

# My healthy future

## health technologies and social impacts

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## 1 Introduction

This discussion paper forms part of a work programme undertaken by the PHG Foundation, a health policy unit focused on the translation of new genomic and other health technologies for more personalised medicine. The work programme is termed *My healthy future*. Its purpose is to set out a vision for health and social care, where each person stands at the centre of their own personalised, prevention-focused well-being, making the most of new scientific and technical opportunities to revolutionise healthcare.

In *My healthy future* we imagine a future health system where technology enables the greater personalisation of health promotion and disease prevention. Individuals are able to acquire and act on a wide range of information about themselves, their health, and their risk of disease and preventive interventions are tailored, not only to risk, but also to the individual's likely response to interventions.

We developed initial themes for *My healthy future* through a series of four 'life-stage' workshops held between January and June 2018 in which we explored the potential of new technologies for personalised prevention. Participants in each workshop then went on to introduce and describe important issues that would arise for individuals and society, and formulated recommendations for actions that would optimise benefit for the whole of society whilst mitigating harms.

These issues were grouped and categorised into a set of themes, which became the subject of further analysis and discussion. These included: the effect on person centred care, the potential for harm caused by overdiagnosis, privacy and autonomy, and the social impacts arising from health inequalities. We prepared a background paper on each topic, complementing this with wider expert discussion with the aim of developing recommendations through which harms could be mitigated and benefits enhanced.

In every workshop, participants voiced concerns about the potential for new technologies to increase health inequalities. Characteristically, in the field of health, it was thought likely that technologies aimed at personalised prevention would be more likely to benefit people who were better educated and better resourced and that this would be detrimental to society. Workshop participants highlighted several mechanisms through which inequalities would be increased alongside some very preliminary thinking on ways in which this could be mitigated going forward.

This discussion paper provides further analysis from a UK perspective on the risk of new technologies aimed at personalised prevention contributing to increases in health inequalities.

We conclude with our own summary of the current position and make recommendations to policy makers about further work that should be undertaken to understand this area better and the steps that should be taken now to mitigate the social impacts that may arise from new technologies aimed at personalised prevention.

## 2 Background

### 2.1 Personalised medicine

Personalised medicine is typically viewed as a comprehensive, prospective approach to preventing, diagnosing and treating disease to achieve optimal results for the individual. It has been enabled by advances in medical technologies, particularly in genomics, but also in other biomedical and digital technologies that allow more detailed information about an individual to be obtained, stored, shared and used in health decision-making. It is congruent with changes in the socio-political context in which healthcare increasingly revolves around the needs and wants of individuals and where empowerment and autonomy are emphasised.

Although there is no single definition of personalised medicine<sup>1</sup> characteristics include:

- Assessment of an individual's disease risk to allow prediction, preventive measures and/or early diagnosis
- Increased diagnostic precision by better characterisation of diseases, including molecular diagnostics and detailed phenotype
- Tailoring of treatment to the biological characteristics of each patient
- Evaluation of objective and subjective clinical outcomes and tangible benefits to the individual patient
- Active participation by patients and consumers in their healthcare, enabled by increasing availability of information through the internet and the development of devices that measure personal information
- Recognition of psychological and social aspects of an individual, recognising them not only as a biological entity but as a person with specific needs, values, hopes and fears

Personalised prevention, which has to date received far less attention than personalised medicine, recognises that people differ in their risk of disease and in their likely response to preventive interventions. It is relevant to preventive programmes that are targeted at individuals or population subgroups rather than those addressing structural, social determinants of health or environmental exposures.

Personalised prevention has been enabled by new technologies that help individuals to understand their own disease risk – for example, their underlying genetic make-up, new sensors that can provide information on personal physiology and the ways in which this may change over time or that can fine-tune an intervention dependent on underlying risk or personal characteristics.

Examples of personalised prevention include:

- Determining and responding to individual responses to environmental exposures such as UV light, cigarette smoking, air pollutants, and drugs
- Understanding personal susceptibility to chronic disease such as heart disease; tailoring behavior modification according to this risk and the likely response of the individual – for example, their level of activation to make a behavior change

- Stratification of individuals according to a multidimensional risk of breast cancer, including particular disease subtypes and tailoring preventive options to optimise benefit and minimise harm (e.g. considerations of lifestyle change, mammography, chemotherapy or surgery)
- Understanding future risk of serious inherited disease by screening to enable preventive strategies (e.g. expansion of newborn screening)

### 2.2 Inequity and inequality in health

Definitions and concepts of health inequality and health inequity abound and are the source of much debate. These debates are important to understanding of the main determinants of health and society's response to these differences. However, a full treatment of both concepts is beyond the scope of this paper. In this section we provide definitions of both 'health inequality' and 'health inequity' and our understanding of the relationship between each term.

Kawachi defines health inequality as 'differences, variations and disparities in the health achievements of individuals and groups'<sup>2</sup>. Defined in this way, health inequality describes differences in health status or health outcomes between individuals or groups; these differences are purely descriptive; they are measurable quantities and do not necessarily imply a moral judgment.

Health inequity, by contrast, refers to distributions of health status or outcome that are unjust or stem from injustice. Inequity is inherently normative, requiring us to have an account of justice and understand when a distribution of health might be just or unjust<sup>3</sup>.

Some refinements have been suggested to the definition of inequity – for example, whether there should be an element of preventability and whether the differences must be 'unnecessary'. These arguments, however, do not detract from the essential crux of the distinction between inequality and inequity. The identification of inequity entails normative judgment premised on theories of justice, coupled with assessment of the background injustices that might underpin differences in health outcome or status.

In this paper, we primarily focus on health inequality.

### 2.3 Determinants of health

Understanding the determinants of health is an essential first step for policymakers working to create a society where all people have a chance to live a long and healthy life. Based largely on epidemiological associations of risk factors of disease, policymakers and researchers broadly describe the determinants of health as, 'the range of personal, social, economic and environmental factors that influence health status'. They fall under several broad categories: policy/politics, social factors, health services, individual behaviour, biology and genetics.

The categories (and examples within them) are depicted by [Dahlgren and Whitehead](#) as a set of concentric circles with the individual at the centre and the wider political and social environment at the periphery<sup>4</sup>. These categories are inherently dynamic, interrelated and subject to change. Current new technologies such as digital technologies, operate and are influential at many levels, from intensely individual to global and their effects are developing and changing rapidly. While the ways in which they might impact on population health is yet to be determined, emerging areas of interest include the effect of social media on mental health.

### 2.4 Social determinants of health

Public Health England describes social determinants of health as ‘the broad social and economic circumstances that together influence health throughout the life course’<sup>5</sup>. The social determinants of health range from consideration of basic resources that meet daily needs - housing, sanitation, living wage that enables healthy eating and lifestyle, education and employment - to wider societal aspects, such as support and networks, norms and attitudes, discrimination, exposure to crime and violence, exposure to mass media, transportation options, and availability of high quality education. Understanding the social determinants of health has been key to the development of policies to tackle the major inequalities in health that exist between the richest and poorest.

