

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Public Health: ethical issues* between May and September 2006. The views expressed are solely those of the respondent(s) and not those of the Council.

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General Comments

The working party should be complimented on a succinct paper which encapsulates many of the dilemmas in public health (PH) ethics. In answering we have concentrated on those issues closest to our immediate responsibilities (vaccination and infectious diseases) but have also commented to some extent on the other questions you ask. However, the principles we have identified are in general applicable across a wide range of issues.

As regards the ethical principles, the document is a sound review of most of them at the population level but some of these principles break down or do not quite apply at the individual level. We return to this point later, but an example is in relation to autonomy and air pollution. Realistically, individuals cannot make personal choices about what air they breathe; so it is clear that some commodities simply cannot be viewed from an individual perspective. The air is therefore something that has to be dealt with collectively by society and governments, and so the concept of autonomy in this situation is almost meaningless. Linked to this there is also the question of how the principles you use map to other sets of ethical principles such as utilitarianism or a rights-based approach.

There are two moderately big issues that are not touched on and would benefit from inclusion:

- i) Healthcare Associated Infection (HCAI). In the "do no harm" section on page 38, HCAI could usefully be included as a current example - far bigger than other issues which are included.
- ii) Surveillance and epidemiological studies of diseases (both infectious and others) – and here the issue is whether or not consent is needed for non invasive observational studies into population health. As you will know this issue is taxing much public health surveillance and research and a statement on the ethical issues around it from the Nuffield Council would be very helpful

Specific corrections or comments

P7 'the responsibilities of individuals'. This mainly focuses on the impact of individual's actions on themselves, but there is also the issue of the impact of individual's actions on the public health. In a sense the Wanless 'fully engaged' model assumes that individuals are fully engaged with both their own health and that of the population as a whole; and we would wish to ensure that both of these approaches are emphasised

p10 last bullet in section on control of IDs. We would not include TB nor HIV/AIDS as 'highly infectious'. They are both major pandemics but they are not akin to flu or SARS – and are nearer to chronic diseases. The sentence would be acceptable and make the point about compulsory testing equally as well if it said "mandatory testing for life threatening diseases such as TB or HIV/AIDS...."

p13 the environment does not affect everyone equally. In general the poorer members of society are exposed to unhealthier and riskier environments

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P 14 (box) – preventive rather than preventative

P15 Factors that affect the effectiveness and acceptability of interventions

Trust is an increasingly important issue. This covers trust in science, in professionals, in evidence and in institutions. One of the biggest challenges for public health organisations is how they develop and maintain public trust and confidence

The perceived risk of the disease. For example meningitis is thought to be scary because it is usually severe while pertussis is thought to be less of a problem because it is more often mild, even if it kills more children.

Lay beliefs about immunity. Immune boosting, immune overload, immune vulnerability have all entered lay conversations about vaccination. Presentation of the evidence is made more difficult because there is little relationship between these lay ideas and immunology, so there is an increasing gulf of understanding between scientists and the public.

P16 Types of measures to influence public health.

The commentary does not include empowerment. It mentions education, but this can be one way. Headstart and Sure-Start start from the premise that to achieve behaviour change individuals need to feel capable and empowered

p18 2nd bullet - whooping cough - spelling
- TB is now no longer part of routine UK vaccination
- specify meningococcal meningitis C
- add pneumococcal vaccination (from Sept 2006)

p18 3rd bullet - specify HiB meningitis not meningitis B (otherwise potential confusion with meningococcal meningitis B)
- specify meningococcal meningitis C

P 19. Benefits and risks. The increase in mumps was not due to the fall in MMR coverage – it is not really relevant here

p20 Another important question is whether it is ethical to treat unvaccinated children differently. If we agree that vaccination is voluntary and that parents are free to choose, are they also free to put other children at risk? Is it reasonable to isolate such children, educate them separately or apply different infection control policies (eg longer school exclusions)? Should there be a different standard of confidentiality – ie should other parents have the right to be able to identify unvaccinated children so they can avoid them?

p39 'Trust' - 4th sentence "For example although the scientific facts underlying the MMR vaccination are far from straightforward, parents". We would dispute the way this sentence reads - the science is clear
- the press and media response to the science is not and perhaps until the aetiology of autism is better understood the press line may continue to damage MMR.

