

INQUIRY INTO MANDATORY DISEASE TESTING BILL 2020

Organisation: ACON
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ACON SUBMISSION TO
NSW Mandatory Disease Testing Bill (2020)
Inquiry

December 2020



Acknowledgment of Traditional Land Owners

ACON acknowledges the traditional owners of the lands on which we work. We pay respect to Aboriginal elders past, present and emerging.

About ACON

ACON is NSW's leading health organisation specialising in community health, inclusion and HIV responses for people of diverse sexualities and genders. Established in 1985, ACON works to create opportunities for people in our communities to live their healthiest lives.

We are a fiercely proud community organisation, unique in our connection to our community and in our role as an authentic and respected voice.

Members of Australia's sexuality and gender diverse communities experience health disparities when compared to health and wellbeing outcomes experienced by the total population. They may also face significant barriers to accessing traditional healthcare pathways. These issues can be compounded by other factors in a person's life, such as living with a disability or being from a culturally diverse background.

We recognise that members of our communities share their sexual and gender identity with other identities and experiences and work to ensure that these are reflected in our work. These can include people who are:

- Aboriginal and Torres Strait Islander people
- people from culturally and linguistically diverse backgrounds
- people who use drugs
- mature aged people
- young adults
- people with disability

We know that how our communities define and describe themselves changes, and we strive to ensure that all people we work for feel welcomed by the services we offer and the language we use.

Contact

Nicolas Parkhill
Chief Executive Officer

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Conversations about mandatory testing legislation have been ongoing in New South Wales for some time now. ACON, working with our partner organisations and communities have always been vehemently opposed to any such legislation.

Such legislation, as ACON noted in our Submission *Feedback on Draft Mandatory Disease Testing Bill 2020*, May 2020, is unnecessary, counterproductive to the NSW globally recognised best practise approach to blood borne virus prevention, and potentially incredibly damaging to people living with blood borne viruses. The proposed legislation ignores international best practice and recommendations from the World Health Organisation.

The specific Bill that the Committee seeks advice about is incredibly problematic. Our submission reflects on our many previous submissions related to such proposed legislation and documents provided to relevant Parliamentarians which outlines potential legislative considerations our communities and partners identified. We will also use this opportunity to highlight specific issues with the current iteration of the Bill.

ACON recommends the NSW Government reject the *Mandatory Disease Testing Bill (2020)*, noting that the Bill is not based on evidence, is in opposition to public health objectives and is potentially harmful for people living with blood borne viruses.

Should Inquiry Committee recommend that the *Mandatory Disease Testing Bill (2020)* be passed into law then ACON recommends the following:

- ACON recommends that the Inquiry Committee and the NSW Government explore solutions to the concerns of frontline workers that are grounded in best practice public health, including education, training and improved access to biomedical prevention methods.
- ACON recommends that s9, s10, s11 and s14 are amended to remove ambiguity in relation to deliberate actions resulting in transfer of bodily fluids.
- ACON recommends that determinations on mandatory disease test orders be made by an independent arbiter, under the guidance of the Chief Health Officer, who has the requisite skills and knowledge to assess potential risk without the potential for a conflict of interest.
- ACON recommends that the Bill be amended to ensure that Testing Orders can only be made when an actual risk of transmission occurs
- ACON recommends that the Bill be amended to provide clarity on the definition of bodily fluids in relation to transmission of disease.
- ACON recommends amending the Bill so that it only applies to people over the age of 18 years old.
- ACON recommends amending the Bill to require anyone who wishes to apply for an order to visit a medical practitioner within 24 hours of the incident.
- ACON recommends amending the Bill to reflect that the determining senior officer must seek out and consider the advice of the medical practitioner in making their decision.
- ACON recommends legislating the decision-making process for determining whether an order is made.
- ACON recommends that should the process for determining whether an order is made not be legislated, that an order cannot be made until the guidelines are published.
- ACON recommends including in the development of guidelines the following organisations: The Anti-Discrimination Board of NSW, the Mental Health Commissioner of NSW, Aboriginal Affairs NSW, Multicultural NSW, The Corporate Sponsor for LGBTI Issues in NSW Police, the Corporate Sponsor Aboriginal Engagement in NSW Police, Australasian Society for HIV Medicine, ACON and Positive Life NSW.
- ACON recommends amending the Bill to remove the ability to use force to ensure compliance with an order by a detained person.
- ACON recommends amending the Bill so that it includes clarification on how people in detention will be supported to appeal a decision in relation to a mandatory disease testing order.

