



PUBLIC HEALTH LEGISLATION IN SCOTLAND

National AIDS Trust response to the Scottish Executive consultation

1. Introduction

The National AIDS Trust is the UK's leading independent policy and campaigning voice on HIV and AIDS. We develop policies and campaign to halt the spread of HIV and improve the quality of life of people affected by HIV and AIDS, both in the UK and internationally.

All our work is focused on achieving four strategic goals:

- Effective HIV prevention in order to halt the spread of HIV
- Early diagnosis of HIV through ethical, accessible and appropriate testing
- Equity of access to treatment, care and support for people living with HIV
- Eradication of HIV-related stigma and discrimination.

The National AIDS Trust (NAT) welcomes the concern of the Scottish Executive to update public health legislation in Scotland and ensure it is appropriate and effective for the modern world. Much of the document is not of immediate relevance to HIV and we therefore propose to concentrate on two key issues, the future of the AIDS Control Act and the merits or otherwise of making HIV a statutorily notifiable disease.

2. The AIDS (Control) Act 1987

At para.3.19 the consultation document raises the question of whether to continue with annual report requirement for NHS Boards laid down in the AIDS (Control) Act 1987. There are justifiable concerns as to whether the current reporting requirements are still the most appropriate, and also doubts as to whether good use is made at present of the information collected.

We understand that a sub-group of the National Sexual Health Advisory Committee is currently considering improvements to the method of allocating health promotion resources. It would be better not to rush to repeal the AIDS (Control) Act 1987 but first for the National Sexual Health Advisory Committee to assess whether and how a revised set of reporting requirements might usefully be used to inform treatment and health promotion interventions by Health Boards and so support an effective response to the epidemic.

3. Notification of HIV

At para.4.23 the consultation document raises the question of 'whether HIV, or other sexually-transmitted infections should be notifiable'.

The consultation document states its definition of a notifiable condition as one 'when knowledge of such an occurrence would help public health agencies take urgent action to prevent others in the community being exposed to the hazard thought to be the cause of the individual's disease or condition'. The disease would have to have 'a significant impact on health' [4.8].

Were such reporting requirements to be extended for the purposes of surveillance for health improvement and service design, the definition would of

course have to be broader than one based on the urgent control of communicable disease. In such circumstances the definition would be 'a disease of public health significance or specific measurable factors leading to its occurrence, knowledge of which will facilitate the planning and delivery of services to prevent or treat it' [4.18].

Not enough consideration is given in the document to the human rights issues relating to the requirement to provide personally identifiable information concerning those accessing healthcare. Whilst there is not a right per se in the ECHR to healthcare, the right to life under Article 2 and the right not to have to endure inhuman or degrading treatment under Article 3 do have profound health-related implications, especially in relation to a life-threatening condition such as HIV. The right to privacy under Article 8 is not an absolute right but there must nevertheless be very good reason to override expectations that health related information remain exclusively accessed and used by healthcare workers involved in the treatment of the individual.

'Urgent action'

Notification to date has been mainly for conditions where 'urgent action' could then be taken in relation to individuals to prevent the spread of a contagious disease. HIV, however, is very different from SARS, avian flu or TB. It is not contagious – infection takes place through blood-to-blood contact (or breastmilk from HIV positive mothers). HIV does not survive for very long outside the body and even in risk-taking circumstances the likelihood of HIV transmission remains low in any one risky act.

In short, the sort of individually based interventions which might be appropriate for a highly contagious and deadly disease (including compulsory examination and detention) are not necessary or effective in relation to HIV. For HIV, longer-term and sustained behavioural interventions and support are necessary for those living with the virus, as is continuing public health information for those uninfected to protect themselves from HIV transmission.

The consultation document rightly states that 'cultural and moral sensitivities' need to be taken into account in considering whether a condition should be notifiable. HIV predominantly affects two groups often stigmatised and marginalised by society – gay men and Africans - and is itself a stigmatised condition. There has been a sorry history of coercive and intrusive statutory interventions in relation to gay men and migrants. The interventions possibly justifiable for, say, TB or SARS are not only unnecessary for HIV but would be immensely counter-productive, deterring those from the communities most in need from accessing testing and care. The same deterrent effect can be expected from compulsory notification itself.

Surveillance

Scotland currently enjoys through the excellent work of Health Protection Scotland one of the best HIV surveillance systems in Europe. The same can be said for the rest of the United Kingdom. This system involves voluntary reporting from clinicians and an identifier system which can maintain individual anonymity. There is, in other words, no epidemiological, surveillance or public health argument for breaching the ordinary privacy expectations of someone accessing healthcare.

The argument against notification goes further than this, however. There is good reason to believe that were the Scottish Executive to make HIV and other sexually transmitted infections statutorily notifiable, this would result in a deterioration in the quality of surveillance information. The loss of confidentiality for people living with HIV would be a significant deterrent to test given the fact that HIV positive status remains seriously stigmatised, particularly in some communities. There are also groups, such as asylum seekers and other migrants, who may well worry that such notification could have a bearing on their claim to remain in the UK, or who have understandable fears relating to authorities and their use of information, given past experiences. Confidential access to GUM clinics has been the cornerstone of a successful UK response both to HIV and other STIs. The public health argument is strongly against making these conditions notifiable.

4. Statutory Powers for Health Protection

NAT notes the current statutory powers in relation to infectious disease – compulsory isolation and compulsory examination – and also the proposal to extend such statutory power to include a power of quarantine. We are not in a position to comment on the merits of quarantine powers in relation to other diseases, though where it has been used for HIV in other countries it has been either ineffective or at too high a cost in terms of the human rights of those living with the virus. Given its possibly useful application in extreme circumstances to some other diseases, NAT does not oppose such an extension of statutory powers. We note that existing powers have not, quite rightly, been used in relation to HIV. We cannot envisage circumstances where the use of such statutory powers would be defensible for someone living with HIV.

Explicit consideration should be given by the Scottish Executive to the implications for Scottish public health law of the recent *Enhom v Sweden* judgement in the European Court of Human Rights, a case involving the compulsory detention of someone living with HIV. Whilst the judgement does not preclude the introduction of new quarantine powers, it is possible that some current public health powers fall foul of the judgement, at least in their detail.¹

At para.3.24 there is discussion of whether those who exercise such statutory powers, in particular the restriction of personal liberty, should be 'competent persons' according to some established definition. NAT strongly believes that the competent person should have appropriate medical and public health qualifications.

**National AIDS Trust
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¹ For detailed discussion, see Martyn R, 'The Exercise of Public Health Powers in Cases of Infectious Disease: Human Rights Implications' *Medical Law Review* 2006 14 (1) 132-143