

# HERE FOR HEALTH

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SUBMISSION TO:

The Statutory Review of the Public Health Act 2010

June 2016



## About ACON

ACON is New South Wales' leading health promotion organisation specialising in HIV prevention, HIV support and lesbian, gay, bisexual, transgender and intersex (LGBTI) health. Established in 1985 as the AIDS Council of NSW, our mission is to enhance the health and wellbeing of our communities by ending HIV transmission among gay and homosexually active men, and promoting the lifelong health of LGBTI people and people with HIV.

## General Comments

The Public Health Act has been an important mechanism in supporting the NSW response to HIV. In particular, many – though not all – provisions of the Act have been highly valued by the community for providing strong legislative protections for the rights and wellbeing of people with HIV and those at greatest risk of HIV.

ACON's concern in this Review is supporting legislative arrangements which:

- Best support the attainment of the goals of the *NSW HIV Strategy 2016-2020*, in particular the virtual elimination of HIV notifications by 2020;
- Best support the health, wellbeing and human rights of people with HIV; and
- Maximise public health outcomes for the people of NSW.

What follows is our response to a number of the issues for consideration raised in the discussion paper. Our response has been informed by consultation with community members (via a survey and community forum), consultation with other organisations within the HIV sector, analysis of trends in other domestic and international jurisdictions, and our experience and expertise in addressing issues of concern to people with HIV and people at risk of acquiring HIV.

We appreciate the opportunity to provide feedback to this Review. Collaboration between government, affected community, clinicians and researchers continues to be the foundation of our effective response to HIV in NSW, and we value the Ministry's ongoing commitment to consultation with affected community.

We thank all the community members who participated in the consultation processes organised by ACON and Positive Life NSW. These contributions helped inform the development of this submission.

# Response to the Issues for Consideration

## (a) 2 Objects of the Public Health Act

The existing objectives that are included in section 3 of the NSW Public Health Act 2010 remain appropriate and relevant. The inclusion of an additional objective in the Act to monitor diseases and infections is not entirely necessary, as these actions are inherent within the other objectives, although we do not express an objection to such an amendment.

However, there are increasing concerns about privacy that many in the community now have, and this concern can be acute in relation to medical information. We consider that a further change noting the ongoing importance of maintaining privacy in the application of the Act would be useful.

## 3 Objects

(1) The objects of this Act are as follows:

- (a) To promote, protect and improve public health,
- (b) To control the risks to public health,
- (c) To promote the control of infectious diseases,
- (d) To prevent the spread of infectious diseases,
- (e) To recognise the role of local government in protecting public health.

(2) The protection of the health and safety of the public is to be the paramount consideration in the exercise of functions under this Act.

(3) The privacy of people affected by or living with a scheduled medical condition or a notifiable disease shall be protected as far as possible, subject to the requirements of subsection (2)."

### **(b) 3.5 (c) Section 56 and notification of HIV and AIDS**

Named notifications is a highly contested issue within NSW, with divergent views within the gay community, among people with HIV, and within the HIV sector. In the section below, we consider the advantages and disadvantages of notifying individuals diagnosed with HIV by name and address.

#### **Advantages**

We acknowledge that there are potential benefits to both public health and individuals newly diagnosed with HIV to transition from a coded notification system to named notification, including:

##### *Improving the completeness of HIV notification data*

Complete and accurate HIV notification data is an integral component of the public health response to HIV, supporting effective monitoring of the epidemic and informing rapid responses to emerging issues. We recognise that the current coding arrangements necessitate time-consuming de-duplication processes, and that this limits real-time monitoring of HIV epidemiology.

In that context, we consider that named notification would provide a **modest benefit** to population-level surveillance of rates and trends of new HIV diagnoses.

##### *Additional follow-up for newly diagnosed individuals*

We recognise that some individuals may be lost to care in the period immediately following diagnosis with HIV. The reasons for this vary but may include: difficulty coping with the diagnosis; lack of rapport with the diagnosing doctor; and reluctance to address the health and lifestyle implications of being HIV positive.

We recognise that named notification would enable public health officers to make direct contact with individuals at risk of being lost to care and to offer alternate pathways to care to those individuals.

