20: Public health dimensions of medical practice

The questions covered in this chapter include the following.

- What do we mean by 'health' and what impact might this definition have on health provision?
- What are the goals of public health practice?
- What are the social determinants of health?
- How coercive should health promotion campaigns be?
- What are the benefits and harms of population screening?
- Should patients be given financial incentives to take up a healthy lifestyle?
- What ethical considerations should be taken into account in priority setting?
- How should the release of information about disease outbreaks be managed?

General principles

Public health is a complex and contested notion, nevertheless from a clinical perspective it is broadly agreed that public health is the branch of medical practice that addresses the health of populations rather than individuals. It is carried out not only by public health specialists, for whom it is their main area of work, but also by many health professionals when they engage in activities such as epidemiology, health advocacy and community involvement or commissioning. Public health practice uses the best available evidence to address the fundamental causes of disease and the requirements for health and well-being, aiming to prevent adverse health outcomes. In undertaking this work, public health practice should:

- promote and protect public health to the greatest extent that is compatible with respecting individual rights
- ensure input from all sections of the community, including those who are unable to speak for themselves
- aim to ensure that the basic resources and conditions necessary for a minimally acceptable level of health are available to all
- seek to prioritise interventions that favour underprivileged sections of society
- seek the best available information for carrying out its role
- provide communities with the information that is required for policy decisions and obtain the agreement of those communities, where appropriate, for their implementation
- act in a timely manner on available information within the resources and the mandate given
- incorporate a variety of approaches that respect the diverse beliefs and values in the community
- implement policies in a manner that promotes the integrity of the physical and social environment
- protect the confidentiality of information where appropriate.[1]

Medical Ethics Today: The BMA's Handbook of Ethics and Law, Third Edition. Sophie Brannan, Eleanor Chrispin, Martin Davies, Veronica English, Rebecca Mussell, Julian Sheather and Ann Sommerville.

The public health perspective

The focus of medical ethics has ordinarily been on the relationship between a doctor and a patient, and this emphasis can be seen reflected in the majority of chapters in this book. At the centre of this relationship lie the interests of the patient, and key ethical principles include a respect for individual autonomy and, stemming from this, the requirement for consent from the patient or, where the patient lacks capacity, a representative, before treatment can begin. (In the absence of a representative, decisions need to be made on the basis of an assessment of the patient's best interests. For further information see Chapters 2 and 3.) The primary duty of doctors in this relationship is understood to be the well-being of their patients. It is increasingly recognised, however, that this one-to-one relationship exists within a wider context, particularly where health provision is publicly funded. Aspects of this broader context include financial limitations, centrally driven targets, the use of health incentives and the health status of broader communities and populations. It also includes social factors with a significant impact on health outcomes such as social inequalities, employment, education and housing.

Although these broader concerns can be diverse, and at times difficult to specify, they share a focus on groups rather than individuals, whether they are local or wider communities, or indeed whole populations. It is this community or population-based approach that gathers many of these issues under the broad umbrella of public health practice. Public health doctors have particular responsibilities in this area, and many of the topics in this chapter deal with areas of practice with which public health doctors will be engaged. However, there is increasing recognition of the impact of these wider considerations on the practice of a range of clinical disciplines which mean that more and more doctors are both exposed to, and interested in, ethical issues arising in this area. This chapter is therefore aimed at all those whose practice has an impact on, or is informed by that broader public health context, as well as all those doctors who seek a deeper understanding of the complex factors that contribute to health outcomes and of the challenging ethical debates they can give rise to.

Sick individuals and sick populations – the prevention paradox

In a seminal 1985 paper, the epidemiologist Geoffrey Rose distinguished between two possible approaches to understanding the occurrence of illness: one focusing on sick individuals and one focusing on sick populations.[2] He identified two corresponding kinds of aetiological question: one seeking the causes of individual cases of an illness, the other seeking to identify the causes of its population incidence. 'Why do some individuals have hypertension', he writes, 'is a very different question from 'Why do some populations have much hypertension, whilst in others it is rare.'[3] 'The determinants of incidence', he goes on to say, 'are not necessarily the same as the causes of cases.'[4] He also identifies separate prevention strategies for dealing with individual cases and with population incidence. For individual cases he outlines the traditional medical 'high-risk' approach which entails identifying individuals who are at a high risk of developing the illness in question and then intervening accordingly. Benefits include the use of interventions appropriate to the individual, enhanced doctor and patient motivation, a favourable ratio of risk to benefit in relation to the intervention, as well as a cost-effective use of resources. Disadvantages, however, include the costs and potential harms of screening, the fact that it does not seek to identify and change the underlying causes of disease, seeking instead to protect those who are vulnerable and the fact that it can require individuals to step outside persuasive social norms of behaviour.

Against the more patient-focused approach to prevention Rose sets the 'population strategy'. This is characterised by an attempt to identify and control population-wide

determinants of incidence. Traditionally it has involved environmental controls. More recently it has focused on encouraging population-wide behavioural change. According to Rose, the benefits of the population approach include the potential to deliver large benefits across a population, and it is 'behaviourally appropriate', in that it aims at changing norms rather than asking people to step outside them. In discussing potential drawbacks to the population approach he reintroduces the 'prevention paradox.' This highlights the fact that measures that may have enormous significance for the population as a whole are likely to offer very little benefit, at least in the short term, to individuals. Given that there is only a small likelihood that any given individual will benefit, even small risks can disturb the cost–benefit ratio. For Rose it is important therefore to distinguish between approaches that remove abnormal exposure, such as smoking cessation, and those that rely on a preventive intervention that may have associated risks, such as jogging or vaccination.

Rose's identification of the paradoxes implicit in an approach to the health of populations, and of the tensions that can arise between individual and population interests, have been enormously influential. Recent work in public health law and ethics has begun to explore some of the ethical and legal challenges raised by these insights.[5]

Public health – a changing practice

Until fairly recently, ethical dilemmas arising in public health have been underrepresented in academic and professional literature, although this has begun to change. There are many reasons for this increasing interest. One important factor is the evolving nature of public health practice itself. The origins of current public health practice lie in the nineteenth century with organised interventions to tackle serious external threats to individual health, such as communicable diseases, poor sanitation and a lack of clean drinking water. More recent examples include the clean air legislation of the 1950s. Many of these early public health interventions proved extremely successful. Between 1841 and 1971, for example, overall mortality rates in England dropped from 23 to 7 per 1,000 for males, and from 21 to less than 5 per 1,000 for females. Life expectancy over a similar period increased from 48 to 80 for women and from 44 to 75 for men.[6] Although the management of these traditional public health threats remains important, and they remain major health threats in the developing world, partly as a result of these early successes, a new generation of public health threats has been identified.

Contemporary public health threats

These include:

- tobacco, drug and alcohol misuse
- obesity
- mental illnesses, such as depression and anxiety
- cancer
- dementia and other forms of age-related cognitive impairment
- climate change.

Contemporary public health threats include diseases associated with ageing, such as cancer and dementia, as well as 'lifestyle' related illnesses resulting from tobacco and drug consumption and alcohol misuse. There are also a new generation of health problems which are thought to be linked in complex ways to wide-ranging social change.

Mental illnesses such as depression, as well as obesity and its associated illnesses, are creating a significant and growing health burden with substantial resource implications for health services. Whereas the more traditional health threats have shown themselves responsive to single interventions, such as vaccinations, or to techniques to deal with individual environmental hazards, the new threats are proving less easy to manage. This new generation of problems have complex origins. Obesity, for example, is influenced by psychological, genetic, social and environmental factors, many of which are resistant to traditional public health tools. In addressing these issues, health professionals and policy experts are increasingly looking at ways to influence individual behaviour, and ethical and political questions arise about the extent to which the state should direct personal lifestyle choices. In the more familiar medical model, it is patients who make the decision to visit doctors in search of remedy for a health problem. In these new areas of public health, the state takes the initiative, actively trying to change people's choices, even where those individuals may not have identified any health problems, and may in fact be highly resistant to state pressures. Live issues here include whether people should be offered incentives to make health-promoting choices, whether patient rights to treatment should be linked to obligations to take responsibility for health, as well as the obligations of large non-health actors, such as fast food or soft drink manufacturers.

'Health' – an evolving concept

Early public health interventions were understandably concerned with reducing overall mortality. More recently, however, along with increased life expectancy has come a concern not only with the length of life, but with the quality of the life that is lived. The provision of direct healthcare has traditionally focused on a clinical model of health, with illnesses being seen as a diversion from ordinary biological functioning, and medicine playing a corrective or remedial role. The increasing understanding of the social, economic and environmental sources of health and well-being has led to a broader, richer and arguably more complex model, a model now somewhat notoriously summed up by the World Health Organization (WHO) definition as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'.[7] Such an inclusive definition of health, although it acknowledges the multi-factorial origins of human flourishing, presents a number of challenges. Such a broad definition inevitably places responsibility for sustaining and promoting health in areas of policy not ordinarily associated with health departments. These include education, the built environment and transport as well as the regulation of commercial organisations that can have an impact on human health, such as airlines and car manufacturers. 'Health' also ceases to be a matter specifically for health professionals and health budgets, and becomes instead a factor in most private and public endeavours, presenting real challenges for health policy. Normative emphasis on ideas of 'total well-being' also raises questions about the imposition of a single universal concept of human functioning that can sit uneasily alongside more pluralistic accounts of necessary conditions for human thriving.

Such an explicitly aspirational definition of health also raises questions about the scope of more traditional health interventions. To what extent, for example, should medical resources be limited to those with identifiable diseases, or should they extend to preventive interventions aimed at those who may not develop a specific disease for many years, if at all? It also invites questions about whether medical technology has a legitimate role in enhancing health and overall well-being, in the meeting of health 'wants' rather than health

'needs', an issue raised by interventions such as tattoo removal or *in vitro* fertilisation (IVF) treatment for infertility. Decline in cognitive functioning, for example, could be said to be a 'natural' feature of ageing. To what extent therefore should public resources be spent to slow or even to reverse this process? On the other hand, acceptance of a 'natural' decline in functioning can lead to less attention being paid to potentially remediable conditions associated with a longer life. Given that life expectancy and the process of ageing are also subject to significant socioeconomic variation, concepts of health will often raise questions of justice. Further, if pharmaceutical interventions are successful in those groups whose cognitive functioning is declining, should they also be offered to those who show no signs of cognitive decline but whose 'ordinary' functioning could be enhanced?[8] Although a detailed discussion of these topics is outside the scope of this chapter, variations in the definition of health or illness can have a significant impact on the nature and scope of the resources available to health budgets. As the definition of health is an important issue in resource allocation, it follows that health has a political dimension, with a profound effect on the way in which needs are prioritised and collective health goods allocated. Resource allocation is discussed in more detail later in the chapter. The box below gives an outline of some of the main conceptual approaches to health.

What do we mean by health?

Health, illness, disease and sickness

Many commentators draw an interesting distinction between illness and disease.[9] Illness is seen as the subjective experience of ill health in terms of pain or suffering, while disease refers to the presence of a disturbance in biological functioning. According to this view it is possible to feel well while having a serious asymptomatic disease in its early stages, and also to feel ill even where there is no underlying pathology. This distinction has clear relevance in a clinical context, enabling a fuller understanding of both the underlying biology of disease and the subjective experience of illness. Some commentators draw a further distinction and see 'sickness' as the adoption of a changed social role resulting from illness.

Health as the absence of disease

According to this approach, health is defined as an absence of any abnormal biological functioning. An influential proponent of this view is Boorse, who states that a disease can be understood as 'a type of internal state which is either an impairment of normal functional ability, i.e. a reduction of one or more functional abilities below typical efficiency, or a limitation on functional ability caused by environmental agencies.'[10] Boorse links 'normal ability' to ideas of species-typical functioning which is ultimately linked to evolutionary concepts of reproductive fitness.

Health as well-being

According to this view, the most important index of health is the individual's subjective feeling of well-being. Although, as indicated above, disease processes can in their early stages be asymptomatic, they will at some point impact upon the subject's sense of wellness. The goal of health interventions therefore becomes the restoration or maintenance of the subjective experience of well-being. As some critics have noted, however, it can be difficult to distinguish between health as a subjective experience of well-being and happiness, a trap that some believe the WHO has fallen into.[11]

Health as agency

Another influential contemporary approach to health sees it as a necessary condition for the achievement of goals. According to this view a person is healthy in so far as he or she has the ability to do those things that are necessary for his or her well-being. Health is therefore a measure of ability, and disease can be understood as anything that restricts an individual's ability to achieve necessary goals. The difficulty here is identifying those things that are necessary for the individual, as opposed, for example, to those that are merely desirable.

Health as a social description

Doctors are involved in more than the clinical assessment of a patient's health. Decisions made by doctors can have an influence on the provision of a wide range of health and social resources. Entitlement to a range of benefits can be dependent on a medical assessment, as can access to social housing. A psychiatric assessment can lead to the restriction of fundamental freedoms, as well as protection from criminal liability, and certain diagnoses can lead to significant social stigma. Notions of health therefore have an important social dimension that cannot easily be reduced to biological functioning.

Public health – the limits to individualism

Another reason for the growth of interest in ethical issues in this area is the increasing recognition, among health professionals, policy makers and the wider public, that a number of important aspects of health cannot be captured by a sole focus on the needs of individuals. While a respect for the informed choices of patients will always be central to medical treatment, there is a danger that too exclusive a focus on patient autonomy can lead to a neglect of other components of health. Health rights may accrue to individuals, and the decision whether or not to have a particular treatment or intervention is always personal, but this can sometimes obscure the reality that the health of any individual is not an exclusively personal matter. Many conditions that are necessary for individual health, such as a positive environment, lie beyond the direct ability of individuals to change them. These conditions require collective action. Influential work by Sir Michael Marmot[12] and others, for example, on the social determinants of health has provided a strong reminder that health is both a shared good and that the health of individuals is strongly influenced by structural factors such as their position in a social hierarchy. In order to improve both individual and population health outcomes, it follows that such structural factors must be addressed.

The individual and the community

Given that a public health perspective can provide valuable insights into the sources of health and well-being that are wider than the individual, a central ethical issue in this area is the relationship between individual freedom and concepts of the 'public good'. Ordinarily, in a liberal country, the usual justification that is given for limiting individual freedoms is the requirement to prevent direct harm to other identifiable individuals. The idea that individual freedoms should be limited on the basis of an appeal to a community, or a population, is less well developed. Partly in response to this problem, public health professionals have traditionally looked to utilitarian reasoning to support their interventions, arguing that it is appropriate to limit certain individual freedoms in

order to maximise health gains across a broad population. Fluoridation of water, for example, may restrict the freedoms of those who do not want fluoride added to their water supply, but it is justified on the basis of the benefits that it brings to the dental health of large numbers of people. Overall benefits outweigh overall harms. Such utilitarian reasoning, however, makes use of a very weak idea of community, which is seen as a mere aggregate of individuals. The benefits and harms are calculated in terms of the numbers of individuals among whom they are distributed. More recent work in public health[13] has argued in favour of a stronger concept of community. According to this view there are social goods that are more than aggregates of individual benefits. Factors seen as vital to well-being, including strong social networks, shared purpose and meaningful activity, cannot be reduced to the sum of the individuals they benefit. This approach sees community less as a necessary negative limit to human freedoms and instead as a fundamental requirement for human flourishing. In this way it becomes possible to speak of individual autonomy and concepts of the public good as being deeply related. Rather than seeing public health interventions in opposition to individual freedoms, they can be seen as complementary, with individual freedom requiring goods held in common. Exploring this relationship presents one of the main challenges for the ethics of public health.

