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***Comments on Public Health Act
2010 Statutory Review
Discussion Paper to NSW
Ministry of Health***

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The Australian Federation of AIDS Organisations (AFAO) is pleased to provide comments on the Public Health Act 2010 Statutory Review Discussion Paper.

AFAO is the national federation for the HIV community response. AFAO's members are the AIDS Councils in each State and Territory; the National Association of People with HIV Australia (NAPWHA); the Australian Injecting & Illicit Drug Users League (AIVL); Anwernekenhe National HIV Alliance (ANA); and Scarlet Alliance, Australian Sex Workers Association. AFAO advocates for its member organisations, promotes medical and social research into HIV and its effects, develops policy on HIV issues, and provides HIV policy advice to the Commonwealth, state and territory governments.

AFAO has had the benefit of perusing ACON's submission to the Ministry of Health on the Discussion Paper, and we fully endorse the points made in the submission regarding the potential disadvantages of named notification. Further to the points made in the ACON submission, AFAO provides the comments below regarding: the proposed repeal of s79 of the Public Health Act 2010 (the Act); and the proposed introduction of named notifications of new HIV diagnoses.

Removal of s79

AFAO welcomes the proposal to repeal s79 and we support the suggested inclusion of principles of expected responsibilities, along the lines of the Victorian *Public Health and Wellbeing Act 2008*.

s3.5(c) Section 56 and notification of HIV and AIDS

➤ Question 15: Should HIV notifications to the Secretary include the person's name and address?

No. AFAO strongly opposes replacing coded notification with named notification given the potential to raise rather than reduce rates of late diagnoses for *National HIV Strategy 2014-2017* priority populations.

AFAO appreciates that the Ministry's consideration of a change to named notification is motivated by a desire to improve surveillance and enhance connection to care, and we strongly support those goals. However, the possibility of unintended effects that are completely contrary to the intended benefits of named notification need to be taken seriously and community engagement is essential to identifying and understanding any potential unintended effects of the change. Amending the legislation without the extensive preparatory activity and consultation with communities affected by HIV is ill-advised.

We cannot agree with the Ministry's view that on balance the potential benefits of named-notifications outweigh the drawbacks. AFAO believes that the proposed change poses a real-risk of decreasing testing rates in NSW and further entrenching late diagnosis among particular populations.

Australia's HIV response and the enabling legal environment

The development of an enabling legal and regulatory environment, including confidentiality and privacy protections, has been crucial to the success of the Australian response to HIV. Although most people readily accept that sharing of information regarding HIV test results among clinicians, including via e-health systems, is for the good of individual health management, sharing information with a government bureaucracy responsible for the administration of coercive powers under the Public Health Act raises different issues. People within particular sub-populations, such as migrants and refugees from countries with high prevalence of HIV where

PLHIV experience high levels of stigma and discrimination can have deeply held fears regarding the state holding information about HIV-positive status. Australian surveillance data show disproportionately high rates of late diagnosis for people among CALD communities and it is likely that named notification would prove a disincentive to test for people from such communities and undermine current efforts to enhance testing rates for these populations.

In canvassing the potential benefits and drawbacks of named notifications, the Discussion Paper states that there is no international evidence to indicate that named notification is a deterrent to HIV testing. The studies cited to justify this come from the United States, where the HIV epidemic and the public health response has been vastly different to that in Australia. In the most recent of the articles by Tesoriero, it is stated that:

“Results indicated a low awareness of states’ reporting laws among high-risk individuals in general and little evidence that HIV testing decisions were being strongly influenced by a concern about name based HIV reporting.”¹

The studies cited in the discussion paper should not be used to anticipate the potential impact of named notification in NSW. Unlike the US, Australia has an excellent and accessible public health system, and all seven national HIV strategies implemented to date have supported the development and maintenance of a supportive legal and policy framework for a public health approach to HIV prevention. This has included the availability of confidential HIV testing. Fundamental to developing that framework are hard-fought privacy provisions, including those ensuring that information regarding a person’s HIV status is not shared beyond a person’s health providers. Apart from those legal protections it is also important to remember that at its most basic level, patients rightly have an expectation that they may have discussions with their doctor that are private. Disclosure by a doctor of a patient’s detailed health information to a third party constitutes a breach of the expectation of doctor-patient confidentiality.

