
Let's Not Weaken the NSW Response to Managing Blood Borne Viruses

The case against mandatory testing and
key legislative considerations if enacted.

December 2019

About ACON

We are a fiercely proud community organisation. For our entire history, the work of ACON has been designed by and for our communities.

Established in 1985, our early years were defined by community coming together to respond to the HIV/AIDS epidemic in NSW, and we remain committed to ending HIV for everyone in our communities. We do this by delivering campaigns and programs to eliminate new HIV transmissions. Supporting people living with HIV to live healthy and connected lives remains core to our work.

About Positive Life NSW

Positive Life NSW is a non-profit peer-led community-based agency. We work to promote a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigma and discrimination. We provide information and targeted referrals, and advocate to change systems and practices that discriminate against people living with HIV (PLHIV), our friends, family and carers in NSW.

About Hepatitis NSW

We are a not-for-profit charity started by the hepatitis community. We are a team of 19 paid staff assisted by 30-40 committed volunteers.

We provide information, support, referral and advocacy for people affected by viral hepatitis in NSW. We also provide workforce development and education services both to prevent the transmission of viral hepatitis and to improve services for those affected by it.

We strive to be representative of people affected by viral hepatitis and work actively in partnership with other organisations and with the affected communities themselves to bring about improvements in quality of life, information, support and treatment, and to prevent hepatitis B and C transmission.

About Bobby Goldsmith Foundation

Bobby Goldsmith Foundation (BGF) is Australia's longest running HIV charity. Founded in 1984, when a group of friends got together to give their dying mate Bobby Goldsmith the care he needed in the comfort of his home, BGF has gone on to provide that same individualised care to thousands of Australians. From the first generation to age with HIV, to a diverse new generation of people facing stigma within their communities reminiscent of the 80s - we're here to help. For life. BGF has no political or religious affiliations, just a deep-seated desire to help people live well on their terms through practical, tailored assistance.

About AFAO

As the peak national organisation for Australia's community HIV response, AFAO (the Australian Federation of AIDS Organisations) is recognised both globally and nationally for the leadership, policy expertise, health promotion, coordination and support we provide.

Through advocacy, policy and health promotion, we champion awareness, understanding and proactivity around HIV prevention, education, support and research. AFAO provides a voice for communities affected by HIV and leads the national conversation on HIV.

About NAPWHA

The National Association for People with HIV Australia (NAPWHA) is Australia's peak non-government organisation representing community-based groups of PLHIV across Australia. We provide advocacy, policy, health promotion, effective representation, and outreach on a national level. Our work includes a range of health and education initiatives that promote the highest quality standard of care for HIV-positive people. Our vision is a world where all people with HIV can reach their full potential free from stigma and discrimination.

About NUAA

The NSW Users and AIDS Association (NUAA) works to advance the health, human rights and dignity of people who use or have used illicit drugs. We are a peer-based drug user organisation representing the voices and needs of drug using communities in NSW. NUAA was founded by people who inject drugs and this community remains central to our work and our mission. At all times, we strive to improve our advocacy for, and services supporting, the diversity of people impacted by stigma and discrimination and the criminalisation of drug use across NSW through working with a broad range of stakeholders and partners to support system change.

ACON acknowledges and pays respects to the Traditional Custodians of all the lands on which we work.

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In Australia, informed consent is required for HIV testing in all but rare circumstances. In fact, it is these “principles of voluntary testing, informed consent and confidentiality [that] have underpinned the improvements in testing coverage achieved in Australia to date.” National HIV Strategy 2018-2022, Australian Department of Health, 2018

Introduction

The authors of this document strongly condemn the introduction of mandatory disease testing for people whose bodily fluids come into contact with frontline workers in New South Wales.

Mandatory testing is not based on any scientific evidence and is in direct opposition to international, national and state guidelines on blood borne virus transmission in occupational settings.

The introduction of mandatory disease testing infringes on the human rights of NSW citizens and will exacerbate stigma and discrimination faced by people living with HIV and other blood borne viruses.

The introduction of mandatory disease testing is legally questionable in relation to informed consent, jeopardises best practice and safety in health care, entrenches ignorance about blood borne virus transmission and potentially poses risks for clinicians, and has no actual impact on reducing the risk to frontline workers.

There have been zero occupational transmissions of HIV in Australia for 17 years, and never an occupational transmission for a police officer.

This proposed legislation has no basis other than outdated bias and misinformation.

In relation to HIV, mandatory testing ignores the significant reductions in HIV in Australia.

