

My healthy future

privacy and autonomy

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1. Introduction

The PHG Foundation project, *My healthy future*, imagines a future health system where new technologies enable individuals to acquire and act on a wide range of information about themselves, their health and their risk of disease; and when ill, to understand more precisely the nature of their disease, its physical, psychological and social impact and the best means of treatment, management or mitigation.

Such a future is built on the biological and technological developments that enable more effective and targeted 'precision medicine' (sometimes called 'personalised medicine'). The potential of these technologies was outlined in a series of PHG Foundation workshops held between January and June, 2018. Focusing separately on reproduction, teenage, adult and elderly life stages, participants predicted that technologies would enable personalised prevention through a number of mechanisms.

Participants in each workshop then introduced and considered important issues that would arise for individuals and society as a whole, as well as considering how to optimise benefit for the whole of society whilst mitigating or reducing harms. Potential threats to privacy and autonomy arose as a consistent theme in the workshops, leading to a decision to address these through further analysis and an expert roundtable.

In this paper we introduce some of the relevant ideas that emerged from the lifestage workshops and provide further background on the general concepts of privacy and autonomy, pointing out some of the issues that will likely arise as a result of new technologies for personalised prevention.

The paper sits alongside other *My healthy future* work that has arisen from the lifestage workshops, notably on person centred medicine, overdiagnosis, health inequalities and various aspects of ethics and regulation.

2. Findings so far

The *My healthy future* project has highlighted a number of new health technologies, as well as a number of issues that might follow in the wake of this new era of personalised prevention.

2.1 The potential

Workshop participants predicted that biomarkers to identify individual health, determinants of risk or early disease would become more pervasive and the data from these tools coupled with new machine learning driven analytics would be able to engage with the whole of an individual's dataset to derive information relevant to current and potential future health problems. These would be followed by prompts to alert the individual to their risk and suggest appropriate actions, whether this was seeking further advice, signposting to helpful interventions or changing some aspect of lifestyle. As well as personal sensors, data may also arise from external sensors, which would include smart sensors around the home or information from the wider environment including digital datasets.

Technologies would also be increasingly used to intervene and promote healthy behaviours and lifestyle in a variety of ways tailored to the individual. Behavioural psychology techniques might be used to effect change in the individual - for example, using gamification to make the behaviour change less tedious and more desirable. These techniques could also be employed to support decision making, to increase access to healthcare and to sense and modify the environment for better individual health.

2.2 Issues

Analysis of the workshop discussions led to a set of emerging themes around the social issues that might arise, with effects on individuals and society as a whole. There were strong concerns about the loss of privacy that individuals might experience as a wide range of personal information was available, collected, stored, shared and used ostensibly to help them to maintain their health. In parallel was the concern that some of the motives and means through which this 'better health' for the individual might be promoted or pursued may become controlling. Whilst personalised prevention may be meant to increase autonomy, it might end up diminishing it.

Quote from the healthy ageing workshop:

'Technologies should be used to empower, support and enable people to achieve what they want for themselves rather than being used to undermine privacy, control people and impose values.'

Underlying all issues was the importance of 'centrality of purpose' for the use of these technologies, which should be driven by an 'understanding of people and society and a desire to serve society and optimise health and well-being, rather than allowing technologies themselves to drive behaviour'. Participants thought that a situation in which new technologies and policy development are largely driven by the commercial sector was, therefore, problematic.

Emerging themes from the workshops also included how availability and access to novel technologies might influence the rights and responsibilities of individuals and health systems for keeping well. Putting responsibility on individuals may lead to them feeling guilty or being blamed for poor health outcomes and, at policy level, may lead to a reduction of responsibility of statutory organisations for health and, particularly a decreased focus on public health.

Particular concerns about social effects also centred on the potential for intrusiveness of the new technologies that people may use to help them take up healthier lifestyles. Individuals may be driven to disclose more personal information than they are comfortable with, personal reminders may become intrusive, or individuals (particularly young people) may get obsessed by particular aspects of lifestyle such as diet or exercise, leading them sometimes to make themselves ill as a consequence.

Technologies might also increasingly be used deliberately to exert control over individuals. There were questions around when nudging individuals to change their behaviour through environmental or physiological cues becomes coercive and diminishes the power of the individuals to make decisions about their own life or future.

