reassurances around data governance, and the protections that will be put in place to ensure that patients are not harmed through the uses of their data and that access to the tools developed through such uses will be equitable.

Two areas that are likely to be of public concern are questions relating to health inequalities and issues relating to the commercial uses of data.

#### *The impact on health inequalities and views about personal responsibility for health*

Unequal health outcomes persist worldwide, both between different countries and within countries. Non-medical determinants of health outcomes include socioeconomic class, educational level, an individual's physical environment (for example whether they live in crowded conditions), and access to good quality health care.<sup>16,17,18</sup>

The increased use of AI and other technologies in healthcare is likely to have a complex effect on health inequality. One narrative is that these technologies are empowering, with wearable tech, for example, giving us all a deeper insight into our behaviours and health data. Armed with the combination of this data and the power of algorithmic insights, the patient could enter a healthcare situation as an equal partner with their healthcare practitioner, rather than as a passive recipient of information and advice. However, others have made the point that the use of wearables and apps presupposes digital literacy, and that access to these tools may be expensive. This may limit access not only to poorer individual users in advanced economies, but potentially to whole healthcare systems in low- and middle-income countries. The type of national healthcare system may also be relevant, in that certain systems, such as the US model, are known to perpetuate, or at least fail to tackle, health inequalities to a greater degree than others.<sup>19,20</sup>

It is not always intuitive who is most likely and able to use these tools, and who might be excluded from them. It might seem common sense, for example, that older people may be reluctant to engage with digital tools due to a lack of digital literacy, but research by Healthwatch England suggests that older people are more familiar with the health service and therefore more comfortable with using a range of tools to access them. This is in contrast to younger people, who, because they use healthcare services less often, seek more human interaction when they do.<sup>12</sup>

One feature of such data with potential impact on health inequality is the lack of 'control' that one has over some, perhaps many, aspects of one's circumstances and behaviours relevant to health. If, for example, a car insurer fitted a recorder to a client's car and based their insurance premiums on their driving data, the driver could take action to improve their behaviour and cheapen their premiums, for example by driving more slowly. However, many of the factors affecting health risks are not like this. There are aspects of a patient's health that are out of their control, such as their genetic sequence, or their past medical history. The same is true in many cases of one's social circumstances, employment and so on. This lack of control may make us more sensitive about our medical data. Similarly, the stigmatising effect of certain conditions, such as mental and sexual health conditions, throughout history may explain why medical data has traditionally been shared in confidence – to ensure that those who have the potential to benefit from treatment are able to access it.<sup>12</sup> By contrast, there may also be situations in which the belief that behaviour change is possible e.g. in smoking or in obesity may lead to uses of data that might be seen as inequitable. An example might be a requirement that patients wear an AI driven device in order to qualify for access to services or perhaps where this simply comes to be expected. Views on this are likely to vary.

## 2.4 Data bias

Data bias – that is, the use of datasets that are not fully representative of the population they seek to typify – is another concern in artificial intelligence that goes beyond its use in healthcare applications. Algorithms trained on biased datasets will provide biased outputs. In their landmark report on 'Data management and use: governance in the 21st century', the Royal Society and British Academy presents this issue as follows<sup>21</sup>:

*“Computational tools [...] unavoidably rely on human decisions about what counts as data in the first place and how data should be ordered, labelled and visualised. These decisions are particularly significant given that not all data are equally easy to digitally collect, disseminate and link through existing algorithms, resulting in a highly biased data pool that does not accurately reflect reality (and in some cases actively distorts it). Far from being purely technical, data management decisions therefore, affect what kinds of uses data can be put towards, and its implications.”*

It is worth noting that it is not a new problem in health. Research conducted by the US Food and Drug Administration (FDA) shows that African-Americans comprise less than 5% of clinical trial participants and Hispanics just 1%, in spite of the fact that they represent 12% and 16% of the total US population respectively.<sup>22</sup> Besides dealing with underrepresentation on the grounds of ethnicity, datasets for use in AI need to ensure balance in other parameters, including gender, age, sexual orientation, educational status and employment status (for example undocumented workers and their families), as well as a factor which perhaps is not normally considered in health contexts: digital literacy.

## 2.5 Commercialisation, economic value and the involvement of commercial partners in research/health

The value of data, both to patients themselves, and to taxpayers in a publicly-funded healthcare system, is an issue that is increasingly in the spotlight. The prevailing model of public-private partnerships used to develop AI algorithms, in which private sector organisations partner with bodies such as hospitals and universities to develop algorithms using data held by the latter group of institutions, has shown potential for success, as with the recent results published by the collaboration between Moorfields Eye Hospital and Google DeepMind.<sup>23</sup> However, many remain concerned that these collaborations may not always be a good way to ensure that the value of data is adequately recouped for patients and citizens, and may even enable exploitation of patients. Should patients be the primary beneficiaries of technologies developed using their data, or it is sufficient to ensure that they are not exploited, even if they derive no direct benefit? Or, should such data and the value that arises out of their use be seen as a public good? Sir John Bell, Regius Professor of Medicine at the University of Oxford and lead on the UK Government's Life Sciences Industry Review, has argued that the data is worth “a fortune”. He mooted a number of different options to ensure value is captured from NHS data, including charging fees to access the databank, or the establishment of a licence system that pays the UK Treasury royalties from sales products developed using NHS data.<sup>24,25</sup>

## 03 Relationships with technology and between humans in health and care

Healthcare has historically been built on relationships between people. Apart from the central interaction between the healthcare practitioner (HCP) and the patient, many other types of relationship have been essential to the delivery of good healthcare: between the HCP and caregivers/relatives; between caregivers/relatives and patients; between different HCPs; between “front of house” administrative staff and the patient; between top-level administrators and HCPs ‘on-the-ground’; and between patients and wider society.<sup>26</sup> AI technologies have the potential to modify all of these relationships.

AI could act as a ‘third participant’ in the previously binary patient-healthcare practitioner dynamic of the consultation, through its ability to combine different data sources to make previously unavailable inferences about patients.<sup>12</sup> Whereas the relationship between patient and HCP is characterised by a two-way flow of information, an autonomous decision-making algorithm, or a cache of health data collected by the patient themselves, introduces a new set of interactions. How will patients and HCPs respond when the inference from the patient’s data contradicts the patient’s own account or is opaque – especially if the patient has no control over the inferences the algorithm makes? How are patients and HCPs to respond when the automated ‘decision’ made by an algorithm contradicts that HCP’s recommendations?

A major concern is that AI technologies could encroach or in some way degrade the patient-HCP relationship.<sup>27</sup> Many commentators have however highlighted the valuable potential for algorithms to perform routine, repetitive tasks, freeing up HCPs to spend more time interacting with their patients. Indeed, the wider effect that AI-driven automation will have on healthcare practitioners’ jobs, both in terms of displacement, or more broadly in terms of changing the nature of jobs, is largely unexplored. As the technology improves and more tasks become automatable, it is increasingly possible that fewer ‘human practitioners’ will be required to run healthcare systems worldwide. To our knowledge, there is no systematic analysis of how HCPs view this potential impact of automation, and whether any preparatory measures are being taken by their professional bodies. We await with interest the results of the Topol Review on ‘Preparing the healthcare workforce to deliver the digital future’, due in early 2019.

In other areas of medical practice – perhaps surgery is a likely example – another important aspect of the relationship between human operators and these technologies is going to be the agreement and oversight of situations in which autonomously-operating algorithms will hand decision-making control back to human operators. Although perhaps more of a future consideration in healthcare, it is a very live issue in other industries. For example, in the Air France Flight 447 crash in the Atlantic Ocean on May 31, 2009, a key factor that led to the disaster was a failure of the human pilots to take over safely as the automated ‘fly-by-wire’ system shut itself off when a pressure probe on the outside of the plane iced over.<sup>28</sup> Similarly, in the autonomous vehicle industry, trials show that significant issues with processes of switching from autonomous to manual vehicle control are yet to be addressed.<sup>29</sup> In healthcare, if autonomous algorithms only handover to human operators in complex situations that they are not designed to handle, how will the human keep up their skills sufficiently to be able to address these situations? Complex surgery is an example where there is evidence that skilled practice depends upon regular use. Furthermore, how should we flag this transition from algorithmic to human control clearly to patients? This is especially important if these AI tools are used by vulnerable patients, such as children.

## 04 Trust in technology

### 4.1 Trust in an institution, trust in a tool?

The preceding discussion suggests that the increased use of AI in healthcare has the potential to raise questions about trust and trustworthiness in two related ways. The first concerns the question of what is required for patients and the public to have well-founded trust in the institutions and individuals who use their data and in those uses. The second concerns trust issues arising out of the transformation of the relationships at the heart of healthcare delivery and medical research. It is currently unclear what makes an algorithm, or indeed the organisation that develops and uses it, trustworthy and/or actually trusted: trust can sometimes be misplaced (as can mistrust). This distinction, between talking about trust in an institution and about trust in a tool, is important. The latter refers to whether, in a one-on-one interaction between a human and a tool, the human will trust it. In this case, studies have shown that the ability to form a relationship with the tool allows us to trust it, and in this regard, anthropomorphising (building machines to look like humans) is a major factor. This is certainly a feature that roboticists keep in mind when designing robotic tools, such as those used in the care of the elderly and other vulnerable people. This leads to the question of trustworthiness: not all such trust is going to be well-placed – whether this is trust in robots or in the institutions or practitioners of data-science and AI. Commentators have argued that the more transparent the system is, the more we will trust it, and the more protected we will feel from the risks of ‘capture’ by a particular organisation or body that may not have the system’s users’ best interests at heart.<sup>12,30,31</sup> What can be done to ensure that structures and requirements are in place to ensure that such trust and confidence is well-placed and that as individuals we are enabled to make informed judgements about this?

Research by Future Advocacy with patients and members of the public suggests that their willingness to trust an algorithm depended on the answers to certain questions, such as:

- What is the AI’s success rate?
- Where does the AI come from, who developed it?
- What kind of data was the AI trained on? If I am a member of a minority group, will the AI work well for me?<sup>12</sup>

With respect to the second question, it is clear from this and other research that a hierarchy of trust exists. The public trusts the NHS, universities and, to a certain degree, pharmacies, to have access to data for research purposes, as these types of organisations are perceived to work in the public interest. Those that are not perceived as always working in the public interest, such as insurance or marketing companies, do not have the same level of public trust when it comes to data.<sup>12,32</sup>

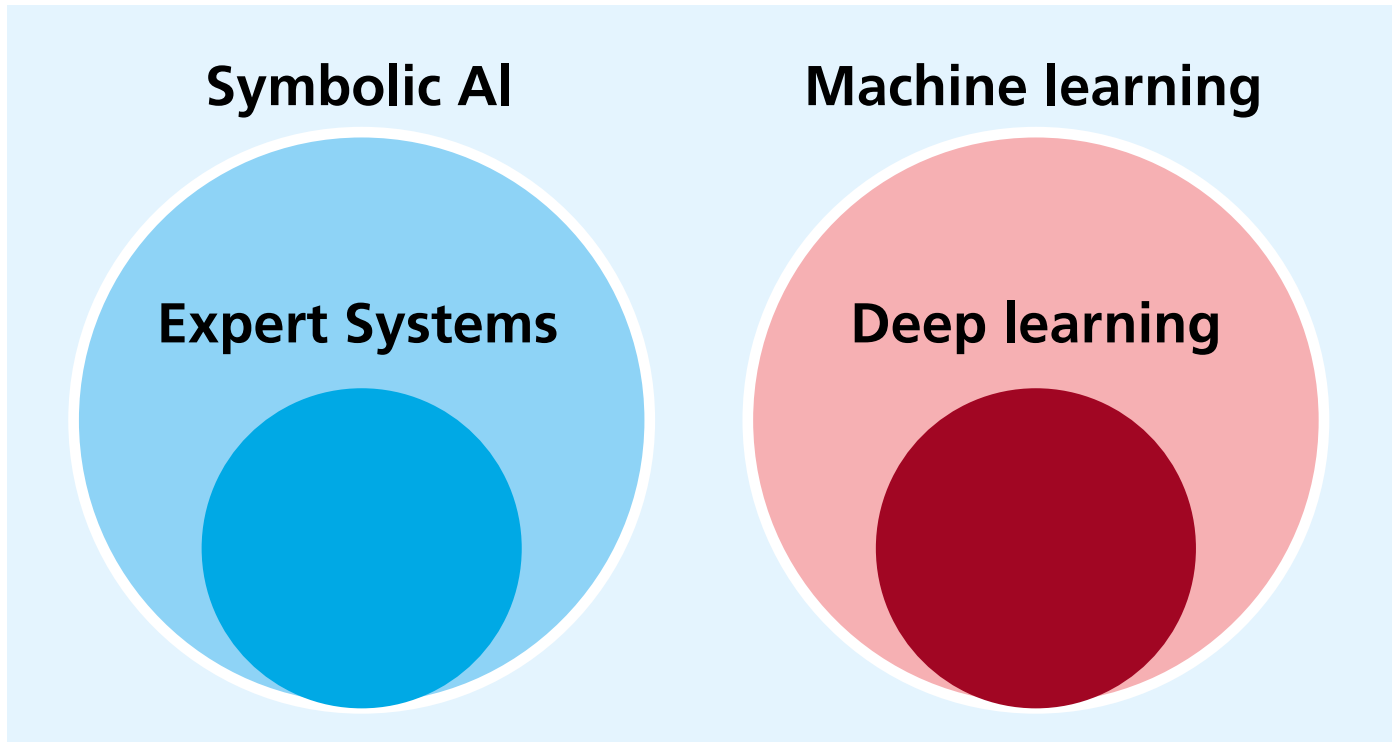
### 4.2 Transparency, explainability, and accountability

Modern machine learning algorithms, particularly neural networks, have often been referred to as ‘black boxes’.<sup>33</sup> Such decision-making systems are often deployed as a background process, unknown and unseen by those they impact. The use of this technology in this way raises significant and justifiable concerns. A notorious example is provided by the COMPAS algorithm, which was used by American courts to assess the likelihood of an individual re-offending. It was found to be two times less likely to falsely flag white people and two times more likely to falsely flag black people as likely to reoffend.<sup>34</sup> Moreover, when challenged, the manufacturers claimed that the algorithm was protected under intellectual property law and was therefore not open to scrutiny.<sup>34</sup>

One possibility could be to restrict the type of algorithms used in healthcare applications to explicitly-programmed, rule-based expert systems (Figure 13.2). These are more interpretable than machine learning techniques. However, advances in machine vision, powered by exactly the type of deep learning algorithms that raise concern due to their impenetrability, have underpinned the superhuman performance shown by some algorithms. If this technology continues to get better and eventually consistently outperforms humans in, for example, image analysis tasks, should the opacity of these algorithms be a bar to their widespread application? It may well be argued that it is in fact unethical to withhold these algorithms from medical practice if they clearly outperform human practitioners. Ultimately, different users and different situations will require different approaches in terms of explainability. The explanation of an output by a medical algorithm that a patient wants and deserves is almost certainly different from the explanation demanded by, say, a student who wants to understand why an automated marking system has failed their last paper, or a prospective homeowner who wants to know why they have been denied a mortgage.

Figure 13.2 A simple classification of the major classes of artificial intelligence

## Artificial intelligence



Source adapted from 'Artificial intelligence: The Road Ahead in Low and Middle-Income Countries', Web Foundation, 2017

It is noteworthy that research shows that human rationality is limited and that human explanations and justifications of their own behaviour are overwhelmingly based on a post-hoc rationalisation of the decision taken, rather than an exhaustive understanding of our brain's decision-making process.<sup>35</sup> Is this human 'black box' very different from the algorithmic black box? Interestingly, some patients and members of the public who contributed to Future Advocacy's research in fact adopted a very pragmatic approach to the issue of algorithmic explainability, pointing out that ultimately what matters is that the algorithm is clinically efficacious and improves patient outcomes, therefore justifying its use.