Although the majority of doctors are familiar, through daily examples, with the social gradient in health many will also ask what effect this should or could have on their clinical practice. A doctor's primary focus will be on the presenting health need, and the ability to change underlying structures in people's lives that can undermine health will be limited. Marmot, Wilkinson and others have started to look at the ways in which the social environment impacts on biology to bring about disease. Factors such as insecurity, chronic anxiety, isolation, low self-esteem and a lack of control over work are all identified as operating through biological stress responses in the body to bring about long-term physiological changes that undermine health.[14] In this way, insights from public health can feed directly into clinical practice, enabling doctors to work with individuals who are identified as being at long-term risk of health problems. While underlying structures cannot be easily changed, increased knowledge about their physiological impact can help doctors working with patients to mitigate their impact.

The social determinants of health

In 2003, the WHO published a second edition of *The Solid Facts*, a paper summarising the available evidence relating to the impact of social factors on health. The introduction states:

> Health policy was once thought to be about little more than the provision and funding of medical care: the social determinants of health were discussed only among academics. This is now changing. While medical care can prolong survival and improve prognosis after some serious diseases, more important for the health of the population as a whole are the social and economic conditions that make people in need of medical care in the first place.[15]

The paper identifies 10 key areas in which social factors have a clear impact on health outcomes.

1. *The social gradient:* the lower an individual is in the social hierarchy, the poorer his or her health outcomes.
2. *Stress:* anxiety, insecurity, low self-esteem, social isolation and lack of control over work and home life have a powerful impact on health.
3. *Early life:* many of the foundations of adult health are laid down in early childhood.

4. *Social exclusion:* the longer people live in disadvantage, the more likely they are to develop a range of health problems.
5. *Work:* people who have more control over their work have better health.
6. *Unemployment:* higher rates of unemployment are linked to illness and reduced life expectancy.
7. *Social support:* friendship, good relationships and strong social networks improve health.
8. *Addiction:* alcoholism, illicit drug use and cigarette smoking are all associated with social and economic disadvantage.
9. *Food:* a healthy diet and a secure food supply are necessary for good health.
10. *Transport:* cycling, walking and the use of public transport provide exercise and social contact. They also reduce accidents and improve air quality.

Politics and public health – the challenge of justice

On average, people living in the poorest parts of Glasgow die 12 years before those living in the most affluent.[16] In some American cities, the gulf between the richest and poorest is wider still. Globally, the differences are even starker. In Sierra Leone, life expectancy at birth is 34; in Japan it is 81.9.[17] Although doctors working within the NHS will be familiar with the politicised nature of health delivery in the UK, with its ceaseless restructuring, its centrally driven targets and its rapidly changing agendas, public health, by concerning itself increasingly with the impact of social structure and organisation on population health, is political in a deeper sense. Nor is it a matter of absolute levels of wealth. Cuba has seen little economic growth since the 1950s but has managed to maintain improvements in life expectancy in line with the USA. A glance at these figures, and at the WHO's 10 messages (see box above), clearly demonstrates the link between public health and issues of the social distribution of goods, that is between health and broad concepts of social justice. One of the ways in which public health practitioners approach this issue is through exploring the link between health inequalities and health inequities.[18]

Health inequalities are generally understood as being differences in the comparative health status or health outcomes of individuals or groups. For example, there are widely recognised health inequalities between men and women. Men have higher rates of cardiovascular disease while women have higher rates of osteoporosis.[19] Inequities in health, by contrast, are said to occur when those inequalities come about as a result of conditions that are seen to be unjust. Health inequalities occurring as a result of genetic makeup, while they can be deeply unfortunate, are naturally occurring and therefore not themselves issues in justice – although the availability or otherwise of treatment and support for individuals with genetic disorders may well be. Health inequalities that arise as a result of poverty, such as those in Glasgow, which are not regarded as natural or inevitable, and arise from social conditions that can be subject to modification, are seen to be unjust and therefore matters of inequity in health.

In 2010, the Department of Health for England published *Fair Society, Healthy Lives*, the report of a strategic review of health inequities in England.[20] The purpose of the review was to propose the most effective strategies for reducing health inequities in England from 2010 onwards. The report corroborated the link in England between social determinants and health outcomes particularly in relation to the impact of social status on infant mortality and life expectancy. The earlier, 2009 'first phase' report that preceded *Fair Society, Healthy Lives* drew an interesting distinction between ideas of 'being well' and 'well-being'. 'Being well' was described as the absence of identifiable physical and

mental illness. 'Well-being', however, was described as a far more inclusive concept, referring to an active and positive state of mental, physical and social functioning. Well-being 'is not just the absence of pain, discomfort and incapacity, it requires that basic needs are met, that individuals have a sense of purpose, that they feel able to achieve important goals and participate in society'.[21] A decision to focus on well-being over and above being well will clearly involve addressing the social determinants of ill health, including underlying structural issues such as social inequality. It will ask far-reaching questions about the obligations that society has to its citizens and that citizens have both to each other and to their communities and, ultimately, to the state. Such questions will ensure that public health remains an irreducibly political enterprise.

Summary – the public health perspective

- Public health is primarily concerned with the health status of populations.
- The majority of doctors have some public health obligations.
- Public health practice involves the management of communicable disease, environmental health and risks for non-communicable disease and addresses the underlying conditions for good health, including its social determinants.
- Public health practice seeks a recognition of the alignment of individual and public goods in health.

Legal aspects of public health

In addition to the broader political and ethical aspects of public health discussed in the preceding section, public health broadly conceived is subject to legal articulation and regulation in the UK. This section gives a brief outline of some of the most significant aspects of the law in this area. Acting in unison, these legal instruments set the parameters for the maintenance of public health and the provision of health services in the UK.

Health as a positive right

The UK is a signatory to a number of international human rights treaties or covenants. These treaties set internationally agreed standards of respect for human rights that all signatory states have committed themselves to upholding. Although the extent to which these rights are enforceable within the UK is open to debate, in ratifying them the UK has made a commitment to maintaining a certain minimum set of standards in the areas to which they relate. The UK is a signatory to the International Covenant on Economic Social and Cultural Rights (ICESCR). Article 12 of the Covenant imposes a duty on the state in relation to health broadly conceived. The Article is given below in its entirety:

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
   (a) the provision for the reduction of the stillbirth-rate and of infant mortality and for the health development of the child

(b) the improvement of all aspects of environmental and industrial hygiene
(c) the prevention, treatment and control of epidemic, endemic, occupational and other diseases
(d) the creation of conditions which would assure to all medical service and medical attention in the event of sickness.[22]

Article 14 (frequently referred to in shorthand as the 'right to health') by looking beyond healthcare delivery to the underlying conditions of health is clearly relevant to a great deal of public health practice. Although the Article is quite abstract, there has been considerable work on developing an understanding of the concrete content of the right. The United Nations Economic and Social Council has issued an authoritative statement on the meaning of the right, known as 'General Comment 14'. It identifies both 'negative' rights, which relate to freedom from interference, and 'positive' rights, which relate to obligations on the state to provide certain minimal conditions and services for health flourishing. It states, for example, that:

> The right to health is not to be understood as a right to be healthy. The right to health contains both freedoms and entitlements. The freedoms include the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation. By contrast, the entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.[23]

In 2003, the UN Human Rights Council appointed a human rights expert, known as a special rapporteur, to develop and explore the right to health, and successive post holders have further elaborated the content and meaning of the right. Their work has included the development of sophisticated techniques for measuring the extent to which states are meeting their obligations as well as a focus on practical issues such as the development of drugs for rare conditions. Although the nature and extent of specific health obligations under these treaties are currently underdeveloped, the right to health is becoming increasingly understood as a framework for articulating the responsibilities of states in relation to the health, broadly conceived, of its citizens.

Rights to healthcare

The NHS Act

The legal scope of the services provided by the NHS is defined in the National Health Service Act 1977. In England and Wales, the Act imposes on the Secretary of State an obligation to promote a 'comprehensive health service designed to secure improvements (a) in the physical and mental health of the people of those countries, and (b) in the prevention, diagnosis and treatment of illness'.[24] The Act also states that services must be provided free of charge unless the law expressly permits charges to be made. The duty is to 'promote' a comprehensive health service, not to provide one, and although the Act refers both to personal health services and public health promotion, the duty is phrased in such a way as to make direct enforcement difficult.[25] In Scotland these provisions are given in the National Health Service (Scotland) Act 1978.

NHS constitution

In 2009, the NHS for England published a constitution for the NHS setting out the values and principles on which the NHS is based.[26] In 2010, the incoming administration committed itself to upholding that constitution.[27] Although the constitution relates to England, in 2008, Scotland, Wales and Northern Ireland had signed up to a high-level statement of underlying principles with the intention of affirming that the NHS was committed to the same principles across the UK, even where local needs and circumstances dictated variations in the way care was delivered. The constitution set out a series of patient rights and responsibilities and also made a series of commitments to realising certain aspirations that were not legally binding. The constitution did not introduce any new rights, and the obligations on patients – such as to follow any course of treatment agreed upon, to participate in important public health programmes, such as vaccinations, and to provide accurate health information – were not legally enforceable.

Public health law

Given the earlier discussion about the potential scope of the definition of health, unsurprisingly perhaps the question of what constitutes public health law is itself vexed. It can focus, as Gostin suggests, on the full range of 'legal powers and duties of the state to assure the conditions for people to be healthy . . . and the limitations on the power of the state to constrain the autonomy, privacy, liberty, proprietary or other legally protected interests of individuals for the protection or promotion of community health'.[28] This inevitably draws the net very wide. Alternatively, it is possible to focus, as below, on a far smaller patchwork of statutes, statutory instruments and government circulars that are aimed at the control of a range of potential health threats. These include legislation to regulate the quality of air and water, to manage infectious diseases, including sexually transmitted diseases, to limit harms generated by motor vehicles and to control potential threats from contaminants, including threats arising from potential terrorist attacks using chemical, biological or radiological substances.

In 2008, new legislation was introduced separately in Scotland, Northern Ireland and in England and Wales to consolidate and to bring up to date legislation relating to threats from both infectious diseases and environmental contaminants.[29] Earlier legislation had been drawn up to reflect Victorian social conditions and had been adapted piecemeal over the ensuing years. Drawing on the WHO's International Health Regulations, this new legislation takes an 'all hazards' approach. Where earlier legislation was restricted to specific diseases, the new approach includes potential contaminants and is flexible enough to deal with new and emerging threats.[30] Additional statutes that are relevant to public health control of a variety of potential threats include the National Assistance Act 1947 and subsequent amendments, the Environmental Protection Act 1990 and the Environment Act 1995, as well as the Water Industry Act 1991.

Infectious disease reporting

Public health legislation contains a number of powers designed to control the spread of infectious diseases.[31] This includes the power to subject individuals to compulsory medical examination, and to remove people who have a notifiable disease to hospital without their

consent, or against a competent refusal if necessary, and to detain them there. Furthermore, people with notifiable diseases can be subject to certain restrictions on their movements and anyone with such a disease is not permitted to use public transport, public libraries or public laundries. Those who exercise these powers must, however, have due regard to the individual rights enshrined in the Human Rights Act 1998.

In England and Wales, doctors are statutorily required to notify the 'proper officer' of their local authority of any patient they believe to have a notifiable disease, which includes conditions such as meningitis, plague, tuberculosis and food poisoning. In Scotland, doctors are required to contact the chief administrative medical officer for the area in which the notifying doctor works. In Northern Ireland, doctors are required to notify the communicable disease surveillance centre.

Infectious disease notification: the current law in England, Wales, Scotland and Northern Ireland

If a registered medical practitioner believes or suspects that a person he or she is attending has a notifiable disease, he or she must send to the proper officer a certificate stating:

- the name, age and sex of the patient and the address of the premises where the patient is residing
- the disease or poisoning from which the patient is, or is suspected to be, suffering and the date, or approximate date, of its onset
- if the premises are a hospital, the day on which the patient was admitted, the address of the premises from which the patient came, and whether or not, in the opinion of the person giving the certificate, the disease or poisoning from which the patient is, or is suspected to be, suffering was contracted in the hospital.

Although consent is not required for the disclosure of this information, the doctor should nevertheless explain to the patient his or her duty to make this report.

Unless consent has been obtained for wider disclosure, only the information required by the legislation should be released. In exceptional cases, the need to prevent the spread of a serious disease may constitute an overriding public interest in disclosure, such that a breach of confidentiality would be justified (see Chapter 5, pages 199–202).

Summary – legal aspects of public health

- The UK is a signatory to a variety of international treaties or covenants that impose obligations relating both to the provision of health services and the maintenance of the underlying conditions for health.
- The NHS is subject to legal requirements to promote both a comprehensive health service and to secure improvements in the underlying conditions of health, but the enforcement of these duties is difficult to achieve.
- New public health legislation in the UK has moved away from specified health targets toward a new 'all hazards' approach based on WHO regulations.
- All doctors have a statutory obligation to provide information to an appropriate person about notifiable diseases.
- The agreement and cooperation of infected individuals should be sought, wherever possible, for both reporting notifiable diseases and contact tracing.

Public health threats – tackling diseases, changing lives

As the introductory section to this chapter makes clear, public health is a dynamic discipline in which there is increasing recognition of the variety of factors that interact to create the background conditions for a population's health. Controlling infectious diseases and identifying non-infectious threats from the environment, while a traditional part of public health practice, require responsiveness both to new organisms and new contaminants or other sources of harm, and strategies have to be adapted to the requirements of each particular threat. Alongside this, changing socioeconomic conditions and the success of earlier public health interventions have, as already indicated, combined to create new and emergent challenges. This section looks at a number of representative current threats to health and at the variety of ethical issues that responding to them raises.