Around 0.1% of the Australian population is living with HIV and new diagnoses among men who have sex with men are decreasing. Prevalence of HIV for sex workers in Australia are estimated to be below 0.04%.

Australia and New Zealand have the lowest prevalence globally of HIV in people who inject drugs, at roughly 1.1% of that population.

Effective treatments mean that the more than 95% of people living with HIV are taking medications which eliminate their risk of transmitting the virus. Other blood borne viruses are prevented, managed and cured.

Fewer than 65,000 people in NSW are living with chronic Hepatitis C. Since 2016, there has been easy access via the Pharmaceutical Benefits Scheme to a reliable cure.

Notifications of Hepatitis C in Australia have declined 18% between 2008 and 2017, with the rate at the lowest level in 10 years. Extensive work by the Justice Health and Forensic Mental Health Network has resulted in the virtual elimination of Hep C in 12 NSW custodial settings.

It is estimated that there are 83,812 people living with chronic Hepatitis B in NSW. Over the last five years, notifications across Australia have fallen by 13%. There is an easy-to-access vaccine for Hepatitis B.

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Political Context

The NSW Labor Party announced on 30 October 2019 that it would introduce legislation into Parliament compelling individuals to undertake a blood test if a police officer or other 'frontline worker' was subject to an alleged assault and a risk of infection was identified. Labor's announcement focused on providing peace of mind that frontline workers are not infected with a disease and noted that other Australian states and territories have similar laws.

Following this the NSW Government announced on 6 November 2019 that it will introduce mandatory testing legislation for individuals who expose police and other frontline workers (including Corrective Services, Youth Justice, Fire and Rescue, Rural Fire Service, State Emergency Service, NSW Health, St Johns Ambulance and Office of the Sheriff).

The Government announcement stated that assessments would be made by senior officers in these agencies as to the requirement for a mandatory test and that a penalty would be introduced for refusal of the test.

We oppose the introduction of mandatory testing in NSW, however we strongly believe that if mandatory testing were to be introduced into NSW, the person or body responsible for ordering a mandatory test should be someone with public health expertise, in line with a public health approach to disease testing.

Contextualising the proposed powers within the principles of a public health approach ensures that the health and wellbeing of all people involved in a suspected transmission of a disease are respected and considered, and that appropriate care can be provided to address both the physical and social implications related to potential transmission.

Situating the issue in a public health framework using well established practices, and ensuring medical oversight also reduces the chances of abuse of testing legislation and unnecessary tests (and associated detention) being undertaken either out of ignorance of risk, or a temptation that verges on a form of extrajudicial punishment.

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Considerations for Legislation

As we have stated, the author organisations of this document reject the need for mandatory testing. If, however, mandatory testing is to be introduced in NSW, the following issues must be carefully considered and addressed in the design of the legislation and associated regulations, and in additional amendments to other impacted legislation.

The NSW Chief Health Officer currently has a number of functions and powers including managing strategies to promote and protect the health and wellbeing of all NSW citizens. These include the power to make orders that restrict individuals' freedom in order to protect the community.

As a result, it is essential that the power to approve an order for mandatory disease testing reside with the NSW Health system administered through the office of the Chief Health Officer.

Ensuring a senior qualified medical professional approves and administers the mandatory blood borne virus testing of individuals is the only way the public can be assured that decisions which may affect freedoms and liberties of citizens are made based upon current, robust evidence and protect the health and wellbeing of workers.

The Threshold For Mandatory Testing: Risk Assessments

Consideration needs to be given to the following policy implications and questions.

- Legislation must ensure that assessments of risk are based on the most recent scientific evidence in relation to transmission of blood borne viruses, rather than an uninformed workforce, or sections of the community who have a lay understanding or set of beliefs.
- Regulations must be developed to accompany the legislation that establishes clear operational responsibilities, permissions and provisions that offer practical advice to improve implementation, including the assessment of risk.
- These regulations must be checked against the legislation to avoid circumstances such as those in Western Australia in which regulations did not align with legislation.
- Accountability for risk assessment, including the decision to order a test, must be a matter of public record and

review, and must be able to be scrutinised by medical and other people with expertise in HIV and blood borne virus transmission, facilitating feedback and increased understanding. These measures will reduce the risk of unnecessary application of powers to mandate an invasive medical procedure.

Mandatory venepuncture testing is an invasive procedure. A person who is not a medical expert and who may incorrectly believe that a person may have been exposed a disease through exposure to bodily fluids, including saliva, should not be ordering a test.

