Public Health and Public Values

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Contents

Introduction

This report identifies the key values relevant to public health policy and outlines the potential conflict and synergies between these values. It sets the scene for the *Public Health and Public Values* project at the King's Fund. The project aims to engage Londoners in a public debate about how public values relate to current public health issues in the capital. Funded by the NHS Executive's London Region, the project will inform the development of the *Health Strategy for London*. It aims to provide a deeper understanding of what Londoners feel are important principles for public health and policy decision-making.

A companion report[1] has reviewed the subject from the point of view of the NHS – a health care delivery service. Here we translate that analysis to the different and somewhat wider sphere of study relating to the health of people generally in a community. A more detailed analysis of the meaning and basis of public values is confined to the companion report, to avoid repetition.

The structure of this report is as follows. In Chapter 1, the meaning of public health and the principal strategies available for achieving its goals are reviewed. In Chapter 2, the wide range of ethical and value-based issues found in the public health literature are summarised.[2] Seven specific values which emerge from this analysis are set out in Chapter 3. In Chapter 4, the conflicts and synergies between these values are reviewed. Finally, in Chapter 5, ethical questions relating to involving the public directly in making policy decisions are addressed.

1. Public health and strategies to achieve it

1.1 What is public health?

Public health has been defined by the US Institute of Medicine as:

> *what we as a society do collectively to ensure the conditions in which people can be healthy.*[3]

Three elements of this definition can be identified. First, public health is an activity for society, through the institutions of the state, and not something which individuals undertake privately. In other words, public health is *defined* as a particular set of government policies. This does not mean that individual action is unimportant, merely that a decision by an individual to choose, for example, a healthy diet is related to 'public health' only when it is influenced in some way by state action. Indeed, whilst medical care can be arranged and paid for privately, in tandem with public health care services, for many types of public health initiative this is not possible. Consider the difficulties involved in 'buying' clean, pollution-free air. Other public health activities, such as screening and immunisation, can be provided outside the public sector but would not be classed as 'public health' interventions if they were undertaken privately.

The second element in the definition is that public health policies create 'conditions' in which people can be healthy, rather than directly treating people in ill health. These conditions can be divided into physical, biological and social.[4] Physical conditions include clean air and water, or good-quality housing; biological conditions include the lack of infectious disease; and social conditions include how people behave in social contexts, the existence of support networks and employment relations. Some conditions, such as poverty, may involve elements of deprivation in all three categories. Other conditions are less easy to categorise, particularly those which involve our choices about how to live. Often characterised as 'lifestyle' choices, these include whether to smoke, type of diet, and how much exercise to take. We may consider these to belong, broadly speaking, under the heading of social conditions given that how we choose to live is intimately bound up with social norms and pressures. In short, public health is not concerned with treating individual ill health directly, but rather with

policies and strategies aimed at creating an environment which will impact on the health of populations. However, the line between medical care and public health is not absolutely clear; *access* (normally free or subsidised in some way) to health care facilities is one element of the conditions required by the definition above.

The third and final element of the definition involves the term 'healthy'. There are severe difficulties in defining what counts as 'health', the very subject matter of the discipline of public health. The World Health Organization's (WHO's) well-known definition of health is 'a state of complete physical, mental, and social well-being, not merely the absence of disease and infirmity'.[5] This immediately raises the question of how far we are to take 'well-being' in all these forms as a legitimate subject for public policy. For while the definition is designed to ensure that 'health' is not considered in a minimal way, involving merely the correction of the most overt physical symptoms, it also allows us to stray into activities which have been construed as 'health fascism and imperialism'.[6] In particular, the relevance of the distinction between 'negative' ill health and 'positive' health and fitness is problematic from a policy viewpoint (and forms the first of the ethical issues reviewed below). Mere 'absence of ill health' is not considered sufficient by the WHO, presumably because this might imply a minimal focus on the absence of observable symptoms, and yet going beyond this involves difficult questions about the differences between healthiness, well-being and happiness.

Public health is often spoken of in terms of 'disease prevention' and 'health promotion', but these are terms with rather loose meanings which are also occasionally used in the context of the delivery of medicine.[7] Promoting health, if this is to mean something distinct from preventing ill health, must refer to activities which raise health status. These may include: renovating damp housing stock to improve the respiratory health of the inhabitants, reducing pollution to achieve the same effect, or subsidising a swimming pool to encourage those with back problems or osteoporosis to take more exercise. All such activities improve the health of people with existing conditions, as well as having as other preventative effects. But performing a hip replacement or treating cancer also involve an attempt to 'promote health' in the sense of ameliorating an existing condition and raising health status. 'Prevention' is another term that is inaccurately used at times. For example, a screening programme in itself prevents

nothing, but merely alerts people early on in the course of a disease that treatment may be necessary. In the rest of this report, the conceptual field of public health will be considered formally in terms of the definition above from the US Institute of Medicine, with 'promotion' and 'prevention' used only where the context is clear rather than in any wide-ranging sense.

1.2 Strategies to achieve public health

According to the *Oxford Textbook of Public Health*, public health can be pursued via four broad strategies directed at the conditions through which people can become, and remain, healthy.[8] These focus on:

1. the preventive aspects of medical care

2. health education and behavioural modification

3. control of the environment for health

4. cultivating the political will for public health initiatives.

The last of these four is rather different from the previous three, since it is less to do with influencing health than with persuasion that this is a worthwhile goal. The other three all represent broad and distinct strategies for influencing the conditions which make or keep people healthy. The rest of this chapter outlines these three broad strategies.

Preventive aspects of medical care

We have already noted that public health is not concerned with the medical treatment of individuals suffering ill health. However, this does not mean that clinicians and clinical interventions have no role to play in public health. As mentioned above, immunisation programmes, such as those for influenza, are provided by medical practitioners to individuals, especially those identified as being particularly at risk from the virus. Screening programmes are also provided to individuals by clinicians, even if the

categories of person to whom screening is offered are calculated with respect to populations and derived from cost-benefit, statistical and epidemiological analysis. The 'conditions' being created in public health terms by these programmes are, on the one hand, the eradication or control of the spread of a contagious disease through a population, and, on the other, the early awareness of the onset of illness.

Health education and behavioural modification

The second major category of public health intervention is that of education and behaviour modification. Such educational policies are particularly concerned with 'lifestyle' issues, reflecting in turn the shift in concern from disease control to how people can influence their own health. This kind of intervention may also be undertaken by medical practitioners. For example, one analysis of cost-effective health interventions cited 'GP advice to give up smoking' as producing the most health gain per unit cost.[9] Clearly, other clinicians in other settings can also provide advice, from a consultant advising on specialised diets to a health visitor suggesting how best to care for an infant – the information and advice being one of the conditions needed for improving health. However, perhaps the most overt form of 'advice' comes from central or local government campaigns designed to influence smoking, diet, exercise or sexual activity.

There are various means by which behaviour can be influenced. Providing impartial information may be most relevant when market suppliers of certain goods have an incentive to withhold evidence on the potentially harmful effects of consumption. Such a policy may further involve targeting this information at sections of the population which are considered most at risk. Another means of influencing behaviour is to tax or subsidise certain goods or services to discourage or encourage their consumption. In extreme circumstances, certain kinds of consumption can be banned outright (such as eating 'beef on the bone'), or certain actions can be made compulsory (such as wearing a seat-belt when travelling by car).

Controlling the environment for health

The final category of intervention involves action focused directly on the environmental conditions (physical, biological and social) which influence health. Control of the physical environment includes polices to: reduce pollution, improve housing conditions, restrict exposure to dangerous substances and minimise the risk of accidents at work. The biological environment can be influenced by: food hygiene standards, safe water supply, adequate sewerage and, in extreme cases, the confinement of people with highly infectious diseases (these are all in addition to those measures undertaken through medical interventions such as immunisation). The social environment is perhaps the most difficult for policy-makers to influence directly. Some possibilities include local planning measures to create strong communities, developing good travel and communications networks, introducing regulations about working conditions, and enforcing certain obligations on parents. Instituting systems of direct public involvement in democratic decision-making might also be a way of making people feel socially empowered and invigorated. However, it is clear that direct government intervention in social relations is fraught with difficulties – it is not easy to legislate for the formation of strong families or other networks of social support.

Access to health care facilities, establishing the effectiveness of treatments, and how best to allocate resources between publicly available treatments have also been claimed to lie within the province of public health.[10] Although these matters are arguably more properly thought of in terms of health care delivery, it is possible to see them in terms of controlling the conditions in which people can be healthy – that people should not have to face too-severe obstacles before they can avail themselves of cost-effective health care services.

However, we should be careful to avoid simply 'defining in' every decision relating to a medical intervention as influencing the 'condition' of healthiness or we will misjudge the essential focus of public health as being on the context, not the treatment, of ill health. Box 1 demonstrates the range of policies which could be implemented for public health reasons.

Box 1: Examples of policies which can influence public health

- Urban regeneration and neighbourhood renewal.

- Measures to reduce road traffic.

- Screening for breast cancer.

- Immunisation programmes: for influenza, rubella, tetanus, mumps, etc.

- Taxing polluters.

- Advice on healthy eating.

- Anti-smoking campaigns, including taxing cigarettes and banning tobacco advertising.