We consider that such follow-up may be of some benefit to a small sub-section of people newly diagnosed with HIV.

However, we note that the literature suggests that such follow-up care is most likely to be impactful where it is provided through a holistic care framework (that is, facilitating access to relevant supports such as housing) rather than a more narrowly focused public health response (Sweeney P, Gardner L, Bachacz K, Morse Garland P, Mugavero M, Bosshart J, Luke Shouse R, Bertolli J).

Given the potential benefits for some individuals with HIV, we query whether – should named notification proceed – consideration could be given to alternate mechanisms for the management of that data. For instance, consideration could be given to developing a service similar to ADAHPS so that skilled and trained health care workers are given responsibility for follow-up of those at risk of being lost to care.

##### *Additional support for diagnosing doctors*

It is well-established that a large and increasing proportion of new HIV diagnoses are made by doctors with limited experience of providing such a diagnosis.

We recognise that named notification may enable additional public health supports to be provided to doctors, and that this may contribute to an increase in retention of newly diagnosed people in care. In that context, named notifications may be of **some benefit** to a **small sub-section** of people newly diagnosed with HIV.

## **Disadvantages**

### *Stigma and discrimination*

There is no question that there has been a welcome and much-needed decline in stigma and discrimination related to HIV over the past thirty years. Many people with HIV have been at the forefront of tackling stigma and we are proud of the progress that we've made on this issue.

That progress notwithstanding, it is our experience that HIV continues to be heavily stigmatised and that many people with HIV continue to experience discrimination based on their HIV status, both within the general community and within health care settings. In particular:

- Community consultation indicated that fear of stigma and discrimination is a pressing and ongoing issue for people with HIV, particularly those from more vulnerable sub-populations and those residing outside the inner-city;
- A number of studies have shown that a significant amount of HIV-related stigma is experienced in healthcare settings;
- HIV-related stigma is frequently reported as a major barrier to access to mainstream health services among people with HIV in outer-metropolitan, rural and regional areas.

We believe that any change to the notification system should be informed by the ongoing reality of stigma and discrimination – and fear of stigma and discrimination – in the lives of people with HIV and the lives of those at highest risk of HIV.

### *Impact on HIV testing*

Coded notifications were introduced to ensure low-threshold access to HIV testing and have been a central tenet of the NSW response to HIV since the early days of the epidemic.

We believe that many people at high risk of acquiring HIV would feel less comfortable with named notifications than they do with coded notifications and that moving to named notifications would potentially introduce an **unnecessary barrier to HIV testing**.

These concerns were a strong theme of the feedback from community members regarding the proposed changes, with a number of participants in the community survey and/or community forum commenting that the proposed change would “lower my trust of medical staff and processes” and adversely impact both how frequently they test for HIV and what information they provide by way of sexual history.

In particular, we consider that named notifications may create barriers to testing among:

- People from culturally and linguistically diverse backgrounds, particularly recent migrants,

people on student visas and people who have arrived as refugees; and people from high prevalence countries in Africa;

- Aboriginal people;
- Highly sexually active men with multiple STIs;
- Sex workers, especially male sex workers; and
- Non-gay identifying men who have sex with men.

We note that:

- A meta-analysis of published literature on barriers to HIV testing in Europe concluded that fear of disclosure was one of the key patient-level barriers to testing, and that this was particularly acute among Black African migrants to the UK (Deblonde, J, De Koker P, Hamers F, Fontaine J, Luchters S, Temmerman M, 2010); and
- Clients of ACON's a[TEST] services who are in the country on visas regularly express concern that the information they provide may be used for purposes outside of their immediate health care. Additionally, the Australian Federation of AIDS Organisations' (AFAO) African Project has advised that named notifications is likely to create an additional barrier to testing among migrants and refugees from African countries. In both these cases, these populations are particularly fearful of their migration/refugee status being revoked, and fearful of negative interactions with government agencies (including health agencies).

We note that the options for those who wish to be tested anonymously should named notifications be introduced are still relatively underdeveloped in NSW. It may be that named notifications will be less contentious in the future when people have increased access to the full range of anonymous testing options. The introduction of HIV self-testing, in particular, is an important step which would allow people to retain greater control over the knowledge of their HIV status.

