

Chapter 2

The historical and social
context

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Introduction

2.1 The previous chapter noted that the developments related to medical profiling and online medicine considered in this report and the claims of increased ‘personalisation’ that are associated with them are heavily shaped by the social context. This chapter aims to sketch in that social and historical context a little further. It argues that the confluence of social change and the technological developments outlined in the previous chapter underlie increasing emphasis by several groups on consumerisation and responsabilisation in healthcare, two of the aspects of ‘personalisation’ we identified (see Paragraph 1.18). Those two themes feature to a greater or lesser extent in all of the case studies we investigate (see also Table 11.1). The developments we are concerned with lend themselves not only to more individualised diagnosis and treatment (the first type of personalisation noted in the previous chapter), but also to more availability of healthcare services as consumer goods for individual purchase in a marketplace, and to more emphasis, at least in policy declarations, on individual obligations to take responsibility for managing health and healthcare. It is less clear whether or not these developments are delivering on all the promises that have been made for them.

Background

- 2.2 Historically, many of the most dramatic improvements in human health and longevity have come – and continue to come – from public health measures, environmental changes or economic growth, which all operate at the level of populations or groups, and across territories of town, region or nation. Clearly such measures do not constitute personalisation in any of the senses identified in the previous chapter – in some ways they have been effective because of their ‘impersonal’ character. Notable and well-known examples of such developments are better nutrition and regulation to ensure safety of foodstuffs, universal programmes of vaccination, the provision of clean air and water, sanitation and other ways of limiting infectious or contagious disease.³³
- 2.3 But healthcare in the sense of direct provision of medical services or treatments to individuals has also played an important role in these improvements.³⁴ Moreover ‘personalisation’ in the first sense identified in the previous chapter – care that is tailored to what is thought to be each person’s specific genetic, physiological or psychological characteristics – has always been thought to be a hallmark of good clinical medicine, whether or not it has actually been found in practice. But successive discoveries in medical science have made it possible to increase personalisation in the sense of adjusting treatment regimes to the individual characteristics of each patient. For example, while the potential of blood transfusions has been known since the eighteenth century, it was only through the discovery of different blood groups in 1901 that it became possible predictably and accurately to use one person’s blood to save the life of another by ensuring that blood transfusions take place only between donors and recipients

³³ See, for instance: Baldwin P (1999) *Contagion and the state in Europe, 1830–1930* (Cambridge: Cambridge University Press); Nuffield Council on Bioethics (2007) *Public health: Ethical issues*, available at: http://www.nuffieldbioethics.org/fileLibrary/pdf/Public_health_-_ethical_issues.pdf; Acheson D (1998) *Independent inquiry into inequalities in health report*, available at: <http://www.archive.official-documents.co.uk/document/doh/ih/ih.htm>; Royal Institute of Public Health (2006) *150 years of public health milestones* (London: Royal Institute of Public Health).

³⁴ The relationship between environmental conditions; cultural and social factors; and healthcare activity on public health and longevity has been discussed at length. See, for example: McKeown T (1976) *The role of medicine: Dream, mirage or nemesis? (Rock Carling Lecture)* (London: Nuffield Trust); British Medical Journal (1976) *Dream, mirage or nemesis British Medical Journal* 2: 1521–2; Bunker JP (2001) The role of medical care in contributing to health improvements within societies *International Journal of Epidemiology* 30: 1260–3; Szreter S (2002) Rethinking McKeown: The relationship between public health and social change *American Journal of Public Health* 92(5): 722–5.

whose blood groups are compatible. A more recent example is the development of modern computer-assisted laser eye surgery that allows surgeons to take into account the exact shape of each individual human eye in a way that would not have been possible in an earlier age.

- 2.4 Many argue that the developments with which this report is concerned offer the possibility for a dramatic increase in personalisation in that first sense of individually tailored treatments. Further, they have claimed that those developments also offer the prospect, not just of tailoring treatments to existing diseases, but of ‘predictive’ personalised healthcare that can identify the future disease risks of each specific individual at an early pre-symptomatic stage. And that in turn is claimed to enable more ‘preventive’ medicine that involves tailored early intervention to mitigate the risks that have been predicted for each particular person. It is easy to see why policy makers are interested in claims that this putative new era of personal, predictive and preventive medicine can improve individual and collective health outcomes and thereby realise both health and economic benefits.³⁵ Increased prevention is widely believed to offer the possibility of offsetting the rising costs of healthcare due to increasing public expectations, inflation in healthcare treatments and demographic changes. In fact, much of what is promised as ‘prevention’ refers to early diagnosis rather than truly pre-emptive actions, and that early diagnosis may extend the period of medical care and hence the overall cost to a healthcare system, rather than reducing total costs. Moreover, the prospect of being able accurately to predict future risk of disease at an early point, and perhaps eventually at the point of conception or soon after, clearly throws up serious ethical issues.³⁶ Such issues include the temptation to recommend earlier and earlier medical interventions when the evidence of benefit against risk is unclear, perhaps including screening embryos for increasing numbers of conditions whose risks may be hard to define and where therapeutic intervention may be unavailable.
- 2.5 The developments in this area that have attracted most attention have been those in genetics, notably those arising from the Human Genome Project of the 1990s.³⁷ These developments involve analysis of genetic material collected from large numbers of individuals and attempting to link specific genomic patterns and genetic variations to their health status and disease profile. The aim is to identify health risk profiles and predispositions for disease for specific individuals, based on the analysis of some or all of their own genome for the tell-tale genetic sequences that increase the chances that this person will develop particular medical conditions.
- 2.6 Other technological developments, notably those that use digital and computing technologies, have made it possible to construct more detailed images of individual patients than was possible with earlier technologies. We have seen the increasing use of computed tomography (CT), magnetic resonance imaging (MRI) and ultrasound for diagnostic purposes, and the growth of commercial organisations that offer screening for asymptomatic individuals. Such developments claim to be able to offer person-specific prediction through their capacity to capture the early signs of diseases such as tumours before they become evident in symptoms, and hence their apparent ability precisely to identify the current and future diseases of specific individuals as a precursor to more targeted prevention and treatment.
- 2.7 In a different way, the use of digital and information communications technologies for the provision of health information, the management of individual health records, the ordering and purchasing of pharmaceuticals, tele-consultations, patient monitoring and even dispensing of drugs on an automatic basis, offers the possibility of new forms of highly targeted, person-