- ACON recommends alterations to the Bill that ensure a fair and transparent appeals process which means that until determination is made by the Chief Health Officer, no mandatory test is required.
- ACON recommends that the Bill be edited to ensure that senior officers named in the Bill must be trained in blood borne virus transmission.
- ACON recommends that the Bill be edited to ensure that senior officers can only delegate the determination of a mandatory disease testing order to another officer who has received the same level of training as a senior officer in blood borne virus transmission.
- ACON recommends the Bill be edited to ensure that senior officers must not delegate the determination of a mandatory testing order to any officer with a potential conflict of interest.

Mandatory Disease Testing does not offer any additional peace of mind to front line workers beyond what would already be available to them through current public health developments. Vaccination programs, post exposure prophylaxis medications, effective anti-retroviral therapies and effective cures which are available to all negate the need for this stigmatising intrusion into the civil liberties of people.

The proposed legislation is rooted in fear, ignorance and an unwillingness to provide appropriate training and education to frontline workers.

We have attached to this submission a copy of our previous submission on this issue from May 2020. We note that the current draft Bill is in many ways worse for individuals and adds no more ‘peace of mind’ to front line workers. In addition, we have attached a copy of our Policy Position Paper “*Let’s Not Weaken the NSW Response to Managing Blood Borne Viruses: The case against mandatory testing and key legislative considerations if enacted*” which was provided to key government Ministers earlier in 2020. This document outlines the significant flaws in mandatory testing legislation, noting especially how these laws are likely to damage the world leading response to HIV and other blood borne viruses in New South Wales.

We also attach a copy of our recently published Discussion Paper *Ending HIV-Related Stigma for All*¹. This document outlines the importance of removing stigma for people living with blood borne viruses. This document is intended to demonstrate the harmful impact that proposed legislation such as this is likely to have on communities who already face marginalisation.

Finally, we refer the members of the committee to *The System is Broken – Audit of Australia’s Mandatory Disease Testing Laws*² produced by the National Association of People with HIV Australia. This document highlights the proven imperfections of such laws introduced in other jurisdictions.

ACON recommends the NSW Government reject the *Mandatory Disease Testing Bill (2020)*, noting that the Bill is not based on evidence, is in opposition to public health objectives and is potentially harmful for people living with blood borne viruses.

¹ https://www.acon.org.au/wp-content/uploads/2020/11/HIV-Stigma-Paper_v8.pdf

² https://napwha.org.au/wp-content/uploads/2019/09/2019_NAPWHA_TheSystemIsBroken.pdf

The Mandatory Disease Testing Bill (2020)

ACON, along with many other expert, qualified stakeholders strongly oppose the introduction of any legislation which allows for mandatory disease testing of people whose bodily fluids come into contact with frontline workers in New South Wales (NSW).

Frontline workers are supported universally across our State. There is no dispute that frontline workers should be well trained, afforded every reasonable protection and treated with respect.

The concern for frontline workers is commendable and shared by us all: however this Bill does not protect our frontline workers – our current policies and procedures do – as evidenced by the fact that there has not been an incidence of occupational transmission of HIV for emergency service workers in more than 15 years.

This Bill is not in line with evidence, not consistent with multiple state, national and international guidelines, it exacerbates unfounded and decades old fears, and does nothing to educate and inform our workers about the contemporary risks associated with bodily fluids. Our existing laws, policies and procedures work: there are other ways to reduce fear, risk and concern about this issue among frontline workers.

