

# Chapter 3

## Ethics

# Chapter 3 – Ethics

## Introduction

- 3.1 This chapter considers how to manage the ethical issues posed by developments in medical profiling and online medicine. By ethical issues we mean the moral what-to-do questions arising in this area that require individuals, organisations, companies and the state (in all its various organisational forms)<sup>63</sup> to evaluate and choose between alternatives.
- 3.2 Chapter 1 sketched out some ways in which developments in medical profiling and online medicine have the potential to change the delivery of healthcare, and set out some of the positive and negative consequences that could flow from such changes. This chapter returns to those matters to consider the ethical issues they present. It then relates the advantages and disadvantages to five ethical values that the Working Party thinks should govern decision making in this area. We argue that: (1) those ethical values conflict with one another for the developments we are considering here; (2) no one of these values automatically trumps the others as a basis for good practice or for intervention by the state or other third parties; and (3) the appropriate ethical approach is therefore to examine each of the developments under consideration in its context with the aim of achieving as many as possible of all the conflicting ethical values that apply to each individual case. The aim is thus to manage, reduce or ‘soften’ the conflicts among the five ethical values. As a simple example of such an approach, the practice of allowing individuals to drive cars has both obvious advantages and dangers. The advantages are individual convenience and collective benefit, while the dangers are to the life and health of the drivers themselves, passengers, cyclists and pedestrians, as well as pollution and noise. Among the ethical values that conflict in this case are the autonomy of individuals and the reduction of harm by state action. Rather than giving one value priority over another, in practice all societies find ways of regulating the practice so that many of the benefits remain and many of the harms are reduced or mitigated. Consequently driving while intoxicated, at speed, or in a poorly maintained car, are prohibited. While, to a degree, such measures compromise individual freedom to drive, it does so in a way that most drivers and non-drivers can accept is a reasonable balance among conflicting values. We describe our approach more fully in Paragraphs 3.15–3.19.
- 3.3 It is possible to imagine societies in which there was a settled and widespread understanding that one or some of the five different ethical values we consider below would invariably and automatically trump the others – for instance, that the achievement of collective benefit or ‘solidarity’ would always outweigh considerations of individual preferences or vice-versa. Nor is that a wholly imaginary example: what is commonly claimed to be the prevalent individualism of societies like the USA is often contrasted with the more solidaristic societies of Scandinavia. However, we do not believe the UK today belongs at either of those extremes, and we suspect that applies to many other countries too. Indeed, as we suggested in the previous chapter, the way these new applications of medical profiling and online healthcare have been marketed and sold as representing a brave new world of ‘personalised healthcare’ and ‘democratising’ access to medical knowledge and therapeutic possibilities, represents a challenge to collectivist approaches to healthcare (while also opening up new modes of group activity and throwing up new ‘spillovers’ and collective-action issues).<sup>64</sup> To the extent that these developments represent a potential challenge to older forms of collectivism, some will see any move as something to celebrate, others as a matter of regret. But in a society where the relative importance of the five ethical values we identify is inherently contestable, intervention by the state or other bodies that puts all the weight on any one of them seems difficult to justify. That is why we have adopted the softening-dilemmas method as the basis of our ethical approach to these developments.

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<sup>63</sup> We use the term state to denote all those bodies, whatever their organisational form, that have legal powers to permit, prohibit, require or punish, at all levels from municipalities to supranational bodies like the European Union.

<sup>64</sup> By ‘spillovers’ we mean forms of individual activity that impose costs or bring benefits to others. See Paragraph 3.11.

## Potential advantages and disadvantages of applications of medical profiling and online medicine

3.4 Table 3.1 develops further the point we made in Chapter 1 – that the developments considered here have the potential for both benefit and harm. For each one of the five developments in medical profiling and online healthcare, the Table identifies several potential consequences that can plausibly be considered as beneficial, and a roughly equal number of consequences that might equally plausibly be considered as potentially harmful. In the case study chapters that follow, we attempt to analyse the evidence that exists as to the extent of these potential advantages and disadvantages in practice. The what-to-do question that then arises in each case is therefore ‘how can we maximise the potential benefits while minimising the potential harms?’