Various potential solutions have been suggested to the problem of algorithmic explainability in other contexts, including having 'explanatory systems' running in parallel with the main algorithm. Sandra Wachter and colleagues at the Oxford Internet Institute, for example, have put forward the concept of 'counterfactual explanations' to be provided with *all* decisions made by an algorithm. These 'counterfactuals' would be the minimal bit(s) of information that would have changed the outcome of the model to the desired one for the user. For example, in the context of an algorithm determining creditworthiness, a counterfactual explanation could be "You were denied a loan because your annual income is £30,000. If your annual income was £45,000, your loan application

would have been approved." Such explanations would inform and help the individual understand why a particular decision was reached, provide grounds to contest the decision if the outcome is undesired, and to understand what would need to change in order to receive a desired result in future – these principles could be applied to the healthcare context.<sup>36</sup>

## 05 Regulation

### 5.1 The role of regulation

Healthcare and medical research are highly regulated in many countries, but the regulation of AI algorithms in health appears unsatisfactory. Most such algorithms are registered with the Medicines and Healthcare Products Regulatory Agency (MHRA) as a class 1 medical device, which is the lowest-risk class of device (the same as wheelchairs or spectacles, for example). All that this process requires is that the manufacturer self-certifies that it complies with the regulations. There is no requirement on the MHRA to review this compliance, or indeed any of the research underpinning the development of the device. Indeed, the MHRA says that this process is purely administrative – the MHRA takes details of the types of devices manufactured, but it does not assess, certify, approve, or accredit devices as part of the CE (European Conformity) marking process. With the implementation of the European Commission’s Medical Devices Regulation (MDR) by May 2020, most algorithmic products will be at least class 2a, which would require a greater degree of oversight by the MHRA.<sup>37</sup>

It does not appear unreasonable to demand that existing regulatory frameworks, including the need to submit new drugs and devices for clinical trials, should be extended to include algorithms. However, there are certain aspects of AI algorithms that deserve specific consideration. Firstly, it is undeniable that the pace of development of these algorithms is much faster than regulators that deal with drugs and medical devices are used to, meaning that new or amended regulatory processes need to be agile and flexible to account for this speed.

Secondly, the concepts of patient safety aren’t firmly entrenched in the tech industry, and indeed may come into conflict with the tendency of tech entrepreneurs to want to ‘move fast and break things’. It is unclear how traditional notions of ‘duty of care’, held by healthcare practitioners and upheld by their own regulatory bodies such as the GMC and the NMC in the UK, apply to software developers and those purchasing software tools on behalf of a healthcare system, for example.

Another interesting consideration around regulation of AI algorithms is centred around the use of ‘fixed’ as opposed to ‘dynamic’ algorithms. ‘Fixed’ algorithms do not change over time, whereas newer technologies could allow the use of ‘dynamic’ algorithms that ‘learn online’ – that is, algorithms that in the course of normal operation – use new data that is presented to them to improve their ability to reach their preset goal (such as making a prediction).<sup>38</sup> It may be easier to regulate fixed algorithms as compared to dynamic ones, and some have gone as far as to say that dynamic regulations should not be used at all for healthcare applications. However, a comparison can be drawn with human healthcare practitioners, who learn all the time. Thus, a process of continuous certification for AI (parallel to regulated continuous professional development and licensing for doctors and nurses) that focuses on the outputs and outcomes of these algorithms could potentially be developed to cater for online learning algorithms. Facebook, for example, already use a process of ‘continuous release’ to update their website and apps, which relies on separate processes continuously monitoring these systems to ensure they are functioning as expected.<sup>12</sup>

### 5.2 Ethics support and advice

No matter how detailed or tightly specified the regulations and guidelines relating to the uses of AI in healthcare and medical research, interpretation and judgement will be required in practice about the appropriate course of action, for example in the care of a particular patient, in the achievement of good quality consent, or in policy decisions about the allocation of resources. Such judgements have a strong ethical component. This suggests that in addition to the requirements outlined above, the successful and appropriate use of AI in healthcare will require health professionals and those who run health systems to have ready access to ethics support and advice and to mechanisms for the sharing of models of good ethical practice between different clinical or research settings. It will also require training in medical and nursing schools to include education on these aspects of students’ future practice.

## 06 Authors' suggestions for policy

- Regulators (predominantly the MHRA, but there may be a role for new AI bodies within Departments of Digital, Culture, Media and Sport and Business, Energy and Industrial Strategy) should develop a framework that clearly outlines:
  - a) The level of evidence, and methodology of research, required to demonstrate safety of an AI algorithm (equivalent to Phase I and II clinical trials)
  - b) The level of evidence, and methodology of research, required to demonstrate efficacy of an AI algorithm in healthcare, including superiority or non-inferiority when compared to standard practice (equivalent to Phase III clinical trials)
  - c) Best practice with respect to post-marketing surveillance of an AI algorithm (equivalent to Phase IV clinical trials).
  - d) NHS Digital should provide hospitals with guidance on best practice when partnering with private sector organisations to develop AI algorithms, building on the Department of Health and Social Care 'Initial code of conduct for data-driven health and care technology'. This could include:
    - a) Best practice guidance on data handling, storage, and sharing for the development of AI tools
    - b) Guidance on determining the value of NHS data held by a particular organisation
    - c) Requiring that healthcare practitioners and patients are materially involved in the development of the tools from the very beginning.
- The UK Government should support a national conversation about the requirements for a social contract to underpin the successful and appropriate use of AI and data science in the interests of current and future patients, on the basis of well-founded public trust and confidence.
- The UK Government should support the development of an evidence-based model of broad consent suitable to the requirements of data-driven AI at the clinical-research interface. This approach to consent will be one element, albeit an important one, of a broader ethics ecosystem surrounding the ethical uses of data.
- The UK Government should support the development of models for the provision of readily-available ethics support and advice around the use of AI in health, to those health professionals and medical researchers who require it. One option could be for these to build on existing models such as the Genethics Forum.

### Box 13.1 CRIS at the Maudsley Hospital, London

*Text kindly supplied by Professor Robert Stewart, Professor of Psychiatric Epidemiology and Clinical Informatics, King's College London*

The Clinical Record Interactive Search (CRIS) data resource was developed at the South London and Maudsley (SLaM) during 2007-2008 with NIHR funding, and it celebrated its tenth birthday in November 2018. CRIS consists of a series of data processing pipelines which create a de-identified copy of SLaM's electronic health record (EHR), rendered available for research use within a robust, patient-led data governance framework. As of late 2018, CRIS contained health records data on over 400,000 patients, and has supported around 150 research publications and a range of funded research across all age groups and mental healthcare specialties.

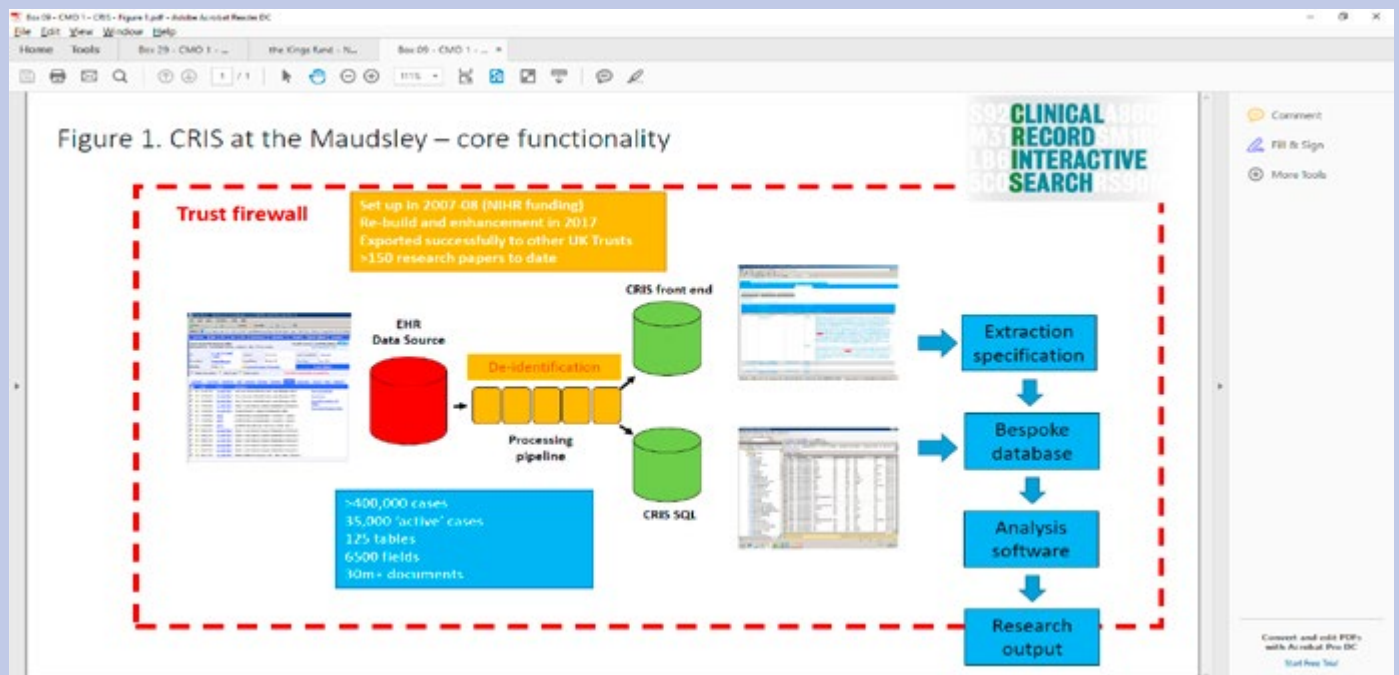
Research data obtained directly from electronic health records are often limited by the format of information contained in the source record. CRIS at the Maudsley has thus been substantially enhanced over the years through linkages with other databases and through the application of natural language processing to 'unlock' information recorded in text fields. Data linkages completed or underway include those with national mortality records, Hospital Episode Statistics, local primary care (Lambeth DataNet), local maternity and neonatal records, the National Cancer Registry, the National Pupil Database, and individual Census data. All have allowed a range of projects to investigate not only the influence of external factors on mental health, but also the impact that mental health may have on issues such as physical health and education.

Natural language processing in CRIS has allowed a wealth of detail from routine clinical care to be used in research projects, substantially enhancing the range of questions that can be addressed. This includes extracted information on interventions received (e.g. medications and psychotherapy), clinical presentations (e.g. over 60 individual symptoms), external factors potentially influencing health (e.g. co-occurring physical health conditions, illicit substance use) and treatment outcomes (e.g. adverse drug events). These resources allow databases to be assembled that are unparalleled in both sample size and depth of information, creating innovative clinical 'big data' for mental health research.

CRIS as a resource has been an influential model for EHR research, in its functionality (Figure A), technical specifications, and governance model, and has more recently been implemented at a number of mental health Trusts besides the Maudsley. It can be readily conceptualised as the seed around which a much wider informatics resource can be built up at a local level and then replicated across sites to underpin national and international data networks (Figure B).

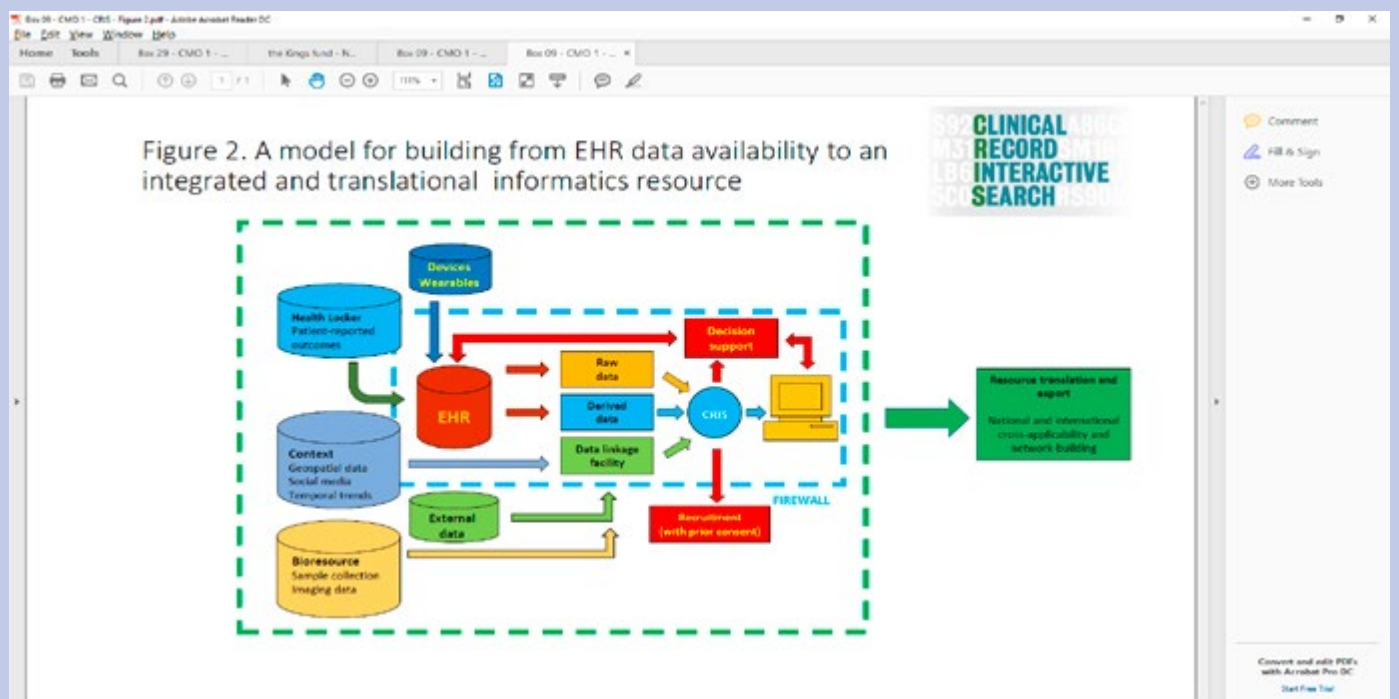


Figure A CRIS at the Maudsley – core functionality



Source Clinical Record Interactive Search, NIHR Maudsley Biomedical Research Centre

Figure B A model for building from HER data availability to an integrated and translational informatics resource



Source Clinical Record Interactive Search, NIHR Maudsley Biomedical Research Centre

### Box 13.2 Technology: a golden thread through the way we deliver patient care across Morecambe Bay

*Text kindly supplied by Colin Brown, Chief Clinical Information Officer, Morecambe Bay NHS Trust*

The pace and scale of digital change led by our clinicians, nurses and IT team in recent years has been staggering and technology is now a golden thread through the way our hospitals and community services are working together, to provide patient care.

The innovative Lorenzo Electronic Patient Record (EPR) system is being used by staff as soon as a patient enters the hospital via the Emergency Department (ED) or outpatient clinic until they are discharged home via an electronic discharge letter.

The Lorenzo EPR system is a fantastic tool to support the triage of our patients across many areas of our hospitals. Teams in our ED's use the system to triage day case patients to our ambulatory care units (ACU's) across our sites where they can have further tests and day treatments carried out. The Ambulatory Care Unit at the Royal Lancaster Infirmary (RLI) sees around 500 patients a month who are suffering from conditions such as chest pain, chest infections, and potential deep vein thrombosis. By triaging these patients to our ACUs, it means they are receiving the right level of care and potentially reducing the volume of patients coming into our ED's.

From nurses carrying out comfort rounds using iPods to midwives using laptops remotely to access the latest information relating to a woman's care – we can see how firmly embedded technology is within local healthcare and how positively our staff and patients have responded to change – and the future.

