phg foundation
making science work for health

our healthy future

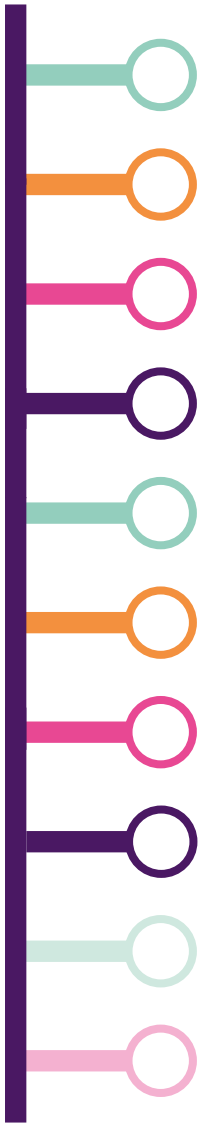
about us

PHG Foundation is a non-profit health policy think tank and a linked exempt charity of the University of Cambridge. The core mission of the PHG Foundation is to make science work for health. Our work has a special focus on how genomics, digital and other emerging health technologies can provide more effective, personalised healthcare and deliver improvements in health for patients and society. Our multidisciplinary team has expertise in biomedical science, law, ethics, regulation, public health and medicine.

By monitoring, analysing and synthesising research findings we help drive the translation of biomedical advances into practical benefits, which has earned us an international reputation for providing comprehensive policy analysis and advice to partners across the public and private sectors.

www.phgfoundation.org

what's inside



science, society and health

Science and technology has a profound impact on civilisations and individuals - including offering exciting new opportunities to protect and improve health. At the same time, it is becoming increasingly apparent that some applications of science and technology can also have detrimental effects.

Looking forward, the biggest questions for society, and for policy-makers, are less about which specific technologies will be the most significant, but rather about how we want to use them for good. What do we want our healthy future to look like, and how can we ensure science helps (and does not hinder) our path towards that future?

- *My healthy future: privacy and autonomy*

future-proofing policy

The way we think about health is undergoing rapid change; whilst the drivers are complex, they undoubtedly include new and emerging scientific knowledge, technological innovation, and social and demographic shifts. Expanding uses of technology by health systems and people could offer radical new approaches to improving and preserving health, requiring a cultural shift in the nature of the relationship between the health system and citizens. In this new reality, the health system will have to serve as a resource to support citizens through a healthy life, not just at times of disease.

Policy planning for the potentially dramatically different health systems of the future and the many societal challenges that may arise is essential. We need to consider the implications for health systems and professionals, thinking about how users interface with technologies, what support they need to do so, and how they can be helped to understand and make informed choices for disease prevention. We must also encourage debate about our expectations of science and technology, and the acceptable balance between possible health benefits and harms. Failure to anticipate and mitigate the risks whilst also seeking to harness the benefits will result in poor outcomes and potentially increase health inequalities.

The PHG Foundation's *My healthy future* project combined extensive research and analysis with a series of structured evidence-building exercises, to consider the possible impacts of new and future science and technology over a 20 year timeframe.

This report identifies critical issues that will help the policy-makers of today make constructive preparations for the as yet unknown healthcare future of tomorrow.

***My healthy future* examines the possible impacts of new and future science and technology over the next 20 years**

data-driven personalisation

Biomedical and digital technologies are enabling a new era of personalised medicine in which an individual's health management is finely tailored to their personal physiology, disease risks and any underlying conditions.

Three important trends will underpin this future. First, we will have more data, creating a 'higher resolution' picture of each person. Second, data will be drawn from many sources, with the line between 'medical' and 'lifestyle' settings becoming increasingly blurred. Third, 'healthcare' will further shift from being something mediated by the doctor-patient relationship, to an activity that often happens outside existing healthcare contexts.

It seems inevitable that the achievement of personalised prevention and care, whilst offering health benefits, will also be accompanied by some loss of privacy and autonomy.

- *My healthy future: privacy and autonomy*

technology trends

It is unlikely that any one technology will be a major disrupter of how we deliver healthcare. Rather it is the application of technologies in general, and especially in combination, that will lead to transformation of the health system.