#### *Impact on disclosure of risk behaviours*

Under present arrangements, individuals being tested for HIV are asked detailed questions regarding any sexual or injecting behaviour which may have put them at risk of contracting HIV. It is our contention that individuals would be less comfortable providing information about their sexual and injecting behaviour if they knew that their full identifying details would then be provided to the Ministry of Health should they be diagnosed HIV positive.

Consequently, we are concerned that a move to named notifications may discourage people from providing complete information on their sexual and injecting risk behaviours, and that this may ultimately reduce the quality of population-level data available to monitor risk practices and trends in HIV acquisition.

#### *Privacy protections*

We have reservations as to the adequacy of current privacy laws and existing mechanisms to protect confidential information held by government agencies:

- In general, there is a move in Australia to weaken rather than strengthen privacy laws (for instance, the proposal to retain metadata and for that data to be accessed by a wide range of government agencies), with arguments in favour of “the public good” being successfully used to wind back protections of individual privacy;
- There continue to be examples of highly confidential information held by corporations and government agencies being inappropriately released into the public domain (for example, the publication of a confidential database recording identifying details of asylum seekers in Australia on the website of the Department of Immigration and Border Protection in 2014).

### *Medico-legal implications*

It is unclear whether the proposed changes will create medico-legal vulnerability for medical practitioners who provide a diagnosis to a person who is unnamed (anonymous testing) or who gives a false name. We are concerned that concern regarding potential medico-legal exposure may influence doctors to minimise anonymous testing as much as possible, which in turn may adversely impact the reach and frequency of testing.

### *Managing access to notification data*

It is our view that there is not yet sufficient information available on how the proposed changes would be operationalized to make a determination as to the sufficiency of protections. In particular, we note that there is limited information available on how the notification database would operate in the future and how access would be managed. We appreciate that it may not be practicable to fully develop an operating model for a change that is under consideration and may not proceed.

In relation to access arrangements, we anticipate that there would be a range of pressures brought to bear on the Ministry once they have access to the full name and address of individuals newly diagnosed with HIV:

- We remain extremely concerned that named notifications would be at risk of being subpoenaed;
- We are concerned that police and other government agencies may seek to access the database when pursuing individuals subject to criminal proceedings relating to HIV transmission;
- We are concerned that, over time, the Ministry may be under pressure to more proactively respond to notified individuals (for instance, highly sexually active men with multiple STIs) who may be considered to be at risk of transmitting HIV to others, and that this may result in a greater number of people being subject to public health orders.

### *Public health follow-up of individuals (i) retention in care*

We are concerned that direct contact from the Ministry of Health to a person newly diagnosed with HIV may be experienced as coercive and may adversely affect that individual’s retention in care.

We expect that those individuals most likely to be targeted for follow-up by the Ministry are those who have the most adverse response to being diagnosed with HIV and have the most tenuous engagement in care. From our experience, this is most likely to be those from marginalized sub-populations, and individuals with complex needs.

It is widely documented that those sub-populations (in particular, Aboriginal people and people from some CALD backgrounds) are more likely to have had negative engagements with government agencies either in Australia or (for people from migrant or refugee backgrounds) government agencies in their country of origin. Given that, we anticipate that the individuals most likely to be targeted in this process are those individuals who are most likely to be alarmed by a direct approach from a public health officer.

In that context, we are concerned that the public health follow-up proposed to accompany named notification will be disturbing to those targeted, and may further isolate them rather than engage them in care.

#### *Public health follow-up of individuals (ii) consent to treatment*

We are concerned that, over time, the supportive follow-up offered to individuals to assist engagement/retention in care may become more focused on public health outcomes rather than balancing individual health and rights with public health. In that context, we are concerned that public health follow up of individuals may come to focus more heavily on treatment compliance at the expense of individual informed consent to treatment.

#### *Public health follow-up of individuals (iii) policy and regulatory arrangements*

We have welcomed the assurances of Ministry staff regarding the proposed model of follow-up for individuals – that is, that the initial approach would be to provide additional support to the diagnosing doctor and that officers of the Ministry would make a direct approach to the individual only if that support had not improved engagement in care. However, we are concerned that the operationalization of this model would be governed by policy or regulation and thus subject to changes at the discretion of the Ministry.