Climate change – opportunities and threats

The scale of some of the most significant contemporary public health threats means that it can be very difficult for individuals, and for individual healthcare practitioners, to identify ways to make a practical contribution. There is a consensus, for example, that climate change presents a very serious potential threat to health, particularly to populations that may already be vulnerable, such as those living in areas exposed to coastal flooding or experiencing very low rainfall. It could also lead to global instability in food and water supplies, to the migration of infectious diseases and to increasing numbers of severe weather events. One way in which public health experts are looking to link these large-scale threats to individual behaviour change is by exploring the potential health co-benefits of action to mitigate or to adapt to climate change. In the UK, for example, physical inactivity and the consumption of excessive amounts of animal fats are leading causes of ill health. As transport and cattle farming are major sources of greenhouse gases, promoting walking and cycling, and encouraging diets with fewer animal products can simultaneously improve health and reduce carbon output. While the evidence is convincing, the big challenge is translating these insights into political activity that can lead to change.[32]

Obesity

According to the Department of Health, obesity represents one of the UK's key health threats.[33] WHO figures suggest that the UK has the highest prevalence of obesity in Europe, with nearly one in four of the adult population having a body mass index (BMI) in excess of 30.[34] In the last 30 years, obesity has trebled in the UK, with projections suggesting that at some point between 2010 and 2015 nearly one-third of the population will be obese.[35] Obesity is an important risk factor for a wide range of chronic diseases including type 2 diabetes, hypertension and coronary heart disease. By 2050, the costs of treating obesity and its health and economic consequences is estimated to be in excess of £10 billion a year.[36] Although the biological causes of individual weight gain are straightforward, resulting from the consumption of calories exceeding expenditure, the underlying factors behind the rapid growth of obesity are far more complex. A recent report by the Nuffield Council on Bioethics points to the influence of a large number factors including:

- the development of more highly calorific and processed foods with increased levels of salt and sugar to make it more palatable

- food becoming cheaper and far more widely available
- increased portion sizes
- changing patterns of home life that have led to a decrease in 'traditional' eating patterns, a loss of cooking skills and a greater reliance on processed and take away foods which often have higher salt, sugar and fat contents
- aggressive marketing of energy-rich foods
- the replacement of walking and cycling with motorised transport
- the increasingly sedentary nature of both work and recreation.[37]

The Government's report *Tackling Obesities – Future Choices* places the responsibility for increasing levels of obesity on the combination of underlying human biology, which has a propensity to store and conserve energy, and an 'obesogenic environment', a combination of sedentary work and leisure patterns and enormously increased availability of energy-rich foods, which has exposed our underlying biological vulnerability.[38] The report groups the factors that regulate our energy balance into four areas: physiology, eating habits, levels of activity and the influence of psychosocial factors. From these it draws the following key determinants of obesity:

- primary appetite control in the brain
- the force of dietary habit
- levels of physical activity
- psychological difficulties in making lifestyle choices.[39]

Earlier in this chapter attention was drawn to those aspects of health that are not easily reducible to questions of personal choice and individual autonomy. Although we are at liberty to make choices about what we eat and how we exercise, environmental factors clearly shape them, inclining some to make healthier choices than others. Obesity has a social gradient and its resulting disease burden contributes to social inequities in health. Doctors and other health professionals can provide advice on diet and exercise, and can address some of the health problems arising from obesity, but the extent to which individuals act upon the information provided will depend upon a variety of factors that have their origins in individual psychology and background. As *Tackling Obesities* points out:

> The encouragement of physical activity in daily life or modifying the nutritional balance of the diet might appear at first glance to be relatively simple to achieve. In fact, the scale of change required to make a significant impact at the population level would need to be very substantial, raising difficult and complex economic and social questions about how public policy can be reshaped across a number of very diverse areas, including food production, food manufacturing, retailing and marketing, healthcare, town planning, transport, education, culture and trade.[40]

Although a successful response to obesity will require widespread change to the 'obesogenic' environment, including changes to transport policy and the built environment, given that benefits stemming from these changes will take considerable time to feed through to individuals, health professionals have also been looking at innovative methods of encouraging behaviour change. While many people may wish to lose weight, dieting frequently has only short-term success and sustaining weight loss can prove difficult. Key issues in promoting behaviour change therefore include inducing people to desire healthy outcomes and, once healthy preferences have been established, encouraging people to

sustain them. One approach that is being explored is the use of incentives, either direct financial incentives or incentives in kind, such as free or discounted gym membership, or, in relation to private healthcare, cost reductions contingent upon healthy choices. The use of incentives raises a number of interesting ethical questions. Although at times incentives are said to reinforce the desirability of choices that people would make anyway, they will also involve attempts to induce people to make choices they would not otherwise. In justifying the use of incentives, appeal must therefore be made to ideas of autonomy more complex than the respecting of short-term preferences. The use of incentives in the management of obesity suggests that public health will make use of a more paternalistic practice. A more objective judgement of the conditions for personal flourishing is used as the justification for directing individual choices, choices that are understood to be beneficial not only to the individual, but, through health savings, the wider public. Greater detail about ethical issues arising from the use of specific public health tools is given later in the chapter.

'Libertarian paternalism' – making healthy choices easier

One approach that innovative public health specialists are currently exploring in relation to lifestyle-based health problems such as obesity has been described as 'libertarian', 'soft' or 'asymmetric' paternalism. Sometimes involving techniques referred to as 'nudging', such an approach involves making healthy choices easier – the 'paternalistic' part – while leaving people free to make less-healthy choices should they so wish – the 'libertarian' part. Examples include replacing high-calorie snacks next to tills with fruit, thus reducing the likelihood of 'impulse' purchases of foods with high sugar or fat content. Those who want to buy crisps or chocolate are able to do so, but it supports those who struggle to make choices in their own longer-term interests.

Public health emergencies

Where obesity presents a structural, developing and chronic threat to population health, unpredictable events such as terrorist attacks, natural or man-made disasters and outbreaks of highly infectious diseases, such as influenza pandemics, can make very different demands. As indicated above, tackling lifestyle diseases raises long-term questions about the nature of the relationships between individuals, the state and the public good. In emergencies, the focus is on tackling the immediate threat to health and utilitarian reasoning is often invoked, ensuring that interventions are justified on the basis of ensuring the maximum benefit to the largest number of individuals. When the risk to public health is very high, even apparently draconian measures may be justified. If the level of risk to public health is low, such actions would not be proportionate. In this section we look at some general lessons that have been learnt from the British experience of the H1N1 pandemic in 2009–2010. Fortunately, H1N1 turned out to be far less virulent than feared, but it nevertheless triggered a great deal of ethical reflection, much of which is relevant to a wide range of large-scale public health emergencies, particularly those where health need stemming from the emergency significantly outstrips available resources.

Policy making in the face of future threats

In developing public health policy the usual process is to assess, as accurately as possible, the level and severity of risk to public health and, on the basis of that assessment, to devise

a system of public protection that is proportionate to those risks. One of the difficulties that frequently arises in practice, however, is the lack of clear evidence on which to base accurate risk assessment. An important part of the role of those planning public health policies, therefore, is to predict, using the best information available at the time, the likely scale of the problem, so that an appropriate response can be initiated. Given that this will always be a matter of judgement, and that it is often not feasible to wait until more evidence is available, these decisions are often controversial. Planning models for the H1N1 pandemic were based on extrapolations from earlier flu pandemics, the 'Hong Kong flu' of 1968–1969, the 'Asian flu' of 1957 and, by far the most virulent, the 1918 'Spanish flu' which is estimated to have killed between 40 and 50 million people worldwide.[41] In hindsight, given the relative mildness of H1N1, questions were asked about how responses drawn from modelling based on earlier pandemics could be made sufficiently flexible to respond proportionately to more modest threats.

The importance of fair process

In order for any response to a large-scale public health emergency to be ethically defensible, consideration has to be given to questions of procedural ethics – to ensuring that decisions are made openly, accountably, transparently, by appropriate bodies and with full public participation. Public acceptance of rationing decisions, and their cooperation in a health emergency, is more likely if citizens accept the fairness and legitimacy of allocation decisions, and have been informed beforehand of the expected response. Advance discussion of the decision-making process, and of the ethical principles and reasoning upon which decisions are made is likely to lead to greater public acceptance.

The need for proportionality

It is possible that decisions about access to scarce resources that are taken during the course of an emergency will result in some people dying who would, in less extreme circumstances, have been saved. Human rights legislation allows for derogation from fundamental rights where it is both necessary and proportional to the required goal.

Resource allocation

Ordinarily, the provision of health services in the NHS is linked to an assessment of clinical need. Those with the greatest need are given priority and treatment is provided until it becomes futile. Where resources are scarce they are effectively rationed by waiting times. In the face of an emergency, decisions about how to meet individual need can give way to decisions about how to maximise overall benefit. The requirement to meet the needs of the most ill individuals may give way to quantitative decisions based on maximising the overall reduction of mortality and morbidity, and the need to maintain vital social functions. Treatment may also have to be withdrawn from some patients to allow their application to patients with a higher survival probability.

During an emergency, decisions may need to be made about whether treatment should be withdrawn from those already receiving it in favour of other individuals who are more likely to benefit, or to benefit more quickly, so that others can be treated. The fact that a course of treatment has already started need not necessarily be determinative. The morally relevant factor will be to ensure the maximisation of overall health benefit from a given health resource, not the continuation of a treatment procedure that has already commenced.

Triage

Triage is a form of rationing or allocation of scarce resources under critical or emergency circumstances where decisions about who should receive treatment must be made immediately because more individuals have life-threatening conditions than can be treated at once. Triage sorts or grades persons according to their needs and the probable outcomes of intervention. It can also involve identifying those who are so ill or badly injured that even with aggressive treatment they are unlikely to survive and should therefore be set aside for non-treatment. Any system of triage has to be simple enough to be practical in emergency conditions and flexible enough to respond to rapid changes in available resources. In disaster triage, priority will normally be given to those whose conditions are the most urgent, the least complex and who are likely to live the longest, thereby maximising overall benefit in terms of reduced mortality and morbidity.

Medical utility

During an emergency, the main focus of health professionals' attention is on delivering the greatest medical benefit to the greatest number of people. Although the majority of health professionals will be involved in making decisions about individual patients, strategic public health decisions will also need to be made about how best to maximise overall utility. During the critical stages of an emergency, it is unlikely that an initial application of utilitarian principles in clinical decision making will be seriously challenged. The difficulty lies in applying the general principles to a complex, unpredictable and evolving health crisis of uncertain duration and extent. Ethical questions are likely to arise, however, where the requirements of medical utility have been met, but choices between individuals with equal need still have to be made. In these circumstances, consideration may need to be given to an egalitarian approach that ensures a fair distribution of resources.

Social utility

If the public health emergency is severe, decisions about the most beneficial distribution of resources will not be restricted to medical utility alone. Where the emergency results in widespread social and economic disruption, decisions about which groups will have first call on scarce resources will also contain elements of social utility. In addition to delivering maximum direct clinical benefit, priorities during a severe emergency are likely to include:

- limiting social disruption
- ensuring maintenance of healthcare systems
- ensuring integrity of social infrastructure
- limiting economic losses.

Scientific and medical functioning

An important aspect of any coordinated response to an emergency such as a pandemic is the need to protect key individuals who are involved in the production of countermeasures, which could include vaccines, antivirals and other essential health products. Special measures will also need to be introduced to protect those personnel who are involved in the provision of health services, and those involved in protecting public health.

Social functioning and critical infrastructure

In addition to those individuals broadly involved in tackling the health aspects of the emergency, many public and private actors are necessary to ensure both the successful delivery of health interventions and the long-term public safety. These include personnel in the emergency services, security, essential products and services, the maintenance of critical infrastructure such as transportation, utilities, telecommunications and sanitation. Priority will also need to be given to the continued function of governance structures. Consideration will also have to be given to the families of key workers.

Management of risk to health professionals

During public health emergencies it is possible that health professionals may find themselves exposed to risks of serious harm. In its 1988 discussion of the responsibilities of doctors to put themselves at risk in the aftermath of a nuclear attack, the British Medical Association (BMA) stated: 'professional concern for the injured should be tempered with reason, and doctors or nurses should not consider it a duty to risk their lives'.[42]

Although this related to the specific conditions of doctors fatally exposing themselves to fallout to treat patients who would almost certainly die, it is possible to apply these general principles more widely. In *Good Medical Practice*, the General Medical Council (GMC) states: '[y]ou must not refuse to treat a patient because you may be putting yourself at risk. If patients pose a risk to your health or safety you should take reasonable steps to protect yourself before investigating their condition or providing treatment.'[43] Discussing review of this guidance in 2005, the BMA's Medical Ethics Committee argued that there were limits to the risks doctors could be expected to accept as part of their professional responsibilities and there may be situations when a doctor could justify not treating a patient because of the extreme risks involved.

Liability issues

Depending upon the nature of the emergency it may be necessary to 'draft in' retired health professionals. The skills of these professionals may not meet expected standards of fitness to practise, but they may nevertheless be able to make a vital contribution. In extreme circumstances, even untrained staff may be required to undertake some functions. In this context, it may be necessary to consider the development of legislation that would restrict liability to cases of wilful misconduct in an emergency.

Managing threats in the face of uncertainty – the case of CJD

Although Creutzfeldt–Jakob disease (CJD) was first identified in the 1920s, public concern about the disease increased with the identification, in 1996, of a new variant (vCJD) linked to bovine spongiform encephalopathy (BSE), more commonly known as 'mad cow disease', and believed to be transmitted through the consumption of infected beef products. Although CJD is rare, with annual deaths in the UK ranging between 28 and 87,[44] given the numbers of people potentially exposed to vCJD through the food chain, there has been concern that cases might rise significantly and the disease could present a major threat to public health. Although by 2010 these concerns had not been realised, the management of CJD and its variants have presented a number of significant ethical challenges. Since the beginning of 2000, the BMA's Medical Ethics Committee

has responded to a number of consultations from government agencies, and this section outlines key ethical questions raised by this evolving public health threat.

CJD – a little understood disease

There is considerable uncertainty surrounding many aspects of the transmissibility of CJD and its variants. It is a rare and ultimately fatal degenerative brain disease, one of a group of diseases called transmissible spongiform encephalopathies (TSEs) which affect both humans and animals. TSEs are thought to be caused by the build up in the brain of an abnormal form of a naturally occuring 'prion' protein, although controversy about its origins remains. The disease comes in several forms, including an inherited form, a naturally occurring 'sporadic' form of unknown origin, iatrogenic forms linked to transmission of the disease during medical treatment and the new variant that is associated – although the link has not been categorically proven – with the consumption of beef products contaminated with the bovine form of the disease. There is no known cure for the disease, nor any currently available prophylaxis, and there is considerable uncertainty about the mode of transmission, the incubation period and the likelihood that exposure to the abnormal prion through food or via medical treatment will result in the development of the disease. Early in 2011 the development of a pre-symptomatic test for vCJD was announced.[45] In the absence of a cure for the disease, such a test can enable infected individuals to make decisions about how to spend the time available to them.

Harmful knowledge

Given the severity of the disease, and given the strong likelihood that it could be passed on via surgical instruments – the abnormal prion is resistant to ordinary sterilisation procedures – and through contaminated blood and tissue products, it was a matter of clear public importance that appropriate precautionary measures were taken to limit transmission as far as possible. Although the removal of potentially contaminated meat products from the food chain was uncontroversial, managing information about people who may have been exposed to the prion in order to minimise secondary transmission was far more challenging.

One of the key ethical questions that needed to be addressed was the extent to which it would be appropriate to inform people that they might have been exposed to CJD.

Informing patients about possible exposure

In August 2002, a patient at Middlesborough General Hospital was unexpectedly diagnosed as having CJD after a brain biopsy. In the period between the biopsy and the diagnosis being received, the same surgical instruments were used in other patients' operations, raising the possibility that they may have been exposed to the risk of transmission of CJD. The Government's advisory group, the CJD Incidents Panel, advised that, of the 34 patients in Middlesborough who were subsequently operated on using the same instruments, 24 should be contacted and informed of their possible exposure, even though at the time there was no test that could confirm their infection and there were no steps that could be taken to prevent or delay the onset of the condition if they had been infected. A subsequent independent review of the incident, carried out for the Department of Health, reported that, after ongoing assessment, it appeared that not all of the patients who were contacted were, in fact, at any real risk of exposure, and for those who were, the risk was described as 'very small'.[46]

In the scenario described in the box above, several interests had to be balanced. Identifying and contacting all individuals who may have been exposed would ensure that future risks from those individuals could, theoretically, be better managed. It could also assist in gathering knowledge about the natural history and progression of the disease and enable researchers to identify potential participants for future studies. Given the lack of a cure or prophylaxis, and the level of uncertainty about what exposure meant in terms of likelihood of contracting the disease, informing people that they had been exposed and might go on to develop the disease clearly involved imparting burdensome information without any direct benefits to the individual. As the independent review demonstrated as well, the risks were in fact very small or non-existent, while the knowledge of exposure presented potential, if unquantifiable, psychological harms. The BMA expressed serious concerns about the potential harm of informing all people who were potentially exposed and argued that an appropriate balance needed to be reached between harms to the individual and broader public health benefits.