My healthy future, as a project, has taken a broad view of anticipated future scientific and social trends to establish how they will underpin an evolving understanding of the fundamental bases of health and disease alongside broader conceptions of healthcare provision.

In the future we can expect to see:

- Personalised prevention

  There will be more detailed characterisation of individuals and populations with respect to disease risk and health status; increasing stratification of populations into disease risk sub-groups; and more precisely targeted information and interventions to reduce risk and prevent or delay disease onset

- Personalised care

  We will see more precise diagnosis of disease, with increasingly personalised prognosis, monitoring and therapeutic interventions

- Blurring boundaries

  Distinctions between clinical care and research will become less clear, as will interfaces between patients and health professionals, commissioned and commercial health interventions, formal health systems and community care

- Data foundations

  Digital tools from within and outside the formal health system will generate increasingly complex data. Infrastructure that supports interoperable systems and standards will be essential to maximise the value of data for health

keeping the human factor

Person centred healthcare has to balance the view that individuals know what is best for themselves against the need for guidance and advice based on the utility of medical tests and interventions assessed at a population level.

New technologies could offer more precise, individualised health information and interventions - but could also undermine the need to place the patient and citizen at the centre. Establishing the roles of health professionals in guiding people through health related decisions will be critical to avoid this.

In an era where individuals will be creating and accessing vast amounts of data about themselves from a wide range of sources, mediated and analysed by technology, the human professional will remain a vital touchpoint, helping people to navigate this new landscape.

- *My healthy future: person centred care / life stage workshops*

citizen-centric health

In the future, the distinction between health and disease will be eroded as the view of health and wellbeing as a continuum becomes the norm, and healthcare will focus increasingly on the individual - both patients and citizens. Expectations on people to understand and manage their own health will increase, ranging from maintaining healthier lifestyle behaviours through to contributing to wider health – for example, by sharing personal data for medical research. The State will play a vital role in supporting health activation and literacy, achieving an effective balance between nudging and pushing, shaping environments and providing services. Greater connectivity between people with similar health conditions will enhance peer-to-peer support within and beyond communities, but outside formal health systems.

- Each to their own

  Individuals and groups will differ in their conception of good health and their choices with respect to managing it

- Real world responsibility

  There are limitations to the responsibilities some individuals will be able to assume for their own health. Tailored support and educational resources will be required, for example for recipients of testing

- Data diversity

  In a data-driven, learning health system of the future, proportionate representation of all population groups will be essential to deliver the richest data sets and prevent bias

- Changing ways

  Health systems will need to undergo a fundamental shift from an interface for engagement primarily with patients, to offering engagement for all citizens

- Calling it fair

  New health tools pose very real risks that some people will enjoy disproportionate benefits relative to others and increase health inequalities

virtual life assistants

Individuals are now generating increasing amounts of health-related data outside formal healthcare settings - either intentionally, through the use of health tools including fitness trackers or home monitoring devices, or passively, through environmental sensors and online activity.

This citizen generated data (CGD) and data generated within the health system could be combined to inform personal virtual life assistants. By integrating sensor and input data, a life assistant might detect early signs of illness and actively encourage behaviour change tailored to the individual, their circumstances and current behaviours, reinforced by knowledge of the local environment and opportunities available.

However, the consequences of integrating CGD with health system data need urgent thought, including the limitations of these technologies, how health systems might use, store, control and share data, and how to avoid inequalities in care.

- *Citizen generated data policy briefings*

health-conscious spaces

The increasing integration into daily life of technologies for monitoring health and related factors such as nutrition and exercise will allow enhanced health tracking and support. This will include increasing scope for care in non-traditional environments via remote surveillance and connected telemedicine systems, with the potential for alerts to indicate when contact with professionals may be needed, generation of advice and online consultations.

Health promotion and disease prevention may be aided by citizen generated data, gathered from digital footprints of activity such as movement, food consumption and online activity to measurement of biomarkers - for instance, via automated analysis of breath, saliva or urine via home appliances. This data may be voluntarily or automatically recorded, and could support independent, healthy living directly - for example, prompting increased movement or changed dietary consumption - or indirectly by contributing to a repository of personal data that could be mined to identify markers of early disease.