³⁵ See, for instance: Hood L (1992) *Biology and medicine in the twenty-first century*, in *Code of codes: Social and scientific issues in the Human Genome Project* Kevles D and Hood L (Editors) (Cambridge, Mass: Harvard University Press).

³⁶ See: Goldstein DB (2010) 2020 Visions – personalized medicine *Nature* **463**: 26–32.

³⁷ That is, the international scientific project (originating in 1990 and completed in 2003) to determine the overall sequence of base pairs (nucleotides) that make up the 23 chromosomes of each human being to identify and sequence each of the 20,000 genes that make up the human genome, and to begin to characterise each of these genes in terms of its functional properties. See, for instance: Sulston J and Ferry G (2003) *The common thread: Science, politics, ethics and the human genome* (London: Corgi).

specific healthcare, not least through automatically linking different kinds of information relating to individuals in novel ways. Examples include sending alerts about new medical discoveries to patients taking particular classes of drugs, notifying particular individuals to clinical trials relevant to them to recruit patients and simultaneously alerting various healthcare professionals to changes in an individual's health indicators.

- 2.8 As we noted in the previous chapter, many individuals, groups and organisations, especially in the USA, see these new technologies as heralding a new era, indeed a new 'healthcare paradigm', of technologically-enabled 'personalised healthcare' (see Paragraph 1.14).³⁸ The 'paradigm' they have in mind links genomic profiling and other forms of testing with other applications of information technology to produce a new world of more personal, predictive and preventive medicine, replacing an older one of more reactive and repair-focused healthcare and involving more active and empowered individuals than in a previous era.
- 2.9 Although preventive medical care has long been central to healthcare systems, many say the new developments move it into a new era. They suggest the new technologies can produce better individual risk predictions. It has also been suggested that if people were presented with information about their individual health profile and their own individual risks, it would be more compelling than earlier methods for the assessment of risk, and thus would motivate them to make the personal changes to their lifestyle to avoid both debilitating sickness and the need for costly treatment.³⁹ Such increasing emphasis on the role of risk assessment and prevention might be seen as elements in a much wider set of social changes and policy developments in what is dubbed by some as a 'risk society' in which the principle of precaution has come to rule, and the aim is not simply to respond to adverse events after they occur, but to predict them in advance and react beforehand to forestall or limit such events. For example, the emphasis on prediction, data mining, risk assessment, profiling, precaution and pre-emption that goes into the model of healthcare outlined above, is shared with developments in crime control (see Paragraph 2.13), although perhaps for different reasons. In the case of health, it involves treating individuals who are not ill in the traditional sense, and who perhaps never will be ill, blurring the boundaries over who is or is not 'a suitable case for treatment' and moving from what in a previous age would have been considered the 'the limits of medicine' into what some have termed "the medicalisation of everyone".⁴⁰ We return to some of these issues in Paragraphs 11.20–11.24.
- 2.10 As we said above, the benefits of such an approach may at first sight seem obvious, following the adage that 'an ounce of prevention is worth a pound of cure', and numerous policy statements have endorsed it.⁴¹ However, looking at benefits in relation to financial costs, not all predictive and preventive measures in fact produce aggregate cost savings to a public

³⁸ See, for example: Personalized Medicine Coalition (2010) Personalized medicine 101, available at: <http://www.personalizedmedicinecoalition.org/about/about-personalized-medicine/personalized-medicine-101/challenges>; Collins F (2010) *The language of life: DNA and the revolution in personalized medicine* (New York: Harper Collins); IBM (2003) Personalized healthcare 2010: Are you ready for information-based medicine?, available at: <http://www-935.ibm.com/services/in/igs/pdf/g510-3565-personalized-healthcare-2010.pdf>; CORDIS (2009) ICT Challenge 5: Sustainable and personalised healthcare, available at: http://cordis.europa.eu/fp7/ict/programme/challenge5_en.html.