An astounding 122,333 inpatient meals have been ordered at the RLI and Furness General Hospital via tablet computers thanks to an electronic eMeals system. The old paper processes could take ward staff up to one hour 30 minutes to complete. Not only do staff on our wards have more

time to spend on patient care, the system has significantly reduced food wastage by 45% and offers greater patient satisfaction.

The innovative online STRATA system has also helped to facilitate the movement of patients around the local healthcare system, including the discharge of patients from our hospitals into community health and care services. The system – with its evidence based, structured templates – gives clinicians a better picture, with up to the minute information on the patient, the referral options for them and waiting times.

Community staff in South Cumbria and North Lancashire are now delivering better integrated care thanks to the Emis web electronic record system which gives them the ability to book appointments for patients across organisations. Power really has been put into the hands of our patients with the touch of a button. The iPlato myGP app allows them to book appointments with their GP practice and order prescriptions online instantly.

The Advice and Guidance service – which enables GPs to access specialist advice from colleagues working in our hospitals – has seen fantastic benefits for our patients including, them being seen more quickly and not have to travel to hospital for their care. The service is a locally-developed system enabling GPs to have a secure electronic 'conversation' with a hospital specialist. This enables them to obtain advice for patients, without the need to refer a person for an outpatient appointment.

Technology really is revolutionising the way staff are working, strengthening partnerships between health and care organisations and giving patients a better experience of local healthcare.

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## Chapter 14

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# Embracing uncertainty: futures thinking in action

### Chapter lead

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# 01 Disruptive uncertainties: how embracing scenario planning can help us prepare for the changes the future might bring

## 1.1 A lot can happen in 20 years

Travel back in time to the cities of 1900 and you'd find the streets full of carriages and carts drawn by horses. Stop someone and ask them if they had seen a 'motor car' and they may not have known what you were talking about. Suggest to them that cars and lorries with combustion engines would start to dominate their streets within 20 years, and they would probably look at you incredulously.

The same people would have been shocked that, by the end of 1920 (less than 100 years ago), not only had over 750,000 people from Great Britain died in the First World War but 228,000 had also been killed from early 1918 by so-called 'Spanish Flu'. People looking "hale and hearty at breakfast could be dead by teatime".<sup>1</sup>

Fast forward to the mid-1960s, and few people watching television on their black and white TV sets would have foreseen that 20 years later there would be video cassette recorders that would allow them to record and watch programmes and films at their leisure.<sup>2</sup> Neither was anyone predicting the possible emergence of an immunodeficiency virus called HIV that would have profound health and social effects worldwide by the mid-1980s.<sup>3</sup>

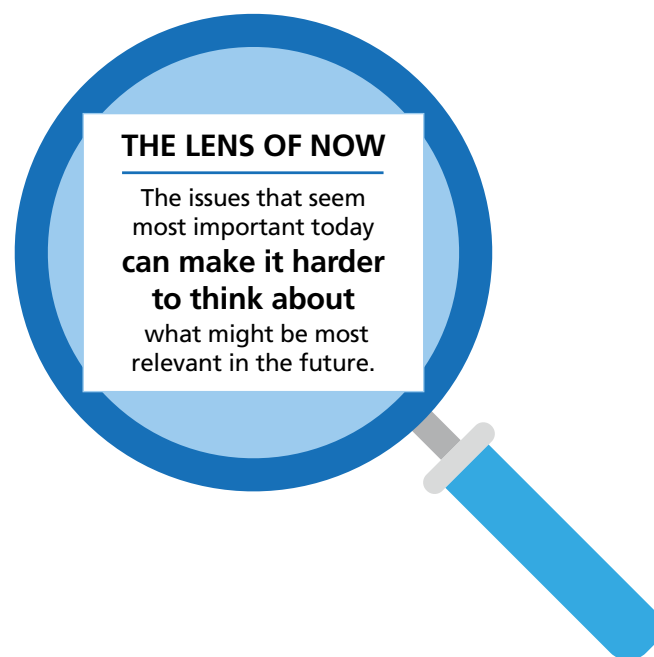
And as recently as 1990, most of those working in the telecoms industry did not conceive that handheld mobile phones would be a mass-market product, let alone that there would be one phone for every person in the UK by 2004 or that smartphones such as the iPhone (first launched in just 2007) would already be on their way to revolutionising daily life by 2010. Neither, we suspect, would they have imagined that after decades of improved life expectancy it would even be conceivable to some that children born in the new millennium might live shorter lives than their parents as a result of 'lifestyle' conditions such as obesity.<sup>4</sup>

## 1.2 Scenario planning helps with imagining what the future might bring

These examples offer plenty of evidence of the scale and rate of change that happens all around us. That should also force us to concede that so much of what lies ahead is full of uncertainty and hard to predict. Indeed, it could be argued that disruptions are happening more frequently and at a faster pace. In particular, increasing global interconnectedness makes it more challenging for governments to predict and combat social and economic challenges.<sup>5</sup>

Yet while we can spot current trends that point to some of the things that are likely to be coming, we are often poor at imagining the more dramatic shifts that could be possible. In particular, we can often be trapped in the 'lens of now',<sup>\*</sup> seeing the future largely in terms of what seems to be important or relevant today. This can be compounded by a natural fear of change, a hope that things will continue to be as they are now and a tendency to misremember the past as being more similar to the present than it was.

**Figure 14.1** Visualisation of 'The lens of now'



Source *The Policy Institute, King's College London*

\* 'The lens of now'; meaning issues that seem most important today can make it harder to think about what might be most relevant in the future.

## Box 14.1 Thinking differently: the discovery of *Helicobacter pylori* and its role in gastritis and peptic ulcer disease

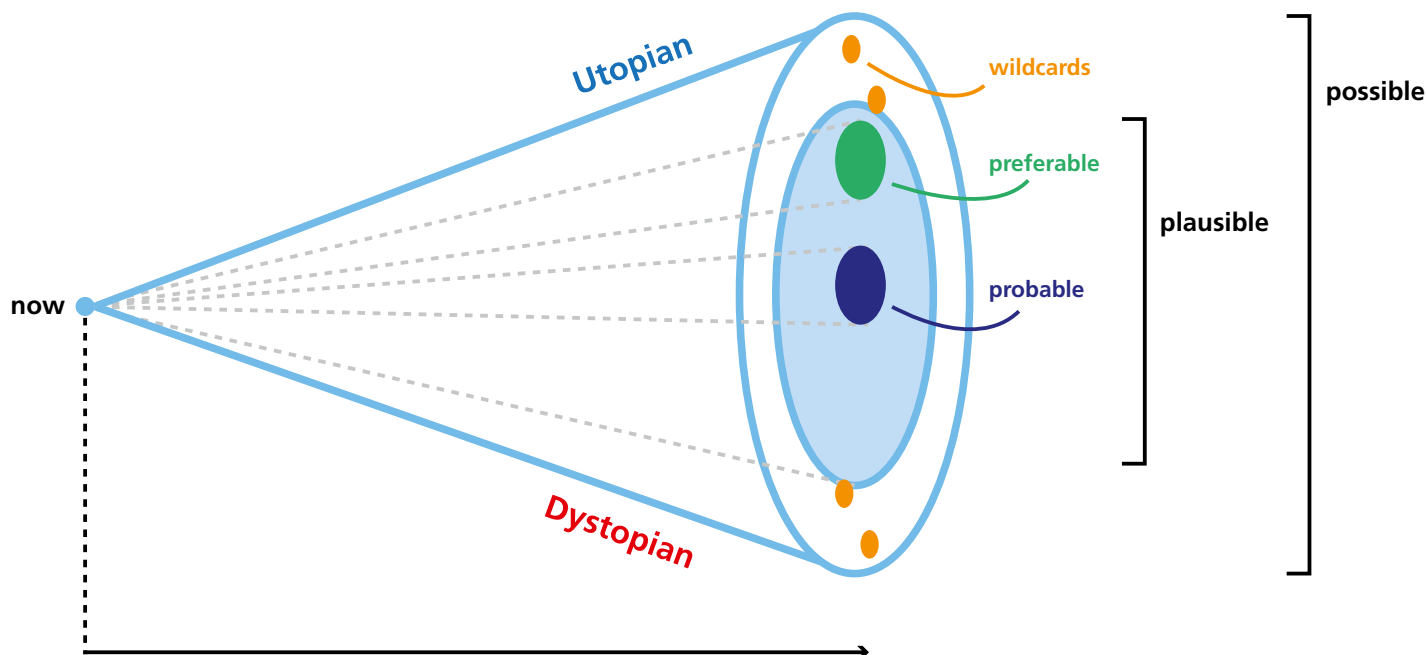
*H. pylori* is a bacterium that causes more than 90% of duodenal ulcers and up to 80% of gastric ulcers. However, as recently as the 1980s, it was believed that bacteria could not live in the acidic environment of the stomach, and that peptic ulcer disease was primarily caused by stress and lifestyle factors. In 1982 pathologist Robin Warren and clinician Barry Marshall challenged the prevailing dogma by making the case that peptic ulcers – one of the most common diseases found in humans – had a microbial cause. To test their theory, Marshall ingested *H. pylori* himself, and subsequently developed gastritis. Marshall and Warren demonstrated that patients could be cured from their peptic ulcer disease only when the bacteria were eradicated from their stomach. As a result of this radical change in thinking, peptic ulcer disease is no longer a chronic condition often requiring surgery, but an infection that can be cured with a simple course of antibiotics and acid secretion inhibitors. The discovery of *H. pylori* and its role in gastritis and peptic ulcer disease has since advanced understanding of the connection between chronic infection, inflammation and cancer. Warren and Marshall were awarded the Nobel Prize in Physiology or Medicine in 2005.

There are a host of methodologies, each with benefits and limitations, that have been developed in recent years to help policymakers and practitioners to plan effectively for increasingly uncertain futures. For the purposes of this report we have chosen to examine uncertainties in health using approaches drawn from scenario planning, as this offers the opportunity to illustrate what alternative outcomes in different health areas might look like in 2040. By acknowledging trends in the health of the population today and imagining the different outcomes they may lead to – from those which are quite likely to potentially more uncertain, disruptive futures – we are able to tell stories about possible futures which can help us anticipate and plan more effectively.

## 1.3 The cone of uncertainty

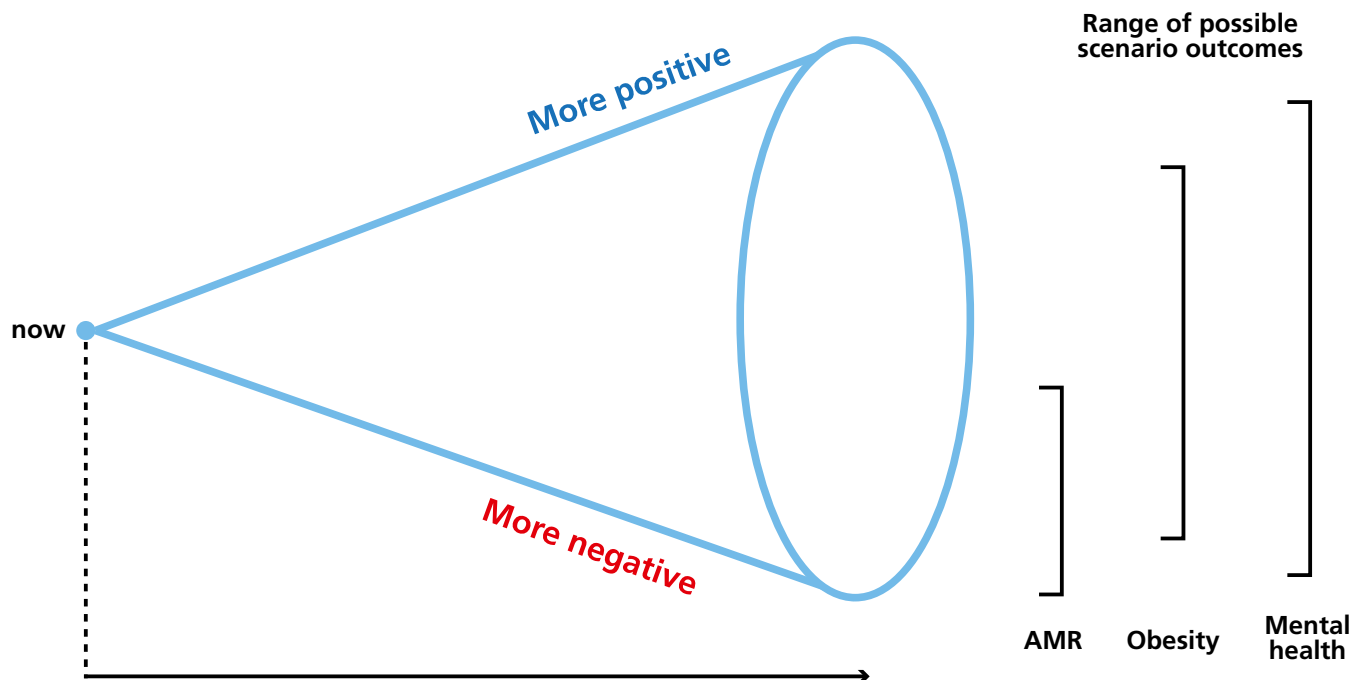
Our approach deliberately focuses on the many uncertainties facing us and forces us to think through different futures, or 'scenarios' that might result. The nature of these scenarios are best conceptualised as a 'cone of uncertainty' that extends out from the present day into the future. The top of the cone can be considered the best-case or 'utopian' outcome that we might hope for. At the other extreme would be the worst-case or 'dystopian' scenario. Much of the scenario planning that takes place focuses on anticipating and insulating against negative, dystopian events. While this is crucial, we also felt it important to include the other, utopian end of the spectrum. Planning around positive developments in health and beyond can help ensure that governments are prepared to take advantage of the opportunities that may arise. Thinking through these more extreme, disruptive utopian and dystopian scenarios helps push our thinking, exploring creatively how the world might evolve in ways we don't currently expect.

Figure 14.2 Visualisation of 'The cone of uncertainty'



Source The Policy Institute at King's, King's College London

Figure 14.3 The 'cone of uncertainty' illustrating the range of possible scenario outcomes



Source The Policy Institute at King's, King's College London



Critically, all the scenarios should be possible, in that the set of conditions that come together to create that particular future should be logically consistent and stand some real chance of happening. For planning purposes, it is useful to consider both a slightly more concentrated cone of scenarios that have a higher likelihood of emerging, and the broader cone, which captures low probability and high impact events. Altogether, these scenarios comprise:

- the 'preferable': the one that will give the best overall set of outcomes, sometimes conceived as a vision that we should aim for
- the 'probable': the most likely to emerge
- the 'wildcards': low probability events or developments that have strong positive or negative impacts.

## 1.4 Much of the value of the scenario planning process is in bringing together stakeholders with very different viewpoints

Once created, scenarios can be used for a number of purposes. Sometimes they help think through potential risks. Sometimes they can be used to generate ideas for new things to do. And sometimes, they enable a group to come to a collective vision of the future they want to try and create.

A powerful example of this 'visioning' is the 1992 'Mont Fleur' scenarios, where a diverse, often opposing mix of political, business and civil society leaders in South Africa came together to try and shape a better future for their country.<sup>6</sup> Four scenarios emerged: 'Ostrich' (head in the sand, non-representative government), 'Lame duck' (incapacitated government), 'Icarus' (populist but unsustainable public spending) and 'Flight of the flamingos' (inclusive democracy and steady growth). By rehearsing the implications of each, the group was able to find a more collective view of the preferable future they could work towards.