- Care and control

  Provision of suitable support for individuals at different times in their lives and when in different states of health without undesirable intrusion will be needed

- Help and hindrance

  Physical and mental health needs should be considered, for example by ensuring that prompts towards healthy activity do not encourage harmful or obsessive behaviours

- Safety and autonomy

  Data and tools for health must be properly regulated and meet proportionate standards for quality and use, whilst continuing to accommodate individual choices and preferences

just enough medicine?

Overdiagnosis – or 'too much medicine' – is a recognised source of physical and psychological harm for individuals. It is also problematic for society, where people are increasingly given a disease 'label', and for health systems, where scarce resources are diverted from areas of greatest need.

There are concerns that the problem of overdiagnosis could be exacerbated by the increasing technological basis of modern healthcare, the multiplicity of providers, and the replacement of human interactions with machines. Risk assessment and early detection in apparently healthy individuals supported by technology also have to be balanced against the possible harms that may occur.

Human knowledge, experience and relationships will be fundamental to managing these challenges, including in supporting patient decision-making.

- *My healthy future: overdiagnosis*

balancing acts

Technologies that enable increasing characterisation of individuals, their health, and options for therapeutic interventions offer many benefits, but also pose new questions for society and health systems. The relative responsibilities and individual capacities of people, professionals and agencies for underpinning and maintaining health are already being debated, and this must continue if society is to reduce health inequalities. However, active and inclusive discussion will also be needed on how to maintain an acceptable balance between risks, benefits and accountabilities in other areas.

- Maintaining trust

  In a health system built on data from an increasing range of sources, how can we enable integration and interoperability whilst also demonstrating consistently responsible practices of data stewardship and governance necessary to build an essential degree of public trust?

- Who decides?

  As medical choices are based increasingly on AI analysis of highly complex data, where does ethical and legal responsibility lie for decision-making? How will medical liability operate in the future, and how can health providers be appropriately regulated to empower but simultaneously protect patients and citizens?

- Keeping it in proportion

  How can we match standards and quality requirements for data gathering, storage and sharing to the nature and purposes of use to appropriately safeguard people's privacy - without blocking benefits for them and others?

- The human factor

  However pervasive technology becomes within healthcare, the value of human contact and good communication between health professionals and people will remain. How can we protect and optimise the use of this most vital element of care in digitally mediated systems?

pulling together

For innovations to meet the needs of populations over time, an ongoing process of communication is needed between users and developers. Early adopters of technologies can have a greater impact on development: while this group might be using a product that is not yet fully refined, they will form an integral part of improvements to that technology, which will be tailored to their needs. Conversely, late adopters benefit from a cheaper and more refined product, but which may not be tailored to their own needs.

We need to support as wide a spectrum of people as possible to be involved in early adoption and ongoing development of health technologies, particularly those from ethnic minorities and disadvantaged socio-economic groups. Research planning should address this equity issue, and improvements to social infrastructure (such as internet access) should remove practical barriers to technology.

- *My healthy future: health technologies and social impacts*

innovation allies

Achieving our healthiest future will rely on a rapidly expanding base of scientific understanding and technological development. Preparing for this fast approaching future means laying the foundations for sustainable healthcare innovation today. Policy-makers have a pivotal role in directing how innovations are developed and used for health to maximise benefits - and minimise harms - for individuals, groups and society.

Alliances of stakeholders should work together to underpin and improve design and delivery of health innovations by:

- Constructive co-development

  Incentives and structures should support wider participation in innovation from patients, citizens and others including healthcare providers, commercial organisations, academia and communities at all stages

- Building smart systems

  Remodelled health systems will need to be flexible and deliver interoperability between different sources of data and technologies, enabling new interfaces and delivery mechanisms for health information and care

- Ensuring equitable access

  Maintaining accessibility of innovations - and health benefits - to different groups and individuals is a challenge that will need consideration from inception to implementation

- Developing responsive regulation

  Swift, proportionate regulation will be crucial for fast-emerging and evolving combinations of information sources, analytical health tools, and preventative and therapeutic interventions

elements of evolution

This vision of the future of health is built on future innovations in science and technology, changing interactions between people, technologies and healthcare, and an understanding of many other relevant issues and influences. These include current and likely challenges for health systems, and drivers including demographics and cultural shifts, and how health policy has been developed and implemented in the past.