³⁹ It is also commonly argued that better-targeted medication could cut costs as well as increasing the efficacy of healthcare, given that patients' reactions to drugs may have a substantial genetic element. The move to pharmacogenetics – to dispense the right medicine for the right patient in the right dose – represents a further move to more targeted medicine, but we do not discuss it further here as it was the subject of a previous report by the Nuffield Council on Bioethics. See: Paragraph 1.13.

⁴⁰ Armstrong D (2002) Conceptualising the patient *Journal of Health Services Research and Policy* **7**(4): 245–7; Armstrong D (1995) The rise of surveillance medicine *Sociology of Health and Illness* **7**(3): 393–404.

⁴¹ See, for example: *Our health, our care, our say: A new direction for community services*, a document that stressed the importance of prevention and prediction and declared that health and social care services will provide better prevention services with earlier intervention (p7) and suggested a "shift in the centre of gravity of spending" is required to achieve this aim (p9). What was less emphasised was that any such programme implies screening of asymptomatic individuals, groups or populations. See: Department of Health (2006) *Our health, our care, our say: A new direction for community services*; Department of Health (2002) NHS Must Highlight "Prevention As Well As Cure" – Milburn, available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Pressreleases/DH_4025964; European Commission (2007) *Together for health: A strategic approach for the EU 2008–2013*, available at: http://ec.europa.eu/health/ph_overview/strategy/health_strategy_en.htm; Prime Minister Brown's speech on the National Health Service (2008), available at: <http://www.number10.gov.uk/Page14171>.

healthcare system such as the UK National Health Service (NHS). There is evidence that some preventive health measures, such as quitting smoking, influenza vaccinations and some forms of cancer screening are cost-effective in reducing mortality.⁴² Whether or not preventive intervention reduces costs in comparison with treatment depends on the particular intervention and the specific population in question, and in some cases the cost-effectiveness of preventive and treatment approaches appears to be rather similar.⁴³ One study from the Netherlands modelling the medical costs of obesity over a lifetime found that, until middle age, yearly health spending was highest for obese people, in comparison to smokers and ‘healthy-weight’ non-smokers, yet over a lifetime health costs were highest for the ‘healthy-living’ people and lowest for smokers. The prevention of obesity and smoking increases life expectancy, but appears to substitute “...inexpensive, lethal diseases [with] less lethal, and therefore more costly, diseases”.⁴⁴ So we should be wary of sweeping claims about the cost-effectiveness of all preventive care in comparison with treatment of diseases as and when they arise.

- 2.11 Whether or not the predictive and preventive approach is more cost-effective for public healthcare systems than the treatment and repair approach, it has been taken up and promoted by policy makers in the UK and elsewhere in numerous statements aimed to encourage individuals, even and perhaps especially when they are asymptomatic, to become more involved in their health and actively to manage their healthcare. Developments in the availability of information and communication technologies such as the internet can also facilitate such a shift. Although, as we shall see in Chapter 4 (Box 4.1), the legal responsibilities of patients relative to medical professionals in the UK has not changed markedly in the recent past, the vision of predictive and preventive medicine seeks to change the traditional idea of patients in a reactive, repair-oriented health system, requiring them actively to understand and manage many aspects of their lives in the interests of their health, to educate themselves appropriately, and to take a considerable share of the responsibility for their current and future health status. That vision of public policy for healthcare chimes with market developments in the form of commercial services offered directly to consumers that encourage them – and promise to enable them – to take more responsibility for their own health. This is why we have identified ‘responsibilisation’ (one of our senses of ‘personalisation’) as a key ethical issue in the developments we are considering. We return to this theme in more detail below.
- 2.12 The new developments we are considering also throw up ethical issues linked to the third sense of ‘personalisation’ identified in the previous chapter, namely a view of health as a kind of consumption good, and hence of health products and services as commodities. Many of the products and services we are concerned with are advertised and traded in the international market place, using all the technologies of modern marketing, not merely to respond to consumer demand, but also to reshape such demand to create and sustain a market. In a social and cultural context that encourages many individuals to regard the management of their own health and fitness as a key part of their lifestyle, the online medicine and medical profiling technologies with which we are concerned readily lend themselves to direct-to-consumer commercial marketing, both to those already diagnosed with a disease, and to those asymptomatic consumers seeking to manage their future risks of disease. In the following two sections, we explore further these senses of personalisation as responsibilisation and personalisation as consumerisation.

⁴² Maciosek MV, Coffield AB, Edwards NM *et al.* (2006) Priorities among effective preventive services: Results of a systematic review and analysis *American Journal of Preventative Medicine* **31**(1): 52–61.

⁴³ Cohen JT, Neumann PJ and Weinstein MC (2008) Does preventive care save money? Health economics and the presidential candidates *New England Journal of Medicine* **358**(7): 661–3.