In 2008, WHO published the report of the Commission on Social Determinants of Health, which was tasked to ‘collect, collate and synthesise global evidence on the social determinants of health and their impact on health inequity and to make recommendations for action’<sup>6</sup>. They took a holistic view of social determinants concluding that ‘the poor health of the poor, the social gradient in health within countries and the marked health inequities between countries are caused by the unequal distribution of power, income, goods and services globally and nationally, the consequent unfairness in the immediate, visible circumstance of people’s lives – their access to health care, schools and education, their conditions of work and leisure, their homes, communities, towns or cities and their chances of living a flourishing life’.

The findings from the WHO report were subsequently acknowledged by Public Health England in the Marmot review<sup>7</sup>. This review describes social factors of health inequalities including material circumstance (e.g. adequate housing and enough money to live healthily), social cohesion (e.g. living in a safe neighbourhood without fear of crime) and psychosocial factors (e.g. good support from family and friends). These, in turn, are influenced by social position, itself shaped by socioeconomic factors (i.e. education, occupation and income), gender, ethnicity and race – all of which are affected by the socio-political and cultural and social context of society.

Influences on the social determinants of health are grouped in the following categories:

- **Early child development:** physical, social/emotional and language/cognitive domains where early childhood influences subsequent risk of obesity, malnutrition, mental health problems, heart disease and criminality
- **Healthy places:** the daily conditions in which people live have a strong influence on health – more deprived neighbourhoods are more likely to have social and environmental risks to health such as poor housing options, higher crime rates, poorer air quality, lack of green spaces, higher access to unhealthy behaviours such as fast food restaurants and betting shops, and risks from road traffic
- **Employment and decent work:** including availability of work, employment conditions (such as precarious employment or lack of contracts) and the nature of the work itself (e.g. exposure to physical hazards, stress, high demand and lack of control)
- **Income and wealth:** including having sufficient money for adequate nutrition, opportunities for physical activity, housing, social interactions, transport, medical care and hygiene
- **Food and health:** eating healthily requires being educated in what constitutes healthy nutrition and having the capacity and means to act on that knowledge. Access to healthy food options are often diminished in more deprived locations. The cost of healthy, nutritious food can also be prohibitive compared to cheaper, unhealthy alternatives
- **Transport and health:** e.g. living in highly congested places with exposure to higher levels of pollution

### 2.5 Health inequalities and inequities

It has been known for more than 150 years that those who are more affluent and better educated tend to have longer and healthier lives. Statistics currently abound documenting inequalities in health both nationally and internationally.

Marmot *et al's*<sup>7</sup> review which was set up and commissioned by two Secretaries of State for Health to advise on the development of a health inequalities strategy for England, provided evidence that people living in the poorest neighbourhoods in England will, on average, die 7 years earlier than those in the richest neighbourhoods. The average difference in disability-free life expectancy between richest and poorest neighbourhoods is 17 years. Further, there is a finely graded relationship for mortality and morbidity, which occurs across the whole range of the socioeconomic spectrum.

Whitehead<sup>8</sup> described seven main determinants of health differentials and distinguished between those that were not accepted inequities (biological variation, freely chosen health damaging behavior and early uptake of health promoting behavior) and four that were thought to be unjust and therefore inequities. These included: health damaging behavior where there is severely restricted degree of choice over lifestyle; exposure to unhealthy stressful living and working conditions; inadequate access to essential health and other public services and health related social mobility, reflecting the tendency for ill people to move down the social scale.

Of particular note are the inequities that may arise from unjust social arrangements, poor governance, corruption or cultural or ethnic exclusion. They are often associated with social, political or economic circumstances which are in themselves morally wrong; for example, the much poorer health in indigenous populations. The differences arise from multiple social, economic and political wrongs, such as dispossession, poverty, inadequate housing, unemployment, lack of access to culturally appropriate healthcare or lack of education.

It is generally accepted that interventions outside the health sector that improve the social determinants of health will have the greatest effect on health inequalities. However, tackling inequalities in the health sector is still important. Whitehead *et al* argue that considerable political vision and investment is required and set out four core strategies: establishing shared values; assessing and analysing the health divide, tackling root causes and building equitable health systems.

### 2.6 Equity in health systems

#### 2.6.1 The inverse care law

The inverse care law was first described by Julian Tudor Hart almost 50 years ago<sup>9</sup> as the 'perverse relationship' in which those most in need of medical care are least likely to receive it whereas those with least need tend to use services more often and more effectively. Variations arise, not only in terms of access to services but also in variations in the quality of services from area to area: for example, at the time of writing he noted the poor quality of primary care services in inner cities or deprived areas where there are also higher caseloads and sicker patients. Over the years there have been various initiatives to tackle these differences, specifically those aimed at improving GP quality, mainly through performance management, reduction in variation in service provision and the allocation of resources.

### 2.6.2 Inequalities and the NHS

Concern for inequalities is enshrined in the *NHS Constitution* and in the *Health and Social Care Act 2012*, which imposed duties on the NHS and more locally on Clinical Commissioning Groups. The *NHS Constitution*, first published in 2012 sets out as its first principle that:

'The NHS provides a comprehensive service available to all ... At the same time, it has a wider social duty to promote equality through the service it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population.'

The national duty for the NHS, as set out in the *Health and Social Care Act 2012* fact sheet c2:

'In exercising functions in relation to the health service, the Secretary of State "must have regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service". The local duties for CCGs state that they must have regard to the need to "a) reduce inequalities between patients with respect to their ability to access health services and b) reduce inequalities between patients with respect to the outcomes achieved for them by the provision of health services".'

### 2.6.3 Access to healthcare

It is important in offering and providing healthcare that different groups in the population have an equitable opportunity to benefit from them. Access is a complex concept with many dimensions. Levesque *et al* define it as 'the opportunity to identify healthcare needs, to seek healthcare services, to reach, obtain or use healthcare services and to have the need for services fulfilled'<sup>10</sup>.

If services are available and there is an adequate supply, the opportunity to obtain healthcare exists, and a population may 'have access' to services. The extent to which a population and individuals within it 'gain access' will depend on a wide range of factors including affordability, physical accessibility, organisational arrangements and barriers, and social and cultural needs.

Overall the services provided must be relevant and effective if the population is to achieve the satisfactory health outcomes that these can enable. This must be considered from different perspectives, taking account of different health needs and material and cultural settings of diverse groups.

### 2.6.4 Health equity impact

Given the strong emphasis on equity enshrined through the Health and Social Care Act, it is vital for public accountability and to enable quality improvement that this can be measured and monitored over time. In 2016, a review was published of work funded by the Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR)<sup>11</sup>. The aims of the review included: developing indicators for socioeconomic inequality in healthcare access and outcomes; and developing methods for monitoring local NHS equity performance in tackling socioeconomic healthcare inequalities. Authors concluded that local equity monitoring could detect areas whose performance is significantly better or worse than the national average at a geographical level containing more than 100,000 people. The most useful indicators were primary care supply, primary care quality and preventable hospitalisation.