If named notification were introduced in NSW, it is AFAO’s view that the testing healthcare worker/organisation would be obliged to inform patients of the new framework as part of obtaining consent for HIV testing, and as part of their responsibility to inform a patient of the use to which their personal data will be put. Whether this occurs in relation to other conditions for which named notification is in place is made immaterial by the very detailed and sensitive nature of the information collected via the HIV notification form, and the availability and use of extensive criminal and public health powers by the state. Given the privacy controls in place for the national PCEHR/My Health Record system, which allow a person to control and limit the sharing of information alluding to HIV-positive status, the advice to a patient would need to be that they can control the sharing of their HIV-positive status among health providers, but not the sharing of that information with the health bureaucracy. This is intrinsically confusing. It is foreseeable that people who are ambivalent or tentative about testing because of confidentiality concerns will refrain from testing or seek out anonymous testing; and that the people most likely to refrain from testing or who will opt for anonymous testing, are people most at-risk of acquiring HIV. With HIV self-test kits already available for online purchase, this has the potential to lead to the very disconnection from care that the change seeks to overcome.

AFAO also has concerns regarding the potential for HIV-positive people to be subject to named notification upon re-testing, for example as a result of HIV testing prior to major surgery or as a result of changing to a new doctor who is needing to prescribe HIV treatment. This is despite the Discussion Paper indicating that there would be no retrospectivity and that only new diagnoses would be notified as named. The Ministry of Health has advanced no explanation as to what mechanism could be put in place that would prevent named notification occurring upon re-testing. The Ministry of Health will be aware that a considerable proportion of notifications relate to previously diagnosed cases, but has not made this clear in the Discussion Paper. At least some

¹ Tesoriero JM et al. The Effect of Name-Based Reporting and Partner Notification on HIV Testing in New York State. *American Journal of Public Health* 2008 April;98(4):728-35

stakeholders have formulated their views on the assurance by the Ministry that the changes would not be retrospective.

Persisting stigma

The high profile of HIV criminal cases is an issue affecting perceptions of HIV and people with HIV in the general community, particularly given that media reporting of such cases dominates mainstream media news coverage of HIV at this point in the HIV epidemic. In the last three years at least three HIV-related prosecutions have been initiated in NSW following the decision by the NSW Government in 2011 to lower the threshold for the criminal prosecution of HIV and to increase criminal penalties for successful prosecutions. The recent need of the Government to do so sits in contrast to the Ministry's assertions that HIV is now similar to other health conditions. The criminal prosecution of HIV generates sensationalist media stories that HIV-positive people are potential criminal vectors of disease. These prosecutions arguably provide a disincentive to test², particularly for people among CALD and marginalised communities who may believe that testing HIV-positive will result in criminal sanctions.

Even if one were to see no change in testing rates among gay-identified men living in the inner city of Sydney, this cannot be presumed to be the case for people from CALD communities, and for all priority populations in rural parts of the state. It is of concern that decreases in testing rates among CALD populations and rural/regional populations could be masked by flat-lining or modest increases among gay men in inner-city metropolitan areas. AFAO thus believes that named notification would bring only marginal gains in terms of data quality; and that the complex issues affecting a person's retention in care would be exacerbated rather than solved by Ministry of Health intervention.

Underlying much of the Ministry's rationale is the assumption that stigma experienced by gay men, and also by injecting drug users and sex workers, is less prevalent than previously. The paper states that:

There have been significant positive changes in the social environment and attitudes towards people with HIV, although it is recognised that people with HIV and affected communities such as gay and homosexually active men, injecting drug users and sex workers can continue to experience stigma and discrimination.

Homophobia may be less prevalent in the community than thirty years ago but it remains a significant factor in the lives of gay men, and is the reason why many men who have sex with men present as heterosexual to family and the general community. The political vitriol associated with opposition to same sex law reform in 2009/2010 and to same-sex marriage now, is often based in undisguised homophobia. The proposed plebiscite on same-sex marriage is bound to elicit a homophobic discourse that will be deeply stigmatising and distressing for the LGBTI community.