⁴⁴ van Baal PHM, Polder JJ, de Wit GA *et al.* (2008) Lifetime medical costs of obesity: Prevention no cure for increasing health expenditure *PLoS Medicine* **5**(2): e29

Responsibilisation and healthcare

The responsibilisation movement

- 2.13 As explained in the previous chapter, the inelegant but nevertheless useful word 'responsibilisation' refers to a movement that arose initially out of criticisms of social welfare practices that were seen as destroying individual responsibility and encouraging dependency. Such criticism of collectively planned and provided welfare provision has a long history, at least from the 1940s to the present day, and has been advanced from a variety of different political viewpoints,⁴⁵ but at least since the 1960s various measures have been proposed. These have, albeit from very different political stances, sought to diminish dependency and enhance freedom, autonomy and choice, by encouraging individuals not just to have greater powers and rights, but also obliging them to take greater responsibility for their own present and future health, welfare and security and that of their families and close communities, rather than allocating such responsibilities to an abstract 'society' or a distant state. Social scientists coined the term 'responsibilisation' to denote policies that combine increased autonomy with increased obligations. The term was taken up in particular by criminologists to characterise policies that sought to place more responsibility for crime control and the management of security onto local communities and individual householders rather than relying solely on collectively funded services provided by police and public-service professionals.⁴⁶
- 2.14 When it comes to healthcare, responsibilisation is a theme that has been taken up in various ways in recent years. The practice of involving patients in the choices to be made over their treatment and shared decision making, rather than presenting them with take-it-or-leave-it options, is a common feature of modern professional healthcare, and one that illustrates the double-edged character of such developments – on the one hand individuals are accorded more power to choose, on the other, they are obliged to take a share of the responsibility for that choice and its outcomes. Just as radical critics of 'medicalisation,' particularly in the women's movement in the 1960s and 1970s, argued for a shift in power relations to empower patients and enable them to understand and take control over their own bodies, the same theme has been taken up more recently by active patient groups, especially but not only in the USA. Such groups have made use of the internet (together with other digital age technologies) to share information and experiences among those immediately affected and lobby for attention and resources for the specific disease that afflicts them and their community. While attractive from many viewpoints, the notion of responsibilisation through new technology raises important ethical issues as well, for example when individuals choose to reject rather than embrace such responsibility or when not all patient groups have equal access to the internet and its power of communication. Such issues arise in a number of our case studies.

⁴⁵ For example from the 1960s to the 1980s, state-provided welfare services were criticised by numerous groups and individuals, particularly in the United States, as not merely inefficient, but also as demeaning, paternalistic and encouraging dependency. Some of the strands of this criticism came from feminist campaigners (such as the Boston Women's Health Collective) seeking to wrest power over women's bodies away from the professionals, and from left or liberal critics of the paternalism of a healthcare system that was perceived as forcing clients and patients into dependency. But other calls for responsibilisation in this sense came from right and third-way sources, such as Gertrude Himmelfarb (see: Murray C (1984) *Losing ground: American social policy 1950–1980* (New York: Basic Books)). It can of course be argued that as a matter of historical fact the founders of the UK Welfare State such as William Beveridge were at great pains to try to ensure that their provisions did not destroy individual responsibility (see: Mead L (1986) *Beyond entitlement: The social obligations of citizenship* (New York: Free Press)).

⁴⁶ See, for example: Rose N (1999) *Powers of freedom* (Cambridge: Cambridge University Press); O'Malley P (1992) Risk, power and crime prevention *Economy and Society* 21(3): 252–75. The underlying idea that the term tries to capture can be seen in policy proposals and developments in other fields as well, for example in relation to policies for safety in the workplace, or in the development of 'contracts' with students and pupils in school and higher education that recognise the strong 'co-production' element of teaching and learning.

Responsibilisation in policy

- 2.15 We summarise the legal responsibilities of patients and medical professionals in the UK in Box 4.1, and also set out the current obligations of patients relative to the NHS. We note there that the legal distribution of responsibility has not changed markedly in the recent past and that the established position relating to NHS care is that ill-health, however caused, is treated as a misfortune rather than as a penalty for irresponsible conduct, and that NHS care is provided on the basis of need alone. In other words, the NHS does not deny people treatment because they have led ‘irresponsible’ lives,⁴⁷ and this position can be justified on the grounds that in the current state of knowledge, the connections between lifestyle choices and particular health outcomes are too complex to hold people formally to account for the choices they make, even assuming that the notion of ‘choice’ is unproblematic. In cases where people have clearly taken action leading to their need for medical care, for instance in alcohol-related injuries or suicide attempts, the principle of treatment according to medical need is taken to be overriding, although, of course, individuals may be advised or even required to listen to advice and counselling.
- 2.16 In principle, some of the developments we are considering might challenge that established position in the future. As we have said, the purported predictive capacities of ‘personalising’ technologies seem to open the possibility of assigning increased responsibility to individuals, if reliable technologies were available that predicted individual responses to, for example, alcohol or consumption of fatty foods. But we think it unlikely that public healthcare systems such as the NHS will change their position of offering treatment even to those who have wilfully and knowingly brought on their own medical needs. The same, however, may not apply to private health insurance systems or for the employment-based insurance regimes typical in the USA.
- 2.17 Moreover, even for public healthcare systems, there have certainly been numerous policy declarations about what responsible individuals should do to look after their health that do not have legal force but are nevertheless intended to shape people’s behaviour. For instance, the King’s Fund noted in a 2007 report that “individual responsibility for health and self-care are key themes in recent health policy documents in England”.⁴⁸ Five years earlier the 2002 Wanless report on healthcare in the UK *Securing our future health: Taking a long-term view* emphasised the importance of individuals taking some responsibility for their health and recommended that the relationship between health professionals and the public could be improved by the “development of improved health information to help people engage with their care in an informed way”.⁴⁹ A 2006 Department of Health report on healthcare in England already referred to (*Our health, our care, our say*) took up the same theme, declaring that patients would be “given more control over – and will take on greater responsibility for – their own health and well-being”.⁵⁰ And the NHS Constitution for England published in 2009 outlined what it considered to be the responsibilities applying both to “patients and the public”, which included the stipulation that “you should recognise that you can make a significant contribution to your own, and your

⁴⁷ Those who undertake irresponsible activities may be accorded lower priority than others where resources are limited because the prospective efficacy of the procedure will be lower, e.g., those facing a liver transplant who cannot give up alcohol.