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P39 'Consent'. While consent is always ideal, there are clearly circumstances where the public good means that it cannot be reasonably obtained. This might be because of

urgency/speed or because considerations of the public good outweigh the need for individual consent. What matters in these situations (as we describe below) is the need for good processes.

Answers to your questions

1. The definition of public health

- Do you agree with the definition of public health introduced above ("What we, as a society, collectively do to assure the conditions for people to be healthy"¹)? If not, please explain why. What alternative definition would you propose?

Firstly, there are other definitions you may wish to look at:

- The Acheson Report offers this one: the science and art of preventing disease, prolonging life, and promoting health through the organized efforts of society.
- one of the efforts organized by society to protect, promote, and restore the people's health
- To prevent rather than treat disease through surveillance of cases and promotion of healthy behaviours

However, there are other issues we would wish to raise:

The words 'public health' have at least three distinct meanings:

- The health of the population
- A (sub) profession
- Activities directed at improving the population's health

Clearly, the review focuses on the latter meaning (though there is a lot of reference to the first), and it might help if you made this clear.

The definition you use has an individualistic feel to it as it relates to people. In a sense, the overall purpose of public health activities is to help improve the health of people, but it is also to improve the health of the society and the population, and this is not always the same thing. There are many circumstances where – as you point out – one section of society benefits from an intervention while another is disadvantaged. A more collective definition of public health might allow a better debate around this sort of issue.

Also, public health is not just about the *conditions* for people to be healthy, it is about the health outcomes for people or populations actually improving.

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2. Factors that influence public health

- Do you agree that interactions between the following five factors are the main influences affecting public health: the environment, social and economic factors, lifestyle, genetic background, preventive and curative health services? If so, do you think some are more important than others? Are there other factors we should include? If so, what are they?

In broad terms we would agree with this account of the key factors that affect public health. However, it might be clearer to talk about the physical environment for the first one. And, it is worth noting that some of these factors have a more collective feel than the others.

3. Prevention of infectious diseases through vaccination

- Some countries have a compulsory rather than voluntary system of vaccination. On what basis can such policies be justified to achieve herd immunity? Should they be introduced in the UK?

In the UK good levels of immunisation uptake have been historically achieved without compulsion, but paradoxically the more the apparent reasons in PH terms for introducing compulsion (especially lack of trust in the vaccine), the greater the public disquiet around compulsion is likely to be. So, while this may need reviewing if the situation changes, we believe that we need to work in the area of public confidence of vaccines (and of science and professionals), rather than to even raise the question of compulsion

- For childhood vaccinations, parents make decisions on behalf of their children. Are there cases where the vaccination of children against the wishes of their parents could be justified? If so, what are they?

As asked, the answer to the question has to be yes, but the challenge is to identify the principles and mechanisms we would wish to apply if this were to happen. In general these relate to the 'normal' ways in which society (at times) allows the state to over-ride the wishes of parents under its child protection arrangements, and to the principle that the needs of the child would over-ride the needs of the parent.

4. Control of infectious disease

- Control measures for specific diseases depend on how infectious a disease is and how it is transmitted. For infections that are directly transmitted from person to person, what justification would be required to render interventions such as forced quarantine, which helped to control the outbreak of Severe Acute Respiratory Syndrome (SARS) in Asia, acceptable in countries such as the UK where such measures may be considered to infringe civil liberties? If you think such measures cannot be justified, what are the principal reasons?

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Decision makers must balance individual freedom against the common good, fear for personal safety against the duty to treat the sick and short term economic losses against the wider implications of the potential spread of serious diseases. This is difficult and it is necessary to rely on science/evidence, value systems and good processes in such situations. As a general approach, decision making that is evidence based, proportionate, transparent and contestable provides a healthy basis to decisions regardless of the details of the value systems that are being used. But, there is no doubt that cultural issues will play a role here as what is acceptable in Asia may not be acceptable in the United Kingdom.