- Food safety regulations, including the new Food Standards Agency.

- Road safety, including drink-driving campaigns and traffic-calming measures.

- Increasing child benefit or other social security benefits for those on low incomes.

- Regulations for health and safety at work.

- Improving the quality of housing.

- Employment policies.

2. Ethical issues raised by public health policies

The subject matter of public health is wide. In this chapter we focus specifically on ethical issues raised by the public health literature. For simplicity, no distinction is made between the words 'ethics', 'morals' and 'values'; they are terms which in any event are very nearly synonymous.[11] Many of the topics will also be recognised as 'political' in the broad sense – also quite commensurate with the nature of this analysis. 'Political' is a common shorthand for disputes over values and ethics.

Some of the areas of policy discussed below overlap with one another in terms of the issues they raise. For example, some policies which seek to influence individual behaviour, such as those to reduce smoking, may also be part of a strategy to tackle health inequalities. Furthermore, many general policies to control the environment for health will inevitably have a distributional effect in social terms and so are included below in the chapter on health inequalities. Thus the principal policy areas within which ethical questions are discussed in the literature relate to:

- the domain of 'health'

- reducing health inequalities and controlling the environment for health

- seeking to influence individual behaviour

- promoting screening

- promoting immunisation

- improving sexual health and the health of unborn children.

Although drawn from policy journals and books, these issues are not irrelevant to daily life for most people. On the contrary, the topics emerge from real and persistent political controversies about how to promote the health of the community. The rest of this chapter is devoted to exploring each of these areas of policy.

2.1 The domain of 'health'

We have already noted that one of the key uncertainties in public health is what exactly constitutes 'health'. There are in fact two issues here. The first relates to how we conceive the meaning of the word 'health'. For example, how far should we accept notions of 'positive' health as opposed to a 'negative' focus on curing disease and disability, and what are the ethical distinctions, if any, between health, fitness, well-being, and simply being well-adjusted?[12] In other words, there are degrees of ill health and healthiness forming a continuum – from the prospect of losing one's life at one end to achieving a state of extreme physical fitness or psychological nirvana at the other. Perhaps it goes without saying that it is not the job of public institutions to ensure the latter. But somewhere in between there is a line to be drawn, and there is no obvious place to draw it. Other difficult areas include infertility, gender reassignment, long-term residential care, dentistry, optical services and cosmetic treatments. Should those who work in public health consider these to be *health* issues*, well-being* issues, or not the concern of public health agencies at all?[13] There is little unanimity about the proper boundary between health and other aspects of 'wellness'.

The second issue relating to the domain of public health involves the legitimate range of mechanisms or policy instruments which come under that heading. For example, it is quite clear that physical violence can result in significant ill health. But does that mean that policies seeking to restrict physical violence, including those within the criminal justice system, constitute a legitimate concern of public health experts?[14] In some ways, this is a practical question of co-ordinating different agencies of the state. But it also involves ethical questions about the legitimate role experts from one discipline can play in areas outside their direct experience but which have an impact on their own concerns. It is possible to argue that what really matters is policy objectives, not the agency within which someone works. Thus, the objective of improving the health of the public would encompass a much wider domain of action than that which pertains to a public health department in a health authority. Nevertheless, such a multi-disciplinary approach raises ethical questions concerning conflicting value bases. For example, one commentator has argued that:

> *public health approaches ... would prefer to find the causes of violence in society than the evil intentions of individual offenders ... Criminal justice practitioners see the public health community as apologists for misbehaviour. Public health practitioners see the criminal justice practitioners as wrathful avengers.*[15]

Furthermore, attempts to work across boundaries, such as a health authority's attempt to pass information about 'injury blackspots' to a local authority, can often face legal and ethical obstacles relating to confidentiality, particularly when health records are involved.[16]

2.2 Policies on health inequalities and the environment for health

There is little doubt that the physical and social environment has a significant effect on people's health, quite apart from the influence of biological agents. A significant literature has grown up on the subject.[17] From an ethical perspective, the issues involved in demonstrating such influences are relatively few. It is rare to find anyone who would argue that the empirical quest to understand the causes of ill health, and to investigate which determinants are the most important, is misguided in ethical terms. We all tend to agree that evidence is important. There may be some apparent differences in value position. For example, there will be questions about how much evidence is required for a particular purpose, and whether further empirical inquiry is a poor use of resources. Some may argue that scientific methods are biased toward certain methods, overemphasising what can be easily quantified, setting overly high standards of 'proof', and generally reflecting an expert (rather than 'lay') understanding of the world.[18] But even here, the disagreement may not ultimately be about values regarding how things *ought* to be, but about how best to understand how things *are*.[19]

Serious and continuing disagreements do exist about what the evidence amounts to. Two camps in particular have emerged over time: those who emphasise socio-economic conditions; and those who emphasise lifestyles or individual choices.[20] Even amongst those who agree that socio-economic conditions are the crucial underlying factors influencing both people's choices and their health directly, disagreements can be acute. For example, in the field of enquiry into the cause of health inequalities sharp divergences exist on whether income differentials *per se* influence ill health, or whether

other factors, such as material conditions, are more likely to be the cause.[21] This debate points up the issue of *how* ill health is caused by the environment: for example, are differences in coronary heart disease the result of variations in physical factors (such as the degree to which people smoke or eat unhealthily in different classes) or are they also caused by sociological, stress-related factors associated with one's position in society and at work?[22] Very often this can be confused as a value debate, with those adopting a particular view on the evidence becoming associated with a value position related to it – such as reading into an assertion that income inequalities are not proven to cause ill health, a value position that income inequalities are not important in themselves. These imputations of ethical viewpoint cannot be derived from the empirical debate.

Perhaps there does exist on occasion a deeper value dissonance hidden beneath the empirical work. Given the complexity of the evidence it is possible to make a case for a variety of policies, depending on whether one is more or less comfortable with an unequal society. If one believes that the basic structure of a capitalist society as a form of social organisation is inevitable or valuable, then one might be led to propose policies focused on particular aspects of that society, such as poor housing. However, if one's value position abhors all income inequality, then more radical proposals may be adopted. The issue is further confused by additional *empirical* questions about the extent to which capitalism and inequalities are necessary drivers for wealth creation.

The essential point is that early scepticism, when the relationship between the environment and health status was suspected of being a statistical artefact, or that it was not one of 'cause and effect', has now been laid to rest by increasingly rich and robust scientific evidence.[23] However, what action to take as a *consequence* of empirical research does involve a debate about values. Of course, where the causes of ill health are currently unalterable (as with many genetic risk factors) there is little that public health measures can do beyond providing data to health delivery and research agencies. But most aspects of ill health do have some link to the physical and social environment, and thus most are in principle amenable to policies directed at these environments. Furthermore, most determinants of health are socially distributed and thus relate to the inequalities debate.

The problem is that correcting (avoidable) unequal health experiences is likely to be hugely costly. Take the response of Patrick Jenkin, the (then) Government minister, to the Black Report of 1980 which argued that health inequalities are so deep-rooted that only a major and wide-ranging programme of public expenditure was capable of altering the pattern:

> *I must make it clear that additional expenditure on the scale which could result from the report's recommendations – the amount involved could be upwards of £2 billion a year – is quite unrealistic in present or any foreseeable economic circumstances.*[24]

Such a sum would have to come either from taxation or out of other areas of public (including NHS) expenditure. Thus the value debate becomes one of establishing how much 'others' should have to give up in order to achieve a more equitable distribution of health. Most policies designed subsequently to target specific aspects of deprivation (such as housing, family poverty, unemployment, child care, education), and which would thus avoid the need for overwhelming change to the balance of public expenditure, still have a significant price tag.[25] In short, the question is 'Whose claims are to be given the greatest weight in the contest for society's resources?'. The Conservative Government in 1980 may have made the case that the sums involved were not justified because the empirical evidence was insufficiently robust at the time. But even now that these links are less controversial empirically, the case for raising the sums of money required still involves difficult value choices. Subsequent Conservative Governments clearly did not believe that the cost was worth the potential benefit. The Blair Government is committed to tackling health inequalities but the amounts of money available remain tightly constrained.

The issues do not always relate directly to inequalities. Policies to reduce urban traffic can be defended in terms of the effect on people's health generally, as can policies to curb pollution and restrict the combustion of fossil fuels. But these policies may be opposed by those who value their freedom to use a car, or by those who might suffer through changes in employment in car production. The costs of such policies must therefore also be measured in terms of the impact on people's lives, including their employment. Some of these effects may be only temporary if people go on to obtain

employment in industries which do not conflict with achieving health improvements; nevertheless the personal cost of such a shift may be real enough.

Despite the many points of disagreement, it is striking that inequalities in the experience of health are very rarely claimed to be irrelevant in ethical terms. It is unusual even to find a specifically non-empirical discussion of the rights and wrongs of health inequalities. When such issues are subjected to a value-based evaluation, a typical conclusion is that inequalities are indeed unethical and that something needs to be done.[26] Others are more sophisticated, and argue that some inequality might be justified but only if it represents informed choices made by people under the same initial conditions.[27] However, the nature of 'free choice' is a complex matter in health care, as elsewhere, and the conclusion is typically that most 'freedom of choice' is itself unequally distributed (as a result of constraints such as income levels) or that the outcomes are not truly chosen (we do not choose to get lung cancer through smoking, we choose only to take a risk). This apparently limited choice over our health may provide a clue as to why health inequalities provoke so much ethical concern, something we revisit below.

