

NUFFIELD COUNCIL ON BIOETHICS

Response to NICE consultation on 'Social value judgements', Second edition

In November 2007, the Nuffield Council on Bioethics published a report on *Public health: ethical issues*. The report uses a number of case studies to illustrate a discussion about ethical issues in public health. In this response we draw your attention to a summary of the principal findings from our report that are relevant to your consultation. Page and paragraph numbers are provided, which refer to the respective sections in the full report, which can be obtained from us or downloaded from: <http://www.nuffieldbioethics.org/go/ourwork/publichealth/introduction>. Some sections have been extracted to this response, but we recommend reading the full report for context and references.

Regarding Section 4.1 'Clinical and public health effectiveness'

Principle 1 in Section 4.1 reads: "NICE should not recommend an intervention (that is, a treatment, procedure, action or programme) if there is no evidence, or not enough evidence, on which to make a clear decision. But NICE may recommend the use of the intervention within a data collection or research programme if this will provide more information about the effectiveness, safety or cost of the intervention."

In our recent report, *Public health: ethical issues*, the Nuffield Council on Bioethics recognised that "information about evidence and risks is often incomplete, ambiguous and contested, and may not lead by itself to a clear indication of which policy is likely to be the most effective" (paragraph 3.55).

Two things that follow are, first, that "incomplete evidence for the effectiveness of policy options should not be used by industry and government as an excuse for inaction" (paragraph 5.10). Consideration may therefore need to be given to the situations in which it is acceptable to proceed without an extensive evidence-base on a certain policy, especially in respect of public health activities and provided the effectiveness of the intervention is appropriately monitored.

Secondly, monitoring the outcome of interventions is especially important in the case of public health measures for which the evidence may be ambiguous: "regardless of whether or not a programme is targeted, its efficacy and effectiveness should be monitored over a suitable timeframe. Monitoring may be complicated by factors such as people moving in and out of areas in which certain public health programmes are trialled, and many interventions, such as changing the food available in schools, relate to deeply engrained social habits which

are difficult to change in the short term. These examples illustrate that care and patience are required in compiling and evaluating data on the efficacy and effectiveness of public health programmes (see paragraphs 4.37, 4.43, 4.50, 5.25, 5.30, 5.36, 6.29, 7.40, 7.42)" (paragraph 8.29)

Regarding Section 6.6 'Self inflicted diseases'

NICE notes "NICE should not produce guidance that results in care being denied to patients with conditions that are, or may have been, self-inflicted, for this reason alone. However, if the self-inflicted condition is likely to continue and can make a treatment less clinically or cost effective, then it may be appropriate to take this into account."

In our report, we considered the cases of obesity and alcohol which are related to the point being made in this section of the Social Value Judgements. We highlight two points. First, while, overall, we broadly concur with the point made, we are less certain about the usefulness of the concept of "self-inflicted conditions". This term has somewhat moralistic undertones and more importantly appears to suggest a high and unrealistic degree of freedom and choice. Perhaps it could be replaced by a more neutral and appropriate term such as "behaviour-dependent" or similar. A brief discussion concerning the related concepts of lifestyle and behaviour from our report 'Public health: ethical issues' is copied below.

"Many of the issues discussed in the context of public health arise from what some commentators call 'lifestyle diseases', such as obesity- and smoking-related conditions. Implicit in the use of this term is the idea that a disease is simply a result of individuals' choices about how to live their lives. Such a view is problematic as a person's health is influenced by a very wide range of factors. Attributing poor or good states of health simply to different 'lifestyle choices' (whether for specific individuals or particular social or ethnic subgroups of the population) ignores the role of several other important factors that have a substantial influence on health. These include: genetic background, social and economic living standards, the built environment, the availability of, and access to, preventative and curative health services, and the influence of commercial organizations such as the food and drink industries. In this Report, we have adopted the term 'personal behaviour' rather than 'lifestyle choice'. Personal behaviour indisputably plays an important role, but is itself affected by external factors that are equally important in ethical and policy discussions." (paragraph 1.4)

Secondly, regarding the last sentence of the above quoted section ("However, if the self-inflicted condition is likely to continue and can

make a treatment less clinically or cost effective, then it may be appropriate to take this into account.”), fairness would require certain conditions to be in place for this approach to be acceptable. This provision might amount to a penalty where there are no facilities that help people change their behaviour. We therefore emphasised the requirement of assistance in our discussion on access to treatment in the case of obesity and excessive consumption of alcohol, as discussed in the following two extracts of our report:

“Obesity has complex causes. It is usually not easy to determine to what extent a person’s weight is under their own control, and to what extent it is influenced by environmental factors that make it difficult to exercise or eat healthily. There is a significant risk of stigmatisation and unfair ‘victim-blaming’, where already-disadvantaged people are held unduly responsible for their poor health state. Any policies that single out obese people could also substantially undermine the concept of solidarity and the value of community. **It would not generally be appropriate for NHS treatment of health problems associated with obesity to be denied to people simply on the basis of their obesity. However, appeals to change behaviour before or subsequent to an intervention could be justified, provided that the change would enhance the effectiveness of the medical intervention, and people were offered help to do this** On the whole, although the case of obesity raises some valid considerations about making the most efficient use of resources at the point of providing treatment, and although difficult decisions have to be made in allocating necessarily limited resources, in terms of public health policy the focus of efforts should be on *avoiding* the need for treatment in the first place. This is a fairer approach, and seems likely to be more promising in economic terms.” (paragraph 5.42)

“We note that current Department of Health guidelines on liver transplantation require patients to have abstained from alcohol for six months, and people who are considered likely to continue to consume excessive amounts of alcohol are not offered a transplant. We agree that, as in this example, **it might be justified for doctors to appeal to patients to change their behaviour in relation to alcohol and tobacco before or subsequent to an intervention provided by the NHS, provided that the change would enhance the effectiveness of the intervention, and people were offered help to do this.** For example, alcohol treatment programmes might be offered in advance of performing a liver transplant as the cessation of excessive drinking would be likely to increase its clinical effectiveness, or could even make the transplant unnecessary. Generally, as in the case of obesity, we take the view that decisions about healthcare provision for people

who smoke and/or drink alcohol excessively raise some valid considerations about the most efficient use of resources. In terms of public health policy, the focus of efforts should be on avoiding the need for treatment for alcohol- and tobacco-related conditions in the first place.” (paragraph 6.17)

Regarding Section 7 ‘Particular issues for public health guidance’

A footnote in this section indicates that you intend to explore further the intervention ladder and stewardship approach found in the Nuffield Council’s report *Public health: ethical issues*. We welcome this, but nevertheless provide the following summary in relation to the issue of when to recommend that a measure should be made mandatory.

The stewardship model established in our report suggests how public health policies to help people lead a healthy life and to reduce inequalities can be justified. We outline the model here:

“Concerning goals, public health programmes should:

- aim to reduce the risks of ill health that people might impose on each other;
- aim to reduce causes of ill health by regulations that ensure environmental conditions that sustain good health, such as the provision of clean air and water, safe food and appropriate housing;
- pay special attention to the health of children and other vulnerable people;
- promote health not only by providing information and advice, but also by programmes to help people overcome addictions and other unhealthy behaviours;
- aim to ensure that it is easy for people to lead a healthy life, for example by providing convenient and safe opportunities for exercise;
- ensure that people have appropriate access to medical services; and
- aim to reduce health inequalities.

“In terms of constraints, such programmes should:

- not attempt to coerce adults to lead healthy lives;
- minimise interventions that are introduced without the individual consent of those affected, or without procedural justice arrangements (such as democratic decision-making procedures) which provide adequate mandate;
- seek to minimise interventions that are perceived as unduly intrusive and in conflict with important personal values.”

The 'intervention ladder' provides a way of thinking about the acceptability of different public health measures. A mandatory public health measure will rank highly on the intervention ladder, and this means that a stronger justification, based on the stewardship model, will be needed. An intrusive policy initiative such as this is likely to be publicly acceptable only if there is a clear indication that it will produce the desired effect, and that this can be weighed favourably against any loss of liberty that may result.

Regarding Section 8 'Reducing health inequalities' (and also Section 6 'Avoiding discrimination and promoting equality')

In our recent report, *Public health: ethical issues*, the Nuffield Council on Bioethics took the view that "the reduction of health inequalities is a crucial element of public health policy" (paragraph 3.27) and that "it is necessary to consider the potential effects on social inequalities of any policy options under consideration" (paragraph 5.46). We therefore welcome the statement that "NICE has a duty to take into account the impact of its guidance on health inequalities, and that its advisory bodies should try to ensure that implementing NICE guidance will not widen existing inequalities."

Principle 8 of the draft Social Value Judgments document reads "When choosing guidance topics, when developing guidance and when supporting people who are putting the guidance into practice, NICE should actively target health inequalities, such as those associated with sex, age, race, disability and socioeconomic status."