Indeed, it is often the planning process itself, rather than the specific plans that are produced, that provide the biggest benefits from working with scenarios. Arie de Geus, a senior executive at Shell, perhaps the foremost organisation in developing the discipline of scenario planning, coined the phrase "planning as learning".<sup>7</sup>

*"Planning is an unnatural process. It is much more fun just to do something. That way failure comes as a complete surprise, rather than being preceded by a period of worry and depression."*

John Harvey-Jones

Such a dialogue – between the public, patients, clinicians, policy makers and politicians – will be critical to securing the health of the nation and ensuring a successful and sustainable NHS over the next 20 years or so. In particular, it enables the diverse perspectives of all to be represented constructively, an essential ingredient in tackling inequalities across the population. This type of process has already been successfully used before in the NHS. The 'Madingley Scenarios' of the mid-1990s explored how new forms and channels of information around health could combine with potential shifts in the attitudes and behaviours of patients and the public.<sup>8</sup> The ideas that emerged from this formed part of the thinking that subsequently led to the formation of NHS Direct, one of the world's first telephone and online services to support the health of a nation.

In addition to the benefit of coalition building, one of the most powerful aspects of scenario planning relates to their capacity to attune people to the possibility of exogenous shocks. These include extremes that it can be very hard to foresee, and catastrophic to ignore. We now turn to some examples of extremes in three illustrative health areas.

### 1.5 Scenarios around antimicrobial resistance, obesity and mental health can help us learn about how to cope with the future

This report has so far explored different aspects of health in 2040. We have a relatively high degree of confidence of what our demography and multimorbidity trends will look like in 2040. We might be reasonably confident about some impacts of emerging technology on population health but less confident about others. We are also unsure about when different changes will start to be seen in a significant way, not least, as Amara's law reminds us, because we tend to overestimate the effect of a technology in the short run and underestimate its impact over the long run.

This section takes that uncertainty even further by looking at different futures in the context of three illustrative areas:

- antimicrobial resistance (AMR)
- obesity
- the impact of technology on mental health.

In doing so, it highlights that the spread of possible futures is much wider for some than others. We shall see that in some cases we can be confident about the likelihood of certain outcomes and the impacts these will have on health and society, and in other cases we do not yet have the evidence to say with any certainty what scenarios we will likely see, and what the impact will be.

For each of these areas, we imagine both a more positive 'utopian' and a more negative 'dystopian' scenario and some of the critical factors that come together to make these possible. Against these different outcomes, we explore one of the biggest future uncertainties, namely how the inequality of impacts on particular places and groups of people that we see in 2040 may be very different to those we tend to see today.

## 02 We are certain that, without significantly changing how we use antimicrobials, AMR will have a devastating effect on future health care

### Box 14.2 An AMR scenario

*"It is a dark July day. Mrs Xu has not been counting, but it is the fifteenth day of her isolation. It started with a wheeze a week after her son's birthday. [...] The wheeze turned into a cough, the cough into a sore throat. Her husband, Jon, gave her that look – concerned but distant, scared of what was coming. He knew. [...]"*

*A few years [ago] .... the government passed new laws making it a criminal offence for the infected to be in public. There were talks of random tests in the street. If you were contagious, you would be committed to one of the isolation sanatoriums that were being built on the edge of all major towns. This was a death penalty. They were referred to as 'colonies'.*

*Mrs Xu wanted to die at home. She has spent two weeks in her room on her own. Jon and [her son] Josh leave her food and medication in the sealed space between the two doors: they use the outer door; she opens the inner door. She speaks to the doctor. He provides her with fever-reducing medicine, pain killers and something to help at the end. He also notifies the authorities. Their home is now identified as an infection spot. The year is 2043."*

*Extract from 'The Drugs Don't Work'*

(Professor Dame Sally Davies, Jonathan Grant, and Mike Catchpole. *The Drugs Don't Work: A Global Threat*: Penguin Specials; 2013)

Antimicrobial resistance (AMR) occurs when microbes – bacteria, viruses, fungi and parasites – no longer respond to the drugs designed to kill them.<sup>9</sup> Resistance is the inevitable consequence of bugs evolving in the same way as all other species. Bacteria that are susceptible to antibiotics will die off, whilst those that can resist will survive. This was noted by Alexander Fleming in his 1945 Nobel Prize speech after discovering penicillin: "It is not difficult to make microbes resistant to penicillin".<sup>10</sup>

It is hard to underestimate the impact Fleming has had on our health globally. The discovery and development of antibiotics, and other classes of antimicrobial drugs, was one of the greatest medical achievements of the 20th century. The World Health Organization estimates that antibiotic treatments add an average of 20 years to all of our lives, thanks to Fleming's discovery in 1928.

### 2.1 There is a strong probability that AMR will be a significant killer in 2040

In a highly dystopian scenario, the health dividend that antibiotics have given the world may come to an end by 2040. Whole classes of drugs are becoming ineffective as bacteria build resistance. At the same time there are very few classes of antimicrobial drugs in development, and even if they were successful and effective, they would need to be carefully curated in the future. Today, up to 50,000 lives are lost each year to antibiotic-resistant infections in Europe and the US. Globally, at least 700,000 die each year of drug resistance in illnesses such as bacterial infections, malaria, HIV/AIDS or tuberculosis.

The consequence of AMR will be devastating, with former UK Prime Minister David Cameron characterising it as a return to the "dark ages of medicines".<sup>11</sup> In a UK government *Review of Antimicrobial Resistance*, the former investment banker, Jim O'Neill, estimates that by 2050, 10 million lives a year are at risk along with a cumulative economic loss of US \$100 trillion worldwide.<sup>12</sup> Similarly, the World Bank, in its report *Drug-Resistant Infections: A Threat to Our Economic Future*, finds that drug-resistant infections have the potential to cause economic damage similar to – and likely worse than – that inflicted by the 2008 financial crisis, with the worst impact on the poorest countries and people.<sup>13</sup> In its worst-case scenario, the world would lose 3.8 per cent of its annual gross domestic product (GDP) by 2050. But, the impact of AMR on GDP would be felt throughout the period to 2050, and low-income countries would experience larger drops in economic growth than wealthy countries, so global poverty and economic inequality would increase.

Compared to the other examples covered in this chapter – on obesity and the impact of technology on mental health – we have a relative degree of certainty that these catastrophic outcomes will occur without radical interventions or innovations.

## 2.2 The development of new types of medicine may combat bacterial infection

AMR will only be controlled through a mix of research and innovation for new drugs such as antibiotics, vaccines and phages, the better and more appropriate use of existing drugs and improved infection control. Some of these policy interventions will be top down, i.e., come from governments and international agencies, and others will be bottom up, being driven by civil society. Critically, such a policy mix will need to be coordinated across countries, through international agencies such as the United Nations, World Bank and World Health Organization, as bugs, whether they are resistant or not, travel across national borders.<sup>14</sup>

That said, there is an increasingly ongoing international and concerted effort to control AMR. Some of this will include changing our usage of antibiotics and other antimicrobial drugs through simple behavioural interventions. For example, in a simple experiment, unnecessary prescribing by GPs in England for antibiotics was significantly reduced through the use of social norms. Every GP in an intervention group received a letter from the Chief Medical Officer stating that their practice was prescribing antibiotics at a rate higher than 80%, more than other practices in its NHS Local Area Team, along with a toolkit on antibiotics.<sup>15</sup> Subsequently, prescribing rates for antibiotics in those practices fell.

In the US, a social movement is forming against the use of antibiotics in farming. Historically, such drugs have been used to compensate for unsanitary conditions in which animals are raised and to promote faster growth. There is increasing evidence that farm animals develop resistance to this high usage and that these resistant microbes get into the food chain. *Chain Reaction III* assesses restaurant industry progress on eliminating the routine use of antibiotics in meat by rating the top 25 fast food and fast casual restaurant chains in the US.<sup>16</sup> The aim of the movement is to “help consumers make educated choices about the meat they eat, and encourage the largest chains in these industries to improve their sourcing policies”. Annual survey results suggest that fast food companies are increasingly responding to pressure, with fourteen of the top 25 fast food and casual restaurant chains having taken steps to limit the use of antibiotics in some or all of their supply chains.

Finally, we need to identify novel ways to encourage the developments of new drugs as well as preserving existing antibiotics through better usage. Currently, pharmaceutical companies are divesting from antimicrobial R&D due to market failure as any newly developed antimicrobials are likely to have restrictions imposed on their use (to prevent future resistance developing), thereby reducing their profitability. Novel mechanisms such as Advance Market Commitments (where the government promise to buy new drugs at a given – likely high – price) could create a market to incentivise and continue R&D. In addition, a focus on reducing infections through vaccine R&D is obviously critical.

One area that could have an unpredictable impact (a ‘wildcard’ in the language of scenario planning) would be the application of phage therapy.<sup>17</sup> At this stage the evidence of potential effectiveness and applicability on a large scale is limited. Phages are viruses that can kill bacteria. A potential advantage of phage therapy is that they only target specific bacteria and so could be aimed at the harmful ones, and there are less of the side effects often associated with antibiotics. However, this is controversial, as they can also develop resistance, and are still in the very early stages of development. Innovations like this more generally could provide an alternative to existing antimicrobial treatments. Within our 2040 timeframe, it may be possible not only to use naturally occurring phages, but to develop synthetic ones that could be used prophylactically in addition to treating bacterial infections alongside other alternative options to conventional antibiotics.

## 2.3 The impact of AMR could see huge inequalities, some of which might be very different to those we see in 2018

The impact of AMR will be distributed unevenly, with those who are rich – whether individuals or countries – likely to be more able to buy access to an ever decreasing stock of effective drugs. Similarly, countries with better governance and controls will be able to do a better job at restricting and targeting existing treatments, extending their effectiveness in the domestic population.

Whilst health inequalities according to level of deprivation is a common phenomenon in health (as examined in Chapter 9 of this report), other forms of health inequalities may arise from AMR. For example, social deprivation is associated with increased antibiotic resistance, where those with poorer living conditions consume more antibiotics than those living in least deprived areas.<sup>18</sup> Moreover, population density has been shown to be an important factor in the development of antibiotic resistance, suggesting that we may see increased health inequalities associated with living in urban centres.<sup>19</sup>

## 2.4 Avoiding a dystopian scenario for AMR requires a radical shift in policy and scientific paradigms

The story about Mrs Xu is a likely dystopian scenario, with devastating consequences, as illustrated by the O'Neill and World Bank reports. To provide Mrs Xu and her family with a future, it is critical that the existing policy mix of international cooperation, infection control and research for new treatments continues.

Some believe that a combination of much tougher laws, interventions that change behaviours amongst clinicians and the public, and far more precise targeting of the currently available antibiotic treatments could lead to a significant recovery in the effectiveness of the drugs we already have. Even then, without a paradigm shift in approach, it could be that this turns out to be more a strategy of minimising and managing the risk, rather than stopping or averting it.

Is there a utopian future where AMR is no longer a huge, global threat to our health in 2040? One radical 'wildcard' intervention that could change this trajectory is the successful development and widespread use of phage therapy. As we saw with the discovery of *Helicobacter pylori* (Box 14.1), scientific paradigms can radically change with significant consequences. But even here it is worth stressing that phage therapy could address bacterial infections, but not other microbial infections.

## 03 We are less certain about the rise of an obesity epidemic, with both positive and negative futures being possible

### Box 14.3 An Obesity scenario

David sits at his kitchen table waiting for his 11-year-old son, Jack, to come home from school. In the past, he would have picked him up, but David is morbidly obese, and has been housebound for two years. Having struggled with his weight for most of his adult life, he developed type 2 diabetes which he is failing to manage. If he can't turn things around, he will lose his foot.

Before his son Jack was born, the government introduced the National Childhood Measurement Programme. Last year, David received a letter from Jack's school warning him that Jack is overweight. David was deeply concerned that his son would go on to develop the same health problems he had experienced: high blood pressure, breathing difficulties, diabetes and depression. Determined to prevent this from happening, David investigated school and community programmes that would help Jack build healthy activities into his routine. He also made small changes to their home environment that made it easier for Jack to eat well, such as ensuring that there were healthy snacks readily available for his son when he returned home from school.

Today when Jack arrives home he appears happy and energised. He is now enrolled in an afterschool football club, and this afternoon they won their match. He is also receiving free 'cooking for kids' classes at their local community centre, which he enjoys. Parents are encouraged to attend, but David is unable to go due to his ongoing health problems. Jack dumps his school bag, grabs an apple from the table, and goes out to play with his friends. David is left alone again, wondering what the future holds for them both.

Despite being a relatively new problem, obesity has quickly become one of the most pressing global health issues. In a sense it's an entirely new type of problem, having too much rather than too little. It is estimated that obesity is currently responsible for more than 30,000 deaths each year, with moderate obesity reducing life expectancy by about three years, and severe obesity shortening a person's life by up to 10 years.<sup>20</sup> Obese men are five times more likely to develop type 2 diabetes and women are over three times more likely, with sufferers 34.5% more likely to die early than their peers.<sup>21</sup> Obesity is also a significant risk factor in the development of heart disease and certain cancers; it's estimated that 5.7% of all incident cancers in 2012 could be attributed to the combined effects of diabetes and high BMI.<sup>22,23</sup> A survey of global trends suggests that, in Europe, 14% of premature deaths could be prevented if people were a healthy weight rather than overweight or obese.<sup>24</sup> Obesity-related conditions are currently costing the NHS more than £6 billion per year, while the total annual costs to society of these conditions have been estimated at around £27 billion.<sup>25</sup>

Childhood obesity levels perhaps give us the best information for what the future will likely hold. Currently, nearly a third of children aged two to 15 are overweight or obese, and younger generations are becoming obese at earlier ages, and, based on historic data, will stay obese for longer.<sup>25</sup> There is now evidence that the rise of obesity in some segments of the population is slowing, such that overall levels of obesity might be stabilising.<sup>26,27</sup> However, analysis of data from the National Childhood Measurement Programme suggests that obesity prevalence in the most deprived 10% of children is now approximately twice that of the least deprived 10%.<sup>28</sup>

## 3.1 It is possible that in a dystopian scenario obesity could be the greatest cause of preventable death in 2040

Historically, obesity has been treated as a problem of information and willpower, but approaches relying on individual willpower alone are generally not effective.<sup>29</sup> The proportion of adults in the UK who are obese has increased from 15% in 1993 to 26% in 2016.<sup>26</sup> The prevalence of obesity in children is also a substantial health concern, with rates for 2017/18 at 9.5% for children in reception, and 20.1% for those in year six.<sup>28</sup> In 2007, the Government Office for Science published a seminal report by Foresight which estimated that by 2050 60% of adult men, 50% of adult women and about 25% of all children under 16 could be obese.<sup>30</sup> The higher rates of obesity we already see in younger cohorts still indicate that we face significant increases in morbidity. Further, we have a substantial knowledge gap regarding the nature of obesity, its risk factors and associated conditions, meaning that as rates continue to rise, we could see an increase in diseases not yet known to be associated with obesity.<sup>31</sup>

A further complicating factor which may lead to a dystopian scenario is that many people are unable to recognise that they or their children are overweight. Research examining weight perceptions among adults in Great Britain found that the majority of obese adults do not identify themselves as either 'obese' or 'very overweight'.<sup>32</sup> Parents' estimation of their child's weight status is also likely to be inaccurate, especially if children are categorised as obese according to their BMI.<sup>33</sup> An inability to recognise overweight and obesity can extend to GPs, who have been shown to regularly underestimate patients' weight, and may consequently be less likely to offer weight management advice and services to potential patients.<sup>34</sup> Future public health campaigns designed to address obesity may be seriously undermined by the inability of health professionals and the public to recognise the issue.