Even those reviewing specifically where there may be 'acceptable inequalities' in health and health care conclude only that '*some* inequalities are inevitable … [and] that the pursuit of equality in health care is undesirable if *pushed too far*'[28] – not that health inequalities are generally acceptable of themselves. This should be contrasted with the more widespread and acute disagreement over the ethical position of general income inequalities, and the notion that social justice may even be a 'mirage'.[29] In health, it seems, the question is how to balance our discontent with the unequal health status of various groups in society against the high cost of correcting such inequalities and the restrictions on freedoms which correcting them may imply. It is policies directed at these latter restrictions to which we now turn.

2.3 Policies which seek to influence individual behaviour

There is little disagreement that engaging in certain activities affects health, for example smoking, certain types of diet and insufficient exercise are all implicated. Although the evidence for these effects depends on large-scale statistical surveys, rather more

straightforward examples are available – driving at 100 miles per hour while drunk is a good way of endangering one's own life (as well as others').

However, it is rare for any of these activities to have anything other than a probabilistic effect. Even the reckless car driver could carry on for years, perfectly unharmed. Thus we are concerned here with risks and probabilities. Even where the probability of an activity causing a given outcome is known with some certainty[30] (where the evidence on the chance we are taking is very good, such as with smoking) the event itself is not bound to happen. As a consequence, people cannot straightforwardly be described as irrational if they undertake some of these risky activities – the pleasure derived from smoking, eating fatty food and driving fast while drunk may be felt to outweigh the possible catastrophic outcome. This may not seem sensible to many of us, but at least as far back as John Stuart Mill's *On Liberty* we have valued the 'right' of individuals to make up their own minds about what is in their own interests. The problem with state interference is perceived in these terms:

> *the strongest of all arguments against the interference of the public with purely personal conduct, is that when it does interfere, the odds are that it interferes wrongly, and in the wrong place.*[31]

This leads to one of the biggest questions in public health ethics: to what extent should the state allow us the 'freedom to be foolish'?[32] Or, to put it another way, what is the legitimate role of paternalism in public health – can the state legitimately act to protect us from ourselves?[33]

It is not always clear that undertaking risky behaviour is foolish at all. Many risky jobs – such as deep-sea diving, construction work or mining – are compensated in terms of higher wages.[34] But even here the state intervenes to set upper limits on the kind of risks that can be taken – for example, safety standards must be complied with. Such action imposes costs on businesses which may be a less efficient form of production than if individual workers voluntarily accepted these higher risks in return for still higher wages. The imposition of standards effectively disallows such choices. But the problem is knowing what constitutes a truly free and voluntary decision and whether in

any case such decisions should be disallowed to protect people from their own 'irresponsible' actions. At any rate, deciding the 'correct' level of risk which people should be exposed to at work is fraught with ethical difficulties.[35] Even where there is no monetary reward, complete security is impossible to achieve.

It may be thought that at the very least providing accurate information about risk would be a universally value-free policy. But even this has been challenged on an ethical basis. Continually reminding people of the risks they are running may promote a culture of anxiety and insecurity, and denies people the possibility of living in 'blissful ignorance', a situation exacerbated by always presenting risks in terms which emphasise the chance of harmful consequences rather than safe outcomes.[36]

Matters become even more complicated when a significant degree of uncertainty is involved. People may wish to gamble when they have a reasonable idea about the probabilities, but they may be less willing to do so when these probabilities are unknown. For example, the threat to human health posed by genetically modified (GM) food is more or less unknown: it could either wipe out humankind or leave us better nourished than ever. But the ground-swell of public opinion opposed to the widespread introduction of GM organisms indicates that such uncertainties are feared. The answer would appear to be scientific trials to establish the relevant probabilities, but these trials are themselves considered of uncertain risk. And, ultimately, a trial cannot truly replicate 'real life' so the uncertainty about what will happen if GM food production becomes the norm will always remain.

Leaving aside questions of probabilities and rational desires to gamble with our health, there is another issue in public health ethics surrounding the nature of choices – what constitutes a 'free' choice? We may accept that we act *as if* we are free in many circumstances – I choose whether to go to the gym five times a week or to eat a low-fat diet. But where does this choice come from? Is it really down to a simple question of will – of reflecting on my likes and dislikes subject to my resource constraints, and then acting on these preferences? Or are my preferences themselves constructed in some way by society, by the pressures of my peers or by other forms of socialisation? Am I constrained by weakness of the will – I know what I'd like to do (what is really good for me) but I am continually tempted to do otherwise. Or, more fundamentally,

are my preferences completely fixed with no actual free will at all – in other words, are my preferences 'programmed', limiting my ability to avoid acting upon them?[37] These questions are profound but of crucial importance for policy-making because they will influence how much responsibility individuals might be expected to take for their actions. Such questions are sometimes characterised as issues in epidemiological theory, to be distinguished from questions of causal science.[38] The latter involves the empirical investigation of statistical relationships whereas the former involves theorising about *why* people choose to act in the ways they do.

The notion that we may be responsible for our actions opens up another ethical issue already noted above: the possibility of stigmatising certain groups in society.[39] If you drink heavily, take drugs, or are sexually promiscuous, and these remain minority pursuits, these activities are likely to be perceived as threats to accepted cultural norms and prevailing morals and in turn as problems to be contained and punished rather than subjected to public health measures. Even if criminal sanctions are not always the result, general social opprobrium can be fostered by those with certain political views. On occasion, the endeavours of public health researchers can inadvertently add to the problem. A public health initiative to address violence can quickly become mired in political issues around the prevalence of crime in certain ethnic communities – particularly young black men.[40] Public health measures can thus potentially reinforce discrimination through policies implemented in good faith. AIDS was exempted from routine testing, reporting and notification in the US precisely because:

> there had never before been a disease that seemed to constitute a de facto *marker for homosexuality, with all the social stigma that this label carries [and furthermore] the confidentiality of testing would inevitably be violated, precisely because AIDS is more stigmatized.*[41]

Attempting to combat public health issues which have at least *prima facie* claims to be related to issues of choice can thereby alert a disapproving majority to the culpability of those failing to take responsibility for their actions. But even if criminalising or stigmatising certain groups in relation to 'unhealthy' activities is unlikely to gain acceptability amongst policy-makers, there remains the awkward question of what position to take about personal responsibility. Presumably we have some control over our willingness to smoke, even if the social pressures are great. Most activities thought

to be bad for an individual are likely to have consequences for others as well; if our decisions affect others (the transmission of HIV is a prime example) to what extent can we expect public health policies to exempt us from certain obligations because of problems of stigmatisation? And even where stigma is not an issue, how can we establish the circumstances under which it is ethically justifiable to expect people to shoulder responsibility for their own behaviour?

2.4 Policies to promote screening

Screening has been defined as:

> *a preventative activity which seeks to identify an unsuspected disease or pre-disease condition for which an effective intervention is available.*[42]

A further factor is appended by the National Screening Committee of the Health Departments of Great Britain, which emphasised that screening involves 'persons who have *not* sought medical attention on account of symptoms of [the] disorder [in question]'.[43] Screening is surrounded by such an aura of respectability and good sense that it is not immediately clear what ethical issues could be involved. It embodies apparently impeccable prudence in anticipating problems, thus saving time, distress and resources.

However, matters are rarely so straightforward, and with screening the key ethical issues derive from the fact that most patients do not voluntarily request screening because they feel unwell; rather they are invited as part of a programme designed to improve population health. This raises the possibility that individuals may be put under pressure to undertake a test. A number of factors make this problematic.[44] Screening is a clinical intervention and is associated with discomfort, anxiety and inconvenience. It may also have health risks. In some cases false positive or false negative results will occur. Catching a disease early does not guarantee its cure, and may simply lengthen the period of time the patient must suffer the knowledge of its existence. Of course, all these factors may be perfectly acceptable to the patient, and are not unethical in themselves. The question becomes one of consent and whether, and in what circumstances, a potential participant can be considered to have been provided with

sufficient information to offer *informed* consent. Clearly there is ample opportunity for health professionals to bias the provision of this information to increase take-up rates.