It is incumbent upon every person involved in this policy process to acknowledge that this Bill is driven by unreasonable fear, and further commit to work assiduously to remove the risks of unintended negative consequences from this Bill.

This is critical not only for frontline workers, but for marginalised communities who will bear the brunt of well-meaning but misguided enactment of a policy that runs the risk of reducing no harm, causing different actual harm, cost money and add to system pressures.

This Bill is the antithesis of evidence-based policy, and counter to our experience with pandemics and epidemics long brought under control by NSW using evidence, education, and a supportive approach. Force, criminalisation, misinformation, and fear is not the answer.

ACON recommends that the Committee and the government explore solutions to the concerns of frontline workers that are grounded in best practice public health, including education, training and improved access to biomedical prevention methods.

Unclear Definitions of Deliberate Actions

Concerns exist among community that the enforcement of public health through policing and legislation may provide opportunity for public health legislation to be unevenly applied across populations, especially those populations who face marginalisation. The Bill in its current state does not adequately define the circumstances around a “deliberate action” in relation to the transfer of bodily fluids.

If such legislation was to become part of the law, it is vital that the focus remain on public health interventions. The implications for such legislation mean that there is no room for ambiguity in the application of the law.

We believe that *should* the flawed Bill be passed, the following changes to legislation could remove ambiguity and protect the civil liberties of individuals:

- Section 9(1) could be amended to add after (e): ‘the factual basis for the worker’s opinion that contact with the third party’s bodily fluid was as a result of a deliberate action of the third party, and any evidence (such as statements from eyewitnesses) that would support that opinion’.
- Section 10 could be amended to require the senior officer to be satisfied as to deliberateness, by adding a paragraph between s 10(7)(a) and (b) that reads: ‘the contact by the worker with the bodily fluid of the third party was a result of a deliberate action of the third party.’
- AND/OR you could amend s 11 to make it a basis for refusal, eg adding in a new (2) that reads: ‘A senior officer must refuse an application if not satisfied on the basis of the evidence provided in the application that the contact by the worker with the bodily fluid of the third party was a result of a deliberate action of the third party’.
- Similarly, s 14 should be amended in relation to Court decisions. You might do this by amending s 14(2) so it reads:
 - (2) The Court may make a mandatory testing order only if satisfied that, on the balance of probabilities:
 - a. the contact by the worker with the bodily fluid of the third party was a result of a deliberate action of the third party; and
 - b. testing the third party’s blood for blood-borne diseases is justified in all the circumstances.

We also suggest making changes to s 24 relating to reviews, to make it clear that the Chief Health Officer will only make a mandatory testing order if satisfied that the contact by the worker with the bodily fluid of the third party was a result of a deliberate action of the third party. You might so this by including a subsection that reads:

- (2) The Chief Health Officer may only make a mandatory testing order only if satisfied that:
 - a. the contact by the worker with the bodily fluid of the third party was a result of a deliberate action of the third party; and
 - b. testing the third party’s blood for blood-borne diseases is justified in all the circumstances.

ACON also suggests that another way to reinforce safeguards would be to have an independent office-holder assess all applications (rather than senior officers within each of the agencies), making it more likely they would properly scrutinise whether the exposure was deliberate. These significant changes would require a significant rework of the Bill, though we see this is a valuable investment in ensuring the safety of communities.

ACON recommends that s9, s10, s11 and s14 are amended to remove ambiguity in relation to deliberate actions resulting in transfer of bodily fluids.

ACON recommends that determinations on mandatory disease test orders be made by an independent arbiter, under the guidance of the Chief Health Officer, who has the requisite skills and knowledge to assess potential risk without the potential for a conflict of interest.

Definition of Bodily Fluids

The legislation must reflect the perceived risk of transmission. Legislation which allows for the mandatory blood testing of individuals for diseases for which no risk exists is entirely unacceptable. For example, in situations where a saliva transmission has occurred, a mandatory testing order must not be able to be made for HIV, given the established science that HIV cannot be transmitted through saliva.