Other priority populations, such as those from CALD backgrounds (including gay men and MSM in these communities), also continue to experience HIV-related stigma as well as racism and anti/migrant/anti-refugee sentiment. This stigma can be complicated by concerns regarding the impact of an HIV diagnosis on migration status, which can compound existing reluctance to test. AFAO held a Mobility and HIV Forum in Sydney on 30 May 2016 to discuss priority HIV-related issues for mobile and migrant populations, with 60 participants attending from HIV and multicultural health agencies from around the country. The proposed changes in NSW in relation to named notifications were discussed, and the overwhelming response from participants, including clinicians involved in the care of PLHIV among migrant communities, was that any reporting of HIV diagnoses to a government department will be perceived by many people from CALD populations as a risk to migration status

² UNAIDS Policy Brief, *Criminalization of HIV Transmission*, p 4.

http://www.unaids.org/sites/default/files/media_asset/jc1601_policy_brief_criminalization_long_en.pdf

and/or a risk of HIV status becoming known in the community, and will result in people avoiding testing. There were also concerns expressed that media attention to criminal HIV transmission cases involving African men are deeply stigmatising for PLHIV among African Australian communities, heightening privacy concerns for PLHIV and fuelling anxieties regarding potential repercussions of authorities becoming aware of their HIV-positive status.

AFAO has also received representations from NSW high-caseload HIV clinicians who are concerned by the changes and believe that the Ministry has under-estimated the number of people who are concerned about confidentiality in testing for HIV, including gay men. The changes will considerably erode the ability of clinicians to provide assurances to patients of the confidentiality of HIV testing.

➤ **Question 16: Should any additional protections be included in the Public Health Act relating to information held by the Secretary, and if so what are they?**

AFAO believes that additional protections would not address the issues outlined above.

We note that the Ministry of Health argued at the community consultation convened by ACON and Positive Life NSW that there would be no disclosure of any named notification data to another government department, such as the Department of Immigration and Border Protection, or the Department of Human Services. However, there is already a perception among people in CALD communities that information regarding HIV status is shared. Health providers routinely need to stress the confidentiality of HIV status and re-confirm that information is not shared beyond treating health providers. Indeed, in a 2009 study a good proportion of CALD respondents (36.1%) were worried that they might be in trouble with government agencies such as Centrelink if they were known to be HIV-positive.³

To address concerns about the confidentiality of named HIV diagnoses the Ministry states that there are safeguards that could be introduced. The paper outlines several safeguards that would militate against the misuse of HIV diagnosis-related information. However, these offer little robust protection. On page 29, in the paragraph preceding “issues for consideration 15 and 16”, the paper states:

Further, if the Act is amended to require named notification of HIV, the Ministry would also like to hear submissions on whether there should be any additional safeguards in the Act relating to information held by the Secretary. This could include, for example, not allowing notifications received under the Act to be subject to subpoena. Not allowing notification information to be subpoenaed may assist in persons with HIV, or other conditions, being assured that information collected under the Act will be used for public health purposes and not for other external purposes while not unduly affecting Court processes (as pertinent information would still be able to be subpoenaed directly from a medical practitioner).

Without a guarantee of support from relevant Ministers and Cabinet, no assumption can be made that such a safeguard would ultimately form part of the proposed change. In the context of at least three prosecutions in NSW over the last three years, fear of criminal prosecution will remain a cogent factor deterring those most at risk from testing and confidentiality of test results is the key legal protection to counter that fear.

The discussion paper also states on page 22 that:

³Asante, A., Körner, H., & Kippax, S. (2009). Understanding late HIV diagnosis among people from culturally and linguistically diverse backgrounds (Monograph 7/2009). Sydney: National Centre in HIV Social Research, The University of New South Wales.

“...community attitudes to HIV have improved markedly over the past 30 years and this has been assisted by the introduction of evidence based laws, policies and programs to address privacy, stigma and discrimination concerns. “

The advent of privacy laws over the last 20 years is welcome, and they provide comfort to people fearing disclosure of their HIV status beyond health providers. The introduction of particular privacy protections in relation to HIV-positive status was in recognition of the fact that HIV is in a different category to other communicable diseases in terms of stigma and in terms of the application of the criminal law in respect of transmission. The criminal law continues to be applied and stigma persists; it should not be assumed that the work of these protections has been done. While there remains a view by the state that criminal prosecutions and extraordinary public health powers are required for HIV, it follows that there will need to be regard for the handling of HIV-related information between clinicians and state agencies.

It needs to be recognised that privacy laws do not offer absolute protection to individuals’ personal information. Under Health privacy principles 10(1)(c) & 11(1)(c) of the *NSW Health Record Information Privacy Act (2002)*⁴, disclosures of health information without consent are permitted:

- to lessen or prevent:
 - a serious and imminent threat to the life health or safety of any person, or
 - a serious threat to public health or public safety.