Having said that, there may well be situations when the interests of public health override some individual rights such as the freedom of movement. In these situations, public health bodies have a duty to inform the public of the nature of the risk, be open in explaining the reasons for over-riding individual freedoms and do as much as possible to assist those whose rights are being infringed. These responsibilities also fall on non public health agencies such as the police, courts and law-makers as they have critical roles in these sorts of situations. Contagious diseases, like wars, test the limits of freedom in societies. SARS is a sobering reminder that the interests of the individual must on occasion be tempered by the best interests of the community. In Toronto, thousands were placed in quarantine, often at home, in order to protect others from possible exposure to a deadly disease, and while there remains some uncertainty about the evidence base for these interventions it is right (in ethics and in law) that such interventions should be possible.

- In general, the earlier that an outbreak of disease is detected, the easier it will be to control. What would be suitable criteria to determine in what circumstances, and to what extent, the state should provide more resources to develop methods of preventing outbreaks of serious epidemics in other countries?

This is very difficult and one of the great challenges of the 21st century is to understand the interconnections between globalization and health, and to find ways of narrowing global health disparities in different regions. A new global health ethic based on solidarity could help make the world a more stable place. Solidarity means recognizing a common cause with others who are less powerful, wealthy, or healthy. Infectious diseases can spread in either direction between poor, rural areas and rich urban areas, anywhere in the world.

There is also a need for transparency, honesty and good communications on health issues at a global level so that people and nations can take appropriate steps to protect themselves.

The new International Health Regulations (IHRs) cover this to some extent in that where a potential Public Health Emergency of International Concern (PHEIC) in a member state is identified an international response may be triggered that would include action by other countries to assist the affected state. Criteria could therefore relate to the definition of a PHEIC. However PHEICs are likely to involve highly infectious acute diseases such as influenza/SARS and the IHR do not explicitly cover the chronic and less infectious diseases such as HIV and TB. If pandemic flu were to emerge in (say) China it could be in the direct interests of the developed and the developing world to support early intervention to prevent or minimize spread. Bacteria and viruses do not respect international boundaries and this could provide a powerful argument for support based on

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self-interest alone. For diseases such as TB and HIV there are wider issues from both an ethical and an "enlightened self interest" perspective. Contributing to HIV/TB control in countries with high prevalence is important for humanitarian reasons, because these countries are a source of migrants to rich countries such as the UK and because assistance could help their social and economic development in ways that could improve other aspects of their (and our) health.

- Travel and trade are key factors in the spread of infectious diseases. Global travel and exchange of goods are increasing rapidly. Each day, two million people travel across borders, including around one million per week between developing and developed countries. Disease-causing organisms and vectors can therefore spread quickly around the world. Are new measures needed to monitor and control the spread of infectious diseases? If so, what would be promising strategies?

SARS was a wakeup call about global interdependence, and the increasing risk of the emergence and rapid spread of infectious diseases. There is a need to strengthen the global health system to cope with infectious diseases in the interests of all, including those in the richer and poorer nations. This will require global solidarity and cooperation in the interest of everyone's health.

One of the key goals of the Health Protection Agency is to contribute to UK international health objectives and to global health. Health protection requires close co-operation and prompt exchange of information both locally and internationally. HPA international activities contribute to improving global public health and also fulfill a humanitarian responsibility to share public health skills on a global basis.

In addition, the contacts and information gained through HPA international links can improve the effectiveness and efficiency of the HPA in dealing with UK health protection priorities.

It is important to note that the International Health Regulations have a very strong emphasis on improving surveillance systems and capacity building and on richer states assisting states with less robust public health systems.

- Under which circumstances, if any, would mandatory testing for highly infectious and life-threatening diseases such as tuberculosis or HIV/AIDS be justified?

Public health officials generally agree that it is in the interest of the public to test for the presence of antibodies to the AIDS virus that indicate HIV infection and to identify "seropositive" individuals (those whose blood tests positive for AIDS antibodies), since most people probably will modify the behaviours that cause the spread of the disease if they know they are infected. There is also general agreement that it is in the interest of infected individuals to get tested, since early treatment with AZT has proven effective in slowing the progress of the disease.