A screening programme may alternatively be directed at establishing the prevalence of a disease in society. It may be helpful to the scientific community, in the quest for treatment or preventive mechanisms, to understand how widespread a disease is, and amongst which social groups. In those mass screening programmes where the tests are not directed at high-risk groups, such as using blood samples obtained in hospital for other purposes, it may not be possible to obtain consent.[45] Or, if consent could be obtained, this may invalidate the sample because it would no longer be truly representative. These difficulties may be particularly acute if the disease in question is severe and does not yet have a cure. Such issues came to the fore with the spread of AIDS in the 1980s and 1990s. One eminent epidemiologist, Sir Richard Doll, argued for the anonymous screening for HIV of blood samples where the link between the sample and an identifiable individual was entirely removed: 'How it can be unethical is incomprehensible, as it can do no possible harm to anyone and could do much good'.[46] However, others argued that this countermined fundamental rights to decide the limits on what others may do with our bodies or their constituent parts.[47] It has also been argued that mandatory screening of pregnant mothers for HIV in order to protect unborn children is not sufficient reason to override the mother's right to refuse such an intervention.[48]

The definition of screening above includes the phrase 'for which an effective intervention is available'; screening has also been challenged more generally on efficiency grounds, namely that it is not necessarily a good use of society's resources.[49] For example, there may be no additional benefit from frequent screening (annually, rather than every three years, for example). Or, simply, the screening procedure may not assist the effectiveness of available therapies, perhaps because pre-symptomatic identification is clinically of little value. It must also be remembered that screening imposes personal as well as financial costs, which must be weighed against the benefits. Particular screening programmes for prostate cancer and breast cancer, and general population screening for high blood cholesterol, have all been criticised on grounds such as these.[50] But even if screening is apparently poor value for money, the ethical

debate is not concluded, since the refusal or termination of a particular programme will affect an identifiable group within a population. Such a group may argue that it has a claim to the service for other reasons, such as its already disadvantaged position in society.

Finally, screening may be advocated to identify individuals who, knowingly or otherwise, carry an infectious agent, so that they can be prevented from passing it on by quarantine, education or other more or less coercive methods.[51] Such a policy will depend on whether the preventive measure will work, but also raises issues of stigmatisation, common to many categories of ill health but particularly acute in the case of HIV and AIDS. If people are identified as carriers of a disease, they may be more likely to suffer various forms of discrimination from employers or insurers.

Genetic technologies bring some of these issues into particularly sharp focus.[52] Most significantly, genetic screening is concerned solely with establishing probabilities of disease development, and not with identifying early onset. Should public funds be used to perform only potentially preventive procedures in these circumstances (mastectomy, for example, in women with higher risk of breast cancer)? Where an unborn child has a risk of disease or disability, to what extent can we legitimately use genetic information as a reason to undertake abortions? There is a possibility that terminating all potentially unhealthy foetuses will increasingly stigmatise disabled people. More fundamentally, many people are uncomfortable about the potential that genetic testing will have to enable the 'design' of children in term of sex, colouring and other physical characteristics.

Genetic testing also raises issues of information. To what extent can people demand information (which is expensive) on their genetic make-up? Is it the role of the NHS to give information which may simply be used to obtain favourable treatment from life assurance companies, or even to obtain a mortgage? Or is such provision defensible on the basis that genetic information may be used to adopt a suitable lifestyle, or aid decisions about whether to have children? Alternatively, if genetic information has to be bought this might unfairly discriminate against those who cannot afford it. Genetic information is also unusual in that it cannot always be privately held by the recipient: for example, a mother who uses her knowledge that she is a carrier of a breast cancer

gene to obtain prophylactic treatment is 'imposing' the knowledge of increased risk onto her children. And to what extent should insurers be allowed to ask for genetic information before supplying cover? This would increase actuarial 'fairness', but also prove more costly for those most likely to suffer ill health – who are also the most likely to have low incomes.

Genetic treatment, such as germ-line therapy (which affects future generations) or somatic therapy (which does not), raises further issues about the limits of public health and medicine.[53] Here, issues of public health and of clinical medicine collide: concerns exist about permanent mistakes being introduced into the gene pool (similar to some of the issues surrounding GM foods) and about the increasingly likely prospect of treatments to enhance already healthy individuals.

2.5 Policies to promote immunisation

The principal rationale for immunisation programmes is that individual action alone may not be sufficient to protect against infectious diseases spreading through society. One person's unwillingness to be vaccinated can impose costs on another who might otherwise have been protected. For some diseases (such as rubella, mumps, diphtheria, tetanus and poliomyelitis) effective population immunity can be the result if sufficiently high numbers (typically over 90 per cent) can be immunised whilst they are children – the so called 'herd immunity'. For this reason, some have suggested that there is a strong case for mandatory immunisations even in the face of counter-arguments in terms of patient rights.[54] Those in favour of mandatory immunisation argue that it is not reasonable to invoke one's 'right' to deny treatment if this may cause harm to someone else. Furthermore, the stress which avoidable illnesses can place on health care systems can affect the chance which others have to obtain treatment – witness the cancelled operations in the wake of the British influenza outbreak in January 2000. These examples of the 'spillover' benefits of immunisation add to the more straightforward wish for people to avoid unpleasant illness themselves.

Some countries have effectively introduced compulsory immunisation; in the US, vaccination is required for school entry and this policy has survived court challenges.[55] However, there is much ethical nervousness about coercing people into receiving

medical interventions, even where there is a community gain at stake. In fact, most commentators come down against compulsion.[56] Their reasoning is based in part on the ethical cost of overriding individual liberty, but also that policies other than compulsion are available, such as compensating people who develop adverse reactions to the vaccine (and which therefore deter take-up) or introducing financial incentives to family practitioners who achieve target levels of cover amongst their patients.[57] If such non-coercive means can achieve high coverage, then the benefits of herd immunity can be achieved, even if some individuals 'free-ride' on the actions of others. The costs of failure, however, may be high: financially; in terms of lives lost; and possibly strengthening an infectious agent's hold in a population.

Others have noted that compulsion can itself have unintended costs, even if the primary objective is achieved. In a study of the South Asian smallpox-eradication campaign it was noted that coercive methods in the final stages succeeded in ensuring disease containment in the short run, but also invoked popular and professional resentment which may in the long run have fostered negative attitudes toward subsequent vaccination campaigns.[58]

2.6 Policies to improve sexual and reproductive health

The central issue in questions of reproductive technologies and sexual health revolve around the legitimate boundaries to 'health' issues, noted above. We may all accept that AIDS is a disease, alongside other sexually transmitted infections, and that these therefore are genuine public health issues. But beyond this, sexual reproduction raises a host of ethical questions about well-being which, though important to people, may not automatically be considered health-related. These range from abortion and contraception, to surrogacy, to the rights of lesbians and gay men to become parents.[59] The questions here involve the potential well-being or 'health' of children or future children. Not just 'does a foetus have a right to life?', but 'does it have a right to a "decent" life?', and what constitutes a decent life? For although the health or well-being of children brought up in various circumstances is to some extent an empirical question, where to draw the line in relation to minimum standards is not.

Ethical questions apply directly to the status of the embryo. How far can we go in manipulating our fertility (including decisions to have an abortion) in order to 'design' the baby of our choice? Should the unwanted embryo be offered for medical research, possibly to contribute to the health of future generations? All of this leads us to consider whether there are signs of a re-emerging issue of eugenics, whereby the whole character and shape of future generations comes within the control of the current generation.[60]

As also noted above, public health policies may unwittingly serve to stigmatise minority groups, or open them to discrimination, or even to encourage general moral denigration. Young teenage mothers have been exposed to this last possibility in the UK where social welfare benefits of various kinds have been criticised as encouraging irresponsible behaviour. This raises wider questions about sex education for children and its place in the public health sphere.[61] Some argue that more, possibly compulsory, sex education at school would limit the number of unwanted teenage pregnancies; others argue that this encourages underage sex. This is clearly an empirical question, but even if that issue could be resolved, the ethical debate would not disappear. Whether, and at what age, children should be taught about sex, and be permitted to be sexually active and become parents themselves, divides people on fundamental grounds which may have little to do with anyone's health.

Finally, overpopulation may be considered as a problem in itself, and some regard it as a cause of hunger and deprivation in some parts of the world. Therefore, policies on birth control can move from being a response to a desire for individuals to control their fertility for personal reasons, to one of a community perspective on the sustainability of a society.

2.7 Concluding comment: facts and values

One of the principles which has run through this discussion has been the importance of distinguishing issues of empirical fact from those of value judgements. That is, we are not here concerned with the actual state of the world, but with how we think it ought to be organised. This is an important distinction to make even when it is acknowledged that empirical research is itself controversial. We have noted that some people think

there are biases in the way that research is currently conducted, and in what is accepted to constitute good evidence. However, even when people differ about methods for researching the state of the world – such as on the relative importance of lay beliefs versus those of experts – this is not a value distinction in the sense understood in this report. Rather, it is a difference of opinion on how we can understand the world, but still with the same objective of finding out what *is* rather than what ought to be.

Value questions do arise concerning who is to make the final judgement when evidence is ambiguous, whether empirical information can ever be withheld by the state, or whether it can be demanded by the individual regardless of its cost. For example, the evidence on what exactly is the risk of contracting new-variant CJD from eating beef is highly contentious, but not a value debate; whether we should be allowed to eat beef despite the risk, and who decides and by what process, *is* a value debate. These are important issues of value about the process of transforming empirical evidence into substantive action and collective decisions.

3. Public health values

What are the values which lie behind the issues raised in Chapter 2? In this chapter we review seven values which synthesise the various ethical concerns implied by those issues. Values are 'concepts of the ethically desirable'[62]; public values relate to state activity (not to what the values of the general public might be). The terms 'ethics', morals' and 'values' are very nearly synonymous for our purposes, all dealing with questions of right and wrong actions, and good and bad states of affairs. A 'value' simply implies a *positive* moral or ethical concept (a *dis*value might indicate an unethical action or state of affairs).