However, it is clear that developing these indicators is complex and time consuming and relies on high quality practice and hospital data, national mortality and morbidity statistics as well as small-area geographical data to provide relevant information on deprivation.

### 2.7 Public health interventions and their effect on inequalities

Public health interventions aimed at improving population health do not necessarily have an effect on the gradient in health and the pattern of health inequalities<sup>12</sup>. If everyone benefits the same amount from an intervention, the gradient stays the same but the whole line shifts upwards. The overall level of health is improved but the pattern of inequalities stays the same.

Frequently, however, a public health intervention may have the effect of improving the health of the most advantaged more quickly, or to a greater extent. Here the absolute level of health in the population is improved but the relative differences get bigger; inequalities are increased. In order to change the pattern of inequalities, the standard UK public health practice would be to adopt a targeted approach whereby, within a programme of universal reach to the population, there is a focus on those with special or greatest need. This is described as 'targeted' or 'progressive universalism'. Within an overall goal of health improvement via delivery to the whole population, those with special or greatest need are targeted in order to get maximum impact.

Notably, whilst acknowledging the importance of individual variables and their effect on mortality and morbidity, Kelly emphasises that the social gradient in health is part of a population pattern that requires explanation at a social level. Since it results from social, economic and political relationships, they also change over time. These relationships and their effects are not well-suited to being captured by traditional evidence based methods and thus there is a danger that they remain unexplored.

The importance of these wider mechanisms underlying health inequalities may also be responsible for the very poor impact of current interventions designed to reduce health inequalities in the UK.

### 3 Technologies and health inequalities

#### 3.1 The wider policy discourse: the impact of technology on the social gradient in health

Over the years there has been much discussion about whether new health technologies can solve or reduce the problem of health inequalities. Wise places the discussion about the possible impact of technology use on the social gradient in health in the context of a historic antagonism between disciplinary approaches and political ideology<sup>13</sup>. He juxtaposes a 'social determinants' argument against a 'technological advances' argument. The origins of this antagonism were in the earliest use of health statistics to support public health. In the Victorian era, the tension was between a focus on public engineering (sanitary reforms) versus the social forces which shaped them.

For those who embraced clinical or technical strategies, the purpose of the technical intervention in a setting of material deprivation was to uncouple poverty from its implications for health. For example, a technical intervention such as childhood vaccination may have the purpose of eradicating the linkage of child mortality from its infectious disease causation. Here the technology has the power to change health outcomes.

Wise argues that 'the reality is that technological innovation does not truly undermine the power of social causation but it can radically transform the mechanisms through which social determinants exert their profound influence. Adverse social influences on a health outcome elevate risk in a population or reduce access to effective interventions or both'. He suggests that this dual currency approach to the aetiology of social differences can offer an analytical footing to bridge perspectives that have separated social causation and technical realms.

He also writes that 'what ultimately determines the relative role of risk and access in shaping outcome is the efficacy of the technological intervention'. Where effectiveness is high, health inequalities in outcome are likely to arise from differences in the various dimensions of access. Effectiveness is therefore crucial to consideration of whether limited diffusion and the eventual distribution of the technologies matter for health inequalities.

#### 3.2 Causes or inequalities arising from technologies

Over recent years there has been a massive investment in research and technological development with the aim of improving health, both in the realms of healthcare and prevention. Much of the investment in genomics and digital technologies, is underpinned by hopes that it will improve the prevention of disease. However, there is significant evidence that innovations increase social inequalities. Two main arguments are propounded to account for this, although undoubtedly the complexities and interrelationships mean that an intricate mix of the two is involved.

##### Fundamental cause theory

In 1995 Link and Phelan developed their theory of fundamental causes to explain why the association between socioeconomic status and mortality persists over the years even though there have been major changes in the diseases and risks that are the most proximate causes.

They propose that 'the enduring association results because socioeconomic status embodies an array of resources - money, knowledge, prestige, power and beneficial social connections - that protect health no matter what mechanisms are relevant at a given time'<sup>14</sup>. Individuals 'deploy' these resources to avoid risk and adopt protective strategies. Strategies may include the effective adoption of new technologies and innovations, often at an earlier stage of their availability and which may lead to 'windfall benefits', including better health over a longer period.

A 'virtuous cycle' then follows in which those with greater prior resources gain earlier, easier access to technologies, thereby increasing the resources at their disposal (including health and healthcare) and increasing social inequalities.

Whilst good for the well-off, the corollary of this is a 'vicious' downward cycle for the less advantaged.

### Diffusion of innovation

The theory of diffusion of innovation seeks to explain how, why and at what rate new technologies and ideas spread throughout a given population or system. Everett Rogers<sup>15</sup> argued that diffusion is the process by which an innovation is communicated over time among participants in a social system. Importantly, new technologies spread or diffuse unevenly across and within populations. Typically, access and uptake is primarily among those with higher social status, income and education. This risks exacerbation of inequalities.

Whether innovations diffuse through different populations in a society is dependent not only on the availability of the innovation but also the means to use it. Roger's theory of diffusion of innovations claims that technological innovation provides a potential mechanism for sustaining social inequalities through the accumulation of benefits to early adopters that accumulate over time. Those with greater resources, being largely from the most socially advantaged populations to begin with, benefit earlier and find it easier to access new resources, thus compounding already existing inequalities<sup>16</sup>.

Korda *et al*<sup>17</sup> examined the socioeconomic lags in the diffusion of high technology interventions. They looked at uptake of coronary procedures as an example and found that rates of angiography and coronary artery bypass surgery peaked sooner for higher socioeconomic status patients before eventually evening out.

Glied<sup>18</sup> *et al* looked at the role of education in the effective uptake of health related technology innovation, hypothesising that those who are more educated are the first to take advantage of technological advances with the potential to improve health. They examined the relationship between number of years of compulsory schooling and changes in mortality for diseases, where there have been differing numbers of new drug treatments that have improved care in that disease area. They found that the education gradient in outcome was steepest for those diseases where there has been more innovation.

A variety of mechanisms have been suggested for how the relationship between education and health could be mediated by technological innovation. These include, that those with more education are better informed and more positive about innovation, more adept at implementing new technologies such as computers at an early stage, more able to understand and tolerate complex dosing regimes or side effects, more effective at locating – or more financially able to access – higher quality medical providers, and more likely to participate in trials.