But in the highly charged atmosphere that has quickly developed in response to the AIDS epidemic, there are serious ethical concerns about HIV testing --particularly

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James Childress in "Mandatory HIV Screening and Testing" cited in "AIDS & Ethics" (ed Fredric Reamer) argues that there are key ethical considerations around this issue:

- A policy which infringes on rights must most probably be effective in realizing an important goal. In the case of mandatory HIV testing, that goal is protecting the public health. Any mandatory testing policy which will most likely have little or no effect on protecting the public health must be rejected.
- It is necessary to show that the proposed policy of infringement will most probably produce benefits which outweigh both the infringement of rights and any negative consequences the infringement causes. In the case of HIV testing, negative consequences can include discrimination against newly identified HIV positive individuals.
- There must be no other way to realize the goal which does not infringe on rights. A policy of infringing on rights to attain an important goal must be a policy of last resort. Many mandatory testing plans fail to meet this condition, often because voluntary testing coupled with an aggressive education program will do just as well (or better) than the proposed mandatory scheme.
- If it is deemed necessary to infringe on the rights of individuals to achieve an important goal, the plan for achieving that goal which infringes on individual rights least must be chosen. Thus if privacy is at stake, the least intrusive alternative should be chosen; if confidentiality is at issue, only the minimum amount of information necessary to achieve the goal should be released, and to as few people as possible.
- Finally, basic respect for the individual requires that those people whose rights are infringed upon must be informed of that infringement, and the reasons for the infringement clearly explained. For example, testing a person's blood sample for HIV without informing that person violates this condition.

5. Obesity

- Food is closely linked with individual satisfaction and lifestyle. This means that any strategy that seeks to change people's behaviour is likely to be perceived as particularly intrusive. How should this sensitivity be considered in devising policies that seek to achieve a reduction in obesity?

It is striking that the recent changes in school meals have been introduced with very little opposition, even though we might have anticipated a lot of bad press around the nanny state argument. It seems reasonable to believe that this was for several reasons:

- Good leadership (Jamie Oliver)
- Strong evidence
- A manifestly important health problem

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In implementing any public health interventions we should learn from the apparent success of this one

- While there is clear evidence about the extent and scale of obesity, there is far less clarity about what measures should be adopted by the government and other stakeholders to prevent it. In view of this uncertainty, what would be suitable criteria for developing appropriate policy?
- What are the appropriate roles and obligations of parents, the food industry, schools, school-food providers and the government in tackling the problem of childhood obesity?
- Is it acceptable to make the provision of NHS services dependent on whether a person is obese or not (see example in Section 4.2 of Part B)? If so, what criteria should govern whether or not interventions are provided, and should similar criteria be developed for other lifestyle-related health problems that are significantly under the control of individuals?

The HPA has little direct involvement with this issue, but would wish to see the 'standard' principles of effectiveness, cost-effectiveness and efficiency being applied here. That means that obesity per se cannot be a reason for excluding people from access to services, but if obesity were to make an intervention less effective, that could be

6. Smoking

- The effects of smoking on health have been known for a very long time. Comprehensive measures by governments to prevent harm to the population are relatively recent. In your view, what are the reasons for this delayed response? Are there any lessons that can be learned from other countries, or from strategies pursued in other areas of public health?
- What are the responsibilities of companies that make or sell products containing hazardous substances, such as nicotine, that can be addictive? Should they be prosecuted for damaging public health or required to contribute to costs for treatments?
- Should smokers be entitled to higher than average resources from the public healthcare system, or should they be asked for increased contributions? Would similar charges be justified for other groups of people who deliberately or negligently increase their chances of requiring public health resources, such as people engaging in adventure sports?
- Smokers argue that they choose to smoke. What rights does the state have to impose sanctions to prevent them from smoking? Does the state have the right to prevent the sale of tobacco, which is known to be addictive and highly dangerous? How

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vigorously is it reasonable for the state to act to prevent children and teenagers from smoking?

The HPA is clear that society and government have responsibilities to deal with issues (such as smoking) that cause ill-health even if there is a considerable element of free choice as regards whether people choose to smoke. While this has been characterized as the 'nanny state', it would be an abrogation of our responsibilities to ignore it. Such interventions will inevitably include measures which make it harder for people to smoke and thus (perhaps) to exercise individual choices, but a caring society cannot be one which simply 'allows' free choice despite knowing the consequences.