The wider consequences that further development and uptake of technologies may have on society was a major theme in all workshops. These included general societal effects, such as growth in health inequalities, and a rise in (sometimes unjustified) public expectations about health and healthcare, consequences on health systems and for the role of health professionals, and the major issue of how we produce, use, store, control and share data.

This paper starts by exploring general issues around technology and control before introducing the topics of privacy and autonomy in the context of the kinds of technology that are likely to be available in the future to personalise the prevention of disease.

3. Technologies and control

My healthy future outlines an exciting future where healthcare technology is tailored to the individual, offering personalised recommendations for prevention, diagnosis, prognosis, and treatment. This is a future where technology promises to make us healthier; to give us more control over our health. However, is this a future where this technology also controls *us*? This paper outlines some of the hopes of what this technology can achieve but also the ethical concerns that this future might raise.

The unifying theme of this paper is the idea of control over one's health, healthcare, and critical life choices. Two key elements of control are:

- Privacy, i.e. the state of or right to be left alone
- Personal autonomy, i.e. self rule or government

The literature on privacy and autonomy is voluminous. This background document presents a view of each subject and how it might apply to health technology, providing an outline of the philosophical literature and a number of special issues that the technology might raise.

4. Privacy

The future of healthcare will likely record more of our lives than ever before, providing more information to individuals, their healthcare providers, and developers. Given this, we might feel the price paid for future health technology might be a reduction in privacy. However, need this be the case? What is privacy and does health technology threaten to shrink this sphere? Can we design technology to both preserve privacy and achieve better health outcomes?

Question: is loss of privacy a necessary and inevitable cost of future health technology?

Personalised prevention, big data

Linking disparate data streams from various devices and datasets could provide holistic views of individuals and lead to health gains. Advanced data analytic approaches such as machine learning can handle vast amounts of data and find patterns that would not be possible through conventional programming methods. Predictions about an individual's health and possible future disease can be made by combining healthcare generated data (e.g. genomics, previous diagnoses or clinical data) with wearable and environmental sensors. This may enable preventative measures or interventions to be put in place or earlier detection of ill health when the data is used to predict the likelihood of experiencing adverse health.

4.1 Privacy and related concepts

One of the first attempts to provide an account of privacy was Warren and Brandeis's late 20th Century account, citing Judge Cooley's right 'to be left alone.'¹ Although this provides a working definition, the notion of privacy is set among a constellation of related concepts, including secrecy, confidentiality, anonymity and data protection, all of which contribute to a fuller understanding (see the box below).

We can distinguish between two different privacy concepts: *privacy loss*, where knowledge of a person is accessed and *privacy violation*, where privacy is violated when knowledge is accessed through impermissible means.⁷

Broadly, we distinguish between descriptive and normative accounts of privacy. *Descriptive accounts of privacy* describe what is in fact private,⁸ *normative accounts of privacy* tell us why and to what extent privacy should be protected.⁹

In regards to descriptive accounts, some argue that privacy is best conceptualised as *control over access to information* about intimate aspects of oneself.¹⁰ This account breaks with our intuitions regarding privacy in two ways. First, a person who voluntarily decides to divulge everything about herself has exercised full control but her life would not usually be thought to be private.¹¹ Second, we can imagine a castaway on a deserted island who has no control over who has access to information about him but whose life is entirely private.¹²

Normative accounts of privacy defend its value and seek to outline when it should be protected.¹³ Some theorists speak of privacy as an interest, others as a moral or legal right.

Concepts related to privacy

Secrecy: is thought of as 'intentional concealment'²; much that is properly called 'secret' is not private, for instance, military secrets.³

Confidentiality: points to information that is subject to a relationship where norms of confidentiality apply. Broadly, a confidential relationship is 'one in which it is understood that communications are not to be shared with non-authorized outsiders.'⁴

Data protection: if data protection merely outlines the means by which we protect data, privacy is only one reason to protect data. For instance, the GDPR protects personal data for reasons of privacy but also for broader consumer protection purposes.⁵ Moreover, data protection law in general routinely protects more than personal data, for instance, corporate data.