As a counterbalance to the expected advantages for early adopters, many recognise that there may be benefits as well as drawbacks to being late adopters, particularly where digital technology is concerned. For example, developers of many digital health technologies are in the consumer market and therefore do not necessarily wait until a product is ideal in terms of technical workings and clinical relevance before launching. This is usually with the expectation that consumer use will enable technology refinement and that there will be several iterations to finally reach the most marketable product. Late adopters may also benefit through receiving the relatively cheaper, improved product which may have fewer malfunctions or 'glitches'. However, they will also receive a product that is tailored to the needs of a different population and potentially of less individual relevance.

### 3.3 The importance of distribution for policy makers

As policy makers weigh up the extent to which they will prioritise the development and diffusion of new technologies to improve health they face several questions. As a basis, they must be satisfied about safety and efficacy. If a utilitarian approach to decision-making is adopted, then they must also be able to demonstrate the cost-effectiveness of the technology for people who adopt the technology so that total gains for the population are increased. In other words, the average incremental gain for those who adopt the technology should be high and there should be a high number of adopters within the population. They must go further and include an assessment that the total costs incurred by implementing the technologies are contained so that overall there are net gains for society. Overall, the incremental gains experienced by those who take up the technology should exceed the costs incurred at societal level of implementing the technology. Such costs may include, for example, the costs of promoting diffusion and changes to health systems, especially when these costs are borne by increases in general taxation.

Coyte *et al* summarise a wider set of concerns, however, which take into account the distribution of the new technologies that have been deemed to be cost effective<sup>19</sup>. They argue that there are many circumstances where benefits to one segment of society would not be pursued unless other segments were also able to benefit. This might arise, for example, if strong feelings of envy were produced in those who felt excluded from the benefits, or if the costs of implementation (for example in diversion of health resources) fell disproportionately on the people least able to benefit from the technology. Assessment of the distribution (or variance) in benefits arising from the new technologies would then be an additional strand of decision making.

In a system such as the NHS, where equity is an agreed goal, policymakers must have regard to this as they compare enhancement in the aggregate average wellbeing of individuals against the potential adverse consequences of increases of variance of wellbeing in society. There are some tools to enable policymakers to do this – see, for example, Hauck *et al*<sup>20</sup>. Whilst noting that much of the literature remains at a theoretical level and that there is ambiguity about what is meant by 'fair', they note that most equity considerations fall under two broad headings: equity in relation to need and equity related to access to services.

Overall, however, these decisions are inherently political – where there is strong aversion to increasing inequality, policymakers may decide to limit diffusion on distributional grounds. With respect to technology it is suggested that 'the best chance for sustainable technological development is offered when product designers, developers and marketers ensure that the adverse distributional consequences from diffusion are minimised and that net gains to society are maximised'.

### 3.4 Characteristics of access

Weiss *et al*<sup>21</sup> examined the relationship between technologies and inequality by looking at characteristics of access and the type of technology, particularly its complexity.

They noted that technologies could be characterised according to the interaction with the end user. Technologies may be directly accessed (direct end user); they may be accessed through a gate-keeper, typically a healthcare provider (direct use gatekeeper); or they may be accessed and used by someone other than the end user, whilst still having an effect on the health of the user, e.g. electronic health record systems (indirect use gatekeeper). Overall, they noted that socioeconomic status influences use of innovative technologies by end users even when access is dependent on the gatekeeper.

For direct end user technologies, access and use is largely dependent on individual agency. Although in ideal circumstances individuals should be equally able to make decisions to access and use technologies to benefit their health, this is usually far from the case.

### 3.5 Complexity of technology

Weiss provided evidence that the introduction of new technological interventions that were more complex tend to increase inequalities whilst those that enabled simplification of management tended to reduce them. Goldman & Lakdawalla (2005) illustrated this by showing that well-educated patients benefitted from a complicated treatment regimen for HIV disproportionately, whilst simplifying drugs for hypertension reduced disparities in outcomes for cardiovascular health<sup>22</sup>.

At a system level innovative technology can reduce inequalities in healthcare access and outcomes, for example, by providing simple solutions in lower incomes countries where none previously existed and that are compatible with current infrastructure. Coloma & Harris (2008) describe the adaptation of routine diagnostic laboratory tests for resource poor settings, which along with programmes to ensure local knowledge of the strengths and weaknesses of such technology, enables the development of diagnostic services for locally relevant diseases<sup>23</sup>.

Similarly, technologies that reduce the importance of individual patient effort (e.g. pharmaceutical breakthroughs in treatment of hypertension) made self-management less important and coincided with contraction of disparities in outcome.

Purely having access to a technology does not guarantee its use. For example, the studies of the use of digital technologies to access health information showed that those with lower levels of health literacy, digital literacy or overall education may use digital technologies in much less effective ways than those with higher levels. Health information searching and processing strategies vary by socioeconomic status and tend to benefit higher educated individuals.

## 4 Personalised medicine and evidence on inequalities

We have been unable to find any systematic reviews of the literature explicitly investigating the association between personalised medicine and inequality in health outcome. However, a number of commentators have considered the potential impact of a personalised medicine at a more general level. In the UK, for example, Horne *et al* note the challenge 'to ensure that inequality of access to [personalised medicine] does not follow from wealth inequity'. Commenting that wealthier people are more likely to invest in preventive healthcare they suggest that 'future health outcomes in old age could become even more dependent on wealth and exacerbate inequalities.

On a global basis health inequalities may be exacerbated if pharmaceutical companies invest preferentially in personalised medicine rather than in research tailored to the healthcare needs in poorer nations.

Savard takes the analysis further, focusing on individuals engaging in personalised prevention as 'consumers' who actively seek out information (such as genetic information predictive of future disease). The healthy person is thought of as a rational and responsible consumer who has the power to take control of their life and future, but who will make further demands on healthcare. Although personalised medicine appears to emphasise autonomy, she argues that 'in reality it may simply privilege consumption'. It follows that, as personalised medicine is most accessible to individuals who can purchase the goods, there is a likelihood that it will 'erode notions of universal care, increase health inequities, and lead to further injustice for those already without a voice.

She also comments that this is paradoxical given the reliance of personalised medicine on epidemiological data derived from large populations and from genomic biobanks<sup>24</sup>.

Finally, personalised medicine also plays into a predominant discourse in public health that promotes the importance of the individual in his or her own care. Some note that there is an inherent danger this emphasis absolves the state of responsibility for the health of its citizens – enabling it to ignore the far more important social, economic and environmental determinants of health, which require large amounts of political will and investment to improve.

### 4.1 Personalised prevention and health inequalities

The assumption with many new technologies providing personalised prevention is that, with knowledge of risk status or early detection, individuals and/or healthcare professionals can choose some preventive action to avoid or reduce the risk or progression of disease. Achieving such benefit requires that results are accurate for the individual, there is mutual engagement with test providers, individuals and healthcare practitioners understand and are able to take action based on the results and, in many cases, lifelong support is available to manage these long-term risks. This process requires an appropriate level of understanding on behalf of the patient and competence within the health system, access to and awareness of services, the provision of appropriate preventive services and the ability to take up the preventive interventions. All of these can be effected by social inequalities.