Ensuring a safe blood supply

One of the most significant sources of potential transmission for CJD was identified as being the blood supply for transfusion. Again the public health interest in ensuring a safe supply of blood is clearly very significant. Anticipating the development of a blood test for CJD, the Health Protection Agency (HPA), working with the UK Blood Services (UKBS), held an expert seminar on ethical and social issues that might arise should a blood test become available.[47] A key recommendation of the seminar and the subsequent report was that, should a blood test become available, potential donors should be asked to consent for testing for CJD and would be informed of the outcome. If individuals did not want to be informed of the outcome, they would not be able to donate.

Such an approach raised a number of ethical concerns. The primary reason for introducing a test for vCJD on blood donations would be to improve the safety of blood transfusions for patients in the UK. Where a reliable test was available, the most effective way of ensuring public safety would be to test individuals and to inform them of their status. Blood that may have been exposed to the abnormal prions would be removed from the supply, and individuals who have tested positive would be advised not to donate blood, organs or tissue, and to notify surgical teams before any future surgery. Secondary benefits would include the opportunities to enrol individuals in research to improve understanding of the disease, its prevalence and transmissibility, and enable individuals to be contacted should treatments become available. If the test had a fairly low specificity, however, a comparatively large number of false positives could be expected. It would therefore be difficult to assess whether a positive test indicated an individual's true infective status or whether a true positive test meant that the individual would go on to develop the disease.

Given the uncertainty surrounding the test, and its potential for both psychological harm and reducing levels of blood donation, in the BMA's view there were strong arguments for changing the UKBS policy in relation to vCJD and for giving donors the option of not receiving their test results. The blood from donors who tested positive could be used for research so donors would not be able to infer their status. Although the HPA expressed some concern about the legal situation where blood was taken but not used as intended, in the BMA's view, if the donor consents to their blood being used either for donation or research, this should not be an issue. However, there were one or two other problems associated with this approach, including the following.

- The full public health benefits of informing individuals of their test results would not be realised as individuals would not themselves be able to inform health professionals, in relation to future surgical or other interventions, that they might be at risk.
- Opportunities for research, and, potentially, for future treatment or management options may not be available to the patient, although all donors could be contacted at a later stage once more information became available.

In the BMA's view, however, donors should be given the opportunity of not receiving information about their test results.

Summary – public health threats

- Public health interventions need to seek ways to promote individual and public goods.
- Large-scale public health emergencies may require an approach focused on maximising overall health outcomes.
- Where public health threats are characterised by very high degrees of uncertainty, careful consideration may be required when informing individuals of potential risks.

Public health tools

Earlier sections in this chapter sketched out some of the central ethical concerns raised by public health practice and also looked at both established and emerging threats to health. Over the years, public health practice has developed, and is continuing to develop, a range of tools designed to tackle these threats. In addition to the benefits that are sought, each intervention may carry inherent risks or necessitate balancing potential restrictions of individual liberties against benefits that may accrue to the wider community. All public health tools therefore have the potential for controversy and can meet resistance from citizens who may question whether the restrictions or sacrifices that might be involved are justified. Although there are a wide range of such tools, this section focuses on a number of key public health interventions that raise indicative ethical dilemmas: health promotion campaigns as a means of influencing behaviour; initiatives to alter the environment to maximise benefit to the health of communities; population screening for diseases; vaccinations and the use of incentives as a preventative measure against the spread of communicable diseases. The section also looks at the impact of the media on public health initiatives.

Health promotion campaigns

Health promotion is clearly a core function of public health. The WHO defines it broadly as the 'process of enabling people to increase control over their health and its determinants, and thereby improve their health'.[48] This section takes a slightly narrower focus, and looks at targeted campaigns designed to change public attitudes towards unhealthy lifestyle choices and to promote the uptake of healthier lifestyles.

Understood simply as a means of public education, health promotion campaigns are a relatively uncontroversial public health tool, which only those who object to any but the most minimal state intervention would criticise. The dissemination of positive health

messages or information about the causes of ill health can empower individuals, enabling them to make informed decisions about lifestyle choices and to improve their access to healthcare. Health campaigns, however, often go beyond public education and actively seek to influence personal choices and change behaviours. These interventions can entail varying degrees of coercion; including legal restrictions, taxation and labelling of risk as well as the active suppression of certain images or messages. This can raise questions over acceptable levels of state interference in the lives of individuals and in the business practices of companies who stand to profit from unhealthy lifestyle choices.

There are numerous examples of campaigns which seek to promote healthy living or better understanding of ill health. Obesity, sexual health and excessive alcohol consumption have all been targeted by health promotion campaigns in recent times. This section focuses on tobacco control, one of the best-established and longest-running health promotion campaigns in the UK and one in which the BMA has been heavily involved.

Tobacco control

The anti-smoking campaign is possibly the most extensive public health intervention of its kind. Since the link between tobacco and ill health was first identified by Sir Richard Doll and Sir Austin Bradford Hill in the 1950s there has been a concerted effort on behalf of the Government to discourage people from smoking and to restrict the freedoms of the tobacco industry. Throughout this time, the BMA was heavily involved in campaigns to raise awareness of the health risks associated with tobacco use and published a number of reports on the social and environmental influences that can normalise smoking behaviour and lead to young people taking up the habit.[49]

Tobacco control encompasses a wide range of interventions entailing various levels of state involvement and coercion. Although the extent of these interventions is perhaps unique to this campaign, many of the tools and strategies that have been developed in this area are now increasingly being applied to other health promotion campaigns – food labelling to help prevent obesity and taxation on alcohol, for example – thereby raising similar ethical questions.

Tobacco control regulation

Control measures include:

- comprehensive ban on advertising and promotion of tobacco products including the sponsorship of sporting events
- restrictions on broadcasting smoking on television and radio to protect young people
- age restrictions on the sale of tobacco to young people
- enforced labelling depicting written health warnings, the disclosure of ingredients, a ban on misleading descriptors like ‘light’ or ‘mild’ and images illustrating the negative health consequences of smoking
- duty imposed on purchasing and importing tobacco goods
- ban on smoking in indoor workplaces and indoor public places.

Combined with hard-hitting and emotive mass-media communication campaigns, the measures outlined in the box above represent a concerted effort to influence behaviour change in individuals. Given that people are broadly informed of the health threats posed by tobacco use, it could be argued that, as people have rights that provide them with the opportunity to make unhealthy choices, coercing individuals into behaviour change is an unacceptable and paternalistic extension of the role of the state. Such an argument, however, fails to take into account the huge costs smoking imposes on the NHS and the

complex factors contributing to tobacco use. Smoking has both age and social gradients and is also subject to gender variation. The addictive nature of tobacco use, and the fact that many people start at an early age when the full implications of the hazards may not be appreciated, also mean that a simple model of autonomous choice is unlikely to be adequate. Most people will, at times, act in ways that they recognise are not in their best interests and a majority of smokers report that, but for the addiction, they would like to give up smoking altogether.[50] As with many other 'lifestyle' threats, a key challenge is therefore developing methods for encouraging people to act on positive preferences in a sustainable fashion. It could be argued therefore that health promotion campaigns have a role in promoting and reinforcing autonomous choices, rather than restricting them.

Although public health campaigns frequently involve widespread dissemination of information about health threats and how best to make health-promoting choices, decisions to start smoking are often influenced by a wider cultural environment which can promote positive images of smoking. Where films, television programmes, advertising and other influential media outlets show positive representations of smokers and smoking, they can generate resistance to health information campaigns. Part of the long-term goal of public health campaigns can be to bring about a change in this deeper information environment, thereby making unhealthy choices less attractive.

The argument that smoking represents an autonomous choice and should not be subject to state interference is also challenged by the recognition that historically tobacco companies had a significant role in encouraging smoking. Advertisements and positive product placements throughout the media have promoted positive images of smoking, and a key part of the public health response to tobacco use has involved curtailing the influence of the tobacco industry. Restricting access to harmful products, minimum pricing, strict regulations on advertising and enforced labelling of health risks are all strategies that make it more difficult for companies to sell tobacco products. Interventions that restrict the freedoms of businesses can face fierce opposition and legal challenges. Nevertheless they can be regarded as necessary in order to ensure that the information environment is balanced and individuals are not subject to coercive commercial pressures to take up or sustain unhealthy choices.

Health promotion campaigns are not just aimed at discouraging those that regularly make unhealthy choices, but also at preventing or discouraging the uptake of these practices, particularly among young people. Here again we see the limitations of an autonomy-based approach to public health. By and large we acknowledge, as a society, that younger people are more vulnerable to manipulation. Given that around two-thirds of current or former smokers started smoking regularly before the age of 18, young people are clearly an important group to target to reduce uptake of the habit.[51] Although age restrictions exist to prevent access to harmful substances, the prevalence of smoking and smoking-related imagery within society can be attractive to young people and can have a negative influence on the lifestyle decisions they make.[52] Hard-hitting education campaigns and interventions deglamourising smoking can therefore help to dissuade young people from making this unhealthy lifestyle choice and therefore help to protect this vulnerable group against the potential harms.

Discussion of the appropriate limits of state intervention in individual life choices often invokes a principle of third-party harm: that the only justification for the state to restrict an individual's freedom is to prevent harm to another, not to the individual. The protection of the public from the harms of second-hand smoke, for example, was a key motivation in introducing the ban on smoking in indoor public places and work places. As the direct burden of ill-health that stems from smoking falls largely upon the smoker, however, once third-party harms are minimised, arguments for intervention into

the personal lives of individuals from this principle are not very strong. The difficulty here is that it is not always easy to identify precisely where harms fall. There may, for example, be considerable indirect harms caused by unhealthy living and policy makers have a duty to consider the cost to the public purse of health-damaging behaviour and to take appropriate action to minimise it. Chronic morbidity associated with smoking places a significant financial burden on state-funded healthcare. The responsibility for meeting these costs falls on all members of society, including those who choose not to participate in unhealthy living. A common argument in defence of tobacco control policies is that some degree of intervention is therefore justified in order to limit these wider harms.

Summary – health promotion campaigns

- Health promotion is a core public health function.
- The dissemination of positive health messages and information about health threats can empower people to make informed choices.
- Key challenges in health promotion include encouraging people to make positive health choices that are sustainable over time.

Changing the environment

A great deal of public health activity is focused on making changes to the overall environment in which populations live. Since the Sanitary Act was introduced in 1866, requiring local authorities to supply running water and to remove sewerage and waste, there have been a number of measures introduced to help secure the environmental conditions conducive to healthy living. The idea of the 'environment' is complex, and ranges from the quality of food, air and water supply, through to the standard of the built environment, the control of traffic, the reduction of noise pollution and the quality of the public service infrastructure. Interventions that alter the environmental conditions in which people live are especially effective public health tools as they enable large numbers of people to benefit but without requiring any significant behaviour change from individuals. By creating or sustaining environments conducive to healthy living, governments can also address the social determinants of ill health and help to tackle inequalities.

Efforts to change environmental conditions can be controversial. The ongoing debate surrounding the fluoridation of the water supply encapsulates both the key motivations for an intervention of this kind and the ethical issues that can arise from its proposed introduction.

Fluoridation of water – state beneficence or individual freedom?

Dental caries (tooth decay) is a major oral health problem in most industrialised countries, with children an especially vulnerable group. In the UK, levels of dental caries vary[53] with children in socially deprived areas more likely to have decayed, missing or filled teeth than those in areas that are more affluent. The benefits of fluoridated water to help combat the problem of dental caries were discovered in the 1930s and there is now a body of evidence to show that the artificial fluoridation of the mains water supply is an effective and economical public health tool for improving the oral health of a particular area.[54] Fluoridation is a redistributive intervention that especially favours children and the underprivileged sections of society that are most at risk of dental caries. Although there

are health risks associated with high concentrations of fluoride, the levels permitted within the UK are considered safe. Dental fluorosis, a developmental defect of tooth enamel, is a known adverse effect of exposure to fluoridated water. The severity of the condition can range from barely visible white speckling to staining or pitting of the tooth enamel which can be of aesthetic concern. Where it occurs, the majority of fluorosis cases are mild. Estimates regarding the prevalence of fluorosis of aesthetic concern can vary; some studies[55] estimate it to be 12.5 per cent in areas where the water supply is fluoridated at one part per million, while other research estimates the prevalence to be lower.[56] Studies into fluoridation have not found evidence to substantiate a link between the artificial fluoridation of the water supply and increased incidence of bone fracture, osteoporosis, cancer or other adverse effects.

Despite evidence suggesting that it can improve oral health and help address dental inequalities, fluoridation remains controversial. Only something in the region of 10 per cent of the UK population receive water that is either naturally or artificially fluoridated and there are no artificial schemes in place outside of England.[57] Despite legislation that allows health authorities in England and different bodies within the devolved administrations to fluoridate water supplies after appropriate public consultation, few have taken up the opportunity. The decision of Southampton Primary Care Trust (PCT) in 2009 to fluoridate its water supply was the first decision of its kind in over 25 years.[58]

Objections to the artificial fluoridation of water centre on the belief that it constitutes the forced medication of a population without the consent of individuals in that area, that it restricts their choices about the water they and their children drink and ignores any values they might have, for example on the purity of the water. That these concerns can be decisive in obstructing the implementation of fluoridation schemes, despite their considerable benefits, highlights the tensions that exist between the need to protect what is sometimes claimed as a 'right' of individuals to drink non-fluoridated water and the need to create conditions that benefit some individuals within a specific area, but at small potential cost to others. It would clearly be impossible to obtain individual consent from all citizens within an affected population. Fluoridating a water supply also inevitably restricts individual choice because it is not possible for those living in the targeted area to opt out or choose an alternative water supply once a fluoridation scheme has been implemented. People are able purchase bottled water as an alternative if their water supply is fluoridated; however, the cost of doing so is likely to be prohibitive for many people. Not all areas would be suitable for fluoridated water and only those known to suffer high levels of dental caries would reap the full benefit from its introduction. Even within these areas there will be sections of the local population who have good oral health that would be forced to receive fluoridated water even though they are unlikely to benefit from its introduction. It is imperative within public health medicine that methods are developed to resolve this type of conflict. Large-scale interventions will rarely be unopposed but where there are limited harms resulting from an intervention, the absence of consent from a minority should not ordinarily be sufficient to obstruct the delivery of a genuine benefit to the majority of a population.

In discussing the ethical issues associated with the fluoridation of water supplies the Nuffield Council on Bioethics stated that the key motivations for fluoridating a water supply – tackling health inequalities, reducing harm to children and creating an environment conducive to health – were all consistent with the responsibilities a liberal state has to intervene in the interests of public health.[59] The Council recognised that, despite the evidence of the health benefits of fluoridation, there was a lack of high quality evidence regarding potential harms. Local consultation and adequate dissemination of the pros and cons of fluoridation were seen as imperative to address concerns regarding the absence

of individual consent and to enable the public to make informed decisions appropriate to the needs of the local area. The BMA supports the fluoridation of water supplies, after appropriate public consultation, on the grounds of effectiveness, safety and equity.

Summary – changing the environment

- Interventions that alter the environmental conditions in which people live are effective public health tools as large numbers of people can benefit but without requiring any significant behaviour change from individuals.
- Measures which alter people's environment can be controversial as it is often not possible to obtain consent from everyone within a population for the measure to be introduced.
- The debate over the fluoridation of water is an example of the tensions that can exist between the motivations for an intervention of this kind and the ethical issues that can arise from its proposed introduction.