The seven values distilled from the preceding discussions are:

- equity

- compassion and altruism

- security

- efficiency

- freedom and autonomy

- democracy

- health.

It is perhaps not surprising that these represent largely the same set of values elicited from the literature with respect to the NHS and reviewed in the companion report.[63] Similar positions on questions of right and wrong crop up right across the public policy spectrum. However, one of the values established in the earlier report does not re-emerge separately here: 'respect for human dignity' relates specifically to the interaction of individuals in the context of service delivery. Its absence here does not mean that *in general* this value is not important in the public health field. Other values have been given slightly different headings reflecting the different context of public health.

3.1 Equity

Most of us agree on the importance of equity as a formal concept, but there is little consensus on how to apply it. At least since the time of Aristotle, there has been an understanding that people should get their fair shares, that everyone should only have what is their 'due', and that inequalities between people in these shares should reflect only morally relevant differences. 'Like' people should be treated equally (horizontal equity), and 'unlikes' should be treated unequally as long as their dissimilarities are morally defensible (vertical equity).

It is beyond the scope of this report to outline all the competing theories of what this means in practice, or of what the relevant differences are between people, let alone to establish what the favoured version of equity should be. Nevertheless, there is no doubt that where health is concerned, equity is a key value. If some people are seen to be in poorer health than others then very often this is sufficient reason for the situation to be considered unfair, even if we pragmatically accept that achieving absolute equality of health status for all is an impossible ideal. The distribution of access to health care should also be fair – the NHS is universally available and treatment is not allocated on the basis of ability to pay. All this clearly requires the state to act: 'fairness' cannot result from the disaggregated decisions of thousands of private choices – there must be a single point of reference to set the terms of a fair distribution and to encourage or force its implementation.

However, equity is not always invoked as a relevant value for state activity when inequalities are observed. When nothing can be done to ameliorate certain forms of ill health, then inequalities in their incidence would not be considered inequitable. Furthermore, on occasion people appear to contribute to their own ill health, which can lead to the claim that some inequalities in health may be fair as they are, and require no further intervention. Such considerations are also sometimes argued to be relevant to the conditions of access to treatment. Equity is also invoked less when a benefit (such as gender reassignment or cosmetic surgery) is considered not to 'count' as a health issue.[64] Nevertheless, equity is a persistent and powerful value which emerges from the controversies outlined above and which reflects a concern that the distribution of health

amongst the population matters, and that it should not simply emerge out of the free play of individual decisions.

3.2 Compassion and altruism

Intimately tied up with equity are notions of altruism, compassion, of caring for others and serving the community. In the companion report, these values were discussed under the heading 'public service'. Properly speaking, they reflect a different kind of value from equity. Equity is a collective concern with how benefits are distributed between people, and with formal theoretical defences of any particular distribution. On the other hand, altruism and caring for others involves a value about a particular form of human motivation – selflessness and putting others before oneself. Although the value of fairness may overlap with the value of selflessness, this does not automatically apply to those, for example, who simply support fairness out of a sense of duty and obligation. Alternatively, 'compassion' may have little concern for the overall distribution of welfare, and focus instead on a single individual – no matter how formally 'just' their circumstances may be. So compassion and altruism may go beyond equity; they may also conflict with equity by allowing pity and fellow-feeling to confuse what is just.

It may be that such a value emerges more regularly in the context of health services, where a single individual is at stake – the 'rule of rescue', for example, which urges us to expend vast quantities of money on a single, very nearly, hopeless case. Perhaps the nearest equivalent in public health would be efforts to rescue lost pot-holers or single-handed sailors in the middle of the Atlantic. However, although specific examples are difficult to identify in a subject which focuses on general populations and conditions, this is nevertheless a value which very often motivates actions towards those in the direst need, such as homeless people or drug users, for whom formally speaking justice may already have been secured.

3.3 Security

In the companion report, the concept of security was discussed in terms of 'universalism', a value governing access to the NHS. Whereas equity is concerned with

the distribution of benefits, universalism establishes that no one can be excluded from the service on the grounds that they have a high income. Such people might nevertheless fail to provide for themselves, perhaps by deciding not to take out private insurance. Thus universalism ensures that people could not leave themselves without care, adding to their security.

The idea of security reflects the importance we place on controlling the future. Dreadful things can befall us in a wide variety of ways, and most of our daily activities have some kind of influence on our future health. In general we are 'risk averse' – we prefer the certainty of £10 to accepting a probability distribution where the mean is £10 but with an equal chance of receiving more or less. In the private sector, we take out insurance for some types of risk. Action is also taken by the state to ensure a certain degree of limitation on what can befall us, or the financial consequences of such eventualities. These include a wide range of policy interventions, from health and safety regulations, universal NHS access, the taxation of unhealthy activities, and compulsory use of seat-belts.

It may be asked why security is not just a private want rather than a public value. Public values are conceptions of the morally desirable, indicating that individuals do not consider it a matter of disinterest what others' views are on the value in question. In contrast, could we not argue that the degree of security which any individual desires is exactly that, a matter solely for that individual? Individuals differ on how important security is to them, just as they do on many other matters.

However, we are here simply noting that there exists a view of the value of security which involves a belief that people should be protected from taking risks *irrespective* of what they might profess is in their interests. Such a view is often referred to as paternalistic, a term with pejorative overtones but long heritage.[65] For example, it may be considered that individuals will misjudge information on safety, if that is all they are provided with, and act in ways that will damage their future interests (the *provision* of information itself is governed by other values, such as efficiency). In other words, security is not just a matter of private taste, but one which rightly involves wider public issues. Other concepts which are often mentioned, such as tradition and continuity, may also relate to this value of security. We feel more comfortable and secure when things

continue much as they have done before; change causes concern and disquiet. In this sense, security values probably work against radicalism in many of its forms.

3.4 Efficiency

Efficiency as a value in public health has a number of interpretations. In general terms it involves a desire to get the most out of the resources available, in particular by paying attention to the costs of actions and decisions. Sometimes this may involve simply maximising the output of a particular benefit, including health, for a given cost – what is known as technical efficiency. However, efficiency may also be applied to policy *objectives*. Thus a policy targeted at achieving equity may involve a choice between various strategies, each of which appear equally effective but some less costly than others. Efficiency demands the least costly option. It also demands good evidence about what works, and on cause-and-effect relationships. Much of the debate about health inequalities and the determinants of health implies a value relating to efficiency – that of good evidence. In order to be efficient, we must obtain a good empirical knowledge of the world.

The value of efficiency also depends on human agents being able to enter into exchange relations with one another to obtain the things they want. Each of us acting individually would achieve little. However, one of the ubiquitous manifestations of the process of exchange – markets – can 'fail' in economic terms. There are three kinds of reasons for the failure of markets: imperfect information, externalities and public goods, and monopolies and strategic behaviour.[66] In public health, the relevant market failures are principally in the first two categories. Most straightforwardly, poor information about the health effects of certain types of good may lead us to make poor choices, and in such cases the state may intervene to improve the level of information.

But market failure can also occur because of externalities – the fact that a private exchange or decision can 'spill over' and affect others.[67] The original parties to the exchange may not take these external effects into account – those who decide not to have a vaccination may not consider the potential cost they impose on others by passing on an infectious agent. Proper public hygiene provision is motivated by similar concerns. The private finance of rubbish collection may not achieve sufficient levels of

provision to avoid external costs – it takes only one or two people to decide to leave their rubbish rotting outside their front door to create a health risk to the whole community. Thus, the state may have a role in encouraging the take-up of vaccinations or subsidising rubbish collection, to more efficient levels which count all the costs imposed, not just the private ones. Externalities also complicate the question of risk. Some risks, such as eating a high-fat diet, essentially affect us individually. However, other risks and uncertainties, such as use of GM crops or nuclear power, are collectively experienced. Exposing people to these risks may require a greater degree of justification than their 'individual' counterparts, for now the risk exposure applies to people who do not choose it.

Another form of efficiency involves the maximisation of a particular beneficial outcome. Correcting market failures involves a desire to maximise welfare in society. But even if there is no market failure there may still be a wish to maximise a particular aspect of welfare, such as health. Such a motivation can be seen in the general desire of government to see decreasing levels of mortality and morbidity. However, efficiency as maximisation requires further explanation of why the particular focus (in this case, health) has been chosen. This will typically require reference to other values – including market failure. It is very easy to slip into circular justifications which essentially claim that it is good for the state to promote health just because it is health. We return below to the question of whether health alone constitutes a value.

It is also claimed that 'maximisation' policies will increase the general productive (non-health) capacity of people and thus the 'efficiency' of the economy. However, these objectives are only *socially* efficient in so far as they are agreed to be the appropriate objectives to pursue. The overall income level of the economy is the aggregate income of the individuals in it. People may wish to take risks with their health for immediate gratification, and consequently take a chance with their own future affluence. In other words, a less productive economy may simply reflect the aggregate consequence of the rationally taken decisions of the individuals within it. Respecting these decisions reflects the value of autonomy, to which we now turn.