We note that several viruses, including Hepatitis C and HIV cannot be transmitted through saliva, and also require blood to blood transmission.

For diseases which are able to be transmitted through saliva or other bodily fluids, in situations where the frontline worker has been vaccinated against the transmission of the disease, a mandatory testing order should not be allowed to be made.

ACON recommends that the Bill be amended to ensure that Testing Orders can only be made when an actual risk of transmission occurs

ACON recommends that the Bill be amended to provide clarity on the definition of bodily fluids in relation to transmission of disease.

Inappropriate Age of Application

The application of the proposed legislation to people aged under 18 years old, and as young as 14 years old is especially egregious and unconscionable. Prevalence rates for HIV in people aged under 18 years old are negligible. In the previous year, three (3) people under the age of 18 years old were diagnosed with HIV, and our recent treatment rates would see these people on treatment within a matter of weeks – leading in nearly all cases to an undetectable amount of virus in their blood. It is important to also add that HIV cannot be transmitted by spitting.

Court involvement and the proposed process of obtaining an order would place unnecessary burden on a system already under considerable pressure. There are questions related to meaningful parental and guardian involvement and influence in the process.

ACON recommends amending the Bill so that it only applies to people over the age of 18 years old.

Timeline for Process

In the interest of best public health advice, anyone with a serious concern about potential HIV infection should be advised to attend a GP within 24 hours of the transmission. This allows for the GP to explain the risk of transmission, and if a significant risk exists, to refer the individual on to an emergency department or sexual health clinic for post-exposure prophylaxis.

The current legislation, which requires a visit to a GP within 72 hours may not allow time for the person to receive information on HIV prevention which could negate the need for a mandatory testing order to be made. Should the front-line worker receive post exposure prophylaxis medication, the third party will not need to be tested for HIV as any potential transmission will have been avoided through the use of the medication.

ACON recommends amending the Bill to require anyone who wishes to apply for an order to visit a medical practitioner within 24 hours of the incident.

Medical Opinion as Determining Factor

The legislation must make clear that the medical advice from a practitioner is required and must be considered in making the determination regarding the order.

Currently, the Bill is ambiguous on whether the advice of the medical practitioner must be sought by the determining senior officer, and whether the senior officer must take the advice of the GP into consideration. The proposed legislation must be in line with best practice in relation to transmission and seek to address the issues raised relating to peace of mind for frontline workers. Ensuring frontline workers have appropriate access to information and biomedical prevention in a timely fashion is vital.

ACON recommends amending the Bill to reflect that the determining senior officer must seek out and consider the advice of the medical practitioner in making their decision.

Determining Guidelines

The implication of this proposed legislation is significant. The Bill seeks to compel people to undergo venepuncture under the threat of fines and gaol time, based on the fear and suspicion of another individual, as determined by a citizen who is unlikely to have formal training in public health or blood borne virus transmission.

It is our assertion that guidelines must be included in the legislation. Further, we believe that any guidelines must include a clear determination of risk which relates to identifying the route of transmission. **The guidelines must identify and require evidence of blood leaving the body of the third party and entering the bloodstream of the person seeking the order. Situations in which a clear route of transmission is not evident must not be grounds for the making of an order.**

ACON also recommends that the guidelines are informed by those in community organisations who have significant expertise in relation to the issue. Consideration must be given to the impact of such laws on communities who experience blood borne viruses at a higher rate than the whole of population, communities who experience incarceration and police interaction at higher rates and people who may not have equal access to the law and justice system.

ACON recommends legislating the decision-making process for determining whether an order is made.

ACON recommends that any guidelines require evidence of a plausible route of transmission to be established before an order is made.

ACON recommends that should the process for determining whether an order is made not be legislated, that an order cannot be made until the guidelines are published.