Population screening

Screening involves the systematic testing of a defined, usually asymptomatic, population for a specific disorder with the aim of identifying those requiring further investigation or direct medical intervention. In the UK, screening programmes are employed to help detect cancer, sexually transmitted infections (STIs), vascular disease and diseases in pregnancy, newborn babies and children, although different schemes are in place in each of the devolved nations. In some respects, screening is different from other forms of healthcare. Typically, it is the patient who approaches the health worker in search of relief or treatment for a particular disorder. With screening, however, the health service usually approaches apparently healthy individuals and invites them to undergo a test or survey from which they may derive some benefit. Clearly, in such circumstances those offering a screening programme need to be certain that there is a substantive benefit to health, and that it outweighs any resulting harms. According to the National Screening Committee (UK NSC), 'it is unknown to find a programme that gives 100 per cent benefit'.[60] It is vital, therefore, that an informed judgement is made about the programme's ability to provide a net good for those being screened. Although screening in the private sector is likely to be driven by market forces, the same rigorous standards should apply.

Criteria for introducing a screening programme

There is general consensus about the basic criteria that must be fulfilled prior to the introduction of any new screening programme and the UK NSC publishes its appraisal criteria on its website.[61]

- The problem must be important. This includes conditions that are important because they affect a relatively high proportion of the population as well as conditions that are less common but are very severe.
- A suitable screening test should be available. The test being used must be not only reliable, but also effective at detecting the condition being sought. It must have both a high sensitivity and a high specificity, as well as a high positive predictive value (a high proportion of positive results should be true positives). A high positive predictive

value is not so important if the screening test is being backed up by a 'gold standard' follow-up test.

- The results must provide useful information. There are a number of ways in which the results of screening may be useful. They may, for example:
  - permit early diagnosis followed by effective management of the condition
  - give information that would offer increased choices
  - provide information to permit planning for the future, for both the individual and the health service
  - prevent the spread of disease
  - in the case of prenatal screening, give time to prepare for the birth of a disabled child
  - permit lifestyle changes to minimise the risk of disability or disease
  - give time to adapt one's lifestyle to an impending disability.

  Screening that provides no benefit to the individuals being tested would not meet these criteria but may be helpful for planning the health needs of populations or groups.
- The benefits must outweigh the harms. Benefits would include the provision of curative treatment, the ability to prioritise treatment services effectively, patient well-being and satisfaction, and the promotion of informed decision making. These need to be balanced against any actual or perceived adverse effects, particularly those resulting from false positive or false negative results, the risks of labelling people as 'sick', the social disadvantages of the information being available and the likelihood of increased anxiety. Some form of cost–benefit analysis is also needed because, whenever different disciplines and treatments compete for limited funding, any screening programme must make good use of resources.
- Adequate provision must be made for information, counselling and privacy. Careful consideration should be given to the provision of information about the test and its implications, and the need for and the availability of counselling. Assurances must be provided that the information obtained will remain confidential. Patients should be made aware if information will be used for planning or research purposes in an anonymised form. Information should be provided about the potential uses of the data that will be collected, including the implications for insurance and employment where appropriate.

Benefits and harms

Before a particular type of population screening is recommended, the UK NSC must be satisfied that the benefits, such as those outlined above, outweigh the harms. One of the known harms of screening is the raised levels of anxiety that have been reported in all forms of screening programmes including cervical, breast and general health screening, as well as genetic screening. (For specific information on genetic screening see Chapter 9.) For some people, simply receiving an invitation to participate in screening causes anxiety and some have been found to be more anxious after screening than before, regardless of the result. It should also be remembered that the motivation of those offering the screening may be different from that of the individuals who accept it. The service is provided in order to identify people who are at risk, but most individuals, believing themselves to be healthy, undertake screening for reassurance that they are not at risk. Some people therefore accept screening without properly considering the implications of receiving an unfavourable result; when they do not receive the expected result, their certainty about their health status shifts to uncertainty and this can cause considerable anxiety.[62]

There is little that can be done to counter such reactions except to ensure that individuals are provided with an adequate supply of accurate information in a manner they are able to understand and are given the opportunity to discuss the information and ask questions. It is important that the purpose of any screening programme is clearly explained as part of the process of seeking consent, including being clear about for whose benefit it is being undertaken. Undoubtedly, some of the anxieties that arise from screening are caused by a misunderstanding of the information provided, particularly about the accuracy of the test and the implications of a positive or negative result. Accurate recall of information, in all spheres of medicine, is a problem and it can therefore be helpful to supplement discussion with written material for people to take away with them.

A number of the benefits that can derive from population screening, such as informed decision making or any relief or reassurance from a negative result, will clearly not be available for adults who lack capacity and participation in screening itself may raise levels of anxiety for these patients. These issues raise questions about whether they should be automatically included in such screening. Their exclusion could, however, be perceived as discriminatory and while the patient may not directly benefit from the results, screening could provide useful information about his or her health for carers. Decisions on the merits of screening for these patients therefore, need to be made on a case-by-case basis, weighing up the risks and benefits for the individual and based on the efficacy of the screening for the early identification of disease. (For more information on the provision of care and treatment for adults lacking capacity, see Chapter 3.)

Screening tests can have four possible outcomes: true negative; false negative; true positive; false positive. All tests generate a certain number of false negatives and positives. Those managing such programmes need to aim at finding the right balance between its sensitivity (picking up a very high proportion of positive cases) and its specificity (giving a negative result in a high proportion of negative cases). This balance usually depends on the consequences of making or not making a positive finding. For example, where a positive finding would be particularly associated with anxiety or stigma, then a higher specificity is desirable. Alternatively, where the adverse consequences of a missed positive are considerable, a higher sensitivity would be preferred.

People who are given a false negative or a false positive result are likely to be harmed in some way, although those with a false positive probably less so than those with a false negative, because the former will usually proceed to a definitive test, which will demonstrate that these people are free of the disease. Those with a true positive are normally regarded as enjoying a benefit, because they go on to receive treatment for the condition, but this is not always the case. Some true positives, for example, would not have gone on to develop a debilitating version of the disease – it may have been a slowly developing condition and they would have died of something else – and the screening may therefore not have been beneficial. This issue has been particularly relevant to the prostate specific antigen (PSA) test used to detect prostate cancer. Prostate cancer is a major health problem, which in 2008 caused around 258,000 deaths worldwide.[63] In the UK, the disease is the most common cancer in men, responsible for around 25 per cent of all newly diagnosed cases[64] and there have been calls for screening to be introduced to help combat this problem. PSA testing can help to detect cancer while it is still localised in the prostate; however, the test can also lead to considerable false positives and over-diagnosis of disease that may not have gone on to present serious health risks. Given these problems, and assessing the test against its criteria, the UK NSC does not recommend screening men for the condition, although testing is available on request from individual patients who are offered support in assessing the relative benefits and harms for themselves.[65]

Screening for breast cancer

In many western countries, mammography is routinely offered to women over a certain age, usually 40 or 50. The majority of medical opinion supports such screening, which saves an estimated 1,400 lives a year.[66] However, the screening process can identify small tumours that are growing so slowly that, without treatment, the woman could live her life without ever knowing of the cancer, which would play no part in the cause of her death. Because the screening process is not 100 per cent effective at identifying which cancers will go on to pose a serious health risk, some women may be treated for cancer unnecessarily. Research exists that points to significant over-diagnosis and over-treatment as a result of screening and a number of commentators therefore claim that the benefits of such programmes remain in the balance.[67]

Individuals who receive a true negative result may of course enjoy the welcome benefit of reassurance. Such a result can, however, inspire a false sense of security. With breast screening, for example, a negative result indicates only that the disease was not detectable at the time of the test. For some, this may be interpreted as meaning that they are not at risk of developing the disease, which consequently prevents them from responding to early warning signs should the disease appear later. There is the additional danger that a negative test is interpreted as a 'green light' to continue with unhealthy lifestyle choices. To an extent, these harms can be moderated by the provision of clear health advice at all stages of the screening process.

Summary – population screening

- Those offering screening programmes need to be certain that they offer a net benefit.
- The purpose of a screening programme, including for whose benefit it is being undertaken, needs to be clearly explained, as part of the consent process, to those who participate.
- For any screening programme, the following five criteria must be met:
  - the problem must be important
  - a suitable screening test should be available
  - the results must provide useful information
  - the benefits must outweigh the harms
  - adequate provision must be made for information, counselling and privacy.

Vaccination

Vaccination programmes are among the most widely used and cost-effective public health tools available. It is difficult to exaggerate the contribution of vaccines to the improvement of health in the years since their development. Smallpox, which plagued civilisation for millennia and which only 40 years ago killed 2 million people a year worldwide, is now completely eradicated as a result of a global vaccination programme.[68] Despite success stories like this, infectious disease remains one of the world's leading causes of illness and death which disproportionately affects socially and economically disadvantaged populations worldwide.[69] In helping to tackle this problem, vaccinations serve two of the key goals of public health medicine: they protect the most vulnerable members of society, saving the lives of an estimated 2.5 million children under 5 every year, and remove one of the key obstacles to human development, thereby helping to tackle inequality.[70]

Vaccines are regulated and tested thoroughly but, as with all health interventions, they may still carry small risks for an individual. A person's decision to vaccinate either themselves or their child therefore entails the need to balance these risks against benefits accrued through vaccination. This gives rise to interesting ethical questions around individual patient choice, community responsibility and the role of governments and doctors in maintaining sufficient levels of immunity.

Vaccination, immunisation and population immunity

There is a clear public health justification for the broad deployment of vaccines. If sufficient numbers of people within a population are immunised, there is less chance of people catching and spreading the disease. Given that the risks are relatively small, vaccination can benefit large numbers of people in return for a small degree of risk to individuals. Population immunity against a disease is only achieved, however, if a substantial majority of people opt to vaccinate themselves – from 85 to over 90 per cent, dependent on the infectiousness of the disease.[71] Individual choices not to vaccinate therefore expose others to risk, and if sufficient numbers refuse immunisation the result can be a 'tragedy of the commons'[72]: population immunity collapses and epidemics sweep through the community. Moreover, not all unvaccinated individuals have chosen to put themselves at risk:[73] neonates may not be old enough for vaccination and the ill and those whose immune systems are compromised are not vaccinated for good medical reasons.

In the UK, vaccination is entirely voluntary. However, there are a number of issues that may lead people to question the advantages of being vaccinated. At an individual level, it can be difficult to weigh up the respective costs and benefits of vaccination. Although vaccination is beneficial to the community as a whole, the likelihood of any particular individual benefiting reduces as the percentage of the population vaccinated increases. This is because if sufficient numbers of the population are immunised, there is a dramatic reduction in the likelihood of coming into contact with the disease. Where there is already population immunity – as is the case with a variety of common diseases in the UK – a vaccination's potential harms, such as side-effects, could be more substantial than the harm that follows from a particular individual not being vaccinated. Considered in isolation, therefore, for any particular individual living in an area with population immunity, the risk of vaccination could outweigh the benefits. This holds true only, however, if that individual remains in the community and does not, for example, travel to an area in which population immunity has not been achieved. Unvaccinated individuals living in communities with highly mobile populations, particularly where people travel from countries where immunisation is not widespread, can also be at risk.

Public perceptions regarding the prevalence and severity of a disease can also influence the decision making of individuals. It could be argued that in this respect vaccination programmes have become the victims of their own success. As the mortality and morbidity associated with their target diseases have become so unusual as to fall out of popular memory, so public perception has begun to focus on potential threats from vaccines, which are comparatively minor. Such perceptions can also affect attitudes towards the risks associated with a particular vaccine. The measles, mumps and rubella vaccine (MMR) controversy (see below) highlighted how susceptible public perceptions can be to stories about potential health threats. It also raised several questions regarding the rights of parents to make decisions about the welfare of their children; the lack of public faith in scientific expertise and government advice; and the role of the media in exacerbating health scares through sensationalist and unbalanced coverage (see pages 833–835).

The MMR controversy

In 1998, *The Lancet* published an article in which the authors speculated about a possible link between the combined MMR vaccine and autism and/or inflammatory bowel disease.[74] The link was subsequently refuted by several studies and a Cochrane systematic review conducted in 2005 concluded that there was no credible evidence of a link between the MMR vaccine and autism.[75] However, the article was widely reported in the press, sometimes in a sensationalist way, which had a detrimental effect on parents' confidence in the combined vaccine and led to notable reductions in its uptake. Between 2003 and 2004, the Department of Health reported that vaccination coverage for MMR in England dropped to 80 per cent; 15 per cent lower than the level recommended by the WHO for population immunity.[76] The controversy around MMR also led to distorted perceptions regarding the relative risks of immunisation compared to those of the disease, such that in 2002, almost one-quarter of UK mothers considered MMR a greater risk than the diseases it prevents.[77] Towards the end of the decade the uptake of the MMR vaccine began to rise again, although only slowly, and by 2009 levels in England, at just over 88 per cent[78] were still less than the WHO target for population immunity.

The MMR controversy (see above) is an example of how sensationalist reporting of potential health threats can seriously undermine key public health messages. That the perception that MMR was unsafe persisted for many years, despite overwhelming scientific evidence to the contrary, shows how difficult it is to change attitudes once fragile public confidence in a public health measure has been compromised. The MMR case is also a cautionary illustration of what can happen when levels of immunity within a population drop below the requisite levels to prevent outbreaks. In 1998, when 91 per cent of 2-year-olds were immunised,[79] there were 56 confirmed cases of measles in England and Wales.[80] In 2008, following the drop in uptake of the MMR vaccination, this figure had jumped to 1,370 cases.[81] In 2006, the UK recorded the first death from acute measles in 14 years.[82]

The reduction in uptake of the MMR vaccine coincided with an increase in parents choosing to vaccinate their children with three separate vaccines. This is contrary to the advice from the HPA, which stated not only that the MMR vaccine is safe, but that individual vaccines represent a comparatively untested and inferior alternative.[83] Opting for separate vaccines increases the risk of infection because the vaccinations need to be spread over a period of time. It also increases the likelihood that the course of vaccination will not be completed, thus exposing children, and the population, to risks in the future. There is also the ethical objection that giving children three separate injections, especially when they could be better protected by just one, causes unnecessary harm to the child.

Given the scientific consensus in support of the MMR vaccine, the government is under no obligation to provide separate vaccines for parents who have lost faith in the MMR vaccine. Discussing the issue in the wake of the MMR controversy the BMA's Medical Ethics Committee agreed that parents are accountable both to society and to their children for the decisions they make on their children's behalf and there is a limit to the risk to which parents can expose their children. The Committee maintained, however, that parents were the best people to make decisions for their children and they had general rights to choose inferior treatments both for themselves and within reason for their children. Society though was not under any obligation to fund inferior treatments and governments had a responsibility to make the best use of scarce public resources. Patients should be supported and encouraged to make the correct decision through better communication and education of the relative levels of risk involved.

Compulsory vaccination for patients

The drop in uptake of the MMR vaccine and the subsequent dramatic rise in cases of measles illustrate the potential weaknesses and risks of an entirely voluntary approach to vaccination and has led some to ask if there is a need for a different approach. Morally relevant considerations here extend beyond an assessment of potential risks and benefits to the individual, to include risks to third parties, for example neonates or those in ill health, and population-level benefits and harms. A key factor that proponents for any move away from a voluntary approach to vaccination will therefore have to consider is the point at which potential harms to others stemming from non-vaccination become sufficiently significant to justify placing limits on individual freedoms.