The health policy makers and shapers of today and tomorrow have perhaps a harder task than ever before, not least due to the sheer speed of change in both science and society. But correctly balancing science 'push' (opportunity) and societal 'pull' (needs and choices) is the key to ensuring sustainable transformation for health.

- *My healthy future: the policy context / the technologies*

agents of change

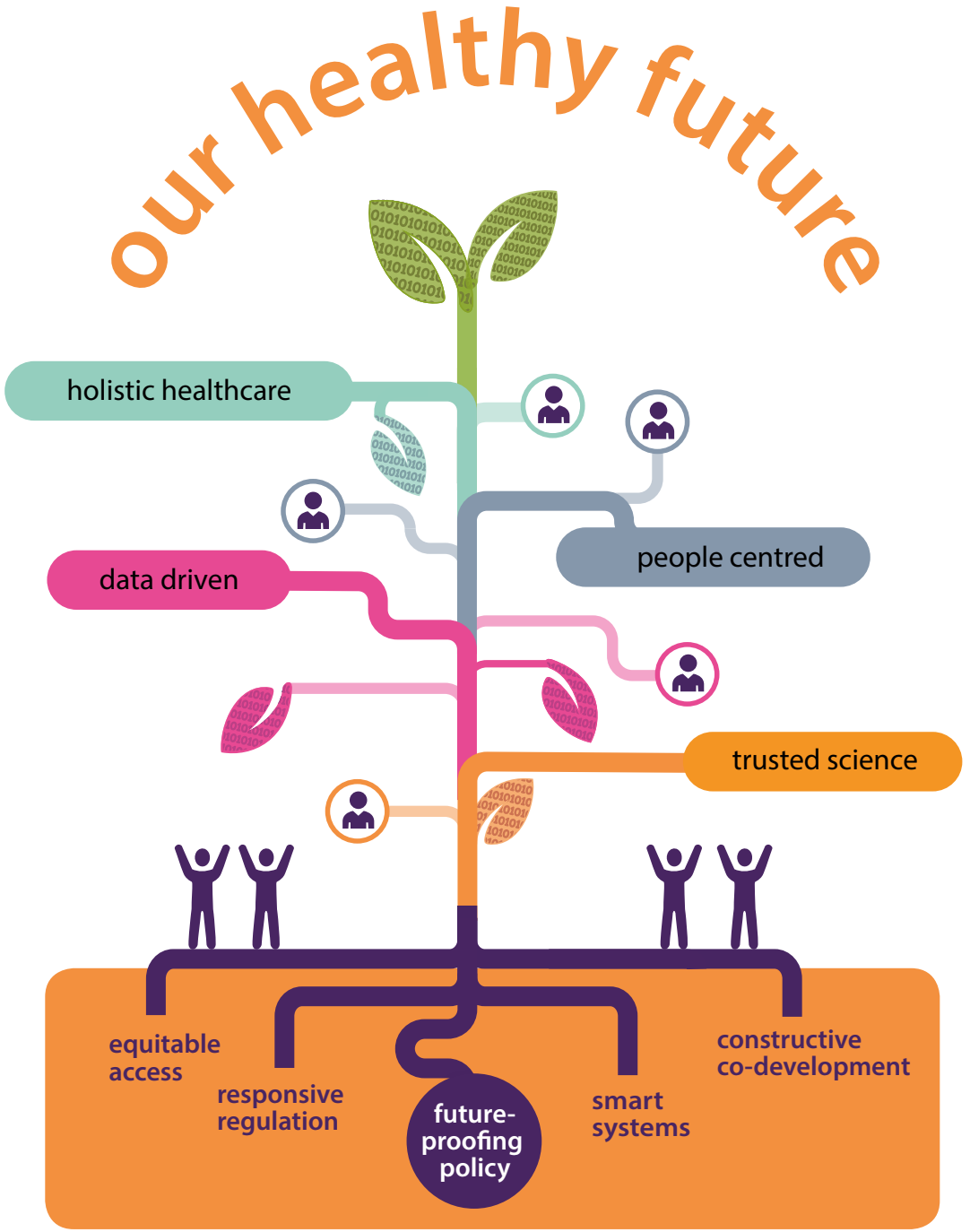
Our healthy future depends on an interactive health support system that will run throughout our lives, is based on the best use of data, and has strong human connections. However, we do not know which yet to be developed technologies will fundamentally change and underpin future healthcare, nor can we fully predict their wider impacts for people and populations – good and bad.