Most of the research on health inequalities and technology is related to new treatments rather than prevention. However, the evidence for the ways in which inequalities arise makes it likely that the outcomes of innovative and particularly personalised prevention will exhibit similar social gradients.

Some evidence exists on the inequalities arising as a result of the use of digital technologies for disease prevention and in genomics.

### 4.2 Digital technologies

There has been long standing concern about the unequal benefit arising from digital technologies. This has been termed the 'digital divide'. Access and use of digital technology is dependent on age<sup>25</sup>, (with the elderly least likely to engage), ethnicity<sup>26</sup>, education<sup>27</sup> and socioeconomic status<sup>28</sup>.

One of the most profound innovative technologies to influence the 21st century is the internet and the subsequent access to vast amounts of information. Perez *et al* found that the influence and use of credible sources of online health information was associated with education, concluding that those from lower socioeconomic status (SES) may be disadvantaged when using the internet to inform health decisions<sup>29</sup>.

Studies carried out in Australia have looked at how people use the internet and have found that access is not necessarily the limiting factor<sup>30</sup>. For example, Kontos *et al* found a clear difference in use by SES, including low SES individuals being less likely to track their personal health information online<sup>28</sup> and Neter *et al* found that younger, better educated and frequent users of the internet have higher eHealth literacy and gained more positive outcomes from such activities<sup>31</sup>.

The level of health literacy and digital literacy has an impact on the utility of these digital technologies. Baum *et al* propose that those from low SES have restricted access to digital information and communication technologies not only due to the cost of such technologies but also the level of digital literacy that is required to use them. This then affects access to a range of social determinants of health, contributing to a cycle of disadvantage<sup>32</sup>.

Differences between uptake of online digital services are also influenced by social factors despite reducing issues with access to services. For example, Sarkar *et al* found differences in use of an online diabetes patient portal dependent on ethnicity and education with the most at risk for poor diabetes outcomes not benefitting from digital access and therefore likely to experience worse health outcomes as a result<sup>27</sup>. In addition, those in disadvantaged groups may have unstable access to technology, for example, intermittent access to credited mobile phones<sup>33</sup>.

The advent of newer, smarter tools for self-tracking is a driving force behind the use of self-care and monitoring of health outside of the health system. The effectiveness of currently available tools to induce behaviour change is contested but undoubtedly self-tracking of health will enable a deeper understanding of what influences health and could therefore improve health literacy resulting in preventive action.

As self-tracking technology gets more sophisticated it is likely to increasingly incorporate medically relevant parameters (e.g. the new Apple watch features an ECG). This could create an unequal divide between those with the material resources and health literacy who can engage with the technologies and those who do not. Whether potential for inequality arises or not depends on whether the individual takes actions that influence health outcomes and how the health system responds to resulting demands.

### 4.3 Genomics

Given the major potential for personalised prevention resulting from applications of genomic technologies, there is a developing consensus that these should be utilised in such a way that inequalities are reduced rather than increased. There has been some research on this outside the UK, mainly in Europe, Australia and the United States. Movements have begun to address this problem and make suggestions for initiatives that would redress the balance, particularly within the United States.

Preventive options arising from genetics lead to applications around reproduction (carrier testing, preconception, antenatal), newborn, diagnostic testing in childhood, testing for risk of adult onset disorders such as hereditary cancers, or testing for susceptibility to common complex disease such as heart disease or diabetes etc. For all these applications, the assumption is that knowledge of genetic status can lead to some preventive action, whether this is to ensure birth of a child without serious inherited disease, undergo 'harm reducing' options such as mastectomy for *BRCA1/2* carriers, drug treatments or changing lifestyle. Achieving such benefit requires that individuals understand the potential, engage with test providers (health system or commercial), understand and take action based on the results. This whole process is relatively complex and in a health system such as the NHS is the subject of detailed care pathways. Investigations outside the UK have shown that access to services, uptake of testing and the ability to gain benefit from the results of testing have all been found to vary according to socioeconomic status. Equivalent research has not been undertaken in the UK.

Added to this complexity, race and ethnicity are important in the special context of genomics. These two factors have dominated much of the debate and investigation around inequalities in this area. Although factors such as socioeconomic status, education and access to services are important in minority ethnic groups, the current potential for gain arising from genomics is not necessarily equal.

Certain diseases such as sickle cell disease and thalassaemias are more common in ethnic minority populations. On a global basis, the countries that would be most able to benefit from genomics at a population level are the least equipped to do so. Further, most of the 'genetic diseases' such as hereditary cancers or inherited cardiac diseases have hitherto largely been studied in white Caucasian populations, meaning that variants that may be pathogenic (disease causing) in non-Caucasian populations may not 'show up' on the standard current comparison databases and vice versa, or at the very least there is less information available concerning the variants found in individuals from non-caucasian populations.

### 4.3.1 Access to testing

Differences in access to genomic testing are driven by a number of factors that are linked to social inequalities. This has been studied in the US where, for example, awareness of cancer genetic testing was positively related to income and to level of education, and less likely in those with public or no health insurance or no usual place of medical care<sup>34</sup>. Lack of awareness was related to limited access to health information and limited healthcare resources in low income communities. Other barriers included financial constraints, limited access to specialists, language and cultural differences, medical mistrust and fear of discrimination<sup>35</sup>.

### 4.3.2 Uptake of testing

Differential patterns in uptake of genetic testing in clinical and research settings have also been reported in cancer settings and in prenatal and childhood genetic testing. For example, in Australia pregnant women from higher socioeconomic groups were more likely to have used the newer, non-invasive and more sensitive prenatal testing for Down syndrome<sup>36</sup>. Lim *et al* undertook a systematic review of parental attitudes to genetic testing in children and found that higher parental education was correlated with uptake or interest in childhood testing for conditions with potential clinical benefit<sup>37</sup>.

Education about the science and the varied considerations in testing are possible factors that affect the decision to take up an offer of testing. It is suggested that this may enable more highly educated parents to make more nuanced decisions according to their own unique family situation. Uptake of direct to consumer personal genomic testing has also been found to have been more likely in white populations, who had health insurance and with college degree education level<sup>38</sup>. McBride *et al* showed that uptake of susceptibility testing was more likely by people who are already more motivated to take steps towards healthier lifestyles<sup>39</sup>.

### 4.3.3 Personal and clinical utility from genetic testing

The ways in which users experience, understand and are able to act on the results of genomic testing also differ according to socioeconomic status. This may undermine benefits, even in situations where there is universal access. It is thus likely that tailored support and educational resources will be required for recipients of testing.

It is also critical to acknowledge that understanding of the effectiveness of genomic testing in influencing health outcomes is currently limited to the populations studied to date, who are mostly of European ancestry, higher education and higher socio-economic level. Going forward, it will be important to understand benefits and risks in other ethnic and social groups.