Currently, no country forces its population to be immunised against a particular disease. In its 2007 report on public health ethics, the Nuffield Council on Bioethics highlighted two alternative approaches operating in different jurisdictions worldwide that go beyond the voluntary system that operates in the UK:[84]

- *Quasi-mandatory programmes:* under this approach, individuals are required to be vaccinated unless they qualify for an exemption. If they refuse, they are subject to possible penalties (Belgium, Italy and Poland) or they are prevented from enrolling their child in school (France, Spain and the USA).
- *Incentive-based programmes:* in some countries, parents can be offered certain benefits if their child has appropriate vaccinations (Australia) or payment for ensuring a child completes a vaccination programme (Austria).

Although there is evidence to suggest that these schemes may increase uptake in immunisation for the targeted disease, they both have drawbacks: quasi-mandatory programmes can lead to a lower uptake in voluntary vaccinations while the cost-effectiveness of incentive-based programmes can vary. Cultural, historical and political factors can also affect the viability of any proposed move away from a voluntary approach. In the UK, public health programmes have traditionally been consensual, which has helped ensure positive public approval and uptake of programmes. A quasi-mandatory approach may therefore be seen by the public as confrontational and could lead to public mistrust of government public health interventions and messages more generally.

In 2009, the BMA's Board of Science rejected calls for compulsory vaccination. In discussing the ethical issues associated with compulsory vaccination, the BMA's Medical Ethics Committee also confirmed its overall support for the UK's current voluntary approach to childhood vaccination but felt that greater use should be made of education, publicity and information provision to improve vaccination uptake.

Vaccination for health workers

As we have seen, an individual's decision not to vaccinate himself or herself can contribute to the spread of a disease and put others health at risk. Health professionals, through their close proximity to patients, have an increased likelihood, not only of contracting a disease, but also of transmitting the infection to patients and colleagues. In addition to the potential harm to patients, if sufficient numbers within a healthcare setting are affected this could have a detrimental impact on staffing and put the provision of essential services

at risk. Authorities therefore need to balance the liberties of healthcare workers against the need to protect patients and ensure the safe provision of services. In 2007, health departments in England[85] and Wales[86] released guidance recommending health clearance checks for new healthcare workers. Similar guidance was also released in Scotland[87] and Northern Ireland.[88] It is recommended that all new healthcare workers in the NHS, including medical students, undergo standard health clearance checks on appointment, with additional clearance checks for healthcare workers who will perform exposure-prone procedures (EPP). The standard health clearance checks include testing and the offer of vaccination, where appropriate, for tuberculosis and the offer of vaccination against hepatitis B. For posts that require the performance of EPPs additional checks include tests for hepatitis B, hepatitis C and HIV. Failure to agree to testing, or declining the offer of vaccination, may mean that new healthcare workers are not permitted to work in environments where the risk of exposure is high and may be prevented from taking up positions where they would be required to perform EPPs. UK-wide guidance on vaccination and immunisation also recommends that staff involved in direct patient care should be up to date with their routine immunisations including tetanus, diphtheria, polio and MMR.[89] Doctors should consult the relevant occupational health departments for further information on these requirements.

Where no contractual or occupational health requirement exists for a doctor to undergo immunisation, tensions can exist between the rights of individuals to refuse vaccination and the need to manage the potential risk of disease outbreak and ensure the safety of staff and patients alike. The introduction of a vaccine in response to the H1N1 swine flu outbreak in 2009 brought these issues to the fore. Although the Department of Health recommended that frontline staff should be immunised, there were reports that a significant number of health workers would not take up the opportunity, either because they saw it as unnecessary or because they lacked confidence in the safety of the vaccine, despite government assurances to the contrary.[90] The GMC advises that doctors should protect patients, colleagues and themselves by being immunised against common serious communicable diseases where vaccines are available.[91] It does not, however, impose an obligation on doctors to be vaccinated and there is no statutory requirement in place for compulsory vaccination in the event of a pandemic. Ethically, any move towards forced vaccination of healthcare professionals in such cases could be seen to compromise the autonomy of doctors. It could also be argued that such a move would contravene a doctor's right to a private and family life enshrined under Article 8 of the European Convention on Human Rights (ECHR), although the Article does allow for state interference in accordance with the law and when deemed necessary in a democratic society for the protection of health.

Summary – vaccination

- Vaccination programmes are amongst the most widely used and cost-effective public health tools available.
- Doctors need to present the risks and benefits of vaccinations objectively, including the public benefits of maintaining population immunity.
- The BMA supports a voluntary approach to vaccination, backed up by education, information and publicity.
- Doctors should be encouraged to take up vaccinations to protect themselves and their patients, but any such decision is ultimately a personal one.

Incentives

Tackling many of the new public health threats, such as the consequences of poor diet, smoking or drug abuse, involves confronting questions of individual motivation. Why do some people make poor health choices and how can these choices be influenced in a more positive direction? This also extends to the failure of certain groups to take advantage of available healthcare interventions, such as screening or vaccination, something that itself presents a significant public health challenge. The use of incentives, either financial or in kind, to address these psychological dimensions of individual behaviour has received increasing amounts of attention worldwide. Incentive schemes aim to provide an immediate reward for behaviour that will ideally provide health gains in the longer term. Their use draws on empirical research in behavioural psychology that suggests that, for many, a small immediate reward will prove more attractive than a larger but more distant one.[92]

Although a relatively recent public health initiative in the UK, the use of incentives is well established in other countries. Incentives aimed at individuals have been used in the German statutory health insurance scheme since 1989 when individuals who attended for regular dental check ups could reduce their co-payments.[93] Their use has subsequently been expanded to the offer of 'bonuses' in the form of either cash, such as a reduction in insurance contributions, or in kind, such as through gifts of sports equipment. In Latin American countries like Mexico 'conditional cash transfer schemes' (CCTS) offer impoverished families money if mothers attend parenting seminars, infants attend for health checks, and a number of other criteria are met. These schemes have caught the attention of authorities in other jurisdictions. The Opportunity NYC project, piloted in New York, builds on the Mexican CCTS model, offering payment for maintaining subsidised health insurance and attending medical and dental check ups.[94] In the UK, health authorities have offered money or the opportunity to enter a prize draw as incentives to help reach government targets on *Chlamydia* screening.

The use of incentives remains controversial. Although there is evidence to suggest that they can deliver positive outcomes in relation to service uptake, successfully encouraging attendance at clinics for example, evidence of their effectiveness in relation to more complex problems such as obesity or smoking is much weaker.[95] Their use also raises a number of ethical issues. For some, incentives are a coercive measure that undermines the autonomy of individuals. According to this view, individuals are being put under pressure to act in ways that are contrary to their considered choices, even where those choices may not, objectively, be in their long-term health interests. The use of incentives is similarly criticised as paternalistic, as promoting and enforcing choices or lifestyles that are not freely chosen or valued by those at whom they are directed. The idea of 'choice' in this context is not straightforward. As the example of tobacco use indicates, there can often be a stark contrast between how we act, and how, ideally, we would like to act. If incentives can help people align their actual choices with their preferred choices, it could be argued that, using a more developed understanding of the term, they enhance rather than restrict autonomy.

An important issue for the BMA is the extent to which the introduction of financial incentives could change the nature of the doctor–patient relationship, and whether any such change would be desirable. Ideally, the doctor–patient relationship is based upon an open and trusting exchange of information between a professional and a patient. Its goal is to promote the overall interests of the patient. The introduction of explicit monetary concerns may alter this relationship in undesirable ways. It may also undermine the longer term development of personal responsibility in patients, constituting only a short-term solution that fails to address the underlying causes of the problem.

One of the explicit goals of incentive schemes is to tackle health inequities, encouraging and rewarding healthy decision making among groups who traditionally have struggled to make such choices on their own. If incentives prove effective in addressing this fundamental issue in public health medicine then this may counter some of the objections raised above. Research suggests that in some cases incentives may in fact exacerbate health inequalities.[96] People in higher socioeconomic groups may be better placed to take advantage of incentive schemes, which means that those sections of the population least in need may benefit most, further widening the gap in health outcomes. If individuals are being rewarded for making choices they would have made anyway this also raises questions about the cost-effectiveness of incentive schemes. These arguments suggest that schemes targeted at specific groups may be more effective in addressing inequities, but these are not without controversy. Some may argue that it is unfair for individuals to be rewarded for behaviour that others undertake unrewarded, that such a system in effect penalises individuals who choose to live healthier lives. Cash incentive schemes may also stigmatise the groups that the initiative seeks to help, not only by marking off those who require such incentives and those who do not, but also by effectively branding those in need as irresponsible or incapable of making the correct decisions regarding their own welfare.[97]

The debate over the use of incentives requires more detailed research and more conclusive evidence before its value as a public health tool can be properly evaluated. Nevertheless, the continuing interest in incentives shows that public health practitioners are looking at innovative approaches to solving problems that have proved resistant to established public health intervention thus far. Incentives may well have an increasingly important role in public health promotion in the future.

Summary – incentives

- Incentives are designed to address psychological aspects of motivation in order to encourage healthy choices.
- Incentives should be used sensitively to ensure they respect and promote individual choices rather than acting coercively.
- Further research is required to assess the efficacy of incentives in a wide range of settings.

The role of the media

The media can have an important role in the promotion of public health. Its influence and ability to reach large audiences means that it can be an extremely useful tool for disseminating a wide range of information, from general positive health messages to specific details of health risks. The media can also present an emotive, human angle to health stories, making them more accessible than scientific evidence or government health warnings. The effect can sometimes be dramatic. The numbers of women screened for cervical cancer, for example, has twice received a boost from media stories relating to the disease. In 2009, the death of reality television star Jade Goody from cervical cancer was widely reported in the media and the coverage led to an increase of over 10 per cent in the number of all women screened.[98] This increase mirrored the effect in 2002 when, following the death of *Coronation Street* character Alma Sedgewick from the disease, the numbers of women screened nationwide rose and were up as much as 21 per cent on the

previous year in the north-west of England where the soap is based.[99] Health reporting in the media can also have an influence on politicians and policy makers. News coverage or public reaction to a story can often provide the motivation for shifts in the prioritisation of funding and changes in public health policy.[100] Although this could have a positive effect, drawing attention and resources to neglected or emerging public health issues, it could also have negative consequences for public health planning, if politicians react impulsively to media coverage without thinking through the overall health implications of their decisions.

Media reporting can also have a detrimental effect on public health. News outlets are keen to maximise their audiences and this can mean that coverage focuses on headline-grabbing stories which may then be reported in a sensationalist way or without appropriate balance and qualification. Although scientific papers or articles may contain carefully modulated and contextualised assessments of public health threats, there is seldom the space in the popular media to provide suitably nuanced comment. The extraction of media friendly 'soundbites' in the search for good headlines can seriously distort evidence and lead to the misreporting of scientific research. These stories are commonplace in the mainstream media and often build up hope over a scientific breakthrough, for example over a new potential cure for cancer, or instil fear in the public with respect to new potential health threats. Public health specialists have complained that media reporting will often favour more exotic or unusual health risks like vCJD, which in reality pose little risk to the general public when compared with more significant and pressing public health threats such as smoking and obesity.[101] There is also a danger that media reporting about conflicting evidence on minor hazards can lead the public to doubt the reality of major health hazards about which there is far wider consensus. Debate about the health benefits of moderate alcohol consumption can, for example, lead to confused messages about excessive consumption, even though the evidence of the potential harms is strong.

The 1998 MMR controversy (see page 829) has become a classic example of how sensationalist reporting, based on imperfect information, can have a detrimental effect on trust in a public health intervention. Despite scientific refutation of the link between MMR and autism, faith in the vaccine was compromised to the extent that parental anxiety over the safety of MMR persisted for over a decade. The story also resurfaced in the media in 2007 when the *Observer* newspaper ran a front page story raising new fears that the vaccine was unsafe, an article which again was shown to be based on misreporting and exaggeration of the facts.[102] This type of story can present difficulties for members of the public who may not have access to the original material or the scientific training to evaluate the evidence presented to them and are therefore unsure whether to take the health threat at face value. Since the MMR scandal, the government has become more aware of the potential impact negative health stories can have on public perceptions of risk. The NHS Choices website has a resource entitled 'Behind the Headlines', which provides independent evidence-based analysis of health and science reporting in the mainstream media and is designed to help both the public and health professionals to assess the validity of scientific evidence and research presented in the media.[103]

When the media becomes interested in a public health issue, and doctors are invited to comment, care must be taken to ensure that only the known facts are disclosed and discussed; speculating about possible dramatic scenarios on the basis of modest information can prove extremely damaging and should be avoided. Care should also be taken to ensure that individuals are not inadvertently identified and, wherever possible, consent should be sought. Nevertheless, there may be health benefits in providing information to the general public when it is not possible to obtain consent about an incident that affects the public health, either to warn about the risks or to provide reassurance

about safety. Doctors therefore need to weigh up the benefits of informing the public against the potential risk to the confidentiality of the affected patients. Even if identifying information is not provided, factors such as general location are probably essential and can lead to identification. A case that found its way to the media in 2002, for example, was so unusual as to effectively identify the individual concerned.

Confidentiality and the media – Britain's first case of rabies in a century

In the winter of 2002 a 56-year-old Scottish man contracted European bat lyssavirus, a type of rabies found in several northern European countries.[104] The release of information about the case to the press raised questions about confidentiality. Once it was known, for example, that someone who worked with bats in a specific region of the UK had contracted rabies, it then became quite easy for the media to identify him. In such cases, consideration needs to be given to the extent to which apparently anonymous information can lead to identification. Furthermore, in the absence of consent, disclosure should be restricted to the minimum amount of information necessary to fulfil the aim.

The hospital informed the press that there had been a confirmed case of rabies, and also issued a statement reassuring the public that people were at risk only if they had handled bats or been bitten or scratched by them. It is not known, in this case, whether the man, or his family, were involved in decisions about disclosure to the media.

Before releasing information about public health risks to the media, it is essential to consult with the local public health department in order to assess the nature and level of risk and the need to inform the public. In some circumstances it may also be important to seek advice from press officers, communications managers or lawyers before presenting the information to the media. (For further information on confidentiality and the media see Chapter 5, pages 216–217.)

Summary – the role of the media

- The media can have a positive role in public health promotion but it also has attendant risks.
- When doctors are commenting on public health stories in the media care must be taken to ensure that only the known facts are disclosed.
- Care must be taken to ensure that confidential information is not inappropriately disclosed to the media.
- Before releasing information to the media, advice should be taken from the local public health department and, if appropriate, press officers or communications managers.

Commissioning services – tackling inequities

A key part of public health practice relates to identifying health needs and commissioning services to address those needs. Public health practitioners gather and assess data on relevant health problems and then develop appropriate strategies to respond. These strategies can then be used to approach decisions relating to prioritising, funding, planning and commissioning health services. Three aspects of this broad public health practice raise particular ethical dilemmas. Given that not all health needs can be met from available resources, difficult decisions have to be made about which needs to prioritise, and any such decisions need to be made fairly. In addition, as discussed earlier in this chapter,

health inequities are an important focus of interest, because they contribute to poor health outcomes and also because tackling social inequality is a wider political priority. There is also an obligation to use public resources justly. This section gives a brief outline of the main ethical issues that need to be taken into consideration in relation to priority setting. It also looks at clinician involvement in rationing decisions, at the legal context that governs these decisions and at professional guidance for doctors in this area. At the end of the section some practical examples relating to the tackling of health inequities are given.

Priority setting

To ration or to set priorities?