Community attitudes and understanding of HIV and blood borne viruses are often out of date, and can be discriminatory and stigmatising. These attitudes are present across society, including in the workforces outlined as being affected by mandatory testing legislation.

Section 134 (d) of the Victorian legislation relating to mandatory testing states that the test may be ordered if it “is necessary in the interest of rapid diagnosis and clinical management, and where appropriate, treatment for any of those involved”. We suggest such wording is essential to any proposed NSW legislation, and note that mandatory blood borne virus testing has no impact on the immediate clinical management of HIV in potential occupational exposures.

Western Australian legislation (Section 7(1)) defines that testing can be ordered if bodily fluid is transferred from one person into the anus, vagina, mucous membrane or broken skin of another person. This definition is too broad, considering the scientific evidence in relation to transmission. Legislation, if introduced, must set a clear threshold for risk which is evidence based and justifiable.

Prescribed Settings For Mandatory Testing

Consideration needs to be given to the following policy implications and questions.

- Which facilities and places will be authorised to conduct mandatory testing?
- How will the definition of prescribed settings ensure the safety of medical staff and other health clients in prescribed places?
- How will the definition of prescribed settings ensure the safety and confidentiality of the alleged offender – including conversations and requirements for the test?

New South Wales consists of vast areas of land where there is minimal access to emergency departments or other public health facilities. Mandatory testing regulations in Western Australia list a number of facilities across the state which are deemed to have appropriate facilities for testing. However, if the authorised persons at these facilities are not willing to complete the test, police are advised to take the individual to be tested to another facility. This can lead to significant consumption of time and resources and any legislation must ensure that safe and appropriate transport arrangements are in place so that an individual is returned to where the incident occurred, their home or another safe place.

Authorised Persons For Conducting Tests

Consideration needs to be given to the following policy implications and questions.

- Clinicians required to perform mandatory tests under State legislation should be those employed by the State Government.
- Will the legislation allow for health practitioners to refuse to comply with the direction to test an alleged offender?
- Can general practitioners and/or nurse practitioners be legally required to perform mandatory tests?
- How will medico-legal risk be mitigated? How will issues related to private business operations for health services funded by the Commonwealth being used for mandatory testing be negotiated? How will peak bodies and other groups who oversee general practice be consulted and negotiations conducted?
- In the case of GPs, what data sharing arrangements will be negotiated with the State to ensure linkage to care and robust reporting of mandatory tests, and results arising from those tests?
- How will the legislation support mandatory tests required in regional and remote areas of New South Wales where there is no access to secure public health facilities – what transportation and legal detention provisions will be enacted?

The ethical and practical concerns of the healthcare sector must be addressed in legislation and associated regulations, especially when considering the context of consent, where non-consent gives rise to an offence (and therefore consent is not freely given [coerced]). Significant consultation with the medical industry should be undertaken before legislation is introduced.

Western Australia’s Health Department regulations are clear that medical staff are not required to perform the

tests ordered by Western Australian Police. They are also clear that Health staff are not required to use force to take the sample. This is not made explicitly clear in the legislation. We believe that similar regulations would be necessary in the NSW context to ensure that medical staff are not compelled to perform test and they are clearly informed that this is the case.

The Rights Of The Person To Be Mandatorily Tested

Consideration needs to be given to the following policy implications and questions.

- How will legislation uphold the requirements of the Public Health Act to maintain privacy regarding an individual being tested and their privacy in regard to possible disclosure of their BBV status?
- Will the use of force be allowed?
- How will the person being mandatorily tested receive the results of the HIV test including information, linkage to care and counselling if required?
- How will the appeal process function? The regulations need to describe the appeals process, including how the appeals process will be conducted and by whom (for example the Chief Health Officer).
- The regulations will need to describe how the person being mandatorily tested will be informed that there is an appeal process available, that they have a right to access the appeal process, and shown how to do so if they wish to take up the option of an appeal.
- The regulations will also need to describe how a person will be treated during the proposed (up to) seven day period that the Chief Health Officer has to make a determination – this includes whether the person appealing being mandatorily tested is held in custody, and if not, how they will be contacted in the event of an adverse appeal finding.
- How will data, records and reporting be maintained? Any legislation and related regulation must make it possible for public review of the efficacy of the program and collect data which accurately reflects whether mandatory testing is being used for proper purpose in line with health advice.

Post-test counselling and the provision of test results to the person being mandatorily tested must also be considered. If a person has been detained and transported for testing, they should be able to receive their results in line with best practice which other NSW citizens are entitled to.