3.5 Freedom and autonomy

What if individual choices lead to lower levels of aggregate health outcome than some might consider prudent? Freedom, autonomy and choice are key values in the public health debate, but they are also easily manipulated terms. To distinguish a clear meaning from other values we are not referring under this heading to the possibility that freedom or autonomy can be *increased* by restrictions on what people are allowed to do. For example, it could be argued that obliging the wearing of seat-belts, or the provision of a universal national health care system, *increases* autonomy by lessening the chance that people are severely afflicted by ill health which in turn diminishes choice. To include this understanding of autonomy with the more straightforward understanding – the absence of restraints in deliberately and rationally constructing plans and making decisions based on one's desires – is to confuse the essence of the latter value in the broader term.[68] We deal with the values which relate to expanding the range of our choices and potentials under other headings, particularly equity and security. Here the emphasis is on the value of being the author of one's own destiny.

This value runs right through the issues noted above, particularly when the possibility is mooted for the state to act to compel or prohibit certain activities. At first it may seem curious that anyone should choose to be unhealthy. But of course decisions about 'being healthy' are complex. Clinicians have been under pressure for many years to allow patients more choice over whether they want treatment, precisely because many treatments are only marginally beneficial and are often associated with harmful side-effects. It is increasingly acknowledged that the patient should be provided with full information which will allow them to make such a choice autonomously (that is, without someone 'protecting' them from full knowledge of the costs and benefits). So it is with public health: people may judge that the beneficial outcome from a screening programme in health terms is marginal, or that they would prefer to avoid the possibility of suffering ill-effects from the intervention itself. Fundamentally, they might simply resent the state interfering in their affairs.

More generally, decisions about promoting health are based on probabilities and uncertainties about whether a policy will have the desired effect, and what other harmful effects it may have in addition. Water fluoridation perhaps offers the clearest

example of these concerns,[69] but so do many screening and immunisation policies. Promotional or fiscal campaigns to discourage clearly unhealthy activities such as smoking implicitly acknowledge the value of autonomy by *not* outlawing the activity outright. The apparent contentment of some people to take on risky jobs perhaps illustrates the case even more acutely: individuals may decide that their interests are best served by risking life and limb for a high reward. The possibility of ill health certainly does not allow us to ignore the value of autonomy.

3.6 Democracy

Democracy is not a value which emerges explicitly from the issues described in Chapter 2. However, the question of democratic legitimacy pervades these debates because democracy is a value which underpins the authority of the state to implement any public policy. In short, any activity based on public values, through the specific policy instruments of public health or anything else, requires the consent of the people.

Democracy is fundamentally an instrumental value but with intrinsic elements. For example, we may value living in a democratic society, even if every policy decision taken in that society goes against our wishes. In other words, we value the process intrinsically, for its own sake – what has been called 'participation altruism'.[70] Such ideas provide an explanation of why people vote at all when the likely influence on the overall outcome for any one individual is negligible (imagine the probability that one's own vote would sway a general election), whilst the inconvenience of voting affects everyone. Other reasons for the popularity of voting include the possibility that people know that they are contributing to the continuation of democracy itself.

However, even these observations cannot altogether avoid the conclusion that democracy is of instrumental value – that ultimately it depends on it providing *outcomes* which are indeed better than the alternatives. If it were not so we may become inclined to ditch it and try another system. Democracies which have impoverished their citizens may not look so attractive next to benign tyrannies that made people rich. But the instrumentality of democracy is nonetheless generally considered of such importance that it deserves a separate place in our taxonomy.

3.7 Health

The value 'health' is perhaps not as straightforward as at first sight. We have noted that values in the sense understood here involve conceptions of the morally desirable. We are also concerned with collective action and the state. So public values are not like private judgements about the economic value of a new car, nor like issues of private morality such as whether we have acted as a true and consistent friend or family member. We are concerned here with the role of the state intervening to promote morally desirable ends, and we have noted why equity and security, for example, might require state action with regard to health. But why should health be a public value *beyond and in addition to* the other values noted above?

This question can be turned around. Consider circumstances where all the other values have been satisfied – there is no question of inequity, the provision of health care appears efficient, the situation is not dogged by risk or uncertainties, democratic procedures have been adhered to, and autonomy is protected. Such situations, one immediately suspects, are few and far between. Nevertheless, in these 'ideal' circumstances, one might expect that an individual can here at least consider health to be a personal matter which is no longer of public concern. We do not require a 'health' value.

However, there are one or two examples where such a value seems to emerge. Typically, these involve the denial of life-saving treatment by the individual concerned, or a request for the removal of life-sustaining treatment. Euthanasia is a well-known policy relating to the latter case; strong religious beliefs leading to a rejection of blood transfusions is an example of the former. Even when these decisions are made by unequivocally fully autonomous individuals (i.e., not young children, nor people with mental disabilities), interventions have been made to impose treatment.

It might still be argued that another of the values noted above – altruism or compassion – can serve to explain this kind of behaviour. Our revulsion at someone's suffering is simply too great to stand by and allow their (autonomously made) decision to stand – we simply must intervene to alleviate their pain and suffering. Another possible explanation in terms of the values above, also relating to altruism, is known by economists as the 'caring externality' – one person's ill health becomes a kind of

'psychic cost' imposed on others.[71] Inefficiency of a rather peculiar kind can then be said to result, because the person refusing treatment does not take account of this external cost. Such a view of the issue would imply that the 'health' value becomes one which should be discussed within 'efficiency' above.

Nevertheless, in some cases where people actively want their own death or mutilation, allowing people to act on such a desire seems to offend some fundamental understanding of what it means to be human.[72] This has resonance with religious beliefs that the right to end one's life belongs only to God, or with more 'rationalist' views such as those of Immanuel Kant who believed that it was wrong for rational people to act to end that very rationality which gives us our moral quality (similar perhaps to Mill's injunction that we are not free to relinquish our freedom and thus enter into voluntary slavery). Or perhaps people who wish to inflict harm on themselves simply create a sense of unease amongst the rest of us, which we feel impelled to resist. Or maybe we dislike the implication of such actions for the continuation of the species. It is worth remembering that the law often reflects such feelings – as recently as 1961 in the UK suicide was still illegal.

In conclusion, these arguments comprise just about enough moral reasoning to indicate that the value of 'health' should remain independent of others, reflecting some abhorrence of people wishing death or ill health rather than an alternative. We thus retain it in the taxonomy of values, but with reluctance and an acknowledgement that health as a public value, rather paradoxically, is the least robust and most morally questionable of them all.

4. Conflicts and synergies

In this chapter we will draw together the issues raised in Chapter 2 with the values discussed in Chapter 3. We have seen how concerns about equity, compassion, security and efficiency require state action to ensure their application. Democracy involves a value about the general form the process should take for deciding how to apply them. Autonomy represents a value that the state should be limited in the extent to which it can influence and constrain people's own decisions. Health itself seems to constitute a value in extreme circumstances.

One of the central themes of the companion report[73] was that pursuing values in the context of the NHS inevitably involves trading off one value against another. It was suggested that it is simply impossible to achieve all values simultaneously: doing better along one dimension, say equity, might involve doing rather worse on another, such as autonomy. Here we revisit this issue, but in addition we will investigate the possibility that certain values can work in harmony with one another.

4.1 Value trade-offs

The most controversial issues in public health ethics involve a fundamental conflict between autonomy and a number of the other values. Take the tension between *efficiency and autonomy.* The desire of the state to intervene to restrict the spread of disease is partly motivated by a desire to assist in the *efficient* control of disease. People acting individually may do too little to achieve an efficient outcome. The state moves in either to make immunisations easily accessible, by minimising their cost for example, or more coercively by making some kinds of immunisation mandatory. But this latter option is fiercely resisted by people who believe it to threaten their autonomy – there are always those who would wish to avoid such interventions. Screening for AIDS illustrates the point well: people feared that they would subsequently be discriminated against, and this had to be weighed against a potentially better understanding of the disease. So even when the value of efficiency is invoked in order to reflect the good that can accrue to everyone, the value of autonomy may ultimately limit how far this can be achieved. What steps would we be willing to take to

encourage people to take influenza immunisations to prevent a recurrence of the recent NHS crisis? Even apparently 'technical' values such as efficiency must ultimately be balanced against autonomy.

This becomes even more acute when we consider the conflict of *security with autonomy*. With these values, the tension is essentially between protecting people from themselves and allowing people to harm themselves or take the risk of doing so. It is difficult to find examples where such a conflict is undoubtedly taking place; very often it can be argued that the value in question is not security but something else. For example, it is often suggested that taxing cigarettes or enforcing the use of seat-belts is justified because it stops people unreasonably imposing a burden on the NHS and thus on others. However, there must be *additional* reasons for these policies because the state remains committed to reducing smoking; it does not simply say 'now that you are contributing to the costs of your health care, go ahead and smoke as much as you want'. Neither is it deemed perfectly acceptable to smoke in private where the smoke cannot affect anyone else. Instead of being legally required to use seat-belts or wear motorcycle helmets, people could be encouraged to pay an actuarial premium and remain free to choose not to use seat-belts or helmets. However, this is not considered an adequate policy response. Furthermore, the very fact that the NHS is a 'compulsory' service – no one is allowed to sell their place in the queue – indicates that there is a desire to prevent people from freely deciding not to take out insurance and take a chance with their health. Implementing such 'security' values must ultimately involve a trade-off with autonomy. In fact, autonomy is rarely entirely sacrificed by completely prohibiting people from activities which might damage their health. And when it is, as with eating beef on the bone, there is usually an outcry.