While it appears that overall levels of obesity are not rising as quickly as expected, we are far from certain that this trend signifies a substantial improvement, particularly given that this development is characterised by increasing health inequalities. While it appears that overall levels of obesity are not rising as quickly as expected, we are far from certain that this trend signifies a substantial improvement, particularly given that this development is characterised by increasing health inequalities. More recent modelling by the OECD estimates that 35% of England's population will be obese in 2030.<sup>35</sup>

In this scenario, it is possible that by 2040, obesity will have overtaken smoking as the leading cause of preventable death.

## 3.2 It is also possible that effortless solutions may slow down and even reverse the obesity epidemic

In June 2018, the UK government announced further action to address childhood obesity.<sup>36</sup> This is a good example of more deliberate, concerted action in the present to avert a potential disaster in the future. The call to halve the rates of childhood obesity by 2030 are certainly ambitious but the pieces are falling into place. It looks as though in many ways we are making the correct future choices, perhaps even reaching a turning point.

A core part of success in reducing the rise of obesity levels is the movement away from a narrative of individual responsibility for weight and towards an appreciation of the environment's effect on our behaviour.<sup>37</sup> Future success will hinge on tackling the obesogenic environments that make it difficult for people to lead healthier lives, rather than just telling them to resolve these problems themselves. This includes making the food that is sold healthier, reducing unnecessary exposure to eating cues and ingraining activity into daily routines.

Reformulation of food is a good example of an intervention that makes it easier for people to be healthier, as individual habits do not have to change to see health benefits. The soft drink industry levy has already had a huge impact, reducing the sugar in soft drinks by 11% before the tax even came in.<sup>38</sup> The forthcoming calorie reduction programme targets, paired with the already existing sugar reduction targets, aim to build on this and remove excessive calories from our diets. Similarly, reducing unnecessarily large portion sizes could lead to a 12% reduction in calories consumed.<sup>39</sup>

Reducing children's exposure to adverts and promotions for high fat, salt and sugar products is another closely related ingredient for success. Advertisements can alter children's preferences and increase consumption.<sup>40.41</sup> The introduction of a 9pm watershed will help, but it is essential that policy makers remain vigilant for digital marketing strategies in a world where traditional broadcast media ceases to be as relevant. As with the added-sugar levy, a key part of the impact comes not from individual level behaviour change, but from reformulation as a result of the changed market pressures, including the development and promotion of healthier alternatives.

The built environment and city planning is crucial for encouraging an active lifestyle. Building regular physical activity into people's daily lives is likely to be more effective than asking them to make regular trips to a gym.<sup>42</sup> With more people living and working in cities, we must consider how we maximise the use of the space we have. Cycling accounts for 2% of all journeys made in London, but almost eight million

more daily journeys could be cycled.<sup>43</sup> Again, there is a case for investment to make this as appealing as possible.

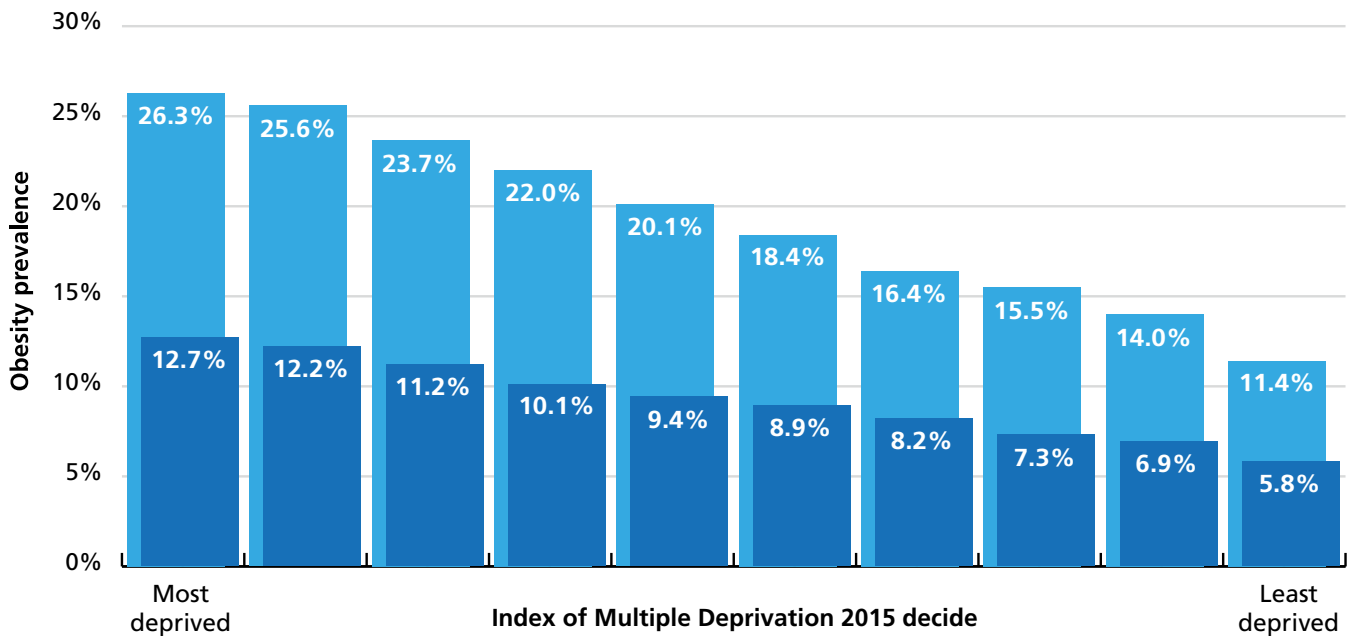
It is entirely possible that continued progress to a more positive utopian scenario in 2040 could lead to the creation of a system that has, for the most part, designed out obesity. There are currently experiments underway in a number of US towns seeking to reverse engineer longevity which have shown interesting results.<sup>44</sup> These experiments are based on identifying and attempting to replicate common features of communities around the world known as ‘Blue Zones’, where people appear to live longer, healthier lives. While it is not necessarily appropriate to replicate all common features of these communities, an environment that encourages regular physical activity, healthier diets and lifestyles could play a major role in reducing levels of obesity. Recent progress in Amsterdam similarly shows change is possible at a larger scale, where the number of overweight or obese children has dropped from 27,000 to 24,500 over three years after the introduction of a comprehensive healthy weight programme.<sup>45</sup> Crucially, this package of interventions includes a health volunteer network targeted at the poorer areas in the city, including among immigrant communities from Suriname, North Africa and Turkey.

### 3.3 Inequalities in the health impacts of obesity are likely to persist

Whichever scenario takes hold, it is likely that health inequities relating to obesity will continue in the future. While obesity can affect all sections of the population, some people are more likely to become obese than others. There is currently a striking level of inequality in both absolute levels and change over time. The Marmot review indicates that income, social deprivation and ethnicity all have a significant impact on the likelihood of becoming obese.<sup>46</sup> These inequalities are particularly evident in childhood obesity, where rates are falling for children in least deprived areas, and continuing to worsen for the most deprived. If we do not develop sustained and effective policies to reduce health inequalities, we will see a future in which obesity levels continue to rise, with a widening gap between those who are least and most deprived.

As with AMR, there is also a cruel twist that obesity is set to become more of a problem in some of the poorest areas of the world, which may ironically be triggered in part by rising incomes which give people access to more calorie-dense food. It is also highly possible that epigenetic effects are at work, especially in rapidly industrialised nations, where older people brought up in low calorie environments are

Figure 14.4 Obesity prevalence by deprivation decile, National Child Measurement Programme 2016/17



Source National Child Measurement Programme, Public Health England



constitutionally configured to hold on to every calorie. This could make those generations especially prone to obesity.

The story of David and Jack's family illustrates that, as we learn more about the impact of different factors on an individual's chance of becoming obese, it will be important to consider the very personalised response individuals can have to different policy interventions. Further work understanding these inequities is needed, as they may generate new types of inequalities based more on individual personalities rather than traditional lines such as economics, geography and class.

### **3.4 Future policies have the potential to design out an issue that was man made in the first place.**

What the future holds with regards to obesity and its impacts is in the balance. The story of David and Jack illustrates the competing set of trends and factors that tip us towards a more utopian or a more dystopian outcome. The hope is that it is David's son Jack that embodies what can be done through positively engaging with an environment designed to promote healthy living, supported by a new policy framework that focuses on facilitating behaviour change through a mix of taxing unhealthy products and investing in urban design and healthy school and community programmes. Innovations can be harnessed to make it easier for people to live a healthy lifestyle without sacrifice, but this requires solutions that are driven by a sophisticated understanding of health inequalities. Whether this is possible at a national scale, or even globally, remains to be seen.

## 04 We are very uncertain about the impact of technology on mental health

### Box 14.4 A technology and mental health scenario

Aisha is studying for her GCSEs. She is a good student, but has found the pressure of revision difficult. She is worried that she will let her parents and teachers down if she does not perform well in her exams. Her friends don't seem to share her concerns, and she has become increasingly isolated. She is beginning to show symptoms of anxiety, including headaches, panic attacks and difficulty sleeping.

One night she is feeling particularly low, and is convinced that she is not clever enough to succeed. It's too late to call anyone, and she doesn't want to wake her parents. Her tutor at school has recommended an app called "StressBess"\* designed to help students address anxiety around exams. Bess is a conversational agent or 'chatbot' that offers a form of Cognitive Behavioural Therapy, by identifying where users are engaging in "negative self-talk" and helping them reframe their thinking in a healthier way. The app has been robustly evaluated, is free to use, and is available at any time, day or night.

Aisha logs into the app on her smartphone and tells Bess that she feels like she's not good enough. Bess messages straight back, and says she's sorry to hear that. She then explains to Aisha that anxiety about a specific event, such as an exam, can balloon into a more generalised negative spiral. Bess invites Aisha to rewrite her thoughts in a way that better reflects reality; she is a good student, who is worried about her exams. Over the following weeks, Bess checks in with Aisha regularly to see how she's feeling. While she's still worried about her exams, Aisha is learning to identify unhelpful negative thought patterns, and is feeling more positive about the future.

*\*Fictitious app conceived for illustrative purposes only.*

Mental illness represents 28% of the national disease burden in the UK. It is the leading cause of sickness absence in the UK, accounting for 70 million sick days in 2007. It was estimated that mental illness costs the UK economy £70–£100 billion per year; 4.5% of GDP. The majority of mental illness begins in childhood and adolescence, with 75% of adult mental illness present by the age of 21 and 50% by the age of 14.<sup>47</sup> About 10% of children have a diagnosable mental health disorder – that's roughly three children in every classroom.<sup>48</sup> The burden of poor mental health for the youngest members of society has significantly increased in recent decades, while the number of children and young people attending A&E with a psychiatric condition more than doubling between 2010 and 2015.<sup>49,50</sup> Increase in mental health disorders is particularly prevalent among teenage girls, e.g. the incidence of self-harm in girls aged 13 to 16 increased by 68% between 2011 and 2014.<sup>51</sup>

There is a popular perception that this rise in youth mental illness is correlated with the advent of social media, and other digital technologies such as gaming. A total of 77% of UK internet users have a profile or account on a social media site or messaging site or app, including almost a quarter of 8 to 11-year olds, and three-quarters of 12 to 15-year olds.<sup>52,53</sup> The total number of social media users in the UK has grown steadily over the last decade and is predicted to continue rising. The games market is also rapidly expanding, having risen by 12.4% in 2017, bringing the UK market value to £5.11bn.<sup>54</sup>

The Chief Medical Officer of England's 2013 annual report, *Public Mental Health Priorities*, noted that there are 'widespread concerns about potential negative effects [of social media], which include increased physiological arousal, decreased attention, hyperactivity, aggression, antisocial or fearful behaviour, social isolation and excessive use or 'technological addiction'<sup>55</sup>, but, as also stated in that report, 'evidence is sparse and contradictory'. Since then, debate continues as to whether there is an adverse connection between social media use, screen time and gaming and mental illness.

In 2015, the Office for National Statistics found that there is a 'clear association' between time spent on social media and mental health problems; while 12% of children who spend no time on social networking websites have symptoms of mental ill health, the figure rises to 27% for those who are on the sites for three or more hours a day.<sup>56</sup> A recent evidence review also found that one in 10 girls was found to be in the top category for time spent on websites, compared to just one in 20 boys.<sup>57</sup> There is emerging literature investigating online social media addiction, which suggests that excessive social media use may lead to the same features of clinically recognised addictions including mood modification, tolerance, withdrawal and relapse.<sup>58</sup> A Huxley-esque view of

the future is that large sections of the population could spend much of their time on addictive platforms, impacting their mental and physical health, as well as their relationships and economic productivity.

Studies examining the relationship between social media use and subjective wellbeing have indicated that users' self-esteem and perception of their own wellbeing may be routinely undermined through their participation on the site.<sup>59,60</sup> Study authors suggested that perceiving others to be happier and more successful had the potential to exacerbate mental health difficulties in those already predisposed to psychiatric disorders. However, a 2017 survey by Royal Society of Public Health reported a more mixed set of impacts from social media on mental health<sup>61</sup>, with problems reported with anxiety, depression, sleep and 'fomo' ('fear of missing out'), and advantages in self-expression and community building.

## 4.1 It is possible that heavy use of social media, gaming and similar products could significantly increase the burden of mental illness

The relationship between electronic media and mental illness is a relatively new research area, so there is little evidence to predict trends and correlations. The paucity of recent data on the epidemiological and service aspects of mental health disorders further contributes to the difficulty of knowing what kind of future we are facing.<sup>62</sup> While concepts such as social networking addiction are not currently recognised as separate mental disorders, it is possible that growing numbers of sufferers will reshape the way in which we categorise and think about mental health problems in this area. That would have a significant impact on the way in which mental health services are funded and organised, given that online social interactions affect an enormous proportion of the world's population.<sup>63</sup>

A significant rise in mental health difficulties associated with social networking and gaming would also be likely to increase demand for stretched mental health services. Between 2015 and 2016 about 1.8 million people were in contact with adult mental health and learning disability services, while children's mental health services are currently failing to meet a dramatic increase in demand.<sup>64</sup> According to analysis conducted by the King's Fund, income for mental health trusts rose by less than 2.5% in 2016/17 compared to more than 6% for acute and specialist trusts, contributing to the trend of a growing spending gap between mental health and acute trusts.<sup>65</sup> In a dystopian scenario, this, combined with insufficient recruitment of psychiatry trainees in the UK and lack of training for GPs, could lead to a future in which the health service is unable to meet the demands of increasing technology-related mental health disorders in the population.

## 4.2 Apps, gaming and the 'connected world' have the potential to transform mental health services for the better

The Chief Medical Officer of England's 2013 annual report, *Public Mental Health Priorities* noted that technology has the potential to support mental healthcare, facilitating the delivery of timely interventions and making assistance more widely available.<sup>55</sup> In addition to the literature raising concerns about the impact of new technologies on mental health, there is also a growing body of evidence that social media, smartphone apps and even gaming could provide radical new ways of managing and treating mental health disorders among other illnesses. It is quite likely that we will see a future in which mental health difficulties are detected and treated effectively through the use of sophisticated and cost-effective new technologies, alleviating the burden of mental health disease, and reducing pressure on mental health services.

There is rapid growth in the number and varying quality of 'health apps', and it is possible that such mechanisms could in the future form part of effective treatments for both mild and serious mental health disorders. We are already seeing the development of therapy bots such as that described in our scenario at the beginning of this section. In 2017, the first randomised controlled trial was published, examining the impact of a conversational agent (or chatbot) known as 'Woebot' delivering Cognitive Behavioural Therapy (CBT).<sup>66</sup> The study produced compelling evidence that conversational agents are an effective means of delivering CBT, that produce results comparable to results obtained through interaction with a human therapist. In the future, the use of such apps could become ubiquitous, and could be used to support treatment for more serious mental health disorders.

