

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.

National AIDS Trust



Introduction

The National AIDS Trust (NAT) is the UK's leading independent policy and campaigning voice on HIV and AIDS. We aim to prevent the spread of HIV, ensure people living with HIV have equitable access to treatment and care, and eradicate HIV-related stigma and discrimination.

The consultation paper raises a number of policy questions where NAT has been active in defending the interests of people living with HIV and advocating an effective public health-based approach. Chief among them are issues around HIV and migration; mandatory testing; criminal sanctions for the transmission of disease; the concept of deliberate or negligent contribution to one's own ill-health having an effect on access to NHS resources.

Questions of public health and their relation to human rights have been and continue to be extensively rehearsed at political and academic levels, and we are not able in a short submission to set them out extensively. We would refer the Council both to works such as Lawrence Gostin's 'Public Health Law' and to key standards produced by WHO and UNAIDS.

The missing perspective – stigma and discrimination

Overall, our criticism of the consultation paper is its overly theoretical cast, which takes little account of the history of public health interventions or the lived reality of discrimination for those who will probably be most affected by intrusive and coercive measures.

In the 1916 polio epidemic the New York authorities enacted coerced separation of parents from children for very long periods, measures which were in fact of doubtful public health benefit. One physician at the time wrote, 'As to the lessons we have learned during the epidemic, we have learned very little that is new about the disease, but much that is old about ourselves' (Tilney 1916, cited in Risse 1988). Of course public health interventions have in the past been effective, but there is a considerable literature detailing the way that measures have far too often simply reflected current political and social mores and paranoias rather than being based on evidence (see for example, 'Contagion and the State in Europe, 1830-1930' Peter Baldwin CUP 1999).

HIV remains a highly stigmatised condition. This relates both to the routes of transmission (sex, sharing drug injecting equipment), and its impact (death if not treated, and with no cure as yet available). It also relates to those most affected, who in the UK come from groups often discriminated against or marginalised – gay and bisexual men, and African men and women (many of the latter group may be asylum seekers, a group also experiencing considerable hostility and stigma). Stigma and discrimination can be experienced in many settings – we have for example been

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. I am very concerned at the recent increase in stigmatising coverage of HIV in the British media sparked by the first prosecutions for reckless transmission of HIV. A recent research study found that 30 per cent of people living with HIV reported experiencing discrimination over the previous year, with the most common source of such discrimination being healthcare workers.

The reason HIV organisations and HIV activists are so suspicious of coercive or intrusive public health measures is precisely because those affected by HIV have recent and current experiences of unjust and intrusive interference in their lives, be it over their sexuality, race, immigration status, or for other reasons. Without a degree of community consent such measures are more than likely to fail, driving people underground. If they succeed, it might well be at the price of increased stigma, which is, we would contend, a cost rarely if ever worth paying.

We recommend the Council give far greater prominence to issues of social bias, stigma and discrimination, social acceptability and community-specific impacts in their consideration of these issues.

The definition of public health

The definition of public health in section 1 is an excellent definition of public health-related interventions but is not a definition of public health. This is apparent from the very next section where there is a list of 'factors that influence public health'. These factors are presented as affecting the health of the population when considered at a population level, rather than influencing our interventions. The distinction is not merely pedantic. Public health is not just about collective action – which could, for example, be exclusively geared to facilitating individual medical care – but also about collective health.

Coercive measures and HIV

Infectiousness

A number of possible public health measures are cited to control infectious disease, with HIV specifically mentioned in a number of contexts. HIV is described in the consultation as a highly infectious disease, and linked with TB in this regard. HIV is very significantly less infectious than TB (or hepatitis, to give just one other example) and we would challenge whether it is accurate to describe HIV as *highly* infectious. It is sadly an example of the way the condition is viewed not on the basis of the facts but on the basis of unexamined stereotypes and assumptions.

No distinction is made in the consultation document between contagious and infectious diseases. This distinction, however, clearly has an important bearing on questions over the need for quarantine and other intrusive measures. This is because it affects both levels of infectiousness and the contributory agency of any person infected.

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The case of SARS cited, which appears to be extremely contagious and quite possibly fatal, appears to meet many of the criteria which would allow in extreme circumstances some form of forced quarantine.

In some countries forms of quarantine have been coercively applied to HIV. A dispassionate view of the facts only demonstrates how inappropriate such measures are, and serves as a warning as to how public health responses to infectious disease have all too frequently in the past been driven by stigma rather than evidence and a proportionate human rights-based approach. As already stated, HIV is not contagious and not highly infectious, except immediately after transmission, during sero-conversion. Of course this is precisely the period when it is very unlikely that a person's infection will have been diagnosed.

Seriousness

The question of seriousness is also relevant to HIV. No one doubts that even in developed countries such as the UK where anti-retroviral therapy is available, HIV infection remains a serious condition. The treatment can have unpleasant side-effects and even though a normal lifespan now seems possible for most people living with HIV, if not diagnosed at a late stage of their illness, HIV positive status still brings with it limitations and challenges. But it is clear from media coverage and court proceedings in cases of HIV transmission that the more generally held view of the seriousness of HIV is that early and unpleasant death is inevitable, that people live in permanent terror of developing 'full-blown AIDS'. Public health measures have to be based on facts and evidence but are as, if not more, frequently based on politics and public fears.