There is disagreement in relation to the terminology used in the area of resource allocation. The term 'rationing' is sometimes thought to be encumbered with negative associations, summoning up images of war-time deprivation, and likely to create resistance and partisan discussion. In its publication on resource allocation, *A rational way forward for the NHS in England*, the BMA states that: 'Priority setting acts at the level of allocating resources to particular services while rationing acts at a lower level in the allocation of resources to individual patients at the point of service delivery.'[105]

Since its inception in 1948, the demand for health services in the NHS has always considerably outstripped available resources. While it has been suggested that greater efficiency in the health service, or the allocation of a greater percentage of the overall domestic budget, would obviate the need for rationing, in recent years need has continued to exceed supply despite significant increases in the overall percentage of UK gross domestic product (GDP) spent on health. Between 1990 and 2010, for example, the percentage of GDP spent on health had risen from 6 to 10.5 per cent. Between 2000 and 2004, the UK also achieved the highest increase in health expenditure as a percentage of GDP, compared with its main European counterparts, and a growth rate three times higher than the EU average.[106] Given that serious shortages remain, it is likely that rationing will continue to be a significant feature of health delivery. In 2007, the BMA called for an open debate about rationing in the NHS. In *A rational way forward* it recommended that there must be explicit recognition of the need to ration services:

> The BMA believes that while the NHS should provide a comprehensive range of services, priority setting, and hence, rationing, is inevitable, if we are to retain an equitable approach within limited resources. This needs to be recognised by politicians so that the right environment will exist for politicians, health professionals and the public to debate and decide upon a process to define a 'core' list of services that will be nationally available. The approach should be national and explicit, setting priorities for the whole service. It should provide an ongoing mechanism to review and change priorities in the NHS, which must include an effective way of incorporating public and patient views.[107]

In order to understand how priority setting works in the UK, a background knowledge of the way health resources are allocated is useful. The structure of publicly funded healthcare is extremely complex and a detailed description is outside the scope of this book. In addition, at the time of writing, the Government has signalled its intention to make wide-ranging changes to the structure of health services in England by means of a new Health and Social Care Bill. Among the many reforms aimed at devolving responsibility

away from central government is the proposal to involve GPs far more closely in the commissioning of health services for their patient populations. A brief outline of resource allocation in the NHS is given below.

How are resources allocated in the NHS?

Initially, the Government makes a decision about the percentage of the overall national budget that will be dedicated to healthcare. This is a decision for the Treasury, which is responsible for allocating Government spending to the various departments. Health professionals and their representative bodies, such as the BMA, can and do have an input in this process. They lobby to ensure that health remains a priority, and they can also influence the way in which budgets are allocated through collective bargaining in relation to terms and conditions of service. The initial budget is then devolved down to local commissioning bodies where overall priorities for services within the regions are decided. Although the budgets are to some extent controlled by the commissioning bodies, many priorities are still set centrally in ways that can have a considerable influence on allocation decisions further down the line. Despite recent changes to the structure of health services in England and Wales, the Government retains the power to insist that treatments recommended by the National Institute for Health and Clinical Excellence (NICE) in England and Wales are funded. In Scotland, the responsibility for providing advice to health boards about new and existing interventions falls to Healthcare Improvement Scotland (HIS). Doctors in Scotland are also supported by the Scottish Intercollegiate Guidelines Network (SIGN) which draws up national clinical guidelines. In Northern Ireland, the Department of Health, Social Services and Public Safety assesses guidance produced by NICE to decide whether it is appropriate to introduce it in Northern Ireland. NICE and SIGN are discussed below, as well as in Chapter 13. Guidelines can also be issued by central government in relation to waiting times, and the treatment of specific diseases.[108] Any such directions have an impact on allocation decisions further down the line, and such decisions clearly relate to the rationing of resources. To date the Government has declined to offer a comprehensive framework within which these decisions should be made. Instead, responsibility falls on commissioning bodies to develop local solutions. Although such responses can be flexible, they can also lead to patchy and ad hoc approaches with, at times, inequitable variation in regional supply.

The National Institute for Health and Clinical Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN)

In addition to the rationing processes outlined above, in 1999 the Government set up what was then the National Institute for Clinical Excellence (NICE), which became, in 2004, the National Institute for Health and Clinical Excellence, retaining the same acronym. NICE produces guidance on health technologies and clinical practice for the NHS in England and Wales.[109] Because NICE assesses interventions on the basis of both clinical and economic evidence – cost-effectiveness is taken into account – it is clearly involved in providing an evidence base for possible rationing and priority setting decisions.

The Scottish Intercollegiate Guidelines Network (SIGN) was set up in 1993. Its aim is to improve patient care by reducing variations in practice and outcome. Like NICE, it does this through the development and dissemination of clinical guidelines based upon the best available clinical evidence. (More information on NICE and SIGN can be found in Chapter 13, pages 552–554.)

Clinician involvement in rationing

Although the BMA argues for a 'national and explicit' approach to rationing, the vast majority of rationing decisions in the NHS are made implicitly, without being recognised as such, and often involving health professionals in decisions that have a significant, and often unacknowledged or unrecognised non-clinical aspect. The length of GP appointment times, for example, reflect the reality of limited staff time as much as the requirement for optimal outcomes from a consultation and clearly have an aspect of implicit rationing. Other examples include decisions to restrict the number of marginal investigations or interventions that may only provide small incremental benefits.

The most high-profile rationing cases usually occur where choices have to be made as to whether a specific individual will receive a potentially life-saving intervention. These cases also present healthcare professionals with acute ethical dilemmas, as they attempt to square their duties to provide healthcare on the basis of need, with the recognition that there are simply insufficient resources available. The obligation to act as the advocate of the interests of their patients can therefore conflict with the need to use available resources as efficiently as possible in order to ensure that the acutest needs can be satisfied. Although individual cases can be the subject of extensive media scrutiny, the overwhelming majority of rationing of this kind is implicit rather than explicit:

> [r]ationing in the NHS has never been explicitly organised but has hidden behind each doctor's clinical freedom to act solely in the interests of his individual patient. Any conflict of interest between patients competing for scarce resources has been implicitly resolved by doctors judgments as to their relative needs for care and attention.[110]

One frequently cited example of this is the use of GPs to act as 'gate keepers'. Although many GPs may not think of their activities as explicit rationing, the decisions they make can largely determine the extent to which individuals will have access to health resources.

Judicial review of rationing decisions – a history of court involvement[111]

The National Health Service Act 1977 imposes upon the Secretary of State a general duty to promote a 'comprehensive health service' to those ordinarily resident in the UK. Those bodies upon whom this responsibility is devolved also have an obligation to operate within their allocated budgets. Because limited budgets will inevitably mean that some beneficial treatments cannot be provided, legal questions arise about the lawfulness of the decisions to restrict certain services and treatments. In England and Wales, legal scrutiny of resource allocation decisions is made by judicial review when the Courts examine the propriety of public authority decision making. The focus is usually on the reasonableness of the decision-making process.

Gender identity dysphoria – the need for a consistent approach

In 1999, a case taken by three individuals with gender identity dysphoria raised some interesting questions about the limits to the treatments or interventions that should ordinarily be provided by a publicly financed health service. The trio challenged their health authority's decision to refuse to provide them with gender realignment surgery.

The case is interesting for a number of reasons. In 1995, the authority had decided to allocate a low priority to such surgery, considering it to achieve little in the way of clinical gain. In its 1998 revision of its policy the health authority stated that: '[t]he health authority will not commission drug treatment or surgery that is intended to give patients the physical characteristics of the opposite gender.' The only exception that it would allow was where 'there is evidence (including consultant advice) that the problem is the cause of serious mental illness, which can be expected to be substantially improved if the exception is granted.'[112] The justification for providing treatment was therefore severe – and treatable – mental illness associated with the gender dysphoria, not the condition itself. The case touched upon the question of whether people who felt they were born into the wrong gender were experiencing a health problem and therefore whether they should receive publicly funded health services. Here clinical judgement is central, and gives some indication of the power of clinicians and their professional clinical organisations in deciding whether individuals will be eligible to receive treatment. The trio won their appeal. The Court stated that as the authority accepted that gender dysphoria was a recognisable clinical condition, restrictions that effectively amounted to a complete ban on providing treatment were unacceptable and the authority needed to review its approach. The Court did not comment on whether an authority should make money available for treatment of gender identity dysphoria. Its concern was with the reasonableness of the decision-making process.

In scrutinising decisions, the courts acknowledge the duty of public authorities to balance competing claims upon their finite resources and have traditionally been extremely reluctant to overturn health authority decisions not to fund particular patients' treatments.[113] Where the court does find in favour of the applicant, the health authority is required to make the decision again, but it is not necessarily required to pay for treatment. As long as the decision is made lawfully, for example by the health authority offering reasons for the decision to refuse treatment and assessing the individual circumstances, rather than operating a 'blanket' ban, it is possible that the authority will come to the same decision again and still refuse to fund the applicant's treatment. Court review is not restricted to decisions by health trusts. As outlined in the case below, decisions by NICE have also been subject to legal criticism.

Court of Appeal questions NICE decision in relation to Alzheimer's drug

In May 2008, the decision by NICE to restrict the availability of acetylcholinesterase inhibitors, such as Aricept, for the treatment of Alzheimer disease was held to be procedurally unfair by the Court of Appeal. Overturning an earlier decision at the High Court, the Court of Appeal held that the decision by NICE not to publish the full version of the cost-effectiveness model that it used when reaching the decision was 'procedurally unfair'. The Court held that as NICE discharged a serious public function it was therefore subject to the general principles of procedural fairness. The Court asked NICE to look again at its decision, taking into account the views of the drug companies involved after they had had time to consider the full cost-effectiveness model.[114]

Resource allocation decisions have also been challenged under the Human Rights Act 1998. Although both the European Court of Human Rights and UK domestic courts have been reluctant to interfere with health authority resource allocation decisions, there was a successful case brought against such an authority under Article 2 of the European Convention, protecting the right to life, in 2008. The House of Lords ruled that hospitals and other health organisations have a positive obligation to protect the lives of patients in their care against suicide attempts where there is a known suicide risk.[115]

Legal review of rationing decisions – the current position

In a 2008 judicial review case, in which a patient challenged a PCT's refusal to pay for expensive renal cancer treatment, Mr Justice Burnett laid down the principles to be applied where rationing decisions are brought before the courts.

- When an NHS body makes a decision about whether to fund a treatment in an individual patient's case it is entitled to take into account the financial restraints on its budget as well as the patient's circumstances.
- Decisions about how to allocate scarce resources between patients are ones with which the courts will not usually intervene unless there was irrationality on the part of the decision maker. There are severe limits on the ability of the court to intervene.
- The courts' role is not to express opinions as to the effectiveness of medical treatment or the merits of medical judgement.
- It is lawful for an NHS body to decide to decline to fund treatment save in exceptional circumstances, provided that it is possible to envisage such circumstances arising.[116]

Seeking treatment overseas

In 2003, after being put on a waiting list for a hip replacement, Yvonne Watts travelled to France for the operation and sought reimbursement from Bedford PCT for the cost on her return. In ruling in favour of Ms Watts, the European Court of Justice held that patients seeking treatment overseas must obtain prior authorisation from their PCT or commissioning body. The possible exceptions to this would be where the delay arising from waiting lists would be unacceptable, based upon an objective test of the patient's medical condition.[117] In 2008, the European Union issued a Directive to provide greater clarity on the question of cross-border healthcare provision within Europe. Although it does not seek to enforce a system of prior authorisation, it holds that it would be legitimate for a state to require prior authorisation where it was necessary to avoid disruption to health planning. The Directive is expected to come into force in 2012–2013.[118]

A defined package of healthcare?

One possible approach to rationing is the development of a core bundle of services that will be universally available, an approach recommended by the BMA.[119]

To a limited extent, and in an ad hoc and decentralised fashion, such an approach to the provision of healthcare is already in place. Not all potential services are available everywhere, with certain services, such as tattoo removal or aesthetic plastic surgery, only being available in some areas. Adult dentistry is subsidised by central government, but considerable costs are passed on to the 'consumer'.[120] On the face of it, it is clearly inequitable that one's place of residence should determine whether one can access a particular service and, in this context, calls for centralising a core list can seem attractive, although drawing up such a list can present difficulties. Even if some of the more obviously 'marginal' interventions, such as tattoo removal in the absence of severe psychological stress, are excluded, the impact on overall funding will be negligible. When it comes to the more substantive and expensive services, we come back to the question of the principle or principles that should guide the decision to fund or not to fund.[121] Among other difficulties faced by this approach is its potential for a rigidity that overrides the clinical flexibility to meet genuine need, and a vulnerability to judicial review for excluding the possibility of exceptional cases.[122]

One of the questions raised by the possible introduction of a defined core set or package of healthcare that is made available to all is the tension that inevitably runs through rationing decisions, between decisions made at the centre and the requirement to meet need flexibly at the local level. While a centralised approach would overcome the so-called 'post-code lottery', it can remove the flexibility to deal with geographical variations in health need. The question then becomes how best to steer a path between excessively rigid centralism on the one hand, and ad hoc local solutions that may not be firmly rooted in evidence.

Ethical priorities in resource allocation

The BMA has identified a number of key ethical issues that both public health practitioners and other health professionals need to consider when thinking through resource allocation decisions. These are given in the box below and are discussed in more detail in the section that follows.

Ethical considerations engaged in rationing decisions

These include:

- need
- welfare maximisation
- clinical effectiveness
- relative cost-effectiveness
- equity
- individual rights
- patient choice
- communication and public involvement
- transparency and rationality of decision making.

Need

Approaches to priority setting in healthcare require an understanding of the healthcare needs of target populations. Although these are usually approached via health needs assessments, which aim systematically to identify unmet healthcare needs, these in turn necessarily require some prior understanding of what is meant by 'need', and of the difference between 'health' and 'healthcare'. On the face of it, the idea of need may seem straightforward, understood as a health deficit that can benefit from an intervention. Nevertheless, on closer inspection it becomes more problematic, with perceptions of need varying according to what interventions are possible, available and affordable.[123] The understanding of need also varies according to the definition of health employed and whether it is limited to discrete medical conditions or widened to incorporate social determinants of health and well-being. It can also be difficult clearly to distinguish between a health 'need' and a 'want' or a 'desire'. (For further discussion, see pages 802–804.)

Welfare maximisation

At the heart of debate about rationing lies the fundamentally utilitarian goal of managing and providing healthcare in ways that maximise the welfare of those who are using them within the available resources.[124] Although much inevitably depends on the definition of

'welfare', where resources are limited and the welfare of some cannot be increased without reducing the welfare of others, attention must be shifted to maximising the welfare of the population viewed in its entirety.

Clinical effectiveness

Decisions relating to an intervention's effectiveness are based exclusively on clinical criteria (both physical and psychological), unaffected by issues of cost. A treatment is clinically effective if it alters a particular condition for the better. One treatment is more effective than another if it alters the condition more successfully or with fewer side effects or under a wider range of conditions.[125]

Relative cost-effectiveness

Cost-effectiveness combines clinical efficacy and cost, with the aim of achieving the most effective use of the limited resources available. A range of measures of health benefit[126] can be used to determine cost-effectiveness but this is not a straightforward process and there are always considerable practical difficulties. Whatever measure is used, several important issues need to be addressed, including the additional length and quality of life a treatment brings and the contribution particular treatments make to an individual's well-being.

Equity

Equity requires that like cases are treated alike, and unlike cases treated differently. This principle, applied to healthcare, demands that people with the same health needs must be given an equal chance of receiving appropriate treatment of equal quality.[127] In broader public health terms it also means that the same conditions for realising good health are equally available to all members of the population. This can mean that where inequalities exist, goods need to be distributed unequally in order to achieve overall equality.