Policy makers will need both agility to keep pace with rapidly emerging opportunities and their implications for health, and vision to create systems that can make the most of new knowledge and tools.

In addition to standard approaches to evaluation and prioritisation, health leaders and innovation allies must actively work together to construct effective policy and make practical preparations, bearing in mind that:

- The adoption of new science and technology into health and social care will change the roles of health professionals, patients and citizens
- Societal debate is needed about the potential impact of emerging new technologies
- Measures to mitigate potential harms from health innovations must take into account wider social, political and economic factors
- A creative and inclusive approach to engagement and implementation is needed involving a wide range of organisations and stakeholders

By taking steps now to monitor emerging trends and issues, and steer uses of science and technology to maximise benefits and minimise harms for people and populations, together we can build a firm foundation to support a healthy future for all.


our healthy future
holistic healthcare
people centred
data driven
trusted science
equitable access
responsive regulation
future-proofing policy
smart systems
constructive co-development

project process and resources

The project included stakeholder workshops examining four distinct life-course stages - reproductive health, infancy and childhood; adolescence and young adulthood; healthy middle age; and older age - and how projected trends could affect health and care for these groups. Person centred healthcare, overdiagnosis, and factors such as privacy, autonomy and health inequality emerged as major cross-cutting themes and led to three expert roundtables

The evidence building exercise, supplemented by extensive in-house research and consultation, informed the production of a whole suite of in-depth reports, including overviews of recent health policy driven by science and of potentially transformative new technologies, barriers to their application in health, and issues arising from their use.

Together, this *My healthy future* library provides a rich resource for those who wish to know more, alongside the conclusions presented here.

For more information contact: intelligence@phgfoundation.org

in depth

The *My healthy future* reports and resources are free to download at **www.phgfoundation.org/my-healthy-future**

1 The technologies
Report of new and emerging science and technology with applications for health; plus overview

2 The policy landscape
Report outlining UK health policy developments relating to science and technology over the last 20 years; plus overview

3 Life stages: fact sheets
Summaries of current facts and figures used in the life stages workshops

4 Life stages: the impact of future technologies
Discussion notes from the four life stages workshops examining reproductive health, infancy and childhood; adolescence; healthy middle-age; and older age

5 Person centred healthcare
Report on the principles and practice of person-centred healthcare and how it may be affected by scientific innovations; plus expert roundtable discussion

6 Overdiagnosis
Report on the issue of overdiagnosis; how it is defined and considered now and how it could develop alongside new technologies; plus expert roundtable discussion

7 Privacy and autonomy
Report on the concepts of privacy and autonomy in relation to clinical research and care ; plus expert roundtable discussion

8 Health technologies and social impacts
Report on other social issues potentially arising from future developments in science and technology for health

9 Citizen generated data
Policy briefing on how user-generated data from different sources are informing and improving the personalisation of health, and the practical, technical, social and ethical issues this poses

contributors

My healthy future, which ran from 2017-2019, involved not only the whole PHG Foundation team, but also a great many people outside the PHG Foundation who generously gave their time, their expertise and their perspectives on issues presented at workshops, in roundtables and via many discussion documents.

Whilst the conclusions and recommendations of all the *My healthy future* resources are those of the PHG Foundation, the invaluable insights of the people opposite have contributed hugely to the overall depth and nuance of the work.

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