Anonymity: if privacy involves the hiding of information, anonymity involves hiding what makes it personal.⁶

Question: will future health technology help or hinder health consumers to control access to their personal information?

4.2 Dimensions of privacy

Privacy has many dimensions, it is not a homogenous, undifferentiated state or value. The following section illustrates some of privacy's dimensions.

Modern concepts of privacy often distinguish between two aspects of privacy:

- *Informational privacy* is often defined as 'freedom from epistemic interference,'¹⁴ as control over personal information.¹⁵
- *Spatial privacy* as the protection of a location against unwanted entry.¹⁶

It is suggested that a genuine state of privacy requires privacy in both its senses. We also suggest that it is important to consider not just whether health technology encroaches upon health consumer privacy but what dimension of privacy is encroached upon and how the technology has led to such a privacy loss.

Dimensions of privacy loss

Smart home systems that connect various personal and environmental sensors are expected to become more widespread in coming years, in particular, for the elderly to enable them to stay as independent as possible whilst living in their own home or in care.

The two dimensions of privacy can be affected by such monitoring systems, for example:

- The data captured by monitoring technology is sent to and assessed by a third party caregiver (e.g. family member) in order to inform decisions about intervening if there are signs the individual may be in danger or suffering ill health. It also may be accessible in a fully identifiable or de-identified manner by health care professionals or by technology companies or developers.
- The environmental sensors could be spatially intrusive due to their physical presence such as pressure detection mats, wall mounted sensors or personal wearable items.

4.3 Public facts, private conclusions

Ideas of privacy are further complicated by the realisation that very personal conclusions can be drawn about someone from ostensibly public facts. Consider the following example. Suppose a geneticist notices a person on the tube with distinctive facial features indicative of a rare but largely unheard of genetic disorder. Without the person's permission, she takes a picture and posts it on her blog, citing this as a classic case of this genetic disorder. Is there anything ethically wrong with the geneticist's actions? If so, might this wrong be explained in terms of privacy? More specifically, can someone's privacy be violated by deriving private conclusions from public facts?

Social media and AI

People are creating an inordinate amount of data through their social media accounts including posts, interactions and time spent browsing. Using AI to derive or infer information pertinent to users' health from internet searches and social media activity is becoming increasingly common. For example, natural language programming algorithms can recognise key words and phrases used in online interactions and advanced image analysis using deep learning techniques can see patterns in the types of photos uploaded by people with mental health conditions. This inferred information about users' mental and physical health could be used to target individuals for interventions or prompt them to access care.

Question: is it ethically problematic to derive 'private' conclusions from public facts?

4.4 The panopticon and observation

An intrusion of privacy that goes undetected is still an intrusion. If a thief enters my home and rifles through my personal documents yet I am none the wiser, my privacy is still violated. While I am not psychologically or physically harmed, ethically, we recognise that a wrong has occurred, legally, we recognise that my interest in maintaining my privacy has been set back.¹⁷ In short, the wrong of a privacy violation is not fully accounted for by counting the psychological harms they might cause.

On the flipside, the mere vulnerability to observation, the idea that one's private sphere has shrunk might harm.¹⁸ While no loss of privacy may occur because no observation occurs, the idea that one *could* be being observed engenders a feeling of being watched, which may itself be harmful. The 'panopticon' of Jeremy Bentham's imagination may offer some parallels, the panopticon being a design for prisons with a central tower from which each cell could be viewed, whilst a bright light obscured the prisoner's view of whether the guard was looking or not. In this way, prisoners would be aware that a guard could be watching and so internalise the threat of observation.

Pervasive technology

Pervasive technology within the home to monitor individuals behaviour, physiology and interaction with their environment is becoming increasingly common. The means to do this through multiple sensors can create a comprehensive blueprint of the individual and what they might be doing. Though there may not be another human watching or reviewing the data produced, the person living within the home may feel that they are being watched.

Question: might subjects of future health surveillance internalise the feeling of being observed?