Individual rights

One of the ways in which the discussion of priority setting has been framed is in terms of individual rights, and the nature and status of these rights have an impact on decisions about resource allocation. The notion of 'rights', incorporating both substantive legal and aspirational moral entitlements, is complex and contentious. However, the NHS is required to ensure that all of its decisions are compatible with the Human Rights Act 1998 and legislation must, as far as possible, be interpreted in ways that are compatible with Convention rights.

Patient choice

There are inevitably recurrent conflicts between centralised rationing decisions and patient choice. Rationing by its nature involves doctors and others in the hard task of denying to some patients interventions from which they could benefit because resources can be more appropriately employed elsewhere. Nevertheless, within this framework, efforts need to be made to maximise patient choice, and a variety of methods for involving

patients in decisions about their healthcare choices need to be employed. These include the following:

- when research on the effectiveness of a treatment is being assessed it is important that outcome measures important to patients are used
- where multiple treatments are available within the priority-setting framework, patients should be encouraged to make their own choices
- the priority-setting framework should be suitably flexible to permit legitimate exceptions based on variations between patients
- the impact of choices on carers should also be taken into account.

Patient choice within a public system will not ordinarily extend to procedures that are not regarded as clinically effective.

Truth telling and resources

While truth telling is generally advocated throughout clinical care, some doctors have expressed concern about the implications of telling patients that there are health services available that could potentially help them but which are not available within the NHS or in the area in which they live. In the BMA's view, part of the role of doctors is to ensure that decision making is returned as much as possible to the patient rather than pre-empting the choice by withholding potentially important information. The BMA therefore believes that, as a general rule, patients should be given information about other treatment options that may benefit them, even if the doctor does not believe that the patient could afford to pay for the treatment. There may be rare cases, however, where such information would clearly be unwelcome and, in these cases, doctors should take their cue from the patients as to the amount of information to impart. Where information is to be provided, the manner and timing of its provision will need to be carefully considered and may need to be supported by professional counselling. In cases where the treatment cannot be funded, patients should have access to information about the factors leading to the rationing decision and it should be made clear whether the treatment is unavailable because it is unproven or solely on grounds of cost-effectiveness.

Although it is important to bear all of these ethical considerations in mind when setting priorities for the allocation of resources, it is inevitable that there will be cases in which they come into conflict. Cost-effectiveness can at times work against individual need, for example, and patient choice often runs into conflict with equity. Difficult choices need to be made and must be justified with clear and transparent policies and decisions in individual cases.

The search for equity

Inequalities in health provision – a tale of two cancers

In 2006, the English media picked up on a story about a married couple – one of whom was a journalist on the *Observer* newspaper – who were simultaneously diagnosed as having cancer, the man with prostate cancer, the woman with breast cancer. Somewhere in the region of 42,000 women a year are diagnosed with breast cancer in the UK. It kills around 15,000 patients a year. Nearly 32,000 men are diagnosed with prostate cancer a year and it kills around 10,000 men a year. At the time, breast cancer

received 10 times more funding than prostate cancer.[128] Questions were raised in the media about whether clinical factors alone could account for the difference in resources allocated to the two diseases. Commentators pointed to the high profile campaigns supporting breast cancer, the passionate and vociferous supporters of the cause and, consequently, to media interest. Prostate cancer, by contrast, had a much lower media profile. The case highlights the potential in media-driven democracies for public opinion to affect decisions about how resources are allocated. The public furore over Herceptin,[129] for example, resulted in an intervention from the Government and a fast-tracking of NICE approval for its use. However, public opinion can sometimes lead to ethically questionable priorities, routinely favouring the health needs of children over, for example, prisoners or the mentally ill.

One of the biggest challenges in public health is trying to rectify health inequities where equity is understood as the requirement that people in equal positions should be treated equally, and people in unequal positions treated unequally, according to the morally relevant differences between them. In the case of healthcare, the most obvious criterion for discriminating between individuals is clinical need. People with similar clinical need should receive similar treatment, those whose needs require more expensive treatment should receive more. It needs to be recognised here, however, that greater need might not entail greater cost. Some very great health needs can be met inexpensively, other lesser needs might entail far more costly treatment. Waiting lists are often cited as one method of prioritising according to need.

Health inequities arise not only through decisions about allocating resources but also through the broader social, economic and biological factors that affect health. It is therefore not enough to ensure an equitable geographical spread of services. Even if this were to be achieved, rates of uptake would still vary considerably, as would disease variations resulting from genetic and socioeconomic factors. The equity challenge for the provision of comprehensive health services therefore lies far deeper than just the research and assessment of health problems and the commissioning of appropriate services to respond to them. It also entails an understanding of the way social inequities contribute to the development and prevalence of disease, the way different population groups take up health services and respond to health initiatives, and the development of innovative ways to contact different communities and to present the issues in ways that are both meaningful and that invite cooperation.

Non-discrimination

An important aspect of any approach to equity is the elimination of discrimination between individuals on the basis of morally unacceptable criteria. In the provision of publicly funded healthcare in the UK this means that healthcare will ordinarily be provided on the basis of a clinically adjudicated assessment of an individual's clinical need and capacity to benefit. Discrimination will not be permitted, however, on the basis of personal characteristics that have no clinical relevance. These will include factors such as age, gender, sexual orientation, gender identity, race, religion, lifestyle, social position, family or financial status, intelligence, disability, physical or cognitive functioning, where they are not relevant to the clinical decision that needs to be made.

The debate about discrimination is particularly concerned with elderly and disabled patients and with patients from ethnic minorities. Some ethnic minorities, for example, have much lower uptake of some key services, such as palliative care. In 2010, the Equality Act 2010 for England and Wales came into force which prohibits age discrimination against adults in the provision of public services and functions. Subsequently, the Department of

Health issued a consultation document looking at age equality in health and social care in anticipation of the implementation of the equality duty in relation to age which was expected to be in force by 2012. Among the recommendations were:

- a review of any age criteria in use in entitlement for health services, such as breast screening, with the intention of replacing such criteria, where appropriate, with more 'pertinent and individualised evidence'[130]
- a review of the use of quality-adjusted life years (QALYS) and other similar support tools to inform decision making.

Public participation and involvement

There is a tension in resource allocation decisions between centralised policy making, which aims at overall equity, and the requirement to respond flexibly to local variations. It can be just to treat people in the same way, but it can also be just to treat different people differently, depending upon their needs and circumstances. A difficulty that can arise in relation to more central decision making is that it can be based upon poor or inaccurate assumptions of the requirements of local populations. One way of addressing this problem is through public participation. Doctors working in the field of needs assessment have been sensitive to the charges of paternalism that have, from time to time, been directed at their practice, and have used a range of methods for involving populations in their work to ensure that autonomy is eroded to the minimum extent possible. Public involvement requires more than just listening to representatives of 'target' populations, however. At its best it is an ongoing dialogue and involves providing population groups with information about individual policies, the reasons for implementing them and the desired outcome. At times it extends to public participation in the actual decision making itself.

The use of sophisticated methods to involve the public and to maintain an ongoing dialogue can lead to better public understanding and acceptance. Where public involvement has worked well, health initiatives have generally been more successful, particularly among traditionally 'hard to reach' populations.[131] Such measures can also help to overcome the resistance some groups have shown to state initiatives and can enhance the involvement of excluded groups, even when the strategy in question may have some elements of coercion, such as restrictions on smoking in public places. It is important therefore that before policies are introduced and services are offered, a wide range of stakeholders is consulted both to inform the development of the policy and to gain the acceptance and cooperation of the local population. Achieving this is not unproblematic, however. It can be difficult, for example, to identify appropriate representatives and many of the most needy can be so disenfranchised as to be almost silent.[132] Local health professionals in both primary and secondary care have important contributions to make, as do local government and voluntary groups. Listed below are a number of methods that can be used to enhance public involvement.

Methods for public involvement

- *Public consultations:* these are an increasing feature of Government activity and are used to ensure stakeholders have an opportunity to have their voices heard in decision-making processes.
- *Health panels:* these are standing panels of local people who are seen to be representative of the local population. They vary in size and in the frequency with which they meet and members tend to be replaced at frequent intervals.

- *Citizens' juries:* these are made up of local people who sit on a jury for a specified time and debate a variety of health topics presented by health practitioners.
- *Focus groups:* these tend to comprise groups of between 6 and 12 local people and are run by a facilitator who promotes discussion on a variety of local health topics.
- *Interviews:* individuals are selected either at random, or because they are particularly representative, and their views are sought on a variety of issues.
- *Questionnaires:* these enable the gathering of structured information from a variety of target populations.
- *Experimental methods:* these are used by professional researchers such as psychologists and economists to elicit and quantify public preferences.

Although public involvement in decision making should be encouraged, it does not necessarily guarantee an ethically justifiable outcome. Public priorities may be inconsistent, based upon a faulty understanding of complex issues or based on individual prejudices.[133] Attempts to ascertain the public's views about healthcare priorities, for example, have shown a clear preference for the treatment of acute, life-threatening diseases among children over similar treatment for older people, psychiatric services or general health promotion. Considerable support has also been expressed for the notion that those who have contributed to their own illness, through smoking, obesity or drinking for example, should have lower priority for treatment.[134] As we have seen, such views are at odds with the general principles that underpin the NHS. While it is important to be aware of these inherent difficulties, they do not outweigh the value of such exercises and the benefits of achieving the agreement and cooperation of the local population in public health policy.

Learning from past successes – Julian Tudor Hart's 'anticipatory care' approach

Discussion of public health goals and methods can, at times, seem remote, dealing with large populations and with abstract ideas such as 'community' and 'the common good' and with impersonal tools such as epidemiology. Health professionals have, however, developed innovative methods for combining public health approaches with the delivery of individual healthcare to members of target populations. In the 1960s, the British GP Julian Tudor Hart started using routine contact with patients – typically he would see over 90 per cent of his patients over a 5-year period – to assess not only immediate health problems, but also anticipated future health needs. Hart's approach focused on preventing future risks, particularly those associated with high blood pressure, smoking, obesity, diabetes and excess alcohol use. As a result of his approach, compared with neighbouring populations with a similar health profile, premature mortality among his patients dropped by 28 per cent. Aspects of Hart's groundbreaking approach have been adopted, and adapted, throughout the UK, and it remains a powerful example of the productive interface between a public health and an individual health approach to health maximisation.[135]

Summary – commissioning services

- The need for priority setting emerges from the gap between the demand for healthcare and available resources.
- Priority setting is an inevitable part of healthcare provision in the UK and this should be openly acknowledged.
- Decisions must be equitable and comply with the Human Rights Act 1998.
- Decisions must be justified with clear and transparent policies and decisions in individual cases.

- Equity requires that equal people should be treated equally and unequal people treated unequally, according to the morally relevant distinctions between them.
- Equity relates to more than just health need – it also requires addressing the underlying determinants of health.
- Public participation is crucial, although public priorities may not in themselves lead to just or equitable outcomes.

Processing health data for public health management

A great deal of the management of public health takes place at a local level. This obviously includes the implementation of national policies and will often involve the application of some of the tools and strategies outlined above. The day-to-day management of public health incidents also operates at a local level. A central feature of this practice is the gathering and processing of health information. This final section looks at some of the ethical issues raised by this practice.

The use of health information

Public health medicine uses a large amount of health information gathered from a variety of sources, including population registers, birth notification and mortality records, disease registries, health service data banks, national and regional screening or surveillance programmes, data specifically collected through surveys and research, and medical notes. Often the data are linked together, for example information from cancer registries is linked to mortality data, to increase its potential uses. The use of these types of data is crucial to the development of public health strategies, and to the delivery of significant public goods, but the usual rules of confidentiality still apply. Specific information about confidentiality and the use of personal health information is covered in Chapter 5 but the main principles that apply to the use of information for public health purposes are summarised below.

When public health doctors use data or design projects that involve data capture, the following principles should be followed.

- Wherever possible, anonymised data should be used.
- Consent should ordinarily be sought for any use or disclosure of identifiable personal health information.
- Occasionally, when it is not possible to obtain consent, information may be disclosed with strict safeguards (see below).
- Where consent is sought from patients for the use of their information, they must be properly informed about the purpose and nature of its use.
- Where practitioners are not directly involved in the consent process, they should accept data only from reputable sources that have in place appropriate mechanisms for information gathering and handling.
- All processing of identifiable health data must comply with legal requirements and must be fair and lawful.
- Information should not be kept for longer than is necessary to fulfil the purposes for which it was sought.
- Disclosure should be kept to the minimum necessary to achieve the purpose.
- All patient identifiable data must be properly protected against inappropriate or inadvertent disclosure.

- All individuals who come into contact with personal health information in their work must be trained in confidentiality issues.

Where it is not possible to use anonymous information, or to obtain consent, information may be disclosed to comply with a statutory requirement or where there is an overriding public interest (see Chapter 5). In England and Wales, disclosure is also permitted, in some circumstances, under the terms of regulations made under section 251 of the NHS Act 2006 (for more information see Chapter 5, pages 209–211).

Statutory exemptions for communicable diseases and other risks to public health

Regulations under the Health and Social Care Act 2001 have been made to permit confidential patient information to be processed, when it is not possible to obtain consent, for the following purposes:

- diagnosing communicable diseases and other risks to public health
- recognising trends in such diseases and risks
- controlling and preventing the spread of such diseases and risks
- monitoring and managing outbreaks of communicable disease
- incidents of exposure to communicable disease
- the delivery, efficacy and safety of immunisation programmes
- adverse reactions to vaccines and medicines
- risks of infection acquired from food or the environment (including water supplies)
- the giving of information to persons about the diagnosis of communicable disease and risks of acquiring such disease.[136]

At the time of writing, there was no equivalent provision in legislation in Scotland or Northern Ireland, and doctors in those jurisdictions should follow the advice in Chapter 5 and consider whether the public interest overrides the duty of confidentiality. They must also be prepared to justify their decisions.

Looking towards the future

Media and public attention frequently focus on exciting and innovative areas of medicine, such as new advances in surgical techniques or developments in genetics and, as a result, the potential for simple public health techniques to deliver extraordinary communal benefits sometimes goes unremarked. Vaccinations, sanitation, a clean water supply and the recognition of the hazards of tobacco use have contributed, and continue to contribute, incalculable benefits both to the developed and the developing worlds. In the West, however, as one generation of problems has receded, others have come to fill their place.

Whereas some of the original problems, many of which still dominate the health agendas of developing countries, were amenable to simple, cost-effective interventions or improvements, many of the new generation of public health issues, such as attempting to modify individual behaviour, have proved less responsive to public health initiatives. This new generation of problems include the health effects of sedentary lifestyles and poor eating habits; alcohol and tobacco use; the effects of social disintegration, such as violence and depression; the continuing consequences of social inequalities; bioterrorism; and the emergence of new drug resistant versions of older diseases. As public health

professionals continue to develop methods to deal with these issues, it is likely that the ethical questions generated by the friction between state beneficence and individual autonomy, and the appropriate balance between benefits and harms, particularly for patients who lack capacity, will be subject to increased scrutiny. As part of this process it is also likely that work will continue on the development of a stronger understanding of the moral goods of community. Where discussion of the ethics of public health practice has traditionally made use of an aggregate understanding of community, the sum of the interests of the individuals who make it up, more communitarian approaches, which will try to articulate a more substantive understanding of the moral importance of shared goods, such as health, will be an increasing feature of reflection on public health.

Public health medicine can provide important ethical insights, insights that can easily be overlooked in the mainstream rights discourse that, at times, dominates discussion of health and healthcare. It reminds us that health is not only a private issue, but also, and inevitably, a shared undertaking.

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