## 5 Reducing inequalities arising from innovation

In the light of evidence that the introduction of new technologies tends to benefit those individuals with more personal resources, thus likely increasing the inequalities, many commentators have considered ways in which this might be addressed. All acknowledge, however, that this would not be a substitute for the fundamental need to tackle the underlying profound effect of social determinants of health. In this section we provide a summary of suggestions included in the literature.

Authors note the importance of a more detailed understanding of how inequalities arise as a result of the introduction of new technologies. They suggest that there is a need to address the main mechanisms through which this happens and in particular stress the requirement of an integrated consideration of the two main pathways – i.e. fundamental causes and mechanisms based on theories of diffusion, access and uptake. However, they note that exploring the various mechanisms and finding evidence of their effect is not straightforward as they are difficult to measure and are highly interrelated. There will be a need to use qualitative sociological methods.

In their further analysis of fundamental causes resulting in health inequalities, Phelan *et al* suggest that innovations are likely to increase social inequalities in health outcomes and describe this as ‘an obvious conundrum’<sup>40</sup>. Emphasising a commitment to reducing health inequalities they suggest some general strategies that encourage advances whilst disrupting the link with personal resources - for example support to develop personal levels of activation following identification of risk. Where, as in the case of many personalised prevention technologies, addressing health problems may still require individual resources and action, they suggest that it will be important to develop resources that are relatively affordable and easy to disseminate and use. These could include clearly stated information about how the intervention can improve an individual’s health, where the interventions are available and how much they cost.

Weiss and Eikeom note that, as an adjunct to looking at individual resource use, it will be vital to investigate mechanisms that are dependent on social and institutional structures<sup>41</sup>. For example, it will be important to look at the ways in which the use of resources is influenced by institutions.

Political institutions are highly influential and, it could be argued, have the overall responsibility for promoting resources for better health and achieving an even distribution across society. They have responsibility for strategic direction and regulation of many sectors, including healthcare, research and the commercial sector through which they have power to influence the type and nature of innovations and the ways in which they may diffuse. For example, they may sponsor ideas or innovations or set priorities and targets for healthcare providers or commissioners.

Where, as in the UK, there is a bias towards innovation, Weiss *et al* note that it is important to understand the political institutions’ ‘attitudes and perceptions of innovations and technology as a potential influencer of both health and inequalities’ – for example by ensuring rapid diffusion of effective innovations or focusing the innovations on improving the position of lower socioeconomic groups. They go on to comment that ‘if the adoption of these innovations comes at a (potentially unanticipated) cost to society, particularly for certain social groups, a pro-innovation bias may encourage inequalities’. In any case, there are limits to the powers of government interventions – whether through strategic prioritisation or regulation – to change the shape and scale of activity of developers, which, in this area, are largely in the commercial sector.

Several authors have made specific recommendations for ways in which improvements may be made in the social gradient in outcomes noted in digital medicine and genomics.

### 5.1 Digital medicine

It is vital that those responsible for health promotion and disease prevention understand that access to the social, cultural and economic capital that enables beneficial use of digital technologies for health may limit benefits for disadvantaged groups. Baum *et al*<sup>30</sup> in their study of how people's existing capital shapes their access to and use of digital technologies – consider a number of actions to interrupt the 'vicious cycle, whereby lack of digital access or the inability to make beneficial use reinforces and amplifies existing disadvantage'. These include:

- The need for data to advocate for equity targets and for digital inclusion to health and well being
- Those responsible for preventive health should not assume that all people have equal access to and ability to use information communication technology (ICT). They should understand the barriers including interaction of digital literacy with health literacy and fundamental literacy and the need to provide resources through other media including face to face
- Increasing the access to digital technologies and providing assistance to support users
- Investing in education - people should be encouraged to learn use of ICT, particularly in relation to specific skills – health or healthcare could be one of them – this could be peer learning, in community locations which are familiar to people from lower SES
- There should be consideration of the practical barriers to access – e.g. access to internet, stable mobile phone accounts and signals. In particular, statistics on broadband access should be questioned with a view to setting targets that would benefit those from lower socioeconomic groups. For example it may not be sufficient simply to look at average broadband speed in an area but it would be important to look at differential speeds between the top 20% and bottom 20% of households
- It will be necessary to be mindful of the different qualities of use with constant upgrades of technologies.

Woodcock *et al*<sup>42</sup>, in their consideration of late adopters and laggards, note the importance of the design process and describe a range of approaches to address inclusion:

- Designing for the different stages of the acceptance curve
- Designing for specific groups who are characteristically late adopters (e.g. designing for older people)
- Meaningful user engagement (e.g. as users, informers, co-designers)
- Involving end users in the change process so that they become advocates and change agents
- Providing a real-life test and experimentation environment which includes periods of co-creation, exploration, experimentation with communities of users and evaluation.

### 5.2 Genomics

A number of commentators have considered how to address the emerging inequities in health outcome resulting from genomic testing. US commentators have made the following suggestions; it should be noted that, although there is a specific focus on ethnic minorities, many are relevant to other disadvantaged communities:

- Ensuring that people of non-European ancestry are included in the genetic databases on which genetic studies rely. Smith *et al* note<sup>43</sup> that there should be 'minority focused genomic research to ensure the full identification and understanding of genomic diversity in all populations'
- The development of community based participatory research focused on the development of interventions that will be effective and sustainable in that community; this would help to promote trust and transparency and promote genetic literacy
- Education: educational challenges for patients and providers exist – particularly in community settings – but given that most people obtain their healthcare services in such settings, support for education in these environments is critical
- The importance of access to the necessary preventive care that is indicated as a result of genetic testing
- Health technology tools in the form of computer generated aids should be developed to provide tailored educational content across a wide range of complicated topics. This should be accompanied by support for decision making and peer support, for example through chat rooms, message boards, and social media. These need to be developed for ethnic minorities and effectively linked to support for overcoming testing barriers. Patient navigators may also be used to engage individuals who are at risk; these might provide assistance with education and counselling as well as managing insurance and financial support.

## 6 Discussion and conclusion

### 6.1 Overview

In this paper we have explored the possible relationship between new personalised medicine technologies and health inequalities. We have focused on the subset of personalised medicine that has been termed personalised prevention. The work was stimulated by the repeated assertion, through our workshops and in the literature, that these technologies would be likely to exacerbate health inequalities.

We looked at background literature on health, the social determinants of health, concepts of inequality and inequity particularly as they are applied in healthcare, as well as the literature on personalised medicine with particular emphasis on personalised prevention. The literature review over such a wide area could not be exhaustive, and the key basic texts were identified with the help of external experts.

The literature search included evidence for inequalities in health outcome resulting from the use of new technologies and discussing theories for how inequalities might arise. A more detailed literature review looked at the relationship of digital and genomic technologies to health inequalities, including an original review of the evidence for inequalities in outcome within the sphere of access, uptake and benefit from genomic testing.