### **Discussion**

#### *Should HIV notifications to the Secretary include the person's name and address?*

We recognise that there are both advantages and disadvantages to moving from a coded notification system to a named notification system. It is a sign of the maturity of our response to HIV that we are able to consider adaptations to our arrangements that would improve outcomes for individuals and for the population.

**On balance, we do not consider that HIV notifications to the Secretary should include the person's name and address.**

It is our view – confirmed and endorsed by the community consultation undertaken in the preparation of this submission – that HIV continues to be sufficiently different to other communicable diseases to continue to warrant coded notification, and that a transition from coded to named notification at this time has the potential to significantly undermine the response to HIV in NSW.

In reaching this conclusion, we note that:

- The benefits associated with the introduction of named notifications are **modest at best**, with the potential to increase retention in care amongst a small proportion of the small number of people currently lost to follow-up in NSW;
- We believe that modest improvement in retention in care could be largely achieved through **alternate means**, including further development of the HIV Support Program. The HIV Support Program has already delivered significant improvements in the capability of diagnosing doctors to educate patients, offer referrals and retain those individuals in care. We support the ongoing work of this program and an approach which focuses on strengthening the doctor-patient relationship rather than introducing an additional party (namely a public health officer) into that relationship.
- The affected community – that is, people with HIV and those at greater risk of acquisition – are largely opposed to a transition to named notification. In particular, community members commented that:
  - A transition to named notification is likely to cause a reduction in HIV testing among people at risk, as those individuals who are concerned about named notification will be less inclined to be tested. HIV negative individuals who participated in the community survey indicated that they personally would be less likely to test, and overall survey respondents were of the view that the transition to named notifications would adversely affect testing behaviours. Over the medium to long term this may contribute to an increase in late diagnosis, with the associated personal and public health implications;
  - The criminalisation of HIV transmission contributes to a level of mistrust between community and government, and causes people with HIV to be wary of their identifying details being held by the Ministry of Health;
  - The differentiated public health response – in particular, the potential for people with HIV to be subjected to public health orders which can potentially restrict their freedom – also causes people with HIV to be concerned by the prospect of their identifying details being held by the Ministry of Health; and
  - The ongoing reality of stigma and discrimination against people with HIV – both in the general community and in health care settings - creates high levels of fearfulness and anxiety among people with HIV regarding any significant dilution of their privacy. A transition to named notifications was strongly opposed by the majority of participants in the community forum and the community survey on those grounds.

**Taken together, the disadvantages of a transition to named notifications outweigh the benefits and we are concerned that the disadvantages are of an order of magnitude that would potentially compromise our ability to virtually eliminate HIV transmission by 2020.**

**(c) 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)**

We are **moderately supportive** of the proposal to remove the prohibition on including a person's identifying details in a pathology request form for HIV **once the individual has consented** to be tested for HIV. Our support is based on the following:

- We recognise that the prohibition on including a person's identifying details on a pathology request form may result in some people not being tested for HIV and that as a consequence some opportunities for timely diagnosis of HIV may be currently being missed; and
- It is our understanding that the majority of community members no longer object to their identifying details being provided on a pathology form which includes a request for HIV.

#### **(d) Additional confidentiality of information that a person has HIV or AIDS**

We recognise that there are both advantages and disadvantages to the proposal to amend s56(4) to allow for information about a person's HIV status to be disclosed for the purpose of providing medical or health care.

We consider that the proposed amendment has the following **advantages**:

- It would potentially improve patient outcomes, in that all treating medical and health care workers would have access to current information about a person's HIV status, co-morbidities and current treatment regimen. Access to this information would potentially improve integrated care and minimise the risk of contraindicated drugs being prescribed to people on antiretroviral therapy; and
- It would improve patient care in that small number of emergency instances in which a patient is unconscious or unable to provide an accurate medical history to the treating physician.