ACON recommends including in the development of guidelines the following organisations: The Anti-Discrimination Board of NSW, the Mental Health Commissioner of NSW, Aboriginal Affairs NSW, Multicultural NSW, The Corporate Sponsor for LGBTI Issues in NSW Police, the Corporate Sponsor Aboriginal Engagement in NSW Police, Australasian Society for HIV Medicine, ACON and Positive Life NSW.

Detained Third Parties

Access to appeal and the upholding of human rights of all people must be paramount when introducing new legislation.

Currently, the Bill allows the use of force on people who are in custody in order to force the third party to undertake venepuncture. This allowance has an incredible potential for use as an extra judicial punishment, especially for marginalised communities.

Further, the limitations on appeal and review makes it potentially impossible for a person who is detained to appeal an order that has been made. The legislation must be clear on how people who are detained can appeal, and how the services detaining them must support their right to appeal.

ACON recommends amending the Bill to remove the ability to use force to ensure compliance with an order by a detained person.

ACON recommends amending the Bill so that it includes clarification on how people in detention will be supported to appeal a decision in relation to a mandatory disease testing order.

Appeals and Reviews

ACON has some concerns about the accessibility of the appeal and review process.

One business day is an insufficient time for people to receive, comprehend and seek counsel on their right to appeal and then put an appeal to the Chief Health Officer. This time frame is even more restrictive for people with disabilities or people who have limited access to support and advocacy.

ACON recommends that amending the Bill to ensure a greater time be allowed for a third party to appeal an order, and that the legislation be clear on how people with disabilities and people who face marginalisation be supported to appeal.

Of even greater concern is the current proposed legislation's appeal process, in which even while an appeal is being considered the order continues to have effect, with the appeal only preventing the transfer of the results of the test.

The right to bodily autonomy and the right to appeal a decision made by a senior officer must be respected. The legislation must make it clear that until a determination has been made on an appeal, the order does not remain effective.

This proposed legislation is deeply flawed, removes the rights of individuals and criminalises the issue of blood borne viruses. The last line of defence in such legislation would be an appeal process which is transparent, accessible and protects the rights of individuals.

It is absolutely unacceptable to ACON for a person who appeals a mandatory disease test to still have to have the test.



ACON recommends alterations to the Bill that ensure a fair and transparent appeals process which means that until determination is made by the Chief Health Officer, no mandatory test is required.

Delegation

ACON would expect that any person who was given the authority under the legislation to determine whether a mandatory disease test should be ordered, must receive some level of training on blood borne virus transmission risk and transmission prevention.

As such, any person delegated to make the decision must also have received the training, in order that a decision is made on best practice and current knowledge on blood borne virus transmission and prevention.

ACON recommends that the Bill be edited to ensure that senior officers named in the Bill must be trained in blood borne virus transmission.

ACON recommends that the Bill be edited to ensure that senior officers can only delegate the determination of a mandatory disease testing order to another officer who has received the same level of training as a senior officer in blood borne virus transmission.

Given the close knit nature of many of the organisations named in the legislation, it may be the case that a senior officer could delegate the determination of a mandatory testing order to an officer in the organisation who is involved in the incident in question, or who has a personal interest in the outcome of the determination. The Bill must remove this risk.

ACON recommends the Bill be edited to ensure that senior officers must not delegate the determination of a mandatory testing order to any officer with a potential conflict of interest.

Ideally, determinations in relation to mandatory disease testing orders should not sit within the organisations named in the Bill. Senior officers in these organisations do not have the required training and information to make such determinations, and in many cases will be unable to avoid a conflict of interest in the determination. In order to ensure fair determinations, based on scientific evidence, an

independent regulator, placed in the Ministry of Health, delegated by the Chief Health Officer would be a preferred option.



ACON recommends that determinations on mandatory disease test orders be made by an independent arbiter, under the guidance of the Chief Health Officer, who has the requisite skills and knowledge to assess potential risk without the potential for a conflict of interest.