ACON SUBMISSION TO

Review into the operation and administration of the Mandatory Disease Testing Act 2021

November 2023

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.

Our head office is in Sydney, and we also have offices in Lismore and Newcastle. We provide our services and programs locally, state-wide, and nationally. We are a fiercely proud community organisation, unique in our connection to our community and 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.

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 from culturally, linguistically, and ethnically diverse migrant and refugee backgrounds; people who use drugs; mature aged people; young adults; and people with disability.

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ACON acknowledges the Traditional Owners of the lands on which we work. We pay respect to Aboriginal Elders past and present.

Executive Summary

ACON strongly opposes the Mandatory Disease Testing Act ('the Act') in New South Wales, which demands compulsory tests for blood borne viruses (BBVs) if someone's bodily fluids touch frontline workers. As we have outlined in previous submissions related to this Act,[1,2] mandatory testing due to such contact is not only baseless, but also increases fear, misinformation and discrimination associated with HIV and other BBVs. This stance contradicts local and global HIV and BBV guidelines and undermines NSW's successful efforts to eliminate HIV transmission.

Stigma and discrimination related to HIV negatively affect the well-being of those living with it. It results in adverse health outcomes and hinders access to care. Stigmatisation also obstructs our goal of halting HIV transmissions in NSW, as it deters people from getting tested, starting treatment promptly, and following their regimen.

We believe the Act is highly likely being used to target marginalised groups already overrepresented in Australian prisons and in interactions with police. When enforcing this Act, everyone's human rights, access to health care, and appeal rights for these orders are essential and must be respected.

The Act fails to safeguard the health and well-being of frontline and emergency workers as it is based on misleading and incorrect information about HIV and BBV transmission and is likely to increase stress and anxiety.

The Act and the associated scheme divert essential resources from providing much-needed accurate and clear information and education on occupational exposure to BBVs to frontline and emergency workers. The NSW government has provided no clear indication of the cost of implementing the Act and no estimation of how many new HIV and BBV infections it has prevented.

The Act harms the people subjected to Mandatory Testing Orders (MTO). It increases stigma and discrimination, emotional and mental distress, alienates vulnerable and marginalised people from essential health care and undermines the patient-clinical relationship.

Recommendations

ACON strongly recommends that The Mandatory Disease Testing Act be repealed.

If the Act and its associated scheme are to continue, then important changes need to be made to the Act to minimise the detrimental impacts of the legislation. ACON makes the following recommendations, with detail provided later in the submission:

1. Increased education and information for frontline emergency workers.
2. Implementation of accurate and practical risk assessments.
3. Strengthening of independent review and oversight processes.
4. Development of clear guidelines on risk based on the "Chief Health Officer's Risk Matrix".