We could also see an expansion of apps that deliver digital lifestyle coaching, as noted by a recent Student-led Health Commission on the future of the NHS at King's College London.<sup>67</sup> The likes of 'Hello Sunday Morning', an online scheme managed by Australian federal states, encourages people to drink less alcohol by getting them to do more activities together, connecting users to one another to arrange activities and providing them with online access to Health Coaches, who help along the way. Results suggest that participation in the programme can significantly reduce alcohol consumption.<sup>68</sup>

It is also possible that gaming could actually reduce the impacts of conditions such as ADHS, PTSD and depression. For example, research at the University of Nottingham involving young people aged 10 to 12 years of age with behavioural problems has shown that games can be effective in engaging young people with their therapists to discuss their reaction to situations met in the games.<sup>69</sup> There is now an emerging research agenda examining the potential of video games to play a positive role in preventative and therapeutic medicine, in addition to burgeoning grassroots

movements amongst online communities dedicated to using video games for healing and recovery.<sup>70</sup> Puzzle games including Tetris and Bejeweled have been shown to alleviate depression and can even prevent the incidence of flashbacks following a traumatic event.<sup>71</sup>

A possible 'wildcard' for the future is that games linked to emotional responses using electroencephalogram headbands and other 'wearables' help users to manage their emotions as a future form of CBT. Greg Toppo's 2015 book, *The Game Believes in You*, reports those with ADHD finding the game 'Throw trucks with your mind' a useful form of therapy as success needs a calm and focused mind to move objects around the screen.<sup>72</sup>

Finally, it is possible to see a future in which digital platforms enable individuals to create and maintain diverse and rich personal networks that lead to higher degrees of social fulfilment. A future where, for most people, connectivity, trust and sense of belonging increases markedly. As Bob Putnam, a world expert on social capital, said of the internet two decades ago: 'the question is whether it will become a fancy TV (isolating and absorbing people to negative effect) or a fancy telephone (connecting people and strengthening relationships)'.<sup>73</sup> Much the same question applies to social media, technology, and evolving markets today. They at once have the capacity to distract, isolate and divide us, or to connect, enrich, and increase trust between us. This goes far beyond treatment of mental illness, reaching deep into the primary drivers of stress, anxiety and depression and of positive wellbeing too. This is a future that remains very much up for grabs either way.

## 4.3 A 'digital divide' could reshape the health inequalities we see in 2040

There is evidence that the use of digital technologies is related to age more than socio-economic factors, with young people across all socio-economic groups more comfortable with using social media, gaming and other digital platforms than older people.<sup>74</sup> As this younger group ages, a willingness and capacity to adopt new technologies across the population will lead to new and more powerful support for maintaining mental health that could help to narrow the more generic socio-economic inequalities.

It would be unlikely though for some sort of 'digital divide' not to emerge. Some of this might be driven by 'access' barriers, such as an ability to pay for technology or get education and training to use it effectively. Some of it may result from individuals and households segmenting in new ways, which may or may not correlate with current health inequalities, perhaps around their risk profiles and willingness to share their data with public and private entities in ways that benefit them in managing their health.

## 4.4 Policy needs to focus on fair access to the increasingly wide range of technologies that will be available to help maintain mental health

The evidence of the effects of digital technology on mental health is currently inconclusive. While the dystopian scenario illustrates how the ubiquitous use of digital technologies could increase mental illness and stretch mental health services, Aisha's experience with "StressBess" paints the picture of a utopian alternative in which digital technologies, whether social media, apps or games, provide effective interventions to manage mental health, especially in young people. So rather than being the causes of mental illness (especially amongst young people), they are the ingredients for a radically different way for people to find and connect with the things that can give them fulfilment in life and enable them better to look after their own physical and mental health.

For policy makers thinking about how technology impacts on the future mental health of the population, a focus on ensuring equality of access seems a key consideration.

## 05 Conclusion

In this chapter, a cast of characters has illustrated the uncertainties around health in 2040. Through the experiences of Mrs Xu, David, Jack and Aisha, we can envision radically different futures, some of which are more positive and others more negative (as summarised in Figure 14.5).

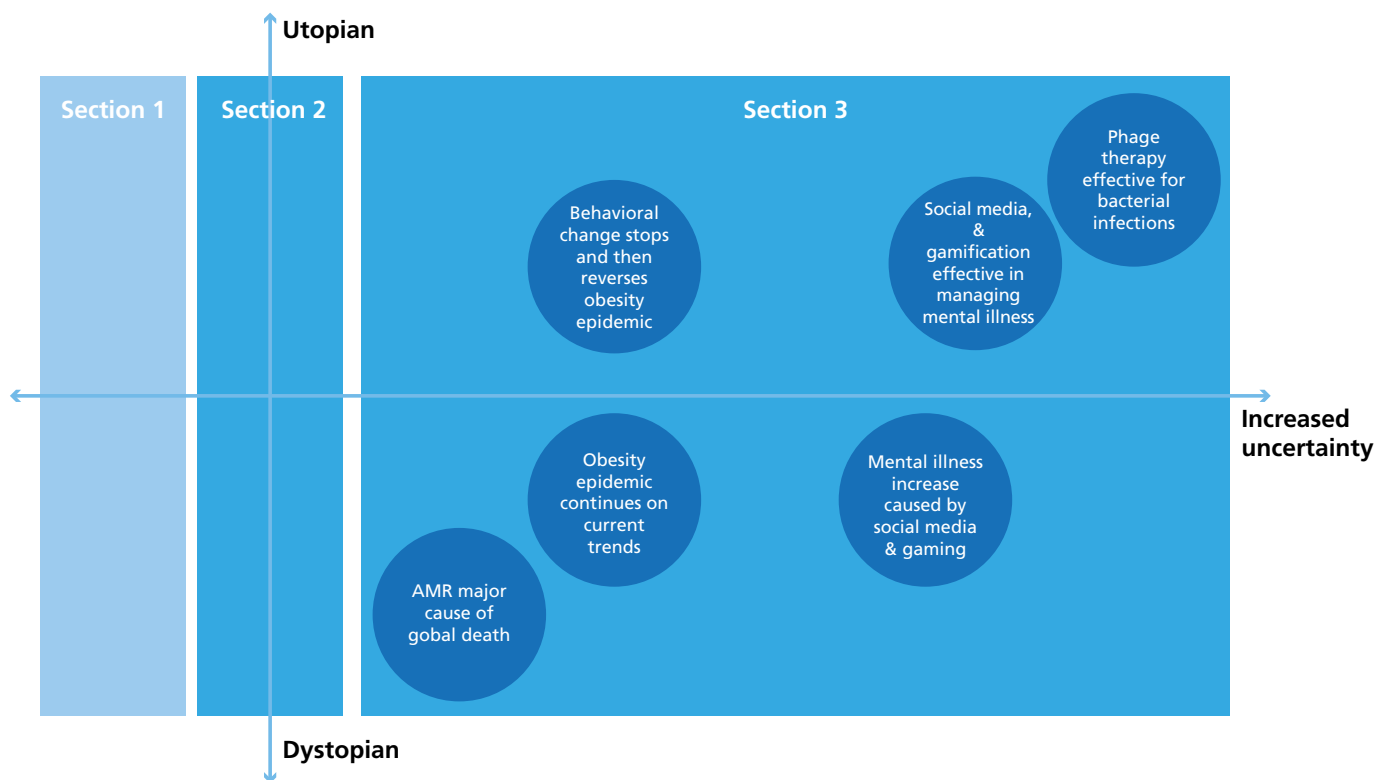
We deliberately used fiction as the means to introduce these futures to emphasise that they are not predictions. Just as the cities of 1900 could not and did not anticipate the motor car, the health system will face powerful and potentially surprising innovations and events up to 2040 that it must successfully respond to. By their nature, these innovations and events cannot be predicted. They emerge from a range of uncertainties, some of which are about how current trends continue to unfold and others which come as sudden shocks. It is the ability to cope with what this uncertainty might bring that the health system needs to plan for.

By applying a form of scenario thinking, we hope we have illustrated how important it is to plan for the disruptive uncertainties the future may hold and the need for the Department of Health and Social Care, the NHS and the broader health system to be prepared to act nimbly for a range of potential futures. Through this process a number of lessons should be apparent.

First, the future is still substantially to be written. Armed with a better understanding of aetiology, evolving technology and the interaction with human behaviour, it is in our power to shape it, not just have it shape us. Therefore, one of the challenges for public health professionals, politicians and policymakers is to crystallise the choices we have to make. Many of these will be collective, rather than just individual choices. We are all affected, directly or indirectly, by the rise in AMR, the impact of obesity and the way technology will shape our mental health in a number of ways. By strengthening the mechanisms, we have to glimpse these futures together, open up a dialogue about the futures we want to create, and encourage citizens themselves to help shape and choose between them.

Second, the different futures we have explored point to new types of inequity that could have a profound impact on the future of health in 2040. These include the rural vs. urban geographies associated with AMR, the individual psychosocial differences for obesity and the digital divide for mental health. This is not to argue that existing regional and socio-economic differences will disappear, but to suggest that there is a risk of letting the 'lens of now' shape the discussion and tackling of health inequities when there is a reasonable risk that new dimensions of inequality may emerge over the next twenty years.

**Figure 14.5** Plotting uncertainty – utopian and dystopian futures



Source *The Policy Institute at King's, King's College London*

The third lesson relates to the policy response to different scenarios. To what extent will alternative types of intervention either help us secure a utopian outcome or prevent a dystopian disaster? Using these and other scenarios to stress test existing and future policies would in our view help create a resilient health system for the future. In particular, they can help answer the question ‘what are the most robust things that we can do now that will prepare us for whatever the future might hold?’

Finally, it seems essential that such ‘future’ thinking should be a mainstream activity for health planning in England. Understanding and testing the drivers and critical pathways behind different scenarios – and assessing the future risks and opportunities they reveal – strengthens the policy process by bringing the full range of relevant stakeholders together in order to ‘learn about the future’. Developing a resource and process to systematically think about the long-term future of the health system in England, and to use the resource persistently in planning, would seem a prudent approach given the epidemiological trends and technological innovations highlighted in the earlier sections of this report. As President Dwight D. Eisenhower once said: “Plans are worthless.... but planning is everything.”

## Box 14.4 Department for Transport Future Mobility Visions – Arup

*Text kindly supplied by Michael Morrell, ARUP*

In January 2018, Arup, a global firm of designers, planners, consultants and engineers, were commissioned by the Department for Transport’s (DfT) Office for Science (DO-Science) to develop a series of visions describing plausible futures in relation to the transport of passengers and goods in 2040. Arup’s Foresight team’s research explored the opportunities, risks and uncertainties in relation to a number of pre-determined areas of technological innovation, including Mobility as a Service (MaaS), Smart Infrastructure and Construction and Hybrid Aviation. They conducted a literature review of relevant reports and analyses, many of which were internal to DfT. They also carried out extensive interviews with a range of subject matter experts from across DfT, Arup and a number of other organisations.

Following this initial research and engagement phase, Arup analysed the trends identified using a Wilson Matrix to surface out those trends most likely to have the greatest impact on mobility in the United Kingdom to 2030. These high trends are called critical uncertainties. This analysis informed a scenario planning approach, using Morphological Analysis, to underpin the visions. Arup identified a number of key factors that encapsulated the critical uncertainties identified.

Together, these key factors define the contextual landscape for each of the focal technologies. Key factors are neutral, as they are accompanied by a range of projections that describe plausible future states. The different projections explore the full range of uncertainty in relation to these key factors. A combination of projections across all key factors were identified to ensure consistency, coherency and plausibility. These informed the scenarios and their narratives.

The visions were then written up in a detailed report that also identified the disadvantages, risks and uncertainties associated with each future. These were also communicated via an accompanying set of trends cards and a series of graphic visualisations. The outputs have been used by DO-Science to frame departmental discussions for policy and strategy development but do not represent DfT policy or objectives. Workshops and presentations in relation to the visions have been made within the Department to an estimated 2,000 employees.

### Box 14.5 Views from a student-led health commission

*Text kindly supplied by Anna Doyle and Osama Suwar, students at King's College London*

In 2018, the NHS celebrated its 70th birthday, providing an opportunity for the public to reflect proudly on the achievements of the health service. To coincide with this milestone, a student-led health commission, overseen by academics from King's College London, was tasked with coming up with radical and creative ideas to ensure that the health service can meet the needs and expectations of those who will use it in the future. The commission offered a fresh perspective, reflecting their generation's experiences.

The commission noted that there are a number of factors that will have substantial negative impacts on our health, including the rising number of people living alone, and increasing levels of obesity. The commission developed the concept of "Shared Health" and identified a need for a digital health platform that connects people living in local communities through their health and social networks. The aim would be to use technological innovation to expand individuals' health capital using tools such as social mapping, access to health coaches and like-minded people, or groups to help encourage users to lead a healthy lifestyle. The commission highlighted the importance of this platform as a vital tool to increase health capital by bridging the gap between communities and health services, and empowering community members to support one another.

The commission also suggested that the benefits of peer to peer support could extend to the NHS workforce. The development of a community-minded patient population, where responsibility for health is shared, could create a valuable resource, alleviating some of the pressures experienced by NHS staff. The commission advocated measures to generate balanced relationships between NHS staff and patients, strengthening patient involvement in the planning of their care and patient participation in the development of services. A process called 'Normovation', where innovation on the part of both NHS staff and patients becomes the norm, could play a role. For example, greater integration could be encouraged via the introduction of patient healthcare receipts which positively reinforce efficient use of health services, and developing 'living' end of life care plans which allow patients to explore and evolve their preferences for their care during end of life.

The commission concluded that technology could help support knowledge-sharing, and improve patient participation, for a better NHS. The full report, with recommendations, is available online at

<https://www.kcl.ac.uk/sspp/policy-institute/publications/Futureproofing-the-NHS-A-generational-shift.pdf>.



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## Chapter 15

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# Forecasts for health in 2040

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### 01 Introduction

With a strong collaboration with Public Health England, results from the Global Burden of Disease Study (GBD) have been used extensively to inform public health policy in England and the United Kingdom (UK).<sup>1,2,3</sup> The recent GBD forecasting framework for 250 causes of death and 195 countries allows extending such analyses into the future.<sup>4</sup> In this chapter, we present results on life expectancy, cause-specific and risk-attributable fatal burden for the UK 1990 – 2040, with forecasted reference, better and worse scenarios. All forecasting results build on the 2016 round of the GBD.

### 02 What are forecasts?

It is useful for health planning and policy making to have an idea of how the future will unfold, should the trends in drivers of health of the past continue into the future, and also what will happen to health under (plausible) more and less favourable alternative future trajectories of the drivers of health. Our reference forecast, and better and worse health scenarios 2017-2040, are an attempt to provide this. The reference forecast is what we would expect to occur in the future if independent drivers of health (for example risk factors like smoking or body mass index) continue to follow their trends of the recent past. The better (85) scenario is constructed by setting rates of change for each independent driver to the 85th percentile of observed rates of change across the years 1990 to 2016 and the 195 countries included in the analysis. The worse (15) scenarios are constructed similarly by setting the rates of change for each independent driver to the 15th percentile of the same distributions of observed annual rates of change.