Finally we gathered views from the literature about what ought to be done to mitigate possible health inequalities arising from new health technologies.

### 6.2 Conclusions

Major inequalities exist in health. These inequalities are important, particularly when they arise through mechanisms that are believed to be unjust. This is usually termed health inequity. In the UK the Government pays attention to inequality particularly in public health and healthcare. Its importance is enshrined in the NHS constitution and the Health and Social Care Act (2012).

Whilst healthcare is important, reviews such as the Marmot Review conclude that the fundamental ways of tackling inequality are by influencing and changing the main social determinants of health. However, this is a complex web and includes wider social, political and economic influences as well as individual characteristics.

**Set against the background dominance of social determinants, new technologies such as those in the area of personalised prevention are unlikely to have a significant effect on existing health inequalities. Certainly they should not be seen as a way of 'fixing' the problem.**

There have been no systematic reviews or meta-analyses to provide direct empirical evidence of an association between socio-economic status and health outcome as a result of new technologies aimed at personalised medicine. International studies have shown an association between SES and outcome, particularly in the areas of new technologies in healthcare, digital and genomic technologies, although frequently these were looking at particular characteristics of SES such as education level or ethnicity rather than SES as a whole.

Many commentators have considered how inequalities in outcome may arise – in the area of personalised prevention they suggest that this is from a mix of fundamental causes (i.e. individuals do not possess the necessary resources to access and make best use of the technologies) and ways in which innovations diffuse and are accessed by individuals to gain health benefit.

In so far as evidence exists, including our understanding of the mechanisms through which inequalities arise, we anticipate that the development and introduction of new technologies aimed at personalised prevention may exacerbate existing inequalities. Capacity to mitigate this risk will depend on the resources available to a given health system, for example, one that is publicly funded and managed or one that is privately controlled.

A number of factors are critical to the impact on health inequalities:

- **The effectiveness of the interventions:** our assumption throughout this report is that new technologies are effective in predicting and preventing disease and in so doing improving health. However, this may not be the case. Indeed some have argued that engaging with new technologies to understand risk may lead to harmful investigations or unnecessary treatments and, at the very least, may provoke increased anxiety in users and result in additional costs to the health system. If the interventions are ultimately ineffective, it will be important to consider the possibility of harm to adopters (likely to be from higher socio-economic groups). Any resulting reductions in health inequalities would likely be small, but, in any case, this would not be a valid way of altering health inequalities.
- **The roles of the private (commercial sector) alongside the NHS:** many new technologies will have been developed and offered by the private sector, with some that are evaluated by the NHS. Whilst they will have been evaluated for safety and validity many will not have received scrutiny on effectiveness at the level that would be required for introduction into an NHS or public health programme (e.g. scrutiny by the National Screening Committee or NICE evaluation). Nevertheless, experience tells us that they are more likely to be taken up and used by those in higher socio-economic groups and, to the extent that they are effective, these groups thus have more ability to benefit.
- **The response of the NHS:** following identification of increased risk or early disease diagnosis through direct to consumer testing and/or private medical access, a consumer may turn to the NHS for further advice, investigation or even treatment. There is a danger that these demands divert resources towards those in higher socioeconomic groups, depriving those with greater healthcare needs.
- **The blurred boundary between disease prevention and enhancing wellbeing:** the boundary between personalised prevention of disease and enhancing wellness through diet, exercise and lifestyle is blurred. Health systems and public health services prioritise disease treatment and management over disease prevention. Increasing focus on personalised prevention arguably places greater responsibility on individuals to be proactive about their health and lifestyle, which might disadvantage those with fewest resources.
- **An inclusive approach is needed:** there are limits to what can be achieved through engaging with health systems and local authorities. Effective interventions are likely to involve a wide range of organisations and stakeholders and require creative novel approaches.

### 6.3 Recommendations

Based on these findings we make the following recommendations:

1. It should be acknowledged that reductions in health inequality will largely be achieved by tackling the fundamental 'social' causes of ill health.
2. The large investment of public monies in research and development leading to personalised prevention (such as the current commitment to genome sequencing) should be accompanied by a restatement of the value of equity – put simply, improvements in health outcome arising from these technologies should, as far as possible, be accessible to all socio-economic groups.
3. Those responsible for preventive health should influence systems to address barriers of literacy in the population, including fundamental literacy, health literacy and digital literacy.
4. Social infrastructure should be improved to address practical barriers to access new technologies for health – for example, internet access.
5. New research should be undertaken to investigate equality in health outcomes arising from the use of new technologies, including digital and genomic technologies. This should include systematic reviews and, if possible, meta-analysis. Attention should be paid to developing an equity audit of the use of new personalised preventive technologies (for example in the provision of, and utility gained from, genetic tests provided by the NHS).
6. The prioritisation, design and eventual implementation of research focused on personalised prevention should include consideration of likely equity and, where necessary, alterations should be made to these processes; for example by the inclusion of individuals with more varied socioeconomic backgrounds at all stages. However, it is worth noting that the current REC IRAS assessment form has this as one of the criteria through which studies are assessed. However it is difficult to recruit representative cross section of the population. Compensating people fairly for participation is one way – making it as simple as possible to participate and having interpreters etc. is another (see [East London Genes and Health](#) as an example)
7. Design processes within research and implementation studies should target specific groups of users, particularly those who may be late adopters. For example, they might include the requirement for purposive recruitment of groups who are expected to be late adopters. Practical standards for design should be developed.
8. Policymakers and healthcare providers should engage with the commercial sector and should develop guidance for how consumers with worrying risk or early disease results derived in the commercial sector, should be managed by the commercial sector or by the health system. See, for example the *Framework of Principles relating to Direct to Consumer Genetic Tests*. This requires commercial companies to have their own counsellors and clinical expertise to manage these results
9. Datasets and biobanks should strive to become representative of the entire population, and to the extent that these continue to be unrepresentative, encourage appropriate global data sharing to address that evidence deficit.