⁴⁸ Jochelson K (2007) *Paying the patient: Improving health using financial incentives*, p2, available at: <http://www.kingsfund.org.uk/document.rm?id=8274>.

⁴⁹ Wanless D (2002) *Securing our future health: Taking a long-term view*, available at: http://www.hm-treasury.gov.uk/consult_wanless_final.htm, p122.

⁵⁰ Department of Health (2006) *Our health, our care, our say: A new direction for community services*, p13, available at: <http://www.official-documents.gov.uk/document/cm67/6737/6737.pdf>.

family's, good health and well-being, and take some personal responsibility for it."⁵¹ Similar themes have been stressed in other countries.⁵²

New services offering increased responsibility

2.18 As we saw in the sample advertisements quoted in the previous chapter (Box 1.1), the theme of responsabilisation has also been stressed by private sector providers of some of the technologies with which this report is concerned. The promotional material of such providers suggests that it is desirable for individuals to 'take control' of their healthcare and take prudent steps to ascertain and diminish their likelihood of developing diseases in the future. Some of that promotional material draws an analogy with people taking their cars for roadworthiness checks; taking active steps to spot problems early and prevent or mitigate them rather than waiting for things to fail in what may be disastrous conditions. We therefore need to investigate how far these services really do allow people to find out useful information and hence put them in a position where they could take on more responsibility in that way.

Responsibilisation as it relates to personalisation

2.19 As briefly noted above, the development of more 'personalised' healthcare in the sense of more individually specific diagnosis and prediction thus has a potentially double-edged character. On the one hand, the doctrine of 'responsibilisation' seems to stress the value of allowing people to act as educated and empowered individuals, knowing more and able to increase their capacities to make informed decisions about the management of their health and illness. But on the other hand it may involve increased obligations and expectations on individuals to take this active role, requiring increasing skills in terms of self-education, and the need to make trade-offs between different options in terms of their relative costs and benefits. Sanctions or other consequences may flow from individuals not taking responsibility, either by not acting on the results of predictive tests, or perhaps, even by not informing themselves about their health risks. It also may mean that people come to feel guilt and anxiety if they do not fulfil these expectations – perhaps even a sense that they themselves, by acts of omission or commission, bear some blame for the illnesses that they or their family may suffer. Those who prefer not to know about the future and instead to live for the day may feel that position is condemned as irresponsible. Further, in the field of health and disease, there may be many cases where, even equipped with reliable foreknowledge of the future, individuals are relatively powerless to affect the outcome, as for example in some types of cancer. It is not hard to imagine cases where, nonetheless, individuals may feel that in some way they should be able to affect their health status or disease progression, and hence are driven to seek unproven or even harmful interventions, perhaps on the basis of information obtained on the internet and available on a commercial basis. Such ethical pressures on individuals are of course far from new, but the

⁵¹ Department of Health (2010) *The NHS constitution for England*, available at:

http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113645.pdf, p9.

⁵² See, for example, a recent Australian health policy document, *A healthier future for all Australians: National health and hospitals reform commission final report* included 'Design and governance principles' naming shared responsibility for health as one of the key principles. It stressed the responsibility of health professionals "to support us [all Australians] to take an active role in our health and treatment" and declared that "The health system has a particularly important role in helping people of all ages and abilities become more self reliant, health literate and better able to manage their own health care needs." Australian Government Department of Health and Ageing (2009) *A healthier future for all Australians: National health and hospitals reform commission final report*, available at:

<http://www.health.gov.au/internet/main/publishing.nsf/Content/nhhrc-report>. See also: Draft 2006 West Virginian *Medicaid member agreement* which specified that residents eligible due to low income should sign documents outlining their responsibilities and rights, such as "I understand that it is my responsibility to do the right things so that I am healthy". West Virginia Department of Health and Human Resources Bureau for Medical Services (2006) *Draft West Virginia Medicaid agreement*, available at: <http://www.wvdhhr.org/medred/handouts/wvmedicaidmemberagrmt.pdf> and Steinbrook R (2006) Imposing personal responsibility for health *New England Journal of Medicine* **355(8)**: 753–6; Bishop G and Brodkey AC (2006) Personal responsibility and physician responsibility – West Virginia's Medicaid plan *New England Journal of Medicine* **355(8)**: 756–8. It has also been argued that "personal responsibility for health...has been explicitly and prominently enshrined in [German] federal health law since 1988. Key elements of recent reforms that entered into force on 1 April 2007 have given even more emphasis to the concept, with immediate effects on policy and practice". Schmidt H (2007) Personal responsibility for health – developments under the German healthcare reform 2007 *European Journal of Health Law* **14**: 241–50.

developments discussed in this report may well intensify them, and we return to that issue in our final chapter.