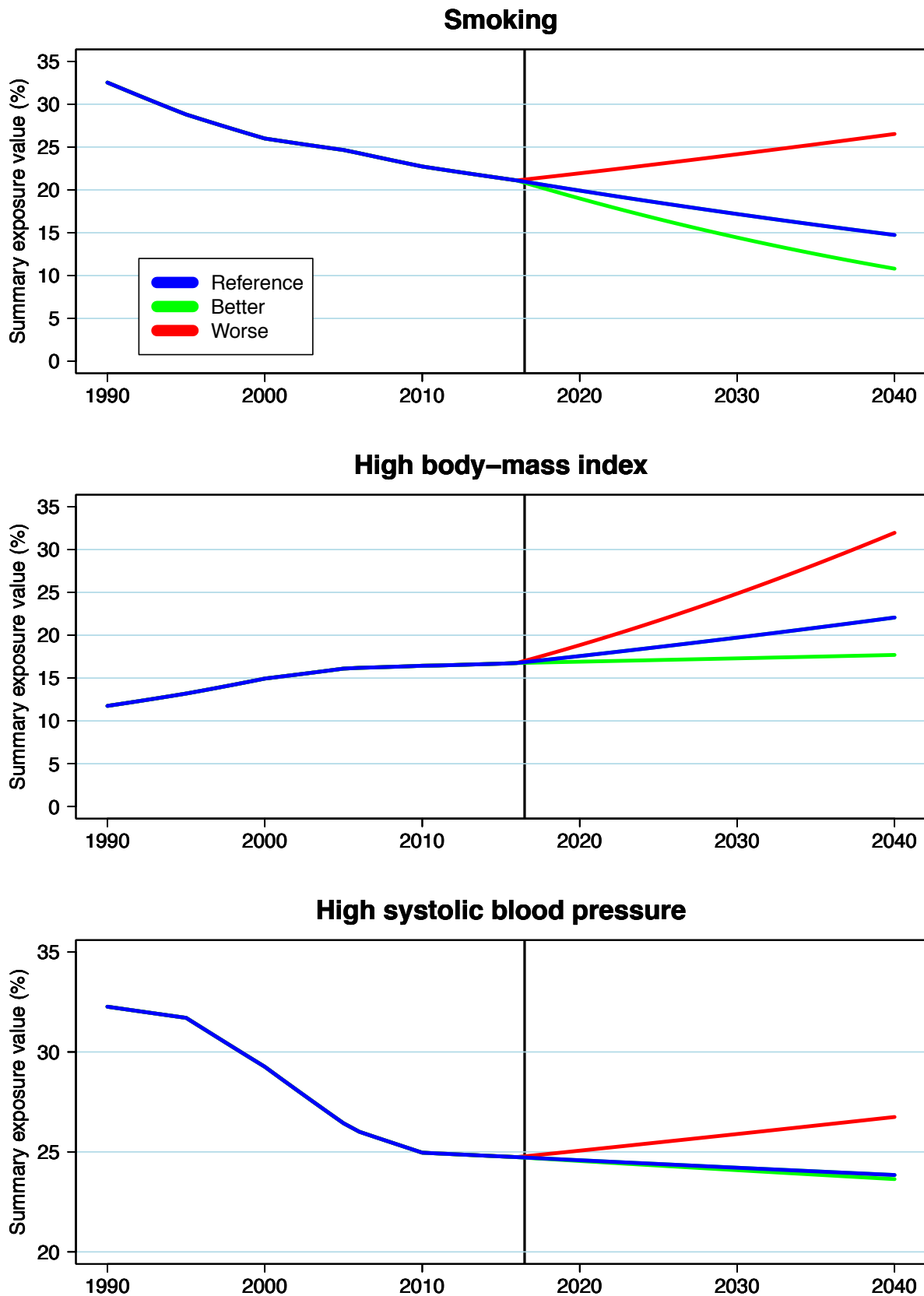
## 03 The GBD forecasting framework

Briefly, the forecasting framework is built on three principles. First, the modelled causal relationships of risk factors to cause-specific mortality are derived from the GBD comparative risk assessment that builds on meta analyses of evidence from randomized controlled trials, cohort studies and other observational evidence.<sup>5</sup> Additional modelled drivers of cause-specific mortality are five vaccines and the socio-demographic index, a composite measure based on income per capita, average educational attainment and total fertility rate under 25 years of age. Second, model performance is assessed with out-of-sample validity holding out the most recent years (2007-2016) and using data from 1990-2006 to make predictions that are compared to what actually happened in the hold-out years. Third, constraints are imposed so that known regularities, for example increasing mortality rates with age, are respected.<sup>4</sup>

## 04 Risk factors – forecasted with the summary exposure value

Risk factors are forecasted using the summary exposure value (SEV) that allows risk factors measured on different scales (continuous and categorical) to be represented on a scale from zero to one. A SEV of zero means that no one in the population is exposed, and a SEV of one that all members of the population are exposed to the maximum level of risk for the given risk factor. Figure 15.1 shows the SEVs for smoking, BMI, and systolic blood pressure. When the exposure is binary (e.g. smoker versus non-smoker), the SEV is equivalent to prevalence. The past trend in smoking prevalence declined from 33% in 1990 to slightly above 21% in 2016. We forecast a continued decline to 2040 for the reference (15%) and better (11%) scenarios, but a rebound of the smoking epidemic in the worse scenario to a prevalence of 27%. Trends in body mass index increased from 1990 to 2016 and continued increases were projected in all three scenarios, albeit a very slight increase in the better scenario (from 17 to 18% of maximum population risk exposure). Systolic blood pressure decreased from 1990 to 2016 with a moderately continuing trend of decline to 2040 for both the reference and better scenarios, and a slight increase in the worse scenario.

**Figure 15.1** Summary exposure values for smoking, body mass index and systolic blood pressure, 1990 to 2040, with scenarios



Source: Institute for Health Metrics and Evaluation, 2018



## 05 20 leading causes of years of life lost in 2016 and the 2040 reference forecast

Figure 15.2 shows the reference forecast of the twenty leading causes of years of life lost (YLLs) in the UK in 2040. Years of life lost is a measure of premature mortality obtained by multiplying each death with the expected life expectancy of that person at the time of death. Expected life expectancies are taken from a common reference life table. In addition to forecasted rank position in 2016 and 2040, the figure shows the percent change between 2016 and 2040 in total number of YLLs, as well as changes in YLL age-standardised rates. Change in counts of YLL for a specific cause may be due to population growth, population aging or changes in age-specific mortality rates (usually a combination of the three). The age-standardised rate is adjusted for population growth and aging. Our forecasts predicted that ischaemic heart disease will remain the top ranked cause of YLLs in 2040. Still we noted important decreases in both YLL counts (-32%) and age-standardised rates (-52%). Stroke was forecasted to move from third to 7th rank position. Alzheimer's disease and other dementias were projected to rise from fifth to second rank with a 51% increase in numbers of YLLs from 2016 to 2040 (despite a moderate decline of 4.6% in the age-standardised rate). The rank positions in the

2040 forecasts for lung cancer, lower respiratory infections (LRI) and COPD were 3 (2 in 2016), 4 (6 in 2016) and 5 (4 in 2016), respectively. While an increase in YLL counts was forecasted for LRI, both lung cancer and COPD had projections of moderate decreases in YLL counts. However, all three have forecasts of substantial decreases of 20 to 36% in age-standardised rates.

Whereas we forecasted increases in number of YLLs for 6 of the 10 top ranked causes, all 10 top YLL causes in 2040 have forecasted declines in age-standardised rates. Only three of the top twenty ranked causes of YLLs in 2040 had reference forecasts of increase in age-standardised rates from 2016 to 2040: a negligible increase for chronic kidney disease, a moderate increase for interstitial lung disease (19.6%), but a major increase of 76% for drug use disorder YLLs. Four causes fell out of the top twenty rank list between 2016 and the 2040 reference forecasts, namely cirrhosis due to alcohol use, stomach cancer, road injury and congenital defects. All four declined substantially in both absolute numbers of YLLs, all-age and age standardised rates.

Figure 15.2 Top 20 leading causes of years of life lost (YLLs) in 2016 versus the reference forecast of 2040

## Leading Causes of YLLs in 2016 and 2040, United Kingdom

**Legend:**

Communicable, maternal, neonatal and nutritional  
Non-communicable  
Injuries

Leading Causes 2016	Leading Causes 2040	Mean % change number of YLLs	Mean % change age-standardized YLL rate
1 Ischemic heart disease	1 Ischemic heart disease	-31.9 (-63.8 to 20.4)	-51.5 (-73.4 to -16.5)
2 Lung cancer	2 Alzheimer's disease	<b>50.7 (23.5 to 93.8)</b>	-4.6 (-27.6 to 28.2)
3 Stroke	3 Lung cancer	-1.0 (-27.8 to 22.3)	<b>-25.6 (-44.8 to -8.2)</b>
4 COPD	4 Lower respiratory infect	23.3 (-7.1 to 65.9)	-20.3 (-45.0 to 13.7)
5 Alzheimer's disease	5 COPD	-5.3 (-29.0 to 17.6)	<b>-35.7 (-54.1 to -17.9)</b>
6 Lower respiratory infect	6 Colorectal cancer	15.7 (-20.6 to 70.0)	-14.3 (-43.9 to 28.1)
7 Colorectal cancer	7 Stroke	-39.2 (-63.9 to 3.7)	<b>-59.2 (-76.2 to -32.4)</b>
8 Breast cancer	8 Breast cancer	2.5 (-24.4 to 37.6)	-16.9 (-39.3 to 10.8)
9 Self-harm	9 Prostate cancer	<b>34.7 (17.5 to 54.4)</b>	-9.9 (-23.9 to 6.1)
10 Other cardiovascular	10 Pancreatic cancer	<b>22.4 (0.2 to 50.7)</b>	-5.5 (-24.8 to 15.8)
11 Pancreatic cancer	11 Drug use disorders	<b>75.7 (47.3 to 105.8)</b>	<b>75.7 (45.5 to 107.2)</b>
12 Prostate cancer	12 Self-harm	-18.1 (-48.9 to 24.6)	-20.8 (-51.6 to 25.1)
13 Esophageal cancer	13 Other cardiovascular	5.9 (-15.2 to 29.6)	<b>-25.6 (-43.1 to -6.1)</b>
14 Cirrhosis alcohol	14 Esophageal cancer	19.4 (-32.8 to 127.2)	-6.0 (-50.6 to 86.4)
15 Other neoplasms	15 Other neoplasms	<b>24.4 (14.6 to 35.1)</b>	-2.2 (-14.3 to 9.7)
16 Leukemia	16 Leukemia	19.8 (-2.9 to 44.6)	-9.6 (-25.0 to 9.3)
17 Stomach cancer	17 Brain cancer	8.8 (-2.1 to 19.5)	-5.5 (-17.9 to 6.0)
18 Drug use disorders	18 Interstitial lung disease	<b>64.9 (48.5 to 80.2)</b>	<b>19.6 (3.9 to 36.9)</b>
19 Congenital defects	19 Chronic kidney disease	51.6 (-26.8 to 185.7)	1.1 (-54.4 to 111.2)
20 Road injuries	20 Aortic aneurysm	9.9 (-21.5 to 44.3)	<b>-25.5 (-46.0 to -1.3)</b>
21 Brain cancer	24 Cirrhosis alcohol		
23 Aortic aneurysm	31 Stomach cancer		
33 Chronic kidney disease	33 Road injuries		
35 Interstitial lung disease	36 Congenital defects		

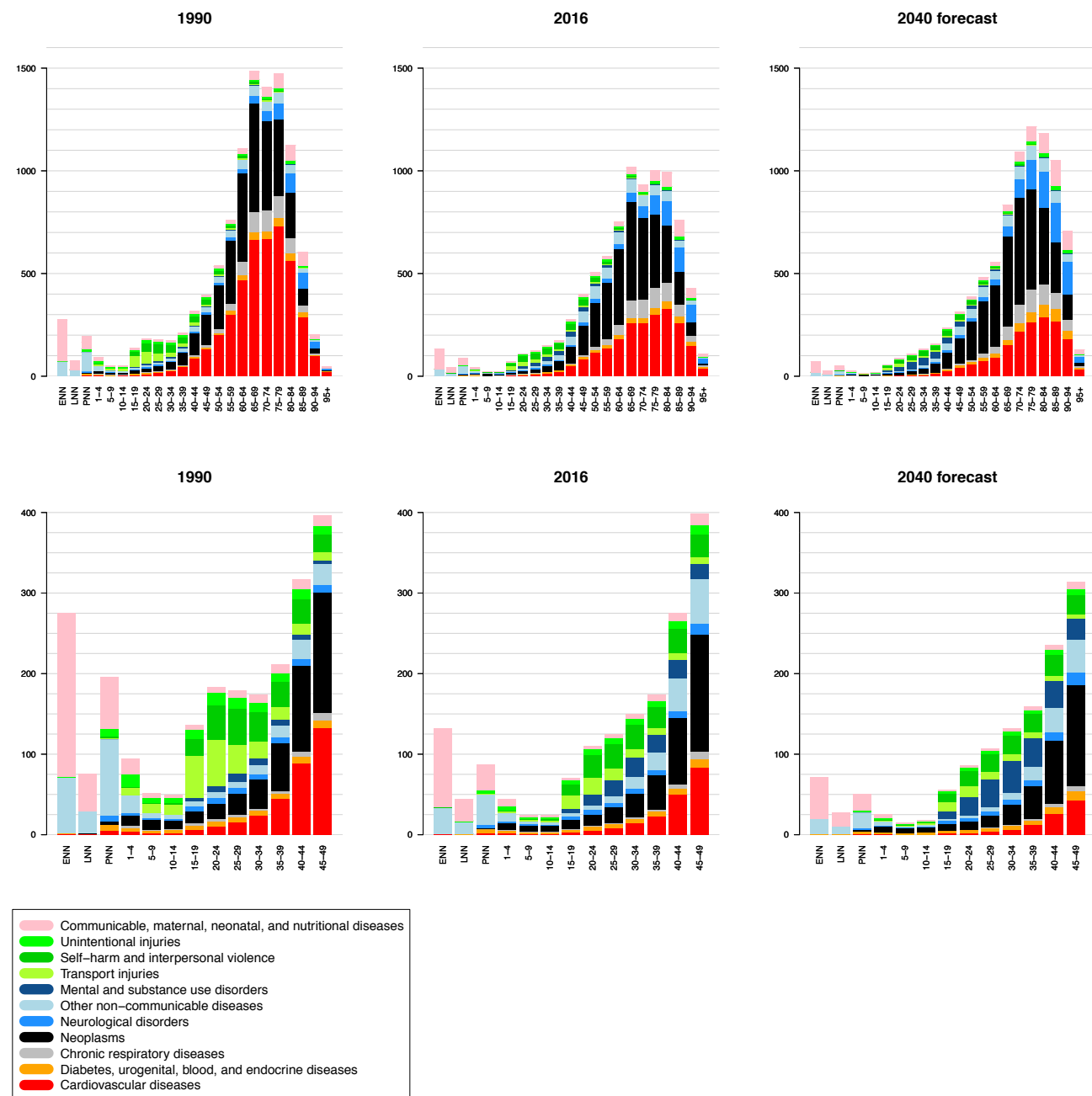
Source Institute for Health Metrics and Evaluation, 2018

## 06 Age distribution of years of life lost in 1990, 2016 and 2040 scenarios

Figure 15.3 shows the distribution of number years of life lost (YLLs) by age in 1990, 2016, and in the three scenarios of 2040. In the upper panel (all ages), we note the diminishing premature mortality from cardiovascular disease from 1990 through 2016 and to the reference and better scenarios of 2040. We also note the slightly increasing YLL-burden of cancer. We also observed an increase in the forecasted number of YLLs due to Alzheimer's disease and other

dementias. In the lower panel (ages < 50 years), we note the dominance of road traffic deaths, suicide and drug use in 1990 YLLs in the 15-35 years age groups. These three causes continued to dominate in the 15-35 years age groups in 2016 and are forecasted similarly across scenarios in 2040, but with a shift from road traffic deaths to drug use deaths while suicide is forecasted to remain more stable over time and across future scenarios.