4.5 How the law protects privacy

There is no general law of privacy in England and Wales, although English law does now have a partial law of privacy. This partial law has arisen from blending the Article 8 right to private and family life from the European Convention on Human Rights (ECHR) with the pre-existing tort of breach of confidence.¹⁹ This has led to the possibility of bringing three distinct actions:

- Breach of confidence, where information is obtained in circumstances where an obligation of confidence is owed.²⁰ Straightforwardly, clinicians owe such a duty to their patients.²¹ The position of developers is less clearcut.
- Misuse of private information, attaches to information where the claimant has a 'reasonable expectation of privacy.' This limitation on speech is balanced against other competing rights and must be necessary and proportionate to protect the claimant's privacy.²²
- Article 8 of the ECHR (via the Human Rights Act 1998) may also be used to secure the right to 'respect for private and family life.'

EU law also provides a number of protections related to privacy, most recently, the General Data Protection Regulation (GDPR). The GDPR also provides special protection to health and health-related data, as well as biometric and genetic data, prohibiting processing of this data unless specific exceptions apply.²³ Further, the GDPR provides a number of data protection rights and principles, namely:

- The right to erasure (Article 17)
- The right to restrict processing (Article 18)
- The right to object (Article 21)
- Rights related to the restriction of automated processing and profiling (Article 22)
- 'Data protection by design and default' (often interpreted as privacy by design), refers to the requirement to uphold many of the above data protection principles and rights through technical and organisational means.²⁴

The Charter of Fundamental Rights of the EU also provides various privacy protections when operating within the scope of EU law. For instance, Article 7 secures respect for private and family life and Article 8 protects personal data.

The UK also has a number of domestic pieces of legislation that might also protect privacy. Chief among these is the Human Rights Act 1998 that implements many of the rights secured under the ECHR, allowing UK courts to issue a 'declaration of incompatibility' if legislation is incompatible with a Convention right.²⁵ The UK's Data Protection Act 2018 fits around the GDPR but also adds protection over and above the Regulation, adding certain provisions like Section 171 that make it a criminal offence to re-identify deidentified data. Also of note is the Computer Misuse Act 1990 that creates a number of criminal offences related to unauthorised access to computers.²⁶

Professional guidelines also protect privacy. General Medical Council (GMC) guidelines emphasise confidentiality as being key to the doctor-patient relationship.

- *Good Medical Practice* notes that doctors have a duty to respect patients' right to confidentiality, further elaborating that doctors must treat information about patients as confidential, even after death.²⁷
- *Confidentiality* provides core principles to flesh out this duty of confidentiality.²⁸ This guidance also notes the special importance of medical confidentiality in establishing trust between patients and doctors.²⁹

5. Autonomy

Personalised medicine promises to make us healthier, tailoring diagnosis and treatment to the individual characteristics of each patient.³⁰ The use of potential technologies to achieve this future vision of medicine raises the question of whether and to what extent individuals are supported to control their own care and empowered to make their own health-related decisions.

Our hope is that future health technology will assist health consumers in ruling themselves; our concern is that this technology will begin to rule them. When developing and implementing future health technology we must carefully consider whether the proposed technology will work to support or undermine this critical value in bioethics. For this reason, we start by exploring the relationship between *personal autonomy* and the future of health technology.

5.1 Autonomy and related concepts

Autonomy is the defining value of post-war medical and bioethics.³¹ In this paper, *personal autonomy* is understood as individual self-government. This concept has two conditions, namely, I am autonomous if 'I rule me and no one else rules I'.³² Consequently, there are two ways to fail to be autonomous:

- A person fails to rule themselves, and is not ruled by another (as in a failed state)
- A person has the capacity to rule themselves, but is in practice ruled by another (as in a puppet state)

Autonomy is not the same as freedom. More freedom may lead to more autonomy but it is important to note that the two concepts are distinct and that less freedom does not necessarily erode self rule. Freedom may be distinguished from autonomy in two ways.

First, some freedom may not contribute to self government. The most basic autonomy right is 'the right to decide how one is to live one's life, in particular how to make critical life-decisions'.³³ While we may make autonomous decisions about what colour of shirt to wear, when to cross the road, and what Netflix show to watch, it does not follow that restriction of any one of these choices impairs our autonomy.