Consumerisation and healthcare

Patients, citizens and consumers

- 2.20 In a historical and comparative perspective, there are at least three broad ways that individuals can relate to the provision of healthcare, which can be loosely denoted as the role of patient or client, citizen, and consumer. The developments in medical profiling and online healthcare with which this report is concerned raise questions about how the balance between these roles may be changing and the ethical consequences of such changes.
- 2.21 The role of *patient* denotes a relationship between an individual and a medical practitioner that is heavily governed by fiduciary obligations on the part of medical practitioners.⁵³ There is a presumption of strong information asymmetry between professional and patient, and some acceptance of the professional authority and expertise of the medical practitioner on the part of the patient, whose ability to instruct the professional what to do is constrained by legal and professional rules. The law governing those relationships tends to stress the professionals' obligation to put the interests of patients ahead of their own interests and to achieve and maintain professional standards and competence consistent with those obligations.
- 2.22 *Citizenship* shapes healthcare provision to the extent that individuals' health entitlements and responsibilities are framed in terms of their relationship with the state or less formally by some sense of claims on, or obligation to, the community.⁵⁴ Political choice and public debate determines who is entitled to what and who is expected to do what. Healthcare came to figure as an aspect of citizenship fairly late in European history (though entitlement to healthcare has commonly been linked to the military service obligations of traditional citizenship). Now, however, citizenship figures large in the relationship between individuals and the healthcare system in most developed democracies,⁵⁵ and some scholars have recently identified the concept of 'genetic' or 'biological' citizenship, bringing a new dimension to citizenship not covered in earlier accounts.⁵⁶ Moreover, as noted in the previous section, the responsibilities of citizens in relation to public healthcare systems such as the NHS have come to receive greater emphasis in recent years, and new market opportunities provided by the developments in medical profiling and online medicine likewise raise new questions about the limits of citizenship entitlements.
- 2.23 In contrast to the roles of patient or client and citizen, the term '*consumer*' is ordinarily used to denote those who purchase goods and services in the marketplace, subject to the ordinary legal principles governing commercial transactions, including the *caveat emptor* ('let the buyer beware') principle that presumes buyers take care to inform themselves about the goods or

⁵³ This role is similar to that of 'client' in professional services more generally, although the client of a legal professional, for example, may have more power in virtue of his or her payment for professional services.

⁵⁴ This is especially true in relation to the acceptance by political authorities of particular responsibility for the health and welfare of children as young or future citizens, as in the provision of maternal care services, medical inspection of schoolchildren and food supplementation in some cases.

⁵⁵ For Thomas H Marshall, in a classic account, the extension of citizenship rights (at least for males in England) began with legal rights and duties, then moved to political ones and only finally moved to social citizenship involving entitlements to health, education and social welfare. The latter was central to citizen-state developments in Germany, France and the UK over the twentieth century, and to a lesser extent and in different ways in the United States. See: Marshall TH (1950) *Citizenship and social class, and other essays* (Cambridge: Cambridge University Press).

⁵⁶ Petersen A and Bunton R (2002) *The New Genetics and the public's health* (London: Routledge); Heath D, Rapp R and Taussig KS (2003) Genetic citizenship, in *Companion to the handbook of political anthropology* Nugent D and Vincent J (Editors) (Oxford: Blackwell); Rose N and Novas C (2004) Biological citizenship, in *Global assemblages: Technology, politics, and ethics as anthropological problems* Ong A and Collier SJ (Editors) (Oxford: Blackwell).

services on offer.⁵⁷ In such relationships, providers are not expected to put the interests of users before their own: they are free to market their wares through any medium and within the general constraints applying to advertising. There is no necessary presumption of authority or superior information on the part of the provider, and buyers with the necessary funds are free to obtain goods or services they want from any legitimate source of supply.

- 2.24 A key feature of the 'consumer-supplier' relationship is that of choice: the ability, at least in theory, to choose between different suppliers. It is conventionally held that consumer choice can encourage the kind of competition among suppliers that will increase the quality or cut the cost of the goods or services provided. Of course there is nothing new about healthcare being treated as a consumer good in that sense, since wealthy individuals have long purchased their medical advice and treatment in that way, and during the eighteenth and nineteenth centuries doctors were in many ways an employee of their wealthy patients but those who did not pay were in the 'patient' relationship of dependence on the authority of the professional. However in the recent past, in the public services in the UK generally, and not only in healthcare, more emphasis by policy makers has been placed on treating users more like consumers, at least by offering elements of choice of provider and by packaging services in ways designed to improve their accessibility to the user.

