

1 June 2016

Health Protection NSW
NSW Ministry of Health

Locked Bag No. 961
North Sydney NSW 2059

By Email to: publichealth@doh.health.nsw.gov.au

Submission - Statutory Review of the Public Health Act 2010

Introduction

In response to the correspondence from Dr Kerry Chant PSM Chief Health Officer and Deputy Secretary, Population and Public Health, Positive Life NSW (Positive Life) makes this submission in reply to the *Public Health Act 2010 Statutory Review - Discussion Paper*.

As the public face and voice of all people living with and affected by HIV in New South Wales (NSW), Positive Life restricts its comments in this submission to Section 56 (the protection of a patient's identity) and to Section 79 (disclosure of an STI including HIV before sex). We base our submission on: 1) analysis of the *Public Health Act 2010 Statutory Review - Discussion Paper*, 2) extensive discussions with the Positive Life Board and staff, 3) consultations with people with HIV, 4) the Positive Life/ACON Community Forum held on the 24th May 2016, where Ministry representatives outlined a rationale for the changes and answered questions from the audience, and 5) results from the ACON/Positive Life Community Survey.

Section 56 – Notifications of HIV and AIDS

Some people with HIV and affected by HIV are understandably anxious and fearful about the introduction of named based HIV notification. While the numbers of people attending the Positive Life/ACON Community Forum were small (approximately 40-50 individuals) and many of these individuals were either HIV sector employees or ex-employees, anxiety in relation to named based HIV notification was noted and has also been observed in responses to the ACON/Positive Life community survey.

Positive Life considers on balance there are more health benefits for named notification of HIV than harms, but acknowledges the significant concerns of people with HIV with regard to this issue. The primary benefits are: 1) improved patient follow up and linkage to treatment and care, 2) improved retention in care, 3) reduced loss to follow up and the potential to re-engage people in treatment and care who are lost to follow up, 4) a better understanding of the relationship between HIV and STIs, and 5) a greater understanding of the risk factors that drive HIV transmissions in NSW.

We understand the requirement to de-identify HIV notifications was introduced in the late 1980s at a time when there was no effective treatment for HIV and limited benefits to HIV testing, the advent of highly effective antiretroviral treatment has transformed HIV infection from a progressive, fatal disease, to a chronic manageable illness for people who regularly access care and adhere to treatment. By treating HIV differently to all other notifiable diseases, we believe that de-identifying HIV notifications may be indirectly perpetuating HIV stigma and engendering discrimination. While we are also aware and acknowledge that there is some discrimination in health care settings, the majority of stigma and discrimination directed toward HIV positive people occurs in sexual contexts.

While people living with HIV will always have the right to choose if and when they start treatment, we acknowledge the important role that named notification of HIV and surveillance of viral load test results will play in facilitating proactive and non-coercive patient follow-up. Maximising linkage to HIV care and re-engagement for those who are lost to follow up is crucial if we are to support people with HIV to improve their health outcomes and prevent transmission. Named based HIV notification would arguably help achieve these outcomes.

Positive Life's considerations around named based HIV notification is contingent upon protections being written into the Act that preclude subpoena of HIV information by Police, Commonwealth and other State Government Departments (e.g. Department of Immigration), and by lawyers building cases in criminal matters. We understand these measures are supported by NSW Health and will be necessary to protect people with HIV from intergovernmental information searches and to build community confidence for named based HIV notification.

There have also been concerns expressed mainly from other HIV sector NGOs but also from people living with HIV that named based HIV notifications will drive down HIV testing rates in NSW, particularly for individuals from: 1) regional and rural areas, 2) culturally and linguistically diverse backgrounds, 3) Aboriginal and Torres Strait Islander populations, and 4) non-community attached men who have sex with men. Positive Life has found no current evidence for these concerns. A study of HIV testing across six states in the USA¹ for 12 months before and after the introduction of confidential name based reporting of HIV diagnosis showed no significant declines in the total number of HIV tests after the implementation of HIV name based reporting. Concerns however have been raised against the relevance of the US studies due to the fact that people without private medical insurance in the US need to test to gain access to treatment through the public health system. However, other places where mandatory name based reporting has been introduced have also found no reduction in HIV testing rates (Catalonia, New York State and Canada).

Section 56 – The prohibition of a person's identifying details being used for the purposes of arranging a diagnostic test for HIV (except in hospital situations or with consent)

Positive Life considers that there is some merit to the inclusion of a person's identifying details when requesting a diagnostic HIV test given that where testing is done for non-diagnostic purposes such as viral load or drug resistance testing, the patient's name already can be included and frequently is included on the pathology request form. This difference and inconsistency in legal requirements can result in confusion for clinicians and pathology laboratories and importantly refutes any privacy protection afforded by Section 56. We also note that not having the inclusion of a person's identifying details can present a barrier to testing in certain situations, particularly in antenatal screening where clinicians currently order an antenatal screen on a pathology request form containing the pregnant woman's name and the pathology laboratory cannot be assured that consent has been given for an HIV test to be carried out.

Section 56 (3) and (4) - Additional confidentiality that a person has HIV or AIDS, and the sharing of HIV information between health care providers

Restricting the provision of HIV information between health care providers in shared HIV/non-HIV care arrangements, adversely impacts on the quality of health care provided to people living with HIV and can have serious detrimental health implications. With increasing proportions of people with HIV ageing and at increased risk of developing multiple chronic health conditions, knowledge of HIV status and medication regimens become important factors in almost all medical and diagnostic consultations. Failure to take HIV into account can lead to health conditions being misdiagnosed, missed or becoming worse. Failure to take HIV and other treatment regimens into account can produce potentially dangerous drug interactions, particularly in emergency situations.

¹ Nakashima 1998, USA CDC Study

The restriction on sharing HIV information with other health care workers will create critical information gaps as NSW moves toward a system of electronic health records. If HIV clinical information is restricted, locked down or omitted, mistakes can be made that result in clinicians delivering health care that is suboptimal, inappropriate or potentially dangerous. We understand that some people living with HIV will view this change as reducing their control over who has access to their health information. However, HIV information is protected by the Health Records and Information Privacy Act, which places strict limits on the use and disclosure of health information and protects against inappropriate disclosure. There are severe penalties for inappropriate disclosure of health information by health care workers.

Section 79 – Disclosure of STI status, including HIV

Positive Life supports the removal of the requirement to disclose HIV/STI status before sex. We believe that relying on disclosure of HIV status to sexual partners to prevent transmission of HIV acquisition is a flawed public health strategy and contributes to HIV stigma and discrimination. Sexual partners are not always aware they have an STI and/or HIV and may have acquired the infection since their last test. We consider that the notion of shared responsibility should be paramount and that the onus of responsibility for prevention of STIs and HIV needs to be shared by both partners. High percentages of people living with HIV in NSW are taking treatment and maintain an undetectable HIV viral load. In addition, we know from interactions at programs such as Genesis, that people newly diagnosed with HIV and yet to start treatment are vigilant about not passing on HIV. We regard people who are infected and unaware of their status to present a substantially greater risk to the HIV transmission dynamic than people who are on treatment with an undetectable viral load.

Conclusion

On the basis of: 1) rationales presented by NSW Health in the *Public Health Act 2010 Statutory Review – Discussion Paper*, 2) presentations from NSW Health at the Positive Life/ACON Community Consultation Forum (24 May 2016), 3) discussion at the community consultation forum, and 4) results from the ACON/Positive Life Community Survey;

Positive Life sees merit in:

- A. The removal of the requirement to disclose HIV status before sex (s79)
- B. Identifying details being used to request an HIV diagnostic test (s56), and
- C. Broadening the definition to allow the sharing of HIV information between health care providers s56 (3) (4).

In relation to the introduction of named based notification of HIV and AIDS:

We acknowledge significant community concerns, mistrust and anxiety remain about the introduction of named based notification of HIV, and how NSW Health will use HIV surveillance information. We believe that some of these concerns are due to fear of discrimination and a lack of knowledge and misinformation about the functions and application of the Public Health Act and the use of routine HIV surveillance information. There is also a lack of understanding regarding models of health service delivery, clinician function and roles, and how this relates to people living with HIV and the public health program more broadly. To address these concerns and misunderstandings, targeted community based education initiatives would provide people living with HIV with a better understanding of the functions of the Public Health Act and existing privacy provisions, the role of clinicians within the existing models of health service delivery, and ease concerns about named notification of HIV diagnoses.

Over the past 30 years, people with HIV have become increasingly accustomed to levels of confidentiality and privacy not experienced by other disease groups. Any change to this paradigm will understandably be examined, questioned, and potentially resisted by sections of the HIV positive community. Persuasive rationales for the change from de-identified to identified HIV notifications

will need to be initiated to gain community trust and acceptance and to allay concerns about the sharing of HIV information and perceptions of potential coercion, infringement on autonomy and depletion of health care rights.

Positive Life accepts that on balance there are potential individual and public health benefits to named notification of HIV diagnoses in NSW, particularly in relation to supporting people living with HIV who are lost from care to re-engage in health care. However, any changes to named based notification of HIV and AIDS would be contingent upon protections being written into the Act that fully prevent subpoena of HIV information by external parties and safeguard the privacy of people with HIV. In addition, community concerns about named based HIV notifications will need to be addressed.

If you require further information in relation to this submission, please contact me.

Lance Feeney
Acting CEO



1 June 2016