Autonomy concerns *critical* life choices, not all undifferentiated choice. The question of whether a choice counts as an exercise of our autonomy and whether an exercise of autonomy deserves protection as 'the most basic autonomy right' are two very different questions.³⁴ For example, suppose a clinician takes an unconsented mouth swab for a routine test. While this action may be objectionable on many grounds, it is a mistake to think that taking the swab violates my autonomy.³⁵ An unconsented mouth swab is not the violation of a critical life decision but a violation of a more general right of bodily integrity as well as contravening many other ethical and legal rules.

Second, it is possible that less freedom may lead to more autonomy. In the mythical tale of Ulysses and the sirens, Ulysses has his men tie him to the post of his ship and plug their ears so he can hear the sirens' song, despite knowing that this would result in madness. In this case, Ulysses is made less free but since this is consistent with his self rule, his autonomy remains unimpaired. To give a real world example, it is possible that an addict confined to a rehabilitation centre may be less free but more autonomous, as her confinement may be consistent with deeply held beliefs, her autonomy.

This is not to say that freedom is unconnected to autonomy. On the contrary, freedom is necessary for but not identical to autonomy. If my life is set on a very narrow path with little to no choice, my environment rules me. For example, if a person's life consists of running away from a beast that hunts her continuously, her life is without meaningful choice and so not an autonomous one.³⁶ To give an applied example, a person beset by poverty who spends much of her existence finding shelter, food, and so on may have limited capacity to rule herself - her life is ruled by her needs, not her will.

5.2 Dimensions of autonomy

Personal autonomy is not the only dimension of autonomy, nor is it safe to assume that different thinkers refer to the same concept when they use the term 'autonomy.'³⁷ The umbrella of autonomy as applied to individuals also includes multiple distinct concepts:³⁸

- The *capacity* to govern oneself, the *capacity* to act autonomously being distinct from actually *acting* autonomously; the possession of capacity being no guarantee of autonomous choice³⁹
- An *ideal of character*, autonomy often being thought of as an ideal that all of us fall short of, the ideal of maximal self-rule. Autonomy as an ideal may be distinguished from *autarchy*, the condition of being minimally self-ruling⁴⁰
- The *sovereign authority* to govern oneself; a moral right to make critical life choices

Apart from this, personal autonomy may also be distinguished from *moral autonomy*, a more complex ethical concept typically associated with Immanuel Kant that refers to the 'capacity to impose the (objective) moral law on oneself.'⁴¹ This idea of autonomy differs from ideas of personal autonomy that emphasise self rule and self government.

Apart from these differences, there are major fault lines in the personal autonomy literature between procedural and substantive accounts of autonomy.

Procedural theories of autonomy emphasise the authenticity of a person's desires.⁴² Procedural accounts are content neutral, perhaps to their detriment. For instance, if someone voluntarily sold himself or herself into slavery, they would be autonomous insofar as this was consistent with their authentic desires.

Substantive theories of autonomy argue that procedural autonomy does not secure substantive independence and so cannot constitute a full account of autonomy. Regardless of the agent's desires, some circumstances of constrained life situations (for example, voluntary slavery) are inconsistent with autonomy.⁴³

Some theorists are critical of personal autonomy, noting that the concept is highly individualistic. *Relational autonomy*, a feminist alternative, underlines that the social embeddedness and relationships must ground any plausible idea of autonomy.⁴⁴

Question: in what senses might future health technology be autonomy promoting or limiting?

Wearables

Fitbits, Apple Watches and other 'lifestyle' technologies that seek to encourage healthier behaviours have been criticised by some theorists. For example, Owens et al argue that Fitbits (and the like), while providing some helpful information to users, do 'little to change a person's capacity to act in the world and to positively enhance their opportunities for achieving better health.'⁴⁵ In other words, often wearable technology does not enhance users' substantive autonomy. In response, this criticism perhaps asks too much of the technology it criticises.

Autonomy is related to other moral concepts, such as the concept of paternalism.

5.3 Shades of paternalism

Paternalism is not the mere restriction of one's autonomy or liberty, it is the restriction of a person's autonomy or liberty *for their own good*.⁴⁶ If I restrict your autonomy for my benefit, that may be wrong but it is not paternalistic. Given this, paternalism requires two things, first a restriction of liberty or autonomy in addition to a particular intention in imposing this restriction for their own good. This should make us question not only the restrictions health technology might pose but also our intention in developing the technology.