Victorian legislation makes it clear that a testing order can only be undertaken if counselling has occurred in relation to the medical and social consequences of the disease for which they are being tested. Due to ongoing stigma and discrimination related to people living with blood borne viruses, much misinformation and fear exists surrounding them. As such, we believe that any proposed legislation should ensure a duty of care to both the individual being tested and the frontline worker potentially exposed.

Similar to Victorian and Western Australian legislation, the results of any mandatory test must not be admissible in evidence in proceedings before any court, tribunal or similar process.

Detention & Transportation

Consideration needs to be given to the following policy implications and questions.

- How will legislation ensure that detention for the purposes of testing is not used as extrajudicial punishment for people who may not have committed an offence, or who may ordinarily not be detained?
- Will the legislation allow employees of frontline services other than NSW Police to restrain or detain people they have designated for mandatory testing while ensuring the safety of the employees and the civil rights of the individual?
- What arrangements will be made for mandatory testing where no appropriate prescribed place is available to administer the test?
- What arrangements will be made to ensure the alleged offender is returned to a safe place or their home community following transport for a mandatory test?

In a situation in which an individual has not been charged with an offence, but has had a mandatory test ordered, the detention of such a person must not be allowed in order to wait until a test can be performed. This would be a gross violation of civil liberties.

Data & Accountability

Consideration needs to be given to the following policy implications and questions.

- Legislation must mandate the collection of data which facilitates accountability and an assessment of the efficacy of the scheme.

Basic requirements include the location of where the

test was conducted, background information on the individual tested, the risk factors used to determine the test's necessity and the result of any mandatory test. It is essential all data is collected and reported in ways which make it impossible to determine the identity of people mandatorily tested, regardless of result. This data must be decoupled so no individuals can be identified to comply with privacy provisions in other legislation. This is especially important when dealing with vulnerable, geographically and culturally isolated communities.

- The nature of the appeal to the NSW Chief Health Officer, and the outcomes of those appeals should also be collected.
- A formal reporting mechanism for this data must be developed and regular reporting must be made to Parliament.
- Legislation must have a mandated review period written in to allow a balanced evaluation of the success of the legislation and associated regulations of no longer than four years.

Other Australian jurisdictions keep poor or limited data on the implementation of similar laws that have been enacted in their state or territory. With mandatory testing potentially challenging so many civil liberties, and heightening stigma and discrimination for already marginalised population groups, it is vital that legislation necessitates transparency in record-keeping with limitations in relation to disclosure as aforementioned.

It is preferable that legislation include an annual reporting requirement similar to those outlined in the Victorian legislation which require reporting on the number of orders and the reason for making each order in the financial year. Western Australian legislation also calls for a review of the operation and effectiveness of the Act to be tabled as soon as is practicable after five years of operation. Such legislative considerations should also be written into any Bill in New South Wales.

Consent

Consideration needs to be given to the following policy implications and questions.

- The model must make clear arrangements and considerations for people who cannot give informed consent, either through temporary or permanent incapacitation.
- How will testing of individuals and recording of results interface with reporting to monitoring and surveillance

bodies and requirements in the federal and jurisdictional Electronic Medical Records legislation?

- How will legislation address the medico-legal risk and insure indemnity for practitioners who may be required to perform tests with coerced or no consent.
- What arrangements will be made regarding management of test results, including provision of consent to share the results with an individual's nominated health professionals?

Education & Prevention

Consideration needs to be given to the following policy implications and questions.

- Legislation should ensure that all workers defined as frontline workers receive clear accurate training and education on blood borne viruses, transmission routes and risk, and prevention technologies and risk, from expert health professionals or trained community experts. Sustained funding for this education needs to be allocated for current and future frontline workers.
- Frontline workers should also be mandatorily vaccinated for all blood borne viruses and when potential exposure has occurred, Post Exposure Prophylaxis for HIV should be initiated as soon as possible on the advice of a trained clinician within the clinical guidelines.

Considerations From Existing Legislation

Consideration needs to be given to the following policy implications and questions.

- Proposed legislation must ensure that consideration is given to existing legislation, in particular the NSW Public Health Act relates to Category 5 illnesses such as HIV.
- The NSW Road Transport Act, or any other pieces of legislation which are not based in a health or public health framework should not be considered an appropriate basis for mandatory blood borne virus testing legislation or associated regulations. Testing guidelines set out in such legislation relate to the detection of illicit activity and are incomparable to testing for the presence of a disease in an individual. Disease testing legislation must also consider pathways to care, disclosure of sensitive information and psychological and medical ramifications of test results which are not addressed in existing NSW legislation relating to mandatory blood testing.