This principle refers to 'actively targeting' health inequalities, and raises important questions about how health inequalities should be reduced. In our report, we comment on three different approaches to reducing health inequalities: targeting disadvantaged groups, targeting at-risk groups and universal provision. Each of these approaches aims to reduce inequalities in a different way and has different advantages and disadvantages with different ethical implications. We provide here an extract of our discussion on this point (paragraphs 3.29–3.34 of the report), but recommend reading the full report for context and references.

"Targeting disadvantaged groups"

"Targeted interventions typically aim to improve health outcomes or opportunities in a particular disadvantaged group (see paragraphs 2.27–2.32). Examples include free nicotine replacement for individuals on income support or the provision of additional resources for specific deprived areas (for example Health

Action Zones or New Deal for Communities). Such interventions may be beneficial in reducing inequalities in health, although individuals in socially disadvantaged groups can find it difficult to change their behaviour because of lack of resources, lack of education, or co-existing social or health problems.⁴⁰ Where this is the case, such behaviour change programmes may produce relatively little aggregate health gain at comparatively high cost. However, targeted interventions should not be dismissed simply because of their comparatively higher costs. It has been observed we are “paying dearly – in higher crime rates, diverging mortality rates and widening levels of education achievement – for the soaring inequalities that began in the early 1980s.

“Several practical issues also need to be considered in targeted approaches. For example, interventions may fail to reach the intended recipients because of uncertainties about eligibility; and they may stigmatise already marginalised groups, or disadvantage those who fall just outside the eligibility criteria. Area-based targeting can raise questions of whether extra services are actually going to the areas where people have the lowest socio-economic status, or only to areas where local politicians or councillors have been highly influential or effective. Area-based approaches are often a combination of targeted and universal services, because although they select deprived areas, all local residents are eligible. As noted above, there is a continuous gradient of socio-economic and health disadvantage. Some targeted approaches seem to have most benefited the slightly better off among the target group, while even harming those lower down the scale. For example, Sure Start, an area-based programme aimed at tackling child poverty and social exclusion, is a universal area-based intervention for all families living in designated areas. The initial evaluation shows few significant differences between intervention and comparison areas, but some indication of adverse effects among the most deprived (those who were teenagers when their child was born, lone parents and workless households).

“Targeting at-risk groups

“Although many strategies that target the disadvantaged face the problem of stigmatisation, this may matter less where interventions seek to help those who are at specific risk because of their general behaviour patterns. For example, where there are clear cause–effect relationships in relation to harm, the offer of an intervention may be more acceptable, such as when HIV screening is offered to groups who frequently engage in unprotected sex. However, there may still be a risk of stigmatisation, especially where those so targeted are also among the most socially

marginalised, such as illicit drug users, prostitutes and homosexual men.

“Universal provision

“The universal provision of public health interventions might appear to be more neutral than the two alternative options of targeting, as it avoids stigmatisation, and simply relies on people taking up available opportunities. For example, there is evidence that structural changes such as Clean Air Acts, or banning smoking in public places, have positive effects on reducing health inequalities. However, in the case of other interventions, especially those that are information based (such as nutrition labelling, anti-smoking adverts or drink-driving campaigns), strategies may actually increase social inequalities as more advantaged groups in society are more likely to avail themselves of health promotion advice.

“Therefore, although universal measures may not aim to target particular groups, they often have the consequence that some groups benefit more than others, and hence these groups might be targeted indirectly. For example, an intervention to provide better food labelling relies on people reading the labels, understanding the information and using the knowledge gained to buy appropriate healthy foods. In reality, the target population may be motivated by factors other than ‘healthy’ eating, such as convenience, palatability, price and availability or custom. They may hold an outdated model of ‘healthy eating’ that differs from that of policy makers, or they may simply be unable to read or understand the labels. This can lead to the argument that supports targeted approaches. If some groups are more likely than others to benefit from particular measures (by being targeted indirectly), it would be preferable for policy makers to consider from the outset who should benefit primarily.

“Thus the two public health goals of improving population health and reducing health inequalities may sometimes be in conflict. Targeting the already advantaged may produce aggregate health gain at relatively little cost, whereas targeting the disadvantaged may produce less aggregate health gain and at greater cost. Providing universal services in order to avoid stigmatisation, or to provide equal access to improved services, may actually increase social inequalities in outcome. It is ultimately a political decision as to how the goals of improving aggregate health or reducing inequalities should be weighted, and monitoring that provides evidence about the effectiveness of particular strategies is of crucial importance in this context.”