Not all paternalism is equal. The literature distinguishes between the following shades of paternalism, but in practice, these blend together as intentions are rarely clear-cut.

Soft paternalism: paternalism is justified only where the person's conduct is substantially nonvoluntary, or where it is necessary to determine whether their conduct is voluntary.⁴⁷ For example, assuming she doesn't actually want to commit suicide, it is permissible to stop a person experiencing psychosis from killing herself.⁴⁸

Hard paternalism: paternalism may be justified to protect competent adults from the harmful consequences of their fully voluntary choices.⁴⁹ An often cited example of this might be the requirements that all passengers - including fully competent adults - in automobiles wear seatbelts.

Weak paternalism: it is only permissible to interfere with an agent's means to achieve their ends, but not the ends themselves.⁵⁰ In this way, it is ethically permissible to interfere with an agent if this interference helps the agent achieve their ends. As an example, if my end is to live a healthier life but I mistakenly think that crystal healing is the way to achieve this goal, it may be permissible to interfere with my mistaken choice.

Strong paternalism: it is permissible to interfere against an agent's end if these ends are mistaken, confused, or irrational.

Question: in what senses might future health technology be paternalistic, if it is paternalistic at all?

Broadly, paternalism is thought to be objectionable for the following reasons.

First, it violates *personal sovereignty*. Following Joel Feinberg, the idea of self-government is not necessarily premised on people making better decisions for themselves - we have a right to make critical life decisions precisely because it is *our* life.⁵¹

Second, while paternalism may promote another's good, it is generally beneficial for people to make their own decisions, to exercise their *moral muscles*.⁵² If I do not routinely make decisions for myself, my ability to make sound decisions atrophies.

Third, paternalism might be well-intentioned but presumptuous, as it assumes that we know what is good for another better than they do for themselves.⁵³ Consequently, if people are the best judge of their own interests, then paternalism may, in fact, not promote the good of the person in question.

Contrary to this, paternalism might be thought to be presumptively unobjectionable if any interference is, by definition, for an agent's own good.

5.4 Choice

Standard accounts of paternalism require that one's choice be restricted or curtailed in some fashion.⁵⁴ Given this, if the future of healthcare technology is paternalistic, it must restrict the liberty of patients and citizens. Certainly, some descriptions of personalised medicine describe a future where a host of suboptimal treatments are reduced in favour of *the* treatment that has been tailored to you. In this way, your healthcare choices have been *curated*. In short, the future of healthcare is personalised but with more optimal and fewer suboptimal options left available. Does this reduction in choice matter if we think the suboptimal choices were not meaningful?

Increase in choice

The commercialisation of 'personalised' services to consumers based on their biological information is expected to increase in the future. Already, a plethora of companies offer tailored recommendations on the basis of consumer genomes, blood type, microbiota etc to inform them of their disease risk, prevent ill health or optimise their health and fitness.

This drive for direct to consumer products is extremely apparent in digital health. For example, there are currently over 100,000 active apps that promise to help the user stay healthy, manage and improve their health, with the number increasing daily. Personal wearable devices are beginning to blur the line between lifestyle and medical device as they are equipped with sensors that can measure parameters, such as heart traces, that were once only medically available.

This explosion of direct to consumer health products and tests mean that citizens no longer have to interact with the health service or be under care to gain medically relevant information about themselves. Thus, citizens have more options than ever before. Whether this increase in choice is a positive development depends on the available options being based on good scientific rigour and evidence, and the effectiveness for enabling the prevention of illness or optimisation of health.

Question: is the future of technologically rich healthcare one in which patients are provided with less choice or more?

In other ways, the future of healthcare might include more options and more technology.⁵⁵ With an increasing emphasis on prevention, self-care, and wearables the policy priority is to convince people to manage their own health so they never get sick to begin with.⁵⁶ As a consequence, the future of healthcare technology is likely to include a larger direct to consumer component for self care. Speculatively, this may result in a large array of choices, which may be confusing.

Often the thought that drives expansion in choice is that *more choice is always better*. However, is this the case? Are there rational reasons to prefer fewer choices instead of more? Could it even be that offering unlimited choice could be psychologically damaging?⁵⁷ Both offering too little or too much choice could be potentially harmful in certain contexts.

