

16th January 2006

Dr Jacqueline Goodall,
Legislative Review,
Public Health,
GPO Box 1670N,
Melbourne VIC 3001

Dear Dr Goodall

This letter is to provide you with the comments and concerns of Positive Women (Victoria) Inc. on the proposed revisions to the present Health Act 1958. While we have chosen to focus on particular issues, we also support the submissions of other community-based groups, which together cover the full range of concerns.

Our organization recognizes that the Health Act must be reviewed in the light of new and life-threatening diseases and the development of improved technology and interventions with which to control and prevent epidemics.

However, clear definitions need to be made about the diseases, their transmissibility and virulence, and the circumstances in which these extended powers would be invoked. Without such clarity, certain recommendations in the review may prove counterproductive to efforts to control diseases such as HIV and HCV, through **informed choice and voluntary behaviour change**.

Our concerns include but are not limited to:

- A significant expansion of powers, and their increased devolution to municipal authorities, without adequate judicial oversight
- Increased access to information about infected individuals, confidentiality breaches and potential misuse of such information.
- Changes which downgrade the quality of the pre-test and post-test counselling for HIV.

In addition, a Charter of Human Rights and Responsibilities has been proposed for Victoria and a number of recommendations have been made after public consultation. Although the Charter is unlikely to be introduced before 2008, it is still timely and appropriate to assess any changes to the Health Act and related legislation for their compatibility with the Charter, and the responsibility of public authorities to comply with the Charter.

Such specifications and clarifications could be included in the set of guiding principles proposed in Section 1.7, Recommendation 13 (pp8-10).

1. Protection of the rights of vulnerable groups

Even in countries where civil and political rights exist, public health and epidemic control remain one of the few circumstances where human rights of freedom of movement and association can be overridden.

The Health Act is based on the traditional approach to communicable disease control, through measures such as compulsory testing and isolation. However, in the case of HIV, such an approach of "**prevention through punishment**" is counterproductive because marginalising those groups most vulnerable to HIV infection, pushes the virus "underground", and allows it to spread undetected.

More than two decade's experience of the HIV/AIDS epidemic has shown the need for and the success of the paradoxical approach of **linking prevention and care**. HIV prevention is best achieved through providing an enabling environment, and including harm reduction, where those most at risk of HIV infection feel safe and supported to come for testing and treatment. Early diagnosis is best in the interests of both the individual and the community, so that clients can delay disease progression, and protect themselves and their partners from further infection, and so prevent further HIV transmission into the wider community.

Confidentiality is crucial to maintain high levels of HIV testing, particularly considering the level of stigma and the potential for discrimination that accompanies a positive diagnosis, as evidenced in the latest Futures 4 study, by the Australian Centre for Sex, Health and Society.

Valuable lessons learnt from the HIV epidemic are also applicable to other diseases, such as Hepatitis C. The Health Act review is inconsistent in the manner it treats HIV, HCV, other blood-borne viruses (BBVs) and sexually transmissible infections (STIs). A uniform approach and enabling environment is needed for HIV, HCV and other diseases which are still stigmatised and where the vulnerable groups are further marginalised, because of the ways in which the diseases are transmitted.

Greater clarity is required for the criteria in which the proposed powers are to be used, so that the affected individuals can have confidence that their rights will be respected and not abused.

It is on this basis of creating a safe supportive environment that encourages voluntary testing and treatment, that Positive Women (Victoria) Inc. supports the following recommendations

Section 5.5 Public health orders

Recommendation 179 that the public Health Act not re-enact the offence of knowingly and recklessly infecting another person with an infectious disease, and instead relies on the Crimes Act 1958 (Vic) for prosecutions of this nature.

Section 5.9 Outbreaks of infectious diseases at schools and children's services

Recommendation 203 that parents or guardians be required to notify schools only in relation to vaccine preventable or excludable diseases. In practice, this would then remove the requirement to notify schools of the positive HIV or HCV status of pupils attending, especially as universal infection control procedures are the required standard. Greater clarity is needed on how the new Health Act would affect the provisions of the Children Services act 1996, dealing with preventing infection through schools and children's services

Section 4.3 New offence of "risk to health"

Recommendation 82 not to introduce a "risk to health" offence.