Less obviously, there is also a conflict between *equity and autonomy*. Perhaps the most significant public health issue is that of health inequalities, with deprived groups suffering worse health than better-off people. Public health policies can tackle the problem in two ways. The first involves measures to tackle inequity through in-kind provision: housing improvement, 'community development or regeneration', reducing smoking or otherwise influencing behaviour, or improving access to a whole host of services and facilities, including 'adequate sanitation, uncontaminated food supplies,

safer workplaces, and health and welfare services'.[74] The idea is that although many in-kind policies of this type will also benefit the better off, it is those in low-income groups who will chiefly benefit, thus reducing health inequalities.

The second strategy chiefly focuses on income levels, either by raising welfare benefits, introducing minimum wages, or generally improving macroeconomic performance. Ethically, the two strategies are quite different. Any income redistribution policy will involve an element of restriction of autonomy because of the need to raise taxes. But simply redistributing income does not interfere with the autonomy of the *recipient* – their increased income simply improves their ability to make choices which, in their view, best serve their interests. On the other hand, the policies which are provided in-kind – whether actual goods or services, advice or encouragement, or grants tied to certain community activity – restrict the recipient to the type of consumption deemed most likely to improve health. This invites the question of why should individuals not decide for themselves how to improve their lot. If the answer is that they might simply spend increased income on non-health-improving (or on health-damaging) consumption, then the response will come that allowing these choices respects people's autonomy – why interfere more than is necessary for equity in terms of people's command over resources? Furthermore, some public health policies such as restricting car use will automatically restrict the autonomy of those who value driving in their car. The tension between these two values is unavoidable. To the extent that health is itself a value, the preceding discussion should also sufficiently demonstrate its potential conflict with autonomy.

While conflicts between autonomy and other values constitute the main ethical tension in the public health sphere, other values may also come into conflict. Within the context of the NHS, the trade-off between *equity and efficiency* has become a commonplace in policy discussions. The trade-off can be overplayed – if the concern is simply to minimise waste in the pursuit of any objective, then efficiency does not conflict with any other value. Whatever we wish to achieve, we can presumably agree that we should achieve it at minimum cost. But in the sense of a choice between maximising an aggregate of health gain from health services, and ensuring a fair distribution of those gains, the issue runs right through the NHS. Should resources be focused purely where

they achieve the greatest health gain per unit cost, or should they be spread around more fairly to include some treatments which are less effective? In public health the issue may not be so prevalent, because there are fewer specific choices to be made between individual treatments or between individual patients or categories of patient. Public health measures tend to involve strategic decisions. However, this is not always the case. Screening programmes in particular are focused at particular categories of patient; they also rely on patients taking up the service offered. It has been suggested that these services are more likely to favour better-off people, who may be more aware that the service is available, or more able to make arrangements to use it; this issue may be even more acute in developing countries.[75] More controversially, it is suggested that a degree of inequality in society is necessary to create incentives and thus foster a dynamic and efficient economy.[76] To the extent that any general income equality will inevitably be accompanied by health inequalities, we will also be faced with the trade-off between macroeconomic efficiency and equity.

It is also worth noting some conflicts involving democracy which are seldom referred to in ethical debates. For example, take *democracy and efficiency.* The old, more representative, health authorities (pre-1991 NHS reforms) were often criticised for being unwieldy and time-consuming in their decision-making ability. The newer, executive-style authorities were designed to be more likely to 'get things done', but were shorn of their representative membership. There is a trade-off here. Endless rounds of public consultation and decision-making bodies packed with representatives from every corner of the community may well result in decisions not being made at all. This may be a highly democratic result in one sense (we all rarely unanimously agree on anything), but it is not effective if there is a pressing problem to be resolved. The conflict also emerges in the vexed issue of 'expert' opinion on certain matters. Whilst no one would support handing over decision-making to experts with no checks and balances, it seems equally unwise (inefficient) to subject every aspect of technical decision-making to be ratified be 'the people'. But where does one draw the line? When members of the public have been asked about who should have prime responsibility for making decisions in the public sector, the professionals (doctors) get overwhelming support – more than the elected representatives.[77] However, as many recent events have shown us in the Bristol children's heart surgery case and elsewhere,

some professionals can act in a high-handed and arrogant manner too. In other areas of life, public confidence is also damaged by scientists who proclaim certain institutions or policies to be 'safe' and are then proved spectacularly wrong. The balancing act seems to involve identifying those areas where experts can safely make their judgements, and those where the rest of us must be involved.

Democracy and equity can also come into sharp conflict when different decision-making bodies within a region or country come to different policy conclusions about identical issues. Water fluoridation operates in only some parts of the country; we saw the beef-on-the-bone ban lifted in Wales and Scotland sooner than in England. People observe others in identical circumstances (and with no apparently morally relevant differences) being treated quite differently. Such inequalities offend horizontal equity. We will revisit issues relating to democracy in Chapter 5, when we consider the specific question of public involvement.

Finally, it is worth emphasising that public health has to compete with the pursuit of other objectives in society. In other words, the values cited here are also relevant to aspects of consumption and welfare other than improving health (even if some of these may have knock-on effects for health). Education, transport and private consumption are all important to people, and so the values of equity, security and efficiency in health terms conflict with these same values in other areas of consumption.

4.2 Synergies between values

In some areas, different values can also act to promote one another, although we always need to be careful not to assume that this will necessarily happen, or that the synergy is 'perfect'. Perhaps the two values which sit together most comfortably are *equity and security*. Policies which successfully reduce inequalities in health are also likely to instil a greater sense of security in people: lessening difference in mortality rates between social classes should create conditions in which people are generally less fearful of serious life-threatening diseases.

Another potential synergy is between *efficiency and equity*: policies aimed at reducing health inequalities might also simultaneously be the best way of increasing the

aggregate health of the population. Water fluoridation, for example, has been argued to improve overall oral health beyond that achievable through individual market choice, whilst simultaneously reducing inequalities in oral health between social groups.[78] Thus, these two values can work both with and against each other, depending on how they are interpreted and on the context in which they operate.

There is also a potential synergy between *democracy* and other values, in addition to the conflicts noted above. Democratic procedures may support the promotion of equity, measures to increase aggregate health and efficiency, the protection of autonomy, and so on. Indeed, without democracy, it may be significantly more difficult to know which objectives are most valued by society. However, we should beware of assuming that the existence of democracy in itself will ensure a clear prioritisation of values. The democratic outcome may be ambivalent about which value should take precedence.

Finally, *health, security, efficiency and equity* may have an inherent synergy in that the latter three seem to become more acutely valued when concerned with health than with other aspects of welfare or consumption. We noted above how fundamental philosophical disagreements exist about general income inequalities in ways which do not emerge to the same degree with respect to health inequalities, perhaps because health is perceived to be less often a consequence of our freely made choices.

5. Involving the public in value-based issues

This report forms part of a process which involves a major piece of public involvement in London to investigate how ordinary citizens view the ethical and value-based issues in public health. In this final chapter we review of some of the particular issues relating to public involvement,[79] and Box 2 presents some thoughts on researching public views about values in public health. It is worth noting at the outset that it is highly unlikely that we will ever arrive at a degree of unanimity on questions of value. This is most obviously true with respect to situations where values are in conflict with one another: some people will wish to trade off values in ways which reflect different views about their relative importance. So public health policy, which like other aspects of public policy is by definition an activity of collective choice, must somehow resolve the inevitable value disagreements between people. These procedures must be fair, in that they should accord with notions of democracy.

5.1 Arguments for and against public involvement

Very often, public involvement is accompanied by the distinct whiff of motherhood and apple pie. There appears to be impeccable good sense and moral progressiveness in taking ethical issues directly to the people and listening to their views, allowing discussion and deliberation, and encouraging members of the public to express their opinion directly on policy issues. There are a number of reasons why public involvement of this kind might be supported on ethical grounds.

- Talking with ordinary citizens directly will lead to a greater likelihood of better understanding their precise concerns and worries, and will facilitate a more direct connection between the citizen and political rulers.

- Increased public involvement may rejuvenate a sense of civic responsibility and promote renewed interest in the democratic process itself.

- Disinterested citizens may be better placed than managers and civil servants to offer imaginative and unbiased proposals for resolving knotty issues of public policy.

Box 2: Researching public values on public health

One aspect of good democracy involves finding out as accurately as possible what people think about issues of public concern. The following list outlines some considerations in researching the public's values about public health.

1. Research will benefit from both large-scale opinion surveys and small-scale, deliberative and interactive forums, which generate complementary information. Large-scale surveys provide an opportunity for representative samples, statistical significance and confidence limits. Deliberative forums allow people to reflect more fully on complex questions about trade-offs and the role of the public. Undertaking both methods will also provide an opportunity for comparing the two sets of results.

2. Asking people about what they value should involve careful separation of questions relating to private valuations of health ('how many years of life are you willing to trade for increased quality of life?') from those relating to 'public values' (i.e. how public, collective life should be conducted, and whether or how the state should act). The two should not be confused.