**Table 3.1: Potential advantages and disadvantages of applications of medical profiling and online medicine**

Service	Potential advantages	Potential disadvantages
<b>Access to online health information</b>	<ul style="list-style-type: none"> <li>i) Convenience</li> <li>ii) Allows people who want to, to be more involved in their own health and healthcare</li> <li>iii) Can empower patients relative to doctors</li> <li>iv) Can provide protection from medical malpractice or incompetence</li> <li>v) Facilitates mutual support</li> </ul>	<ul style="list-style-type: none"> <li>i) Misleading information</li> <li>ii) Misinterpretation</li> <li>iii) Breaches of privacy</li> <li>iv) Can undermine traditional doctor-patient relationship</li> </ul>
<b>Online personal health records</b>	<ul style="list-style-type: none"> <li>i) Secure and useful storage</li> <li>ii) Convenience</li> <li>iii) Interactive records, e.g. alerts</li> <li>iv) Worldwide access</li> <li>v) Benefit from research on pooled data</li> <li>vi) Safeguarding function</li> </ul>	<ul style="list-style-type: none"> <li>i) Misuse of stored information</li> <li>ii) Advantages of centralised information may possibly be lost through separate information systems</li> <li>iii) Difficulties for healthcare professionals if they have to rely on inaccurate or incomplete records maintained by patients</li> <li>iv) Opportunity for promotion of unnecessary or inappropriate treatments/services</li> </ul>
<b>Online purchasing of pharmaceuticals</b>	<ul style="list-style-type: none"> <li>i) Convenience</li> <li>ii) Price competition</li> <li>iii) Availability</li> <li>iv) Privacy</li> </ul>	<ul style="list-style-type: none"> <li>i) Obtaining inappropriate or harmful medicines</li> <li>ii) Adverse interactions with other medicines</li> <li>iii) Limited or no opportunity for advice</li> <li>iv) Risks from incomplete information about adverse effects and contraindications</li> <li>v) Increased danger of obtaining fake or low quality medicines</li> <li>vi) No limits on quantity bought</li> <li>vii) Possibility of increase of antibiotic resistance arising from misuse</li> <li>viii) Reduction in the quality of relationships with health professionals if health conditions not discussed</li> </ul>
<b>Telemedicine</b>	<ul style="list-style-type: none"> <li>i) Benefits of being at home rather than in institutional care</li> <li>ii) Convenience</li> <li>iii) More equitable access to</li> </ul>	<ul style="list-style-type: none"> <li>i) Dangers of misuse</li> <li>ii) Reduction in the quality of the doctor-patient relationship</li> <li>iii) ‘Virtual brain drain’</li> </ul>

Service	Potential advantages	Potential disadvantages
	healthcare iv) Cheaper care v) Earlier return home from hospital	iv) Inappropriate early discharge from hospital v) Surveillance of lifestyle
<b>Predictive testing: personal genetic profiling and body imaging</b>	i) More information ii) Allows early intervention iii) Allows more personal control iv) Possibility of saving public healthcare resources if testing and treatment conducted privately v) Can alert relatives to important genetic conditions (all of the above depend on the accuracy of the results given)	(i) Costs to individuals of tests that yield little determinate information (ii) Harms caused when tests themselves can be damaging (e.g. through radiation) (iii) Social harms when private testing can undermine equal access to healthcare (iv) Costs of consequences of having information: a) for individual when inaccurate or hard to interpret, b) for individual when nothing can be done, c) for individual if inaccurate risk assessments lead to false reassurance or misplaced anxiety, d) for individual if results lead to stigma or information abuse (e.g. blackmail) or other effects that may be regretted, given that information once known cannot be 'un-known' (e.g. for insurance declarations), e) for taxpayers when unnecessary follow-up testing and treatment is carried out (v) Costs and harms to third parties – when children or third parties are tested without consent, or when embryos are tested for conditions whose risks may be hard to determine (vi) Can change perception of wellness and illness through medicalisation of normal variation, including for children

## Common ethical values

3.5 Although each case considered in this report is different, we find that the issues identified in Table 3.1 all connect with a series of widely acknowledged ethical values, which we set out below, and do so in ways that can generate moral dilemmas. Accordingly it will be necessary in the chapters that follow to explore whether the dilemmas do occur in any substantial form, and what might be done to mitigate them.