Those advantages notwithstanding, we consider that the amendment has the following **disadvantages**:

First and foremost, it undermines the right of people with HIV to disclose their HIV status to medical and health care workers at a time of their choosing. In 2013, 27.6% of people with HIV reported experiencing HIV-related stigma and discrimination in healthcare settings (Grierson J, Pitts M, Koelmeyer R, 2013) and control over release of this information is very highly regarded by people with HIV;

- The majority of people with HIV are skilled health consumers and are very competent in navigating the health care system; and as such are able to make decisions which best enable medical and health care workers to care for them;
- There have not been sufficient examples of non-disclosure causing adverse effects to warrant the proposed change;
- We are concerned that a small but important sub-population of people with HIV would be less likely to be retained in care should they lose a sense of control over when and how they disclose their HIV status to medical and health care workers;
- The definition of medical and health care workers is very broad. We are concerned that a broad interpretation of what constitutes a medical or health care worker is likely to result in information regarding an individual's HIV status being provided to staff that do not need that information in order to address the needs of the individual;
- We do not consider that the protections within the *Health Records and Information Privacy Act* to provide sufficient safeguards to protect people with HIV from the consequences of that information being inappropriately accessed. The provisions of the *Health Records and Information Privacy Act* allow for audits of access to the data and consequences for those

found to have accessed the data. However, these provisions provide consequences for breaches of the Act, rather than proactively protecting the privacy of the person with HIV; and

- There is not sufficient understanding of the privacy protections within Electronic Medical Records and eHealth for the general community, including people with HIV, to feel confident that their privacy is well-protected.

**On balance, we do not support s56(4)b being broadened to allow disclosure of HIV status for the purposes of all medical or health care.**

We believe that removing the existing additional confidentiality provisions regarding HIV status has the potential to cause unnecessary anxiety among people with HIV regarding loss of control over their health information, and as such may undermine their engagement with the medical/health system.

In addition, we consider that the current arrangements strike the appropriate balance of protecting individual privacy and improving health care:

- Under the current arrangements, knowledge of HIV status can be provided to any health care provider by the person with HIV themselves, or with their consent. As such, individuals have the capacity to provide information regarding their HIV status to any and all health care providers (including specialists and allied health staff). This enables people with HIV to navigate the health system whilst retaining control over their own personal health information.
- As indicated above, discrimination in health care settings continues to be a significant issue for many people with HIV, and fear of discrimination is a key concern for people with HIV, particularly in rural and regional areas. In this context, we believe that it is imperative to protect the right of people with HIV to make informed decisions about which health care providers are able to access this information.

We note that at the community consultation, a NSW Health representative indicated that some of the problems associated with non-disclosure were due to differing understanding of the current provisions and that some health care professionals interpret these too narrowly. If this is the case, there may be better mechanisms to improve understanding of these provisions, and therefore patient outcomes, without the risking the potential disadvantages.

### (e) 3.5(d) Disclosure of STI status – s79

We are **strongly supportive** of the removal of s79 from the Public Health Act. It has been our long-standing position that s79 is an obstacle to **mutual responsibility** in the prevention of HIV, and believe that the removal of s79 would have significant benefits for individual and public health:

- Under s79, there is an inappropriate reliance on disclosure by a person with HIV as the means by which HIV transmission is prevented. This undermines mutual responsibility. Removal of s79 would place the onus on each individual to consider and negotiate sexual and injecting practices;
- As it currently stands, s79 contributes to an expectation that unprotected sex is safe if the person has not disclosed that they have HIV. It is widely documented that a substantial number of transmissions continue to be associated with people with undiagnosed HIV.

In addition, we believe that removal of s79 would contribute to a de-stigmatising of HIV, which over the long term will improve individual and public health outcomes.

The addition of a statement of principles that set out the responsibility of all individuals to take reasonable precautions to ensure infections are not transmitted would be welcome. The Victorian model described in the discussion paper is a good example of this.

**(f) 3.5(e) Public Health Orders**

Public Health Orders are an important intervention, particularly in responding to outbreaks of the highly infectious diseases in Category 4.

These orders have been rarely used in NSW with respect to HIV. The process that is undertaken to review these cases has the benefit of ensuring in most cases that these situations are responded to within a health framework rather than through the criminal justice system. However, the knowledge that these orders can be imposed on people with HIV can be a source of concern.

**ACON strongly supports the proposal to increase transparency requirements in the Act**, as this would provide the community with improved knowledge of how and why these types of orders are made, which may in turn lead to reduced concern.

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