

Collective response of a group of individuals with HIV to proposals for mandatory testing for blood borne viruses

Positive Voice is a self-help organisation for people living with HIV in Lothian. On 1st June 05, Positive Voice organised an event to provide HIV+ people with information relating to the proposals for blood testing following criminal incidents where there is a risk of infection. Arguments for and against the proposals were provided in turn by Bill Barron of the Scottish Executive and Rosemarie McIlwhan of the Scottish Human Rights Centre.

The views of the participants at the event regarding the proposals have been summarised here.

While participants recognised the importance of providing support to the police and others to ensure their safety, appropriate medical treatment and freedom from anxiety, they objected in very strong terms to the proposals as a way of ensuring this on the grounds that they were disproportionate, ineffective, likely to lead to increased stigmatisation of already marginalized groups. The participants proposed a number of alternative approaches.

There were concerns raised about confidentiality. If a test was successfully applied for and the result came back "positive", concerns were raised about what would happen with this information. Clearly there is the unfettered opportunity for abuse of this information on the part of the applicant. Applicants may feel motivated to act vindictively. The process of application for a test, even though it may fail, has the potential to cause distress. Also concerns were raised about possible future implications in terms of insurance and immigration following a test being carried out. Would the result of the test, and the fact of the test having been carried out be recorded in medical records? This would mean the loss of the choice regularly exercised by people who apply for an HIV test to do so anonymously. Would the Sheriff Court hearing be private – or would this constitute yet another opportunity for a breach of confidentiality? For someone who knows himself or herself to be positive, being obliged to disclose their status would constitute an excessive pressure. In terms of disease progression, it is important that people with HIV are not exposed to excessive stress.

Participants pointed out that a "suspect" could be required to have a blood test even though he or she had not been found guilty of any crime. An erosion of rights would follow from a mere suspicion of guilt. The process to be followed for a test to be required would be based on suspicion, value judgements and prejudice. The proposals will disproportionately affect already marginalized groups such as gay men, Africans and people with HIV themselves. The upshot of the legislation is that someone may be criminalized for refusing to take a blood test – while they may have very good reasons for doing so. This was seen as unfair by the participants - exercising one's rights to choose whether or not to disclose should not be seen as a crime. It was argued that, in fact, the proposed procedures may well be counter-productive, as introducing compulsion would stigmatise disclosure and potentially operate as a bar to voluntary testing in other circumstances. Participants argued that there is no logic

in restricting the proposals to criminal cases and therefore no reason for them to applied in these circumstances.

The risk of transmission of HIV within an occupational context is extremely low. The proposals were described by participants as an extremely cumbersome and also destructive instrument for dealing with this problem. Of far greater value would be better guidance for the police and others. If the police were aware of how unlikely it is that transmission may occur, the anxiety that these procedures are set in place to alleviate would not be there in the first place. The participants would also like to see universal HEP B vaccination for the police and others who feel themselves at risk of occupational transmission. Participants were unable to reconcile an individual decision not to get a HEP B vaccination with an application to have the HEP B status of another person made known. Participants felt that all testing for blood borne viruses should be voluntary – and those taking the tests should have access to appropriate counselling and support. Voluntary testing could facilitate the sharing of information where appropriate without recourse to the draconian measures proposed. Finally participants at the event would like to see better counselling and support for police following events where they feel there is a chance that there has been a risk of transmission of HIV or another blood borne virus.

Participants went on to question the value for police in having access to blood test results. Participants pointed out that a positive result from the source would necessarily lead to a great increase in the stress experienced by the applicant (although the risk of transmission in nearly all cases is low) while a negative test result could not be seen as a clear indication that the source was not HIV+ at the time of the incident. Because of this, the worried would continue to worry under such circumstances. Testing would therefore not offer the reassurance or absolute grounds for discontinuing PEP, which is presumably the aim of applying for a test.

Participants questioned whether there would be parity if a member of the public felt that he or she had been subject to a risk of transmission of a virus from a police officer following an incident. If a police officer found themselves to be positive following an incident with a positive individual, how would it be possible to determine the officer wasn't already positive prior to the incident.

It is significant that for people with HIV, the use of criminal or civil law to as a form of sanction or threat will influence their perception of the police. Participants felt moved to stress that to be HIV+ is not a crime. There seemed to be proposed a two tier system of justice, where someone with a blood borne virus would be 'more guilty' following certain criminal incidents than someone who did not have a virus – irrespective of any intention to pass on the virus. Participants stated that the proposals felt very much like an attempt to criminalize HIV status. What is necessary, participants argue, is a de-stigmatisation of HIV, not legislation which could lead to increased stigmatisation.