### 1. The value of safeguarding private information

3.6 The value of safeguarding private information refers to individuals being able to keep information about themselves and their health private and free from unauthorised access or use if they so wish. Being able to keep such information private is often said to be important in promoting dignity and autonomy, and invasion of privacy can lead to harm to individuals, for example if it leads to ostracism, blackmail or discrimination.<sup>65</sup> All our case studies raise questions about the creation, possession, transmission and security of highly personal information about individuals. For example, the increasing amount of information about people that is available on the internet and being processed online raises key issues about the scope and limits of privacy and confidentiality, and the same goes for genetic testing where information about an individual may be of crucial relevance to his or her relatives.

<sup>65</sup> Laurie G (2002) *Genetic privacy: A challenge to medico-legal norms* (Cambridge: Cambridge University Press).

- 3.7 That means that established information governance principles (such as the professional obligations – and common law – of confidentiality applying to healthcare professionals, data protection laws and the international agreements and human rights conventions protecting the confidentiality of personal data) are relevant for the many actors involved in providing the goods and services we are considering. But as with other ethical values we are considering, privacy and confidentiality does not always trump all other considerations, and there are situations when data protection can and should be overridden if the consequences of not doing so are sufficiently serious.

## **2. The value of individuals being able to pursue their own interests in their own way**

- 3.8 It is widely held that individuals should where possible be able to pursue their own interests in their own way, and this value is sometimes known as respect for personal autonomy. It is commonly argued that there are at least two reasons why people should have such autonomy. First, individuals can be thought to be the best judges of their interests, and so are likely to make better decisions concerning their wellbeing than others would for them. Second, whether or not the first argument holds, it can be demeaning or insulting not to take decisions for oneself, even though we know that, in practice, individuals rarely take decisions in isolation, without any reference to the views and opinions of others they trust. But as with privacy and confidentiality, personal autonomy is not a value that always outweighs all others, and there are often powerful contrary reasons that can limit it.

## **3. The value of efforts by the state to reduce harm**

- 3.9 Even in the more individualistic societies, the value of personal autonomy is not always recognised as decisive. In many countries the state in all its various organisational forms (law courts, legislatures, civil and military executive bodies) restricts autonomy to varying degrees to make it less likely that individuals will cause serious harm to themselves and others (for example by making seatbelts or motor cycle helmets compulsory),<sup>66</sup> and that too can be seen as a major ethical value. The value of reducing harm by such action is commonly thought to be particularly applicable to children and other individuals considered to be vulnerable in some important way, as for example in prohibitions on children being able to purchase alcohol or tobacco. Indeed, preventing individuals from taking decisions for themselves out of a desire to prevent harm is commonly called ‘paternalism’, assuming that the state or its various agents have the right to treat adults in the way a parent would decide what is best for a child and enforcing those decisions against the will of the individuals concerned. The value of acting to prevent harm in such a way can often be expected to conflict with that of personal autonomy, and we identify numerous clashes of that kind later in the report. For example, if, as some claim, purchasing restricted pharmaceuticals over the internet without a prescription involves high risk of harm to the purchasers that is preventable by various forms of regulation, the value of personal autonomy conflicts directly with that of the value of state action to reduce harm. But state action may also be directed to prevent the actions of individuals harming or imposing costs on others, rather than on themselves – the ‘spillover costs’ problem to which we have already referred. We find many examples of such costs in the cases considered in this report.
- 3.10 While it is often argued to be more important for the state and its various organisations to use their powers to prevent harm rather than to convey benefits or provide for enjoyment,<sup>67</sup> those two elements can blur into one another, for example over issues of access to clean air or

<sup>66</sup> We note that there are other reasons for restricting autonomy in some jurisdictions, such as the exercise of state power.