Agency, Proportionality, Solidarity

Degree of infectiousness and route of infection is also relevant to the question of agency in infectious disease. Whilst people might find it hard not to be unwittingly in the vicinity of someone with a highly contagious disease, in the case of sexual transmission of HIV, putting aside cases of rape, there is a significant degree of agency not only on the part of the infector but also the infected. Both agree to have sex, and agree knowing in almost all cases of the possibility of the transmission of infection if the sex is unprotected.

Consistent condom use with new sexual partners is a highly effective way of not getting HIV. Relying on disclosure of HIV status before using a condom is not an effective strategy, both because some people diagnosed with HIV will not disclose and because a third of all people infected with HIV in the UK do not as yet know their status anyway.

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In cases where quite straightforward actions by the general public can protect them from a serious disease, we do not believe that a coercive focus on those already infected is ethically justifiable. This relates to the question of proportionality – if a measure is available equally or more effective in controlling infection than a coercive measure which restricts human rights, then the less coercive approach must be the preferred option. In addition to the principle of proportionality, this also evinces the principle of solidarity. Those still healthy are sharing the burden of responding to the epidemic with those who are ill, instead of placing the whole burden of responsibility for controlling infection on those who are already struggling with the physical and psychological impact of diagnosis. It is this policy and ethical context which is behind NAT's opposition to prosecutions for reckless HIV transmission (we are not opposed to prosecutions for intentional HIV transmission – see www.nat.org.uk/prosecutions).

In successfully challenging a proposal by the Scottish Police Federation for mandatory blood tests for suspected criminals in certain circumstances, NAT and others made the point, accepted by the Scottish Executive, that it would be wrong to introduce such measures whilst proven consensual interventions remained untried (see NAT submission at www.nat.org.uk 'Blood Testing Following Criminal Incidents Where There Is A risk Of Infection').

Evidence of public health effectiveness

As has already been stated, measures such as those discussed in the consultation paper are often introduced with little evidential justification. The United States has had entry restrictions in place against those living with HIV since the early years of the epidemic. This has not prevented the US having one of the highest rates of HIV infection in the developed world. The same might be said of criminal prosecutions for HIV transmission, which again are fairly frequent in a large number of states in the US.

We have already made the point that a public health measure which increases stigma or the burden of state surveillance on a group already smarting from such experience is more likely to fuel the social conditions which make that group vulnerable to disease rather than address their real needs.

Too often proposals are made without a clear sense of their aim or function, never mind evidence of success elsewhere. When calls are made for mandatory HIV testing at borders, it is usually without any statement of what exactly will be done with a positive test result, whether treatment and counselling will be available to the person newly diagnosed, whether this is a doorway to care and support or a barbed wire fence against entry, how fraud can be avoided or subterfuge or an increase in illegal immigration. Measures are often attractive as signals of an ethical position rather than because they will clearly do any good.

Sharing responsibility

NAT accepts the need for individual responsibility in public health. Whilst arguing against criminal prosecutions for HIV transmission, we are interested in how an

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ethical dimension can be reintroduced into discussions of behaviour within the HIV sector. But the consultation paper in our view neglects public health measures when it comes to infectious disease. It is interesting that putting aside the case study on supplementation of food and water, which is about a particular intervention, all the case studies apart from that on infectious disease end with a section on 'Public health measures' – in the case of infectious disease, however, this is replaced by 'Methods of control'. This again demonstrates the unwarranted and socially generated bias towards such measures. What about education, efforts to combat discrimination and promote inclusion, the links between infection and poverty or poor accommodation, failures to explain risks of transmission in a culturally sensitive way, severe cuts in funding for prevention efforts across the country? Before numerous 'methods of control' are adopted we should assure ourselves that all is being done through voluntary and consensual means. We are far from sure that is the case.

Contributory negligence?

At a number of places in the consultation document, the question is posed as to whether those deemed to 'deliberately or negligently increase their chances of requiring public health resources' should be asked either for increased contributions to their care or receive fewer resources from the state.

NAT strongly opposes any such approach. It is a particularly sensitive issue for those living with HIV where the discourse of fault and blame remain not far below the surface in public debate.

There is a legitimate question in certain very specific circumstances as to whether a particular course of treatment will benefit someone who gives every indication that they will not act in a way to ensure the treatment gives any sustainable or long-term benefit.

It is quite another matter to deny care on the basis of some view of 'fault' or 'responsibility'. The greatest burden of ill health is found amongst the poor and the marginalised, and such ill-health may often relate to so-called lifestyle choices, be it smoking, poor diets, unsafe sexual behaviours, lack of exercise or immoderate drinking, to give just a few examples. Whilst accepting the place of personal choice and responsibility in health outcomes, it is as apparent that social factors such as inequality, poor education, social stress and a lack of genuine personal autonomy are extremely powerful predictors of ill health. To penalise people for the health-related consequences of their deprivation or marginalisation is profoundly unfair. Taken to its logical conclusion, we would withdraw free healthcare from the majority of conditions, with the exception of those inherited and those resulting from accidents where there could be no question of contributory negligence.

In practice, what would probably happen is simply that charging would be applied to those lifestyle choices which society currently stigmatises, reinforcing patterns of discrimination. HIV from unprotected gay sex could well be high on the list of lifestyle decisions deprecated, whilst skin cancer from excessive sunbathing on the Costa Smeralda remains terribly bad luck.

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Conclusion

NAT looks forward to the outcome of the consultation, and would be happy to provide additional comments, references or elucidation of this note should the Council find that useful.

National AIDS Trust

September 2006