Consumer choice in healthcare

- 2.25 Policies that aim to put more emphasis on consumer choice and consumer empowerment in the provision of public services belong to our third sense of 'personalisation' in the previous chapter, since they imply that users of healthcare and other services need to make choices among different elements of provision to compile a package that is adjusted to their personal circumstances and priorities.⁵⁸ Such policies aim to alter the relations of power and authority between professionals and those who use their services, requiring healthcare providers to compete by making themselves attractive to those who choose to use them. This requirement is often believed to act as a counterweight to the paternalistic power of professionals, forcing those professionals to be more attentive to the needs of those who use their services, and making them more accountable to those users. As in other domains where individuals act as choosing consumers, treating healthcare as a consumer product also imposes a certain responsibility on the users to make the choices that are appropriate for their needs, and in turn produces a requirement for the provision of education and information to assist individuals in making those informed choices.
- 2.26 In many domains, from car insurance to holidays, the development of the internet is transforming processes of consumer choice. In healthcare, the internet has increased the possibility of seeking out health information from a range of public, professional and commercial providers, such that the general practitioner, family doctor or specialist consultant may become only one source of information and advice for people among many (see Chapter 5). Many people have become familiar with comparing goods and services on the internet to choose among the different goods or services available for purchase (and many price comparison websites have developed to help users do so), and it may be that such behaviour is also coming to apply to some extent to healthcare decisions. We shall take up this point in our final chapter where we consider the implications of changes in the traditional doctor-patient relationship. We shall see in Chapter 5 that such developments carry the risk that individuals may be harmed, or not optimally treated, by accessing information that is incorrect or that they cannot interpret adequately but that it may also protect them from medical malpractice or incompetence (in the form of out-of-date or careless treatment) and provide valuable extra sources of information. To the extent that such a change is taking place, it suggests a need for professional organisations

⁵⁷ It should be noted that the importance of this principle has been reduced somewhat in the context of consumer transactions by legislation such as the Unfair Contract Terms Act 1977 and various common law principles.

⁵⁸ For a discussion of different ways of thinking about the consumerisation of public services, see: Hood C, Peters G and Wollman H (1996) Sixteen ways to consumerise public services: Pick 'n mix or painful trade-offs? *Public Money & Management* 16(4): 43–50.

and those concerned with health policies to consider the kinds of education of both doctors and patients that may be appropriate for this new situation of provider and information pluralism and individualised consumer choice.

- 2.27 Increasing stress on the ‘consumer’ aspect of healthcare has also come from commercial providers of health or health-related services seeking to break into new markets, often crossing national borders. This includes those offering direct provision of health-related services. Central to the issues that we discuss in this report is the growing market for those offering genomic sequencing technologies claiming to be able to predict susceptibility to common diseases. They are said to constitute a substantial market opportunity for commercial organisations and investors because it is thought that there will be a rapid increase in the use of such technologies for the predictive testing of individuals in the coming decades. Thus there are developing alliances between the biomedical researchers seeking to identify relevant genetic sequences linked to disease susceptibility, the commercial organisations seeking to develop the researchers’ work into tests and devices that can be sold for profit to health providers in both the public and the private sectors, and those private and public sector providers arguing for the importance of practices based on predictive genetic tests for future healthcare.
- 2.28 Moves towards a more consumerist approach to healthcare also come from the behaviour of some individuals. For instance, the much-observed phenomenon of ‘medical tourism’ in various forms in the recent past, often linked to the development of the internet, by people seeking treatments overseas that are not available or are much more costly in their home countries, represents a notable shift in the balance between patient, citizen and consumer roles in healthcare. So does the number of individuals who choose to buy pharmaceuticals online for reasons of access, cost, privacy or convenience, as we discuss in Chapter 7. In each case, we can observe an increased emphasis on the individual person as having the rights, powers, and responsibilities to manage key aspects of their medical care. We return to the role of the individual as it relates to healthcare in the final chapter.

Links between responsabilisation and consumerisation in healthcare

- 2.29 Ethical issues associated with responsabilisation and consumerisation are linked together in many of the developments we are concerned with. While the development of arguments for greater choice and responsibility in healthcare stem from government policies, economic arguments, the logic of commercial development and the activity of some pressure groups, including patient groups, it is not clear to what extent, and in what respects, greater choice and responsibility is demanded by, or welcomed by, recipients of healthcare services.⁵⁹ Personalisation is sometimes represented as a response to demand, but in some cases at least it seems to be a case of supply looking for demand.
- 2.30 Nonetheless, these developments embody something that numerous commentators on the development of welfare systems have written about, namely challenges to earlier ideas of uniformity and universality in collective forms of risk sharing which were embodied in the social insurance schemes that developed in the twentieth century. Such schemes pooled risk across whole populations, and were embedded in moral and ethical beliefs about social solidarity and collective responsibility which we discuss further in Chapter 3. In many policy domains however,

⁵⁹ Some studies in the USA indicate a majority of patients surveyed said they valued choice of doctors and hospital and that relatively socially-advantaged groups were somewhat more likely to be aware of healthcare-related performance information. See: Lambrew JM (2005) “Choice” in Health Care: What Do People Really Want?, available at: http://www.commonwealthfund.org/usr_doc/lambrew_853_choice_ib.pdf; Schneider EC and Epstein AM (1999) Use of public performance reports: A survey of patients undergoing cardiac surgery *Journal of the American medical Association* **279**(20): 1638–42. Some studies in England have indicated that the importance of being able to choose hospitals varied among survey respondents, but was not, on the whole, a high priority for most NHS patients surveyed in England. See: Fotaki M (2009) Are all consumers the same? Choice in health, social care and education in England and elsewhere *Public money & management* **29**(2): 87–94.

we now see exhortations for individuals to take on more responsibility for risk (for example in saving for retirement rather than relying on state entitlements), and in some we see policy shifts as well (for example in moving investment risk over pensions from employers to employees by abandonment of defined-benefit pension schemes in many companies).⁶⁰ Perhaps the clearest example of moves to 'de-pooling' of risk can be seen in the market for car insurance, where advertising urges individuals to shop around for the best deal that matches their own personal characteristics – age, area of residence, form of employment and professional status, history of accidents and so forth – so that everyone pays only for the risk of their particular risk pool, and staid middle-aged professionals do not share the financial risks posed by, say, 18-year-old males driving their first car.

- 2.31 While in the UK such individualisation or de-pooling of risk in domains such as insurance or private-sector retirement pensions has not been accompanied by a reduction in communal risk pooling in most aspects of national health⁶¹ and social insurance, the developments in healthcare with which we are concerned throw up ethical issues relating to both responsabilisation and consumerisation, as will be seen in Chapters 5 to 11. For patients or potential patients, individualisation of what may previously have been treated as shared chances of ill-health is accompanied by the possible expectation that each person will ascertain and manage their potential future health risks in a responsible way. However, the healthcare developments we are concerned with do not necessarily imply some one-way move from social solidarity to individual prudence. In some cases they can facilitate new forms of group solidarity, for instance through the creation of new group allegiances formed around disease-specific identities. Such activity builds on a longer history of pressure groups and self-help groups that have formed around particular diseases, that organise activities aimed at understanding and reducing risks to their own particular disease group, for example breast cancer, HIV or haemophilia. The creation of such groups may be thought of as a move from 'society' to 'groups of people just like me who are at risk'. Today, such movements make heavy use of internet technologies, such as social networking and patient group websites that not only share information, direct users to relevant research, and seek to raise funds, but also campaign for research investment and policy changes beneficial to the conditions for their own disease group. Such group activity both feeds into policy development and provides examples of new ways of organising healthcare that can be used, copied and encouraged by subsequent health policies. Again, such developments seem to be double-edged in terms of ethical issues relating to responsabilisation and consumerisation, since they can plainly lead to new forms of group empowerment, but also to new forums for political competition over which groups have the loudest voices or the most politically salient illnesses.
- 2.32 There are other more specific links between responsabilisation and consumerisation. For example, the development of direct advice services to individuals (as with the UK's NHS Direct web service and its equivalents in other countries, based on an 'expert system' algorithmic approach) represents consumerisation to the extent that it can enhance choice by providing another source of health advice to individuals on top of traditional sources such as pharmacies, friends and direct consultation with doctors. But that development can also be used to drive responsabilisation by putting new moral obligations on individual citizens, for example during epidemics or pandemics to use a teleservice before or instead of presenting themselves in person to the hard-pressed medical services, so as to avoid burdening, and potentially infecting, healthcare professionals (a move that constitutes 'depersonalisation' in at least one of the senses discussed in the previous chapter).
- 2.33 Other developments in the NHS less directly relevant to our inquiry here that represent a mingling of consumerisation and responsabilisation include 'personal care budgets' and choice of providers for specialist treatments. The former is a form of voucher system for public services

⁶⁰ See, for example: Ericson, RV and Doyle A (2004) *Uncertain business: Risk, insurance and the limits of knowledge* (Toronto: University of Toronto Press).

⁶¹ Dentistry is perhaps the main exception.

originally introduced for social care but now extending to healthcare,⁶² that both gives the purchasers an element of consumer choice (among different public or private providers) and puts the responsibility onto them to see that the money is spent effectively in relation to their own personal needs and priorities. The second also represents a mixture of consumer choice and responsibility for selecting the best provider of treatment. Many of the developments that we assess in later chapters also entail a similar mix of responsabilisation with consumerisation, and hence generate some of the same ethical dilemmas in balancing the virtues of individual choice with the obligations of personal responsibility.

Conclusion

- 2.34 This chapter has aimed to show how the developments in medical profiling and online medicine with which this report is concerned intersect with broader social and economic changes. Those changes include the development of the global healthcare industry, as in the new genetic profiling market, changes in public policy and in consumer behaviour, much of it linked to, and intensified by, modern communications technology. And those developments in medical profiling and online medicine throw up some perplexing ethical questions related to responsabilisation and consumerisation, as we foreshadowed in the previous chapter and will explore further in Chapters 5 to 10. The questions include issues about the proper uses of information which pertains to individuals but can be of strong collective or group benefit when pooled; about the new obligations and expectations that may be placed on individuals by new forms of 'personalisation'; about the dilemmas individuals face when purportedly predictive information is inaccurate or ambiguous or carries other harms; about the loss of solidarity that could result from a greater ability to predict individual health risks or to bypass collective provision; about the potential to change priorities away from collective provision of public health through environmental and other 'impersonal' measures; and about how to balance individual choice with avoidance of unnecessary harm. We turn to these issues in the next chapter.

⁶² Department of Health (2009) *Personal care budgets: First steps*, available http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117262.pdf.