Another concern is that technologies may reduce the type and range of choices available to health consumers. Replacing human contact and care with technology could undermine personal autonomy but also frustrate person centred healthcare. Person centred healthcare seeks to ensure that care delivery is responsive to an individual's physical, emotional and social needs, that interactions with staff are informative, empathetic and empowering, and that individual values and preferences are taken into account. By respecting personal autonomy, care is more likely to be person centred but other objectives would also need to be met, such as gaining holistic understanding of individuals, and ensuring that people are treated with dignity, compassion and respect. This topic is explored more fully in other parts of the *My healthy future* project.

There is no such thing as an optimal amount of choice in healthcare. However, it is clear that the future context of health technology should avoid vices on either side: providing too little choice or a bewildering array of choice.

Question: will the future of health technology involve a bewildering array of choice for patients and other health consumers?

5.5 Nudging

The future of healthcare likely includes technology to promote healthy behaviour and discourage unhealthy behaviour. Many of these technologies will seek to give effect to these changes, not through restricting choice, but by framing our choices in such a way that makes us predisposed to pick healthier options. In short, both policy and technology will seek to nudge us into being healthier. Nudges are 'an aspect of choice architecture that alters people's behaviour in a predictable way without forbidding any options or significantly changing their economic incentives.'⁵⁸ These nudges may take many forms (see below).

Health technology that nudges

Many future technologies are expected to involve nudging individuals to make better choices related to their health. The following two examples explore some of the technology that may be used in the future.

An app that helps the user to select healthier options for them based on their genomic information. The app is synced to a bar code scanner on their smart watch which they can use whilst food shopping to alert the user how healthy that option is for them. The app will actively nudge the user to make healthier food choices on a personalised level.

An augmented reality mirror in the home that shows the user what impacts decisions made today will have on their future self (tomorrow, a year from now, 20 years from now). They may be able to ask questions such as how will I feel tomorrow if I eat a burger and have ice cream for dessert this evening? How will I feel and look in a years time if I increased my step count to 10,000 steps per day? What will I look like in 20 years if I continue to smoke 10 cigarettes a day? Showing the individual how they will physically look and feel based on the health choices they make could be coupled with nudges to make healthier decisions.

Thaler and Sunstein explain that nudges are consistent with a principle of *libertarian paternalism*, that is, efforts to influence people's behaviour for their own good without restricting their freedom of choice.⁵⁹ The attraction of nudging is that it achieves healthier outcomes without the controversial element of state coercion or force. In other words, people voluntarily choose healthier options and, all considered, that is better than forcing their hand.

While this may be a laudable goal, nudging is not without controversy. Broadly, two objections to this idea of libertarian paternalism and nudging have been raised. Both concerns attack the premise that nudging is consistent with voluntary choice, the thought being that impairment of voluntary choice might constitute a violation of autonomy.

Voluntariness has three main elements:⁶⁰

- The choice cannot be the result of *force*. In this way, if I am held down and vaccinated, this is hardly a choice to begin with, let alone a voluntary decision
- The choice cannot be the result of *coercion*. If I chose to be vaccinated because a gun is held to my head, while I choose vaccination, this is not a voluntary choice
- The choice cannot be the result of *manipulation*. If I choose to vaccinate on the basis of subversive persuasion that bypasses and undermines my rational powers, I choose vaccination but this choice is not voluntary

The first objection questions whether nudging is really free from coercion, since it might 'involve steering people towards making choices to promote ends and interest other than their own.'⁶¹ Such accounts may be criticised on the basis that coercion is framed too broadly, failing to distinguish threats (coercive)⁶² from offers (not coercive). Second, current uses of nudging lack the elements of control necessary for coercion and do not exert the kind of leverage over behaviour that coercion might require (see box 'Health technology that nudges').⁶³

Question: might future health nudges exert sufficient pressure to be coercive?

The second objection considers whether nudging might count as manipulation. Manipulation is distinct from coercion in that it does not interfere with a person's options but instead 'perverts the way that person reaches decisions, forms preferences, or adopts goals.'⁶⁴ It is difficult to give precise conditions for what counts as 'manipulation,' in fact, it may be more appropriate to instead consider the intention of the nudger and if the nudgee (the person being nudged) consents to the nudge.⁶⁵ Given this, when considering whether a technology or policy might be manipulative, we should consider the goal of that technology or policy and the relationship between the nudger and the nudgee.