Likewise, it is on the basis that proposed measures may increase victimization of vulnerable groups and create a disincentive to testing and treatment that Positive Women (Victoria) Inc. does not support the following recommendations, if there is no clarity about their use.

Section 3.6.2. Information sharing

Although this issue was not specifically raised in the discussion paper, further integration of health reporting requirements is suggested under the new Health Act. Recommendations 69 and 70, which refer to disclosure powers by the Secretary and municipal councils cannot be supported, unless there is some process for the regulation and review of the use of such powers, that involves Privacy Commissioner and the Health Services Commissioner.

Section 4.8 Authorised officer's powers of inspection

Recommendations 105-114

There appears to be no differentiation between emergency powers and routine, day-to-day powers. There also does not appear to be any judicial overview or check and balances accompanying these powers. There is considerable disquiet over recommendation 111, that entry, search and seizure powers would not require a warrant. There is also no confidence in the delegation of powers to municipal councils to appoint "authorized officers", without any specification of the competencies, qualifications or experience for such appointments (section 1.12.3 Authorised officers , Recommendations 23-31)

Section 5.3.2. Contact Tracing

Recommendations 159-161. We oppose the extension of existing contact tracing powers for HIV, HCV, and other STIs. In particular access, we have concerns over access to medical records and research data, as this is a disincentive for HIV-positive people to give full and complete information, and would therefore put clinical care, public health and research at risk. A recommendation for an offence "not to give contact information" needs further discussion in its implications for researchers, service providers and their clients.

We opposed any proposal to override existing privacy and confidentiality provisions of legislation, such as the Health Act Records Act 2001 and the Information Privacy Act 2000.

We also oppose the authorisation of municipal council staff as contact tracers for HIV and HCV, for reasons of confidentiality, misuse of information, and the lack of specification of the training, competence, qualifications and experience.

Section 5.4 Compulsory testing orders

We oppose an extension of compulsory testing to the vaguely-worded "wherever there is a potential risk of ongoing transmission of a disease" (p.89). Although recommendations 164 and 165 make no specific reference to this, it could be included under the wide scope of 5.5 Public health orders.

Compulsory testing must be accompanied by appropriate pre-test and post-test counselling, and by access to treatment, if the person requests it.

Section 5.5 Public Health Orders

Overall, the recommendations in this section raise concerns over human rights and about the balances and checks on the use of powers. We echo other community recommendations that public health orders be issued sparingly and that the numbers and circumstances of their use be available for public scrutiny on an annual basis.

Recommendation 172 (g) The power to order treatment for HIV should be opposed and requires further clarification as individuals have a civil right to refuse treatment. Instead of compulsion, it would be preferable to examine the processes in which the benefits and disadvantages of treatment are discussed, so that the client can make an informed choice.

The reproductive health rights of HIV-positive women and the prevention of perinatal HIV transmission (aka mother-to-child transmission or MTCT) remains a complex area, fraught with potential harm.¹ Prior to mid-1990s and the advent of effective anti-retroviral therapy (ART) and other interventions to reduce MTCT, HIV-positive women who became pregnant were routinely advised to terminate. In some countries, such as PNG and Thailand, HIV-positive women were forced to terminate their pregnancies and/or forced to undergo sterilization.

In Australia, there have been some "horror stories" but more HIV-positive women are choosing to have children, and undergo interventions that reduce the risk of MTCT. Women have more confidence in ART, because there is now a choice of alternative combinations, with fewer side effects and many babies have been born uninfected, without apparent long-term effects after ART exposure. However, despite the accumulating evidence of best practice, women's consent or co-operation should not be taken for granted and shortcuts must not be made to the process of negotiating their healthcare choices. Medical interventions, including HIV antiviral treatments and Caesarean section, must remain as choices, and should not be made mandatory.

All HIV-positive pregnant women, regardless of their cultural background, lifestyle, and treatments choices, should be supported in making informed decisions about their own health or that of their newborn in an environment that is free from emotional or legal coercion. Consistent national guidelines should be developed, that support HIV positive women to make informed decisions in regard to pregnancy and newborn babies, and that inform women where these decisions may have legal ramifications.²

The non-compliance in the prevention of perinatal HIV transmission or the refusal of parents or guardians to allow ART treatment of HIV-positive children pose particularly complicated ethical and legal situations. However, the threat of mandatory action may cause them instead to abandon the health system, to the detriment of their own health and/or their children's. Far better to have a proper process of counselling people, to make the best informed choices and to engage their co-operation.

Section 5.6 Notifiable conditions

It appears inconsistent that HCV is not a notifiable disease in Group D.

Section 5.6.4, Form of notification (pp98-99), there is a suggestion that Group C and D conditions (including HIV and AIDS) no longer be reported in coded form. We oppose any

¹ Kirsty Machon. Pregnancy and HIV: a human rights perspective. In *HIV and hepatitis C; policy, discrimination, legal and ethical issues*. Australasian Society of HIV Medicine, 2005, p86-96. Also available online at www.ashm.org.au under publications

² *ibid*

proposal to change to a name and address notification of these conditions, because fears of confidentiality breaches would lead to a decline in testing.

Section 5.7 Human Immunodeficiency Virus

Again it appears inconsistent that there is a major section on HIV, but not on HCV when much of the same is applicable to both.

Recommendation 186 cannot be supported if the new Health act may override existing privacy and confidentiality provisions of legislation, such as the Health Act Records Act 2001 and the Information Privacy Act 2000.

Recommendation 188 against closed court hearings is opposed because of the negative consequences of disclosure of a client's HIV status in court hearings.

2. Importance of high quality pre-and post-test counselling and informed consent

Although antiretroviral therapy has reduced illness and mortality due to HIV/AIDS, the diagnosis of HIV remains a traumatic event. Therefore an HIV test must never be regarded as an ordinary test, but requires the informed consent of the client and good pre-test and post-test counselling.

Pre-test counselling is essential for the client's awareness of their risk, and to prepare them for the possible consequences of a positive result. It is possible that after pre-test counselling, a client may choose not to have the test, or alternatively, consent to have blood taken, but never return for the results. But at least the counsellor has had the opportunity to discuss at-risk behaviours with the client, so that s/he can make a better informed choice to modify their behaviour.

Post-test counselling for a positive result needs skilful handling when often the client is in a traumatised state, and in a confusion of "what next?". However, post-test counselling for a negative result is equally important to reinforce safe sex and/or injecting behaviour

Voluntary counselling and testing is the entry point into the "continuum of care". The quality of the VCT process is central to those first critical steps in a client's journey to cope with the impact of HIV. However, we know from the experience of many PLWHA that the VCT experience is far less than ideal - that people are tested without consent, with no or poor pre-test counselling, no or poor post-test counselling, and some particularly bad experiences with doctors, who have never received training but are judged to be competent counsellors under the Health Act.

The need for informed consent and good quality pre-test and post-test counselling doesn't only apply to HIV. Nowadays, people can undergo tests for other diseases which, like HIV, can be devastating in their consequences. Prospective parents can go for genetic counselling and testing for diseases like cystic fibrosis, Huntington's chorea, Tay-Sach's. Women with familial histories of breast and ovarian cancer can be tested for breast cancer genes, BRCA1 and 2, to help make decisions about preventive mastectomies.

Section 5.7.1 Pre and post test counselling provisions

Pre-test and post test counselling has been included under section 5.7 on HIV, but should also be legislated for HCV. However, legislation for pre-test and post- test counselling should not only apply to HIV and HCV, but also some other specified diseases or conditions.

(Sometime in the future, legislation or other measures may also be needed to protect clients diagnosed with certain conditions against discrimination by insurance companies.)