3. 'Baseline', socio-demographic information should be collected in order to allow an analysis of responses by social class and other variables of interest.

4. An interesting empirical question is whether views about values differ between public health workers, policy-makers, and 'ordinary' citizens. This may have implications for understanding the motivations of different people in different groups, and give clues about why certain policies are more popular or successful than others.

5. A subsidiary and related issue would be to try and design ways of establishing whether people's expressed values vary from implied values derived from what they say they would do, or actually do, in certain situations. This would require carefully constructed 'scenarios' to tease out people's 'enacted' values. One problem with researching the public's values is that respondents or participants might be prone to offer 'warm words' about values, similar to the 'acceptability bias' thought to operate in opinion polls about political issues, whereby people give the response thought more socially acceptable.

6. More specifically, when asking about overall levels of support for specific values, it may be useful to arrange for some questions to be answered anonymously. This would enable those who reject some of the values, but feel uncomfortable doing so in public, to communicate their views freely.

7. How do people feel about trading-off values? This could be asked as a general question of principle initially: do people accept that this is necessary? Have they thought about these kinds of trade-offs in their private lives? What trade-offs do they think are most common? Then questions could be asked about where trade-offs should be made. This may be difficult to design into an opinion-survey format, but would be well suited to the deliberative forums. In particular, questions should elicit how the public views health in relation to other valued objectives in life. How easy or difficult is it for people to acknowledge the competing areas of social welfare in which we have value concerns?

8. Finally, to what extent does the public believe that it should have a direct role in shaping public health decisions? Or do people believe that this is a job for other representatives, with democracy being enhanced by increased accountability or transparency instead?

- Public involvement can offer real power to otherwise disenfranchised people.

- Involving citizens on public bodies can make sure that the debates they conduct are undertaken in an accessible way.

Thus far, it is hard to see how such proposals could provoke any ethical controversy. But the wide range of the beneficial consequences itself raises questions about what public-involvement strategies are setting out to achieve. This confusion about objectives has been drawn out in more detail in relation to citizens' juries: are they about empowerment, self-development (of the individual citizens), providing an informed view to authorities, or arbitration?[80] This is not necessarily an ethical problem; it may simply be a consequence of lack of clarity about objectives. However, not being clear about objectives can lead to a great deal of wasted time, effort and resources, and this in itself might be considered unethical.

Different views about the objectives of public involvement lead us to consider more directly ethical issues about the status of the public's view: in short, should it have any real authority? Ethically, it could be argued that involving members of the public without giving them any authority is deceitful – a kind of window-dressing designed to give the impression that 'good democratic practice' is taking place. Nonetheless, such involvement can be useful, providing state agencies with valuable information about what the public thinks. On the other hand, to give the public binding authority, as in a referendum, general election or legal jury, has its own risks. Perhaps the most serious is that the public will not have enough information or time to deliberate on issues sufficiently to come to a reasoned position. This is perhaps the key value problem: the more real authority the public is given, the more it will be necessary to control and constrain the possible abuse of that power, and the more questions will be asked about the fitness of any particular portion of the public to make the decisions in question.

Even if the public is provided with ample information, time and deliberative space, ethical problems remain. Representative systems of decision-making identify individuals who are continuously responsible for and accountable to the whole community for their decisions. Ordinary citizens, however, are accountable formally to no one – they will typically disappear back into the community after their involvement. This may lead some to question the legitimacy of their decisions: without continuing to face, and answer for, the consequences of their decisions, why should they come to well-reasoned judgements? And yet, without any real power, the public may become

increasingly disillusioned with a process which appears to do no more than pay lip-service to its position of ultimate authority in a democracy.

A related point involves whether the public's position is automatically on a par with that of other groups. The lay citizen may have one view on a matter of public concern which is then challenged by 'expert' opinion (we will leave aside the possibility that other sections of the public may also challenge it). There may be two grounds for such a challenge from experts.

1. The outcome of the public's decision may be argued to be not in itself ethically defensible.[81] It could be said that, even with extended time for deliberation, no one who has not thought deeply over long periods of time can hope to untangle and judiciously resolve all the competing aspects of complex moral problems.

2. The second challenge may come from those who believe that an issue is so complex that, again, without years of training and experience, it is simply impossible for citizens to come to a reasoned judgement about it.[82]

In the second case, everyone might agree about the objectives to be pursued but there might simply be technical miscalculations about the actual consequences of certain types of decision (for example, whether taking waste material by car to a recycling centre results in an overall reduction in fossil-fuel use). This is not to say that citizens cannot make either value judgements or decisions about technical matters, merely that in some cases sheer lack of expertise may lead them to judgements which they might not come to if they had had the time and training of experts.

This raises difficult questions about the respective roles of the expert and the public. Whereas it may be reasonably well accepted that experts should not rule absolutely, they will nevertheless have greater access to elected representatives, and so might be thought to wield undue influence on the decisions of those in power. Furthermore, experts themselves can be wrong, and under these circumstances it may be better for the mistakes to come direct from the public – at least that way trust in the political system may not be so badly damaged. But the problem remains about how to best make

use of the expertise that can only come with extended and dedicated study, when by its very nature the outcome of these deliberations may well be difficult to understand.

5.2 Can public involvement be representative?

One possibility is to give the public some direct form of veto over certain kinds of controversial decision. Alternatively, members of the public could be allowed to exercise a degree of tightly controlled choice over various policy options, along the lines of a citizens' jury.[83] These options would allow experts to present possibilities to the public which the latter could reject or choose between. Members of the public would be given some real formal power without being expected to act as if they were experts. But even here we come up against a version of the accountability problem noted above: could the chosen public group demonstrate adequate representativeness, so that it could properly make decisions on behalf of the wider community affected by the outcome of the decision? Traditional notions of representative democracy expect that those making the decisions continually answer to all those affected for what they have decided. No direct equivalent of this is possible with public involvement. The best that can be done is to make the chosen group reflect the socio-demographic characteristics of the 'parent population'. But even achieving this partial form of representativeness constitutes one of the most intractable ethical issues in public involvement. The larger the number of citizens involved in order to reflect statistically all shades of social class and ethnic background, the less opportunity there is for informed, deep and lengthy debate. The matter is largely one of cost: Athenian-type democracy would be prohibitively expensive and even if we could afford to devote the resources to it, it would take so much time that it is likely that little would be decided.

Could it be possible to sacrifice some degree of socio-demographic representativeness and still retain democratic authority? This will partially depend on the degree to which we assume that different social groups have inherently different values. Unless all the social bases are accounted for, runs the argument, there will be an intrinsically partial representation of the values themselves. If some communities are left out, then 'their' values will also be left out. How can we justify that? Everyone's values are as 'valuable' as everyone else's.

However, it may not always be people's *values* which differ, but their interests. Involving the public in order to ensure that all interests are represented on an issue is not necessarily appropriate to a process which seeks to resolve conflict *between* various interests. This latter objective will need to adopt an approach which refers to values as a guide to compromising one set of interests with another – not values which exist separately in different communities, but values which exist in most of us to some degree. So a 'problem-resolution' approach for public involvement may require the participation of people who are literally *disinterested* in the outcome. Accordingly, for certain types of public involvement, the recruitment process may need to *exclude* those with a particular interest in an issue, precisely because they will not be in a position to act impartially.

5.3 Implications for equity and other values

Even if problems of representativeness and accountability are dealt with, others emerge. One is that public decisions taken at the sub-national level may result in different outcomes in different parts of the country. This is true for all systems of local democracy, but the problem may become more acute through the legitimacy which arises from direct public involvement. For there is no guarantee that different groups of members of the public will come to the same decision in different regions. This is not to reject such outcomes: as we noted above, democracy is essentially a process. Nevertheless, if one public-involvement process decides that smoking should be banned in public places and another elsewhere does not, the result in ethical terms is an offence against horizontal equity: similar people in similar circumstances will find themselves subject to very different rules.

Finally, there is the question of whether it is ever justified to compel members of the public to take part in aspects of public involvement, and thus make it some kind of civic duty. This may be particularly important when some kind of specific representativeness (or non-representativeness!) is required. Furthermore, it would allow for the inclusion in public-involvement programmes the whole class of 'hidden' person who is perhaps reticent, shy, introverted, etc., and whose absence may subtly bias the outcomes of other involvement exercises. Needless to say, this is a controversial ethically, because it

radically conflicts with value of autonomy. But there are precedents, both in the legal jury system and, more weakly, in countries with compulsory voting at elections.

To summarise, the difficulty of public involvement is that as more formal authority and influence is designed into the process, thus avoiding the charge of lip-service and window-dressing, new ethical problems emerge. Simply engaging the public to help inform the decision-makers about their opinions is relatively uncontroversial from an ethical perspective, precisely because these opinions have no formal authority. But if influence is increased, value conflicts become unavoidable. The value of democracy as represented by public involvement may conflict with efficiency (it is expensive), with equity (it may reach morally questionable decisions, and they may vary from one place to another), and potentially with autonomy (if people need to be 'encouraged' to take part, or if decisions restrict the liberties of others). As with all other social problems, and with other aspects of public health policy, doing better along one dimension of the value spectrum is likely to lead to doing worse along others.

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