<sup>67</sup> For example Jeremy Bentham observed: ‘The care of providing for his enjoyments ought to be left almost entirely to each individual; the principal function of government being to protect him from suffering.’ (Bentham J (1843) *Principles of the Civil Code*, in *The Works of Jeremy Bentham published under the superintendence of John Bowring Vol. 1*, Bowring J (Editor) (New York: Russell and Russell), p301.)

unpolluted water supplies. Moreover, as we shall see in the next chapter, intervention can take a range of forms, from legal obligation or prohibition accompanied by penalties to various softer forms of action that are designed to steer opinion or behaviour by persuasion, advertising or other actions that fall short of compulsion. Indeed, some have argued that the state is legitimately entitled to use its compulsorily derived tax funding to support interventions designed to convey benefits to individuals even where harm to third parties was not palpable. For example, the 2007 Nuffield Council report *Public Health: Ethical issues* argued,<sup>68</sup> as part of what it called a 'stewardship' model of state activity, that an important function of government was to ensure that conditions were in place that made it easy (or easier) for people to be healthy.

#### **4. The value of using public resources efficiently and fairly**

3.11 While individuals might be considered to be entitled to spend their own money wastefully or carelessly if they choose to do so, there is normally considered to be a special obligation to allocate public resources efficiently and fairly. Efficiency is conventionally taken to mean output or effect relative to input or expenditure, for example in how health benefit can be secured by particular forms of medication or treatment. In principle, efficiency is a value that can be related to any goal, but in public healthcare systems it is often related to fairness, since the finite resources available to such systems are expected to be used in such a way as to produce effective results, given the alternative uses to which those finite resources could be put. That often involves difficult choices over the cost thresholds that are considered justifiable for publicly-funded treatment or medication for individuals, and the National Health Service (NHS) and other public healthcare systems have mechanisms (e.g. the National Institute for Health and Clinical Excellence in the UK) for deciding how those limited healthcare resources should be allocated (in the form of guidelines over which treatments should be provided and to whom). Indeed, throughout the NHS, organisations and individual practitioners are charged with ensuring that limited resources are used in the most effective manner. We recognise the difficulties this value presents, although the rationing issues involved are not the focus of our report. The issue of managing spillover costs that was discussed in the previous section can have an impact on the use of limited public healthcare resources, as the examples we gave there indicated. And even less directly than in the examples given in that section, provision of, and common access to, new forms of medical services could lead to the degradation of existing services, through diversion of resources and attention, if those new services require investment of time and money that might be more effectively spent in other ways.

#### **5. Sharing risks, protecting the vulnerable: the value of social solidarity**

3.12 Somewhat overlapping with the values of harm reduction and the efficient and fair use of public resources, it is often argued that the NHS, and similar systems of publicly-funded healthcare, embody a valuable notion of social solidarity in the sense of shared responsibility and pooling risks in a way that protects the vulnerable. Such systems also embody a principle of equity for all members of society, at least in access to a certain minimum of care, support and financial security, thus also protecting those most vulnerable.

3.13 The ethical principles embodied in the notion of social solidarity in the sense of sharing risks and protecting the vulnerable are complex and contestable – and indeed they are more contested than the four values mentioned above. Such a view of the world places an independent ethical value on measures that foster and enhance the sense of collective

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<sup>68</sup> Nuffield Council on Bioethics (2007) *Public Health: Ethical issues*. Along similar lines to the framework introduced in the next chapter, that report described how the state had at its disposal a range of tools for stimulating individual behaviour. It could encourage some behaviours and discourage others by using methods of intervention such as providing information, incentives or disincentives, that typically did not amount to compulsion. There is also the possibility of shaping how choices are presented to citizens, such as governments choosing carefully what is to be the 'default' choice, and how hard it is to deviate from this default. As we also argue in this report, the 2007 report argued that where the state had regulatory power to prohibit, require, permit or punish, it should do so when the stakes were high enough and alternative less coercive measures did not seem to be adequate.

obligations and responsibilities for one another, irrespective of whether, in this or that particular, a measure or policy delivered an immediate health or other desired benefit.