We recognize that people fear imposed risks much more than they fear risks they take themselves. That logically leads to the legitimacy of society in taking measures to control imposed risks such as passive smoking more strongly than self-imposed risks such as smoking itself.

7. Alcohol

- The effects of excessive consumption of alcohol on the health of individuals and society have been known for a very long time. It can be argued that in view of the significant harm to individuals and society, comprehensive measures by governments to prevent harm are lagging behind those for tobacco. In your view, what are the reasons for this?
- In view of the impact of excessive consumption of alcohol on individuals and society, what are the roles and responsibilities of agents other than the government to limit consumption? Are there different responsibilities for producers and, for example, retailers? If so, which?

8. Supplementation of food and water

- Fortification of some foodstuffs such as flour, margarine and breakfast cereals has been accepted for some time. Why has the fluoridation of water met with more resistance? What are the reasons behind international differences in the acceptance of fluoridation of water? What criteria are there that determine acceptance?
- Which democratic instruments (for example, decision by Parliament or local authority, consultations or referenda) should be required to justify the carrying out of measures such as fluoridation?
- Achieving population benefits of fluoridation means restricting choice of individuals. Children benefit the most from fluoridation. However, as with vaccinations, adults, rather than children, are making decisions about whether or not to receive the intervention. Under what circumstances is it acceptable to restrict the choice of individuals in order to protect the health of children?

9. Ethical issues

- In your view, is there one of the following principles that is generally more important than the others: autonomy, solidarity, fair reciprocity, harm principle, consent, trust (see Section 5 in Part B)? If so, which one and why? Are there any other important principles that need to be considered?

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While the principles you identify are valuable and helpful, others have used different principles to help decision making. It is hard to argue that one set is better than any other, but there may be approaches used elsewhere that we could usefully draw on. For example, the principles below were drawn from a critique of how Toronto dealt with SARS. They overlap the principles you propose but they also add to them:

Individual liberty. In the UK as in many other liberal democracies, the idea of virtually unfettered personal freedom has become a strongly held value. In recent years, the global community have faced a number of serious public health issues-including tuberculosis, AIDS and influenza, that have required decisions that seek to balance the rights of the individual and the common good of society. SARS has created an even sharper test of which rights should prevail at what time. The law allows individual rights to be overridden for the common good, under defined circumstances. The goal is to do this in an ethical and even-handed manner so that people are not unfairly or disproportionately harmed by such measures.

Protection of the public from harm. When clear, serious and imminent harm to the population is demonstrable, public health authorities have a duty to restrict certain individual rights in the interest of the health and well-being of the community. In turn, citizens have a civic duty to comply with such restrictions for the common good.

Proportionality. When protecting many from harm is ethically necessary, and when the use of public health powers to achieve those goals can be justified, authorities must also protect individuals from needless coercion. Restrictions of liberty must be relevant, legitimate and necessary. They must be exercised by people with legitimate authority, and those people should use the least restrictive methods that are reasonably available. Such restrictions should be applied without discrimination.

Transparency. In modern democratic societies, all legitimate stakeholders need to be properly informed about the issues, including the risks and benefits of various options, and have input into discussions on issues that affect them, particularly those that affect their health, well-being and personal liberty.

Reciprocity. Society has a duty to see that those quarantined receive adequate care, are not kept in quarantine for excessively long periods, and are not abandoned or psychosocially isolated. There may also be a need to eliminate economic barriers, such as loss of income, which would otherwise prevent someone from obeying a quarantine order.

- Can these principles be ordered in a hierarchy of importance? If so, how would such an order relate to the five case studies (infectious diseases, obesity, smoking, alcohol, and the supplementation of food and water)? Would the order have to be redefined for each new case study? Are there particular principles that are of special importance to some case studies?

There is a case that the principles most important in terms of infectious diseases are solidarity, the harm principle, trust and consent.

- In cases such as vaccinations or fluoridation parents decide on behalf of their children. Which ideas or principles should guide parents in their decisions?