## 7 References

1. Hall A, Kroese M, Burton H, *et al.* 'Personalised medicine': what's in a name? *Pers. Med*; 2014: 11(2), 197–210
2. Kawachi I, Sabramaniam, SV. A glossary for health inequalities. *Journal of Epidemiology and Community Health*; 2002: 56: 647
3. Rawls J. *A Theory of Justice*. 1971. 52-56.
4. Dahlgren G and Whitehead M. *Policies and strategies to promote social equity in health*. Institute for Future Studies. 1991.
5. Public Health England. [Health profile for England](#).
6. World Health Organisation. *Closing the gap in a generation. Health equity through action on the social determinants of health*. 2008.
7. Marmot M, Goldblatt P, Allen J, *et al.* *Fair society, healthy lives. The Marmot Review*. 2010.
8. Whitehead M and Dahlgren, G, *Concepts and principles for tackling social inequities in health: Levelling up Part 1*. World Health Organisation. 2006.
9. Tudor Hart, J. The inverse care law. *The Lancet*; 1971 Vol. 297, Iss. 7696, P405-412. [https://doi.org/10.1016/S0140-6736\(71\)92410-X](https://doi.org/10.1016/S0140-6736(71)92410-X)
10. Levesque JF, Harris MF, Russell G. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *Int J Equity Health*; 2013: 12:18.
11. Cookson R, Asaria M, Ali S, *et al.* Health Equity Indicators for the English NHS: a longitudinal whole-population study at the small-area level. *Health Serv Deliv Res*; 2016: 4 (26).
12. Kelly M. P. The axes of social differentiation and the evidence base on health equity. *Journal of the Royal Society of Medicine*; 2010: 103(7), 266-72.
13. Wise, P. Emerging technologies and their impact on disability. *The future of children* Vol 22 no 1. *Children with disabilities*. 2012. 169-191.
14. Link, BG. and JC. Phelan. *Social Conditions as Fundamental Causes of Disease*. *Journal of Health and Social Behavior* 35; 1995: Extra Issue:80–94
15. Rogers, EM. *Diffusion of innovations*. Free Press; 1962.
16. Rogers, EM. *Diffusion of Innovations*. Free Press; 2003
17. Korda, R. Clements M, Dixon J. Socioeconomic inequalities in the diffusion of health technology: Uptake of coronary procedures as an example. *Social Science & Medicine* 2011; 72: 224e229.
18. Glied S, Lleras-Muney A. Technological innovation and inequality in health. *Demography*; 2008; 45: 741-61.
19. Coyte, P and Holmes D, *Healthcare technology adoption and diffusion in a social context*. *Policy, Politics, & Nursing Practice*; 2007. Vol. 8 No. 1, 47-54.

20. Hauck, K, Smith P and Goddard M. The economics of priority setting for healthcare: a literature review. The International Bank for Reconstruction and Development/The World Bank. 2003.
21. Weiss D, Rydland HT, Øversveen E, *et al.* Innovative technologies and social inequalities in health: A scoping review of the literature. *PLoS One*. 2018; 13(4):e0195447.
22. Goldman, DP, and Lakdawalla, DN. A Theory of Health Disparities and Medical Technology. *Contributions in Economic Analysis & Policy*; 2005. 4(1).
23. Coloma, J, Harris, E. Sustainable transfer of biotechnology to developing countries: Fighting poverty by bringing scientific tools to developing-country partners. *Annals of the New York Academy of Sciences*; 2008.
24. Savard, J. Personalised Medicine: A Critique on the Future of Health Care. *Bioethical Inquiry*; 2013. 10:197–203.
25. Niehaves, B, Plattfaut, R. Internet adoption by the elderly: Employing IS technology acceptance theories for understanding the age-related digital divide. *European Journal of Information Systems*; 2014. 23(6), 708–726.
26. Senecal, C, Widmer, RJ, Bailey, K, *et al.* Usage of a Digital Health Workplace Intervention Based on Socioeconomic Environment and Race: Retrospective Secondary Cross-Sectional Study. *Journal of Medical Internet Research*; 2018. 20(4), e145.
27. Sarkar, U, Karter, A J, Liu, J Y, *et al.* Social disparities in internet patient portal use in diabetes: Evidence that the digital divide extends beyond access. *Journal of the American Medical Informatics Association*; 2011: 18(3), 318–321.
28. Kontos, E, Blake, KD, Chou, WYS, *et al.* Predictors of ehealth usage: Insights on the digital divide from the health information national trends survey 2012. *Journal of Medical Internet Research*; 2014: 16(7), e172.
29. Perez, SL, Kravitz, RL, Bell, RA, *et al.* Characterizing internet health information seeking strategies by socioeconomic status: A mixed methods approach. *BMC Medical Informatics and Decision Making*; 2016: 16(1).
30. Harris, C, Straker, L, Pollock, C. A socioeconomic related “digital divide” exists in how, not if, young people use computers. *PLoS One*; 2017: 12(3): e0175011.
31. Neter, E, Brainin, E. eHealth literacy: Extending of the digital divide to the realm of health information. *Journal of Medical Internet Research*; 2012: 14(1), e19.
32. Baum, F, Newman, L, Biedrzycki, K. Vicious cycles: Digital technologies and determinants of health in Australia. *Health Promotion International*; 2014: Vol. 29, Iss 2, 349-360.
33. Gonzales, AL, Ems, L, Suri, VR. Cell phone disconnection disrupts access to healthcare and health resources: A technology maintenance perspective. *New Media & Society*; 2016: 18(8), 1422–1438.
34. Mai PL, Vadaparampil ST, Breen N, *et al.* Awareness of cancer susceptibility genetic testing: the 2000, 2005, and 2010 National Health Interview Surveys. *Am J Prev Med*; 2014: 46: 440-8.

35. Forman AD, Hall MJ. Influence of race/ethnicity on genetic counseling and testing for hereditary breast and ovarian cancer. *Breast J*; 2009: 15 Suppl 1: S56-62
36. Hui L, Barclay J, Poulton A, *et al.* Prenatal diagnosis and socioeconomic status in the non- invasive prenatal testing era: A population-based study. *Aust N Z J Obstet Gynaecol*; 2018: 58: 404-10.
37. Lim Q, McGill BC, *et al.* Parents' attitudes toward genetic testing of children for health conditions: A systematic review. *Clinical Genetics*; 2017: 92:569-578.
38. Bloss CS, Schork NJ, Topol EJ. Effect of direct-to consumer genomewide profiling to assess disease risk. *N Engl J Med*; 2011: 364:524-534.
39. McBride CM, Alford SH *et al.* Characteristics of users of online personalised genomic risk assessments: Implications for physician-patient interactions. *Genetics in Medicine*; 2009: vol. 11, 582-587.
40. Phelan, J, Link, B, and Tehranifar P. Social Conditions as Fundamental Causes of Health Inequalities: Theory, Evidence, and Policy Implications. *Journal of Health and Social Behavior*; 2010: 51(S) S28-S40
41. Weiss D, and Eikemo TA. Technological innovations and the rise of social inequalities in health. *Scandinavian Journal of Public Health*: 2017: 45:714-719
42. Woodcock, A. Late adopters and laggards: should we care? *The International Journal of Design Management and Professional Practice*; 2014: vol. 7 (3): 53-61.
43. Smith CE, Fullerton SM, Dookeran KA, *et al.* Using Genetic Technologies To Reduce, Rather Than Widen, Health Disparities. *Health Aff (Millwood)*; 2016: 35(8):1367-73.

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PHG Foundation  
2 Worts Causeway  
Cambridge  
CB1 8RN  
+44 (0)1223 761900

[www.phgfoundation.org](http://www.phgfoundation.org)

Contact: [intelligence@phgfoundation.org](mailto:intelligence@phgfoundation.org)

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