**Figure 15.3** Number of YLLs for level 2 causes by age for 1990, 2016, and 2040 with reference, better, and worse scenarios



Note

Top panel shows all ages and both sexes combined  
Bottom panel shows ages less than 50 years

Source *Institute for Health Metrics and Evaluation, 2018*

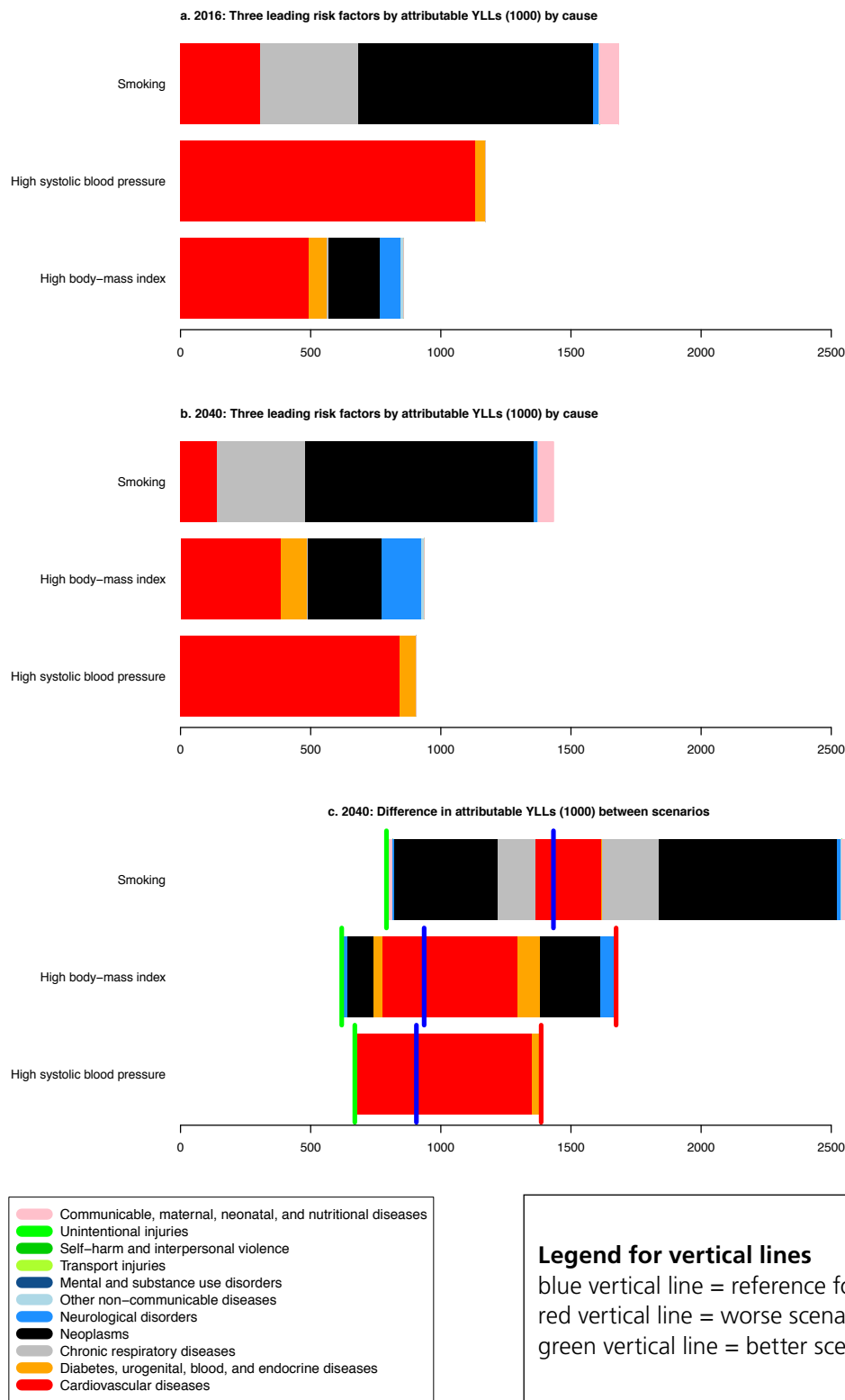
### 07 YLLs attributed to risk factors in 2016 and 2040

Figure 15.4 (panels a and b) show the three leading risk factors ranked by attributable YLLs in 2016 and 2040: smoking, high body mass index, and high blood pressure. The total YLL burden from these risks was forecasted to decrease between 2016 and 2040 for smoking and blood pressure, but increase slightly for body mass index. The figure also shows the cause composition of the risk attributable YLLs.

### 08 Difference between worse and better scenarios in risk attributable YLLs

Figure 15.4 (panel c) shows the three risks with largest difference in attributable YLLs in 2040 between better and worse scenarios. The range between better and worse scenarios were based on past patterns of annual rate of change across countries and gives us a range of plausible futures. This range may provide an indication of the scope for change that may be achievable by efficient interventions or policies, or lack of such. Smoking and high body mass index has the largest scope for change (for better or worse). If we instead focus on potential policies or interventions for better health (the difference in attributable YLLs between reference and better scenarios), the ranking of the three risk factors remain the same.

**Figure 15.4 3 top risk factors of attributable YLL burden**



Note  
 Panel a – 3 top attributable YLL risk factors in 2016 (with level 2 cause decomposition)  
 Panel b – 3 top attributable YLL risk factors in 2040 (with level 2 cause decomposition)  
 Panel c – Differences between reference, worse and better scenarios in 2040 for the three top attributable YLL risk factors (with level 2 cause decomposition)

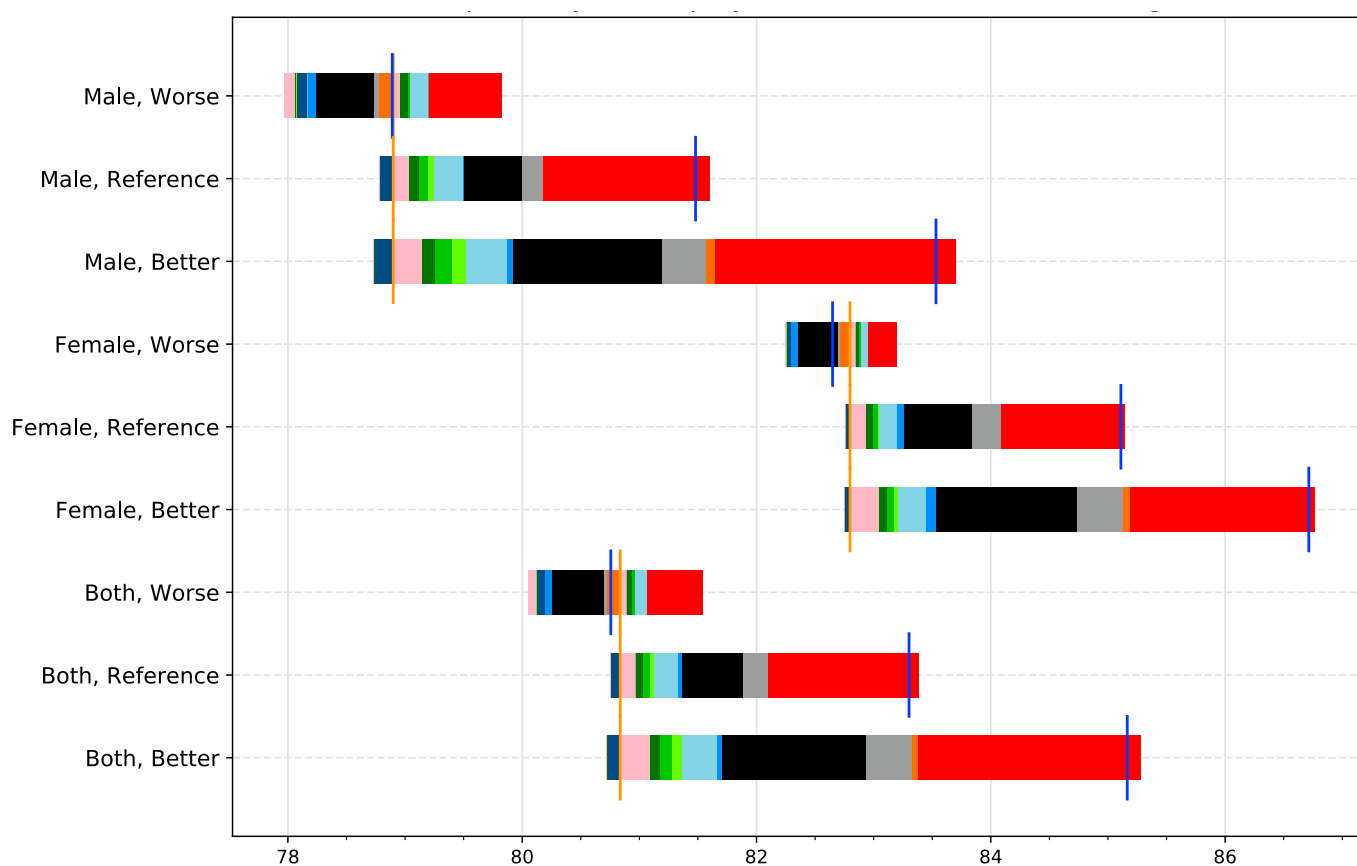
Source Institute for Health Metrics and Evaluation, 2018

## 09 Forecasted changes in life expectancy from 2016 to 2040 by cause

Figure 15.5 shows the changes in life expectancy between 2016 and 2040 for the reference, better and worse scenarios (both sexes combined, and for males and females separately). In the both sex reference scenario, life expectancy at birth is forecasted to increase by 2.5 years. The major causes contributing to this increase are also shown in the figure. Decrease in cardiovascular mortality contributes 1.3 years, decrease in cancer mortality 0.5 years, and decrease in chronic respiratory death rates 0.2 years. Each of 4 other NCD-causes (cirrhosis, digestive diseases, diarrhea, LRI and other common infectious diseases and neonatal disorders) and 2 injury causes (suicide and unintentional injuries other than transport deaths) is forecasted to contribute to a gain

each of 0.1 year of life expectancy, while increase in drug use death rates contributes to a loss of life expectancy of 0.1 year. In the better scenario life expectancy is projected to increase much more, by 4.3 years; the main drivers being further decreases in cancer, cardiovascular and chronic respiratory disease mortality. In the worse scenario life expectancy is projected to decrease by 0.1 year between 2016 and 2040. The major drivers of the difference from the reference scenario are a more moderate decline in cardiovascular, increase in cancer mortality and minor increases in several of the NCDs that contributed with slight declines in the reference scenario.

**Figure 15.5 Change in life expectancy with level 2 cause decomposition for the United Kingdom, 2016 to 2040 for reference, better and worse scenarios**



- Communicable, maternal, neonatal, and nutritional diseases
- Unintentional injuries
- Self-harm and interpersonal violence
- Transport injuries
- Mental and substance use disorders
- Other non-communicable diseases
- Neurological disorders
- Neoplasms
- Chronic respiratory diseases
- Diabetes, urogenital, blood, and endocrine diseases
- Cardiovascular diseases

**Legend for vertical lines**  
 blue vertical line = life expectancy 2040  
 orange vertical line = life expectancy 2016

Note  
 Results are given separately for males, females, and both sexes

Source *Institute for Health Metrics and Evaluation, 2018*

## 10 Life expectancy 1990 to 2040 in the UK and 8 comparison countries

Table 15.1 shows life expectancy and rank position for the UK and 18 comparison countries (EU-15 plus United States, Canada, Australia and Norway). In the past, from 1990 to 2016, the UK rank has consistently been in the lower half of the rank tables (rank 12 in 1990 and rank 17 of 19 in 2016). The rank position of UK is forecasted to improve moderately to rank positions 11 to 13 in all three scenarios.

**Table 15.1 Life expectancy with rank position for the United Kingdom and EU-15 countries, United States, Canada, Australia, and Norway for 1990, 2016, and 2040 with reference, better, and worse scenarios**

	Life expectancy at birth (both sexes)									
	1990		2016		2040					
	LE	Rank	LE	Rank	Reference		Better		Worse	
	LE	Rank	LE	Rank	LE	Rank	LE	Rank	LE	Rank
<b>United Kingdom</b>	<b>75.7</b>	<b>12</b>	<b>80.8</b>	<b>17</b>	<b>83.3</b>	<b>13</b>	<b>80.8</b>	<b>11</b>	<b>85.2</b>	<b>13</b>
Australia	77	8	82.5	2	84.1	6	81.9	6	85.8	6
Austria	75.7	11	81.6	10	83.9	9	81.5	7	85.6	9
Belgium	76	10	81	13	82.9	17	80.4	16	84.7	17
Canada	77.3	2	81.6	11	83.1	16	80.7	12	85	15
Denmark	75.2	16	80.7	18	82.9	18	80.2	18	84.3	18
Finland	75.1	17	81.8	8	84	8	81.9	10	85.5	5
France	77.2	3	82.3	4	84.3	4	82.1	5	85.9	4
Germany	75.5	13	81	15	83.2	15	80.7	14	84.8	14
Greece	77	7	80.9	16	83.7	10	81.3	2	86.7	11
Ireland	74.8	18	81.1	12	83.3	14	80.6	17	84.6	16
Italy	77	6	82.3	3	84.5	3	82.3	4	86.3	2
Luxembourg	75.2	15	82.2	5	84.1	5	81.8	8	85.6	7
Netherlands	77	5	81.6	9	83.5	12	81.2	13	84.9	12
Norway	76.9	9	82.1	7	83.6	11	81.4	15	84.8	10
Portugal	74.3	19	81	14	84.5	2	82.1	3	86.6	3
Spain	77.1	4	82.9	1	85.8	1	83.7	1	87.4	1
Sweden	77.6	1	82.1	6	84	7	81.8	9	85.5	8
United States	75.3	14	78.7	19	79.8	19	76.8	19	81.9	19

### 11 Limitations and potential future advancements to forecasting

Many factors, which were not included in our models, could have substantial implications for the future health of the UK population. For example, we currently do not attempt to capture the potential effects of climate change, antimicrobial resistance or predict pandemic infections. Second, our forecasting models for independent drivers of health were relatively simple extrapolations of the past. Even though they also had reasonable out-of-sample predictive performance, we cannot be certain of their long term accuracy. Third, our model deviated from the demographic tradition of extrapolation to the future based on time as the only independent driver. We achieved comparatively good, out-of-sample predictive performance while incorporating causal relationships where they have been established (eg, for smoking and ischaemic heart disease). Fourth, our forecasts have only been done at the national level. Accordingly, we do not have projections for the individual countries of the UK or the local authority areas of England.<sup>3</sup> Our plan is to include the GBD subnational units in future iterations of forecasts. Further, our plan for future iterations also include forecasts of incidence, prevalence, non-fatal health loss and disability-adjusted life years (DALYs).

### 12 Summary and policy implications

Below we list key findings from the UK forecasts for 2040:

- UK falls in the lower half of life expectancy rank tables among 19 comparison countries 1990-2016 and across scenarios for 2040
- Ischaemic heart disease remains the top cause of number of years of life lost (YLLs) in 2040, followed by Alzheimer's disease and other dementias, and lung cancer
- The number of Alzheimer's disease and other dementias and drug use years of life lost increase most between 2016 and 2040
- Drug use deaths takes over from road traffic death as a major cause of years of life lost in young adulthood
- Among the risk factors, smoking, BMI, and systolic blood pressure, remain the three most important contributors to risk attributable years of life lost in 2040
- Key risks for policy attention judged by the difference between reference and better scenarios (scope for improvement) in 2040 is smoking, followed by body mass index and blood pressure.

Overall, these forecasts are informative and relevant to the UK government in planning and health services. Although the forecasts do not give a recipe for how to lessen premature mortality, they suggest that attention and focus must be upheld on the well-established current and past major risk factors.



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