Question: might future health technology nudge us in a way that perverts our decision-making powers?⁶⁶

5.6 How the law protects autonomy

Different areas of law protect autonomy, namely: professional standards, common law actions, and doctrines related to contract law.

Professional standards issued by professional regulatory bodies such as the General Medical Council (GMC) directly protect patient autonomy.

- *Good Medical Practice* emphasises that doctors must 'listen to patients, take account of their views, and respond honestly to their questions.'⁶⁷
- *Consent* provides more specific advice noting that doctors must respect a patient's decision to refuse treatment, even if they think their decision is wrong or irrational.⁶⁸

The common law protects autonomy in an oblique manner via the following actions.

- In negligence, *Montgomery v Lanarkshire* recognises the importance of autonomy, Baroness Hale stating: 'It is now well recognised that the interest which the law of negligence protects is a person's interest in their own physical and psychiatric integrity, an important feature of which is their autonomy, their freedom to decide what shall and shall not be done with their body.'⁶⁹
- Trespass to the person, specifically battery, has long recognised a right to bodily integrity and that touching (even slight) of another person may amount to battery.⁷⁰ The classical statement of this principle is by Justice Cardozo in *Schloendorff v Society of New York Hospital*: 'Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent, commits an assault, for which he is liable in damages.'⁷¹

Many health technology providers will have contracts with their respective health consumers and users. Contract law, equity, and consumer law provide various protections.

- Duress makes contracts voidable. If duress is found, the aggrieved party will have the option to affirm or set aside the contract.
- The doctrine of undue influence provides that transactions may be set aside where the transaction has been secured via 'unfair advantage.' In the medical context, there is a legal presumption of undue influence with respect to the doctor patient relationship.⁷²
- The Unfair Contract Terms Act 1977 restricts the use of certain contractual terms, making them unenforceable, for instance, clauses that purport to exclude liability for death or personal injury resulting from negligence.⁷³
- There are also various legal mechanisms (both present and potential) that seek to give data subjects further controls over their digital selves, for instance, the variety of rights provided for in the GDPR and the proposed EU 'Data Producer's Right.'⁷⁴

6. Conclusion

New technologies such as genomic and digital technologies are enabling a new era of personalised medicine in which an individual's health is finely tailored to their personal physiology and the precise nature of any underlying disease. This new era will likely be accompanied and underpinned by three trends. First, we will have more data, a higher resolution picture of each health consumer. Second, this data will be collected from different sources, with the border 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 typical healthcare contexts. It seems inevitable that the achievement of personalised prevention will be accompanied by some loss of privacy and autonomy

Loss of privacy may arise from specific individual technologies and also as the cumulative effects across multiple technologies. Privacy concerns are not solely related to privacy loss and violation, though these are often the focus for developers and implementers. Harm can be derived from the subtle suggestion of being observed. In other words, the mere thought that your actions or interactions with technology are being monitored may cause psychological harm.

Reduction in autonomy may arise as future technologies are used to encourage people to make healthier choices for themselves, either through lifestyle changes or preventive interventions related to specific conditions. The range and nature of these choices may be led by the priorities of developers or others and not based on individual preference.

As these developments take place over the next twenty years or so, it is important that policy makers acknowledge these challenges, encourage debate about the acceptable balance of harm vs potential health benefit, and discuss and implement how developments can take place in ways that minimise harm. This might include understanding the motives behind the development of personalised prevention interventions, the interface between user and technology, the design and implementation of individual technologies, the tactics used to change behaviours and the ways in which users may be helped to understand and make informed choices for disease prevention.

In this document we have set out some of the concepts of privacy and autonomy and provided examples of how these may be challenged by new technologies aimed at personalised prevention. The particular challenges are highly nuanced in relation to the technologies, purposes, context, circumstances and user target group. In the roundtable we will discuss how these technologies might work in practice and the safeguards that might be put in place in the health sector and more generally through regulation. In the light of this further analysis we will invite and develop ideas for how these challenges might be mitigated.

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