- 3.14 We think the value of solidarity is sufficiently widely held in the UK and similar societies for us to ask whether new developments in medical profiling and online medicine could undermine the collective benefit and intrinsic social solidarity of a national health service, and if so whether governments ought to try to reduce these possibilities or even protect existing systems. We noted in the previous chapter that the NHS in the UK does not deny treatment to individuals because they have led ‘irresponsible’ lives, but some of the developments we are considering here offer the potential for placing more obligations on individuals for the management of their health. Such developments might in principle increase the view that health risks are not shared equally among all citizens, and therefore that those at low risk should not be expected to make financial contributions to support those who, for genetic or other reasons, are at higher risk, thus potentially threatening the democratic legitimacy of a publicly-funded health service free at the point of need. We will explore whether the possibility of increasing personal responsibility implies that individuals should be faced not merely with the consequences of their choices, but also with the consequences of their own biology, or whether the principle of social solidarity and the sharing of risks can and should still prevail in an era of increasing medical profiling and the individualisation of risks of disease. But at the same time some of the developments we are considering offer the possibility of new forms of social solidarity, for example in new ways of pooling data in medical research and providing mutual advice and support.

### Managing ethical dilemmas: taking a ‘softening’ approach

- 3.15 Each of the examples listed in Table 3.1 can be seen as potentially generating a clash between some of the considerations set out in Paragraphs 3.6–3.14. The pressing question for this report, therefore, is how these dilemmas are to be resolved. How, for example, is it possible to adjudicate a conflict between individuals pursuing their interests in their own way, and the state attempting to reduce harm, if it is suspected that their chosen behaviour will lead to harm?
- 3.16 One possible approach would be to attempt to find arguments that show that one principle should always, or at least in a clearly defined range of cases, take priority over another. For example, the principle that fire service vehicles should be able to access a burning building could plausibly be thought to have clear priority over the principle that vehicles should not park on a double-yellow line. If similar priority rules could be discovered in the cases here in question then the dilemmas would be solved. But even if that approach can be applied in a few of the issues related to the cases considered here, we do not think such an approach can be applied to most of the issues that arise. All the values identified in this chapter are important, and any argument that one is more fundamental than another, even within a limited range, is likely to be highly controversial, and not command general assent.
- 3.17 Consequently, we need to examine each case in detail, as we do in the chapters to follow, to identify the ethical values invoked in each case and see where they conflict. That requires going through the tricky exercise of trying to establish the benefits and harms in each case, to see whether the potential dangers to which we have referred do in fact arise in any substantial form, or will come to do so over time, and to understand how serious any clash among the five ethical values is in practice for each of the cases. Where there is no evidence of actual or incipient clashes among ethical values or serious violations of any of them, there is no need to make a case for any practical action, even though we may want to comment on what we think are desirable and less desirable trends.
- 3.18 Where there is a case that practical dilemmas arise and harm may be substantial as it would seem they are in some cases, there is a real question as to how to deal with them. As we mentioned in Paragraph 3.3, when we introduced the idea of ‘softening’ dilemmas, the approach we follow in this report is not so much to attempt to solve the dilemmas but to propose forms of oversight and voluntary conduct so that society can manage its way around them and reduce

the conflict while gaining general assent. This approach means trying to accommodate as many as possible of the different values we have identified without giving one absolute priority over another.

- 3.19 Inevitably the question arises of what level of harm justifies what kind of intervention by the state or other third parties, and we deal with this issue in the next chapter. In the case study chapters (5 to 10), we apply the ethical approach sketched out here, of respecting genuine ethical values with a pragmatic approach of finding a solution that is at least acceptable to a wide community. Before we do so, we set out in the next chapter what we mean by intervention by the state and other third parties, what key choices have to be made among types of intervention and what principles should govern such choices.