The very existence of these exemptions points to HIV being in a different category to that of other health conditions.

It is no stretch of logic to assume that this lawful exception may be relied upon by the Ministry if they believe that someone lost to care may be potentially be putting others at risk and so may disclose information to police. There is an equivalent provision under Australian Privacy Principle 12.3 of the *Privacy Act 1988 (Cth)*⁵, which regulates the handling of personal information by private sector organisations, were the Ministry to outsource any of its information handling.

Unfortunately, the safeguards outlined are not adequately robust to ensure confidence that named notification information will remain confidential.

Assertions about benefits of new system unclear/unsubstantiated

The Discussion Paper fails to detail in concrete terms *how* a named-notification would facilitate better follow up for individuals ‘lost to care’. At the community consultation hosted by ACON and Positive Life, the Ministry of Health was asked to explain why the Ministry believes that the current system is inadequate. The Ministry stated that it can take time to get in contact with the diagnosing doctor, that there can be flaws in the coded notification, and that a return call from the doctor is not always forthcoming. This is an understandable challenge, but does not seem insurmountable. Changing the whole nature of how HIV diagnoses are reported based on this issue is over-reach; it is a disproportionate response and unwise given the potential repercussions as outlined in this submission.

The Discussion Paper states on page 24 in the section entitled “Requirement for notifications to the Secretary to be made in a de-identified format”, that:

⁴*Health Records and Information Privacy Act 2002 (NSW)* Handbook to health privacy

http://www.ipc.nsw.gov.au/sites/default/files/file_manager/hripa_health_handbook.pdf

⁵Privacy fact sheet 17: Australian Privacy Principles, accessible at: <https://www.oaic.gov.au/individuals/privacy-fact-sheets/general/privacy-fact-sheet-17-australian-privacy-principles>

Named notification would enable the confidential follow up of individuals diagnosed with HIV to determine whether or not they are retained in care or have effectively linked to services after being referred. ...

The Ministry, in possession of individuals' names and addresses following diagnoses, may continue to have difficulty in reaching hard-to-locate newly-diagnosed people. It seems that the fundamental difference between the potential success the Ministry would have under the proposed regime of being able to directly contact newly diagnosed, and current access via treating doctors, is that they would be able to use their greater resources to search for individuals and authority to seek to persuade them to adopt particular prevention measures, treatment and/or care. It is this very surveillance and tracking by "the state" that populations most subject to stigma, and most at-risk of contracting HIV, fear. Apart from anything else, it is difficult to imagine how a letter or phone contact from a state authority would achieve connection to care without a degree of coercion. Those lost to care and/or not treating for HIV generally have more complex life circumstances. The most effective means of engagement will not occur via state intrusion in the lives of these individuals, but through their careful engagement by trusted and supportive clinical and community services. AFAO believes that greater consideration of strategies to achieve this engagement is required.

Mission creep: from benign to coercive

The discussion paper on page 24 continues:

...These efforts conducted in *a non-coercive* (emphasis added) way would be for the purpose of supporting retention in care and effective health care management.

There is no guarantee that the Ministry can ensure, into the future, that efforts to locate people diagnosed with HIV for the purpose of encouraging linkage to care will indeed be non-coercive. The Ministry at the public forum cited the fact that in last seven years, there have been no public health orders mandating that an individual be on treatment, presumably as an illustration that there is no history of coercive treatment in NSW. People who are told that their test results will be shared not just with their health providers but with the Health Ministry will not necessarily appreciate this nuance; and in any case, it is conceivable that in the future, with a new testing regime in place, Ministerial/Government philosophy may change and individuals will be required to be on treatment. It is not inconceivable, for example, that in the future treatment for HIV could become a condition for accessing certain social security entitlements or state supports, just as eligibility for components of family assistance are currently conditional on vaccination of the child against communicable diseases.

Conclusion

AFAO believes that there is appreciable risk that a change to named notification of HIV cases would create fear among key populations leading to reduced HIV testing rates among populations with disproportionately high late diagnosis rates. The safeguards that are proposed do not adequately address this, and the evidence from other countries is unconvincing given the Australian context. The potential improvements to individual follow up could be achieved by the current system through more effective communication between the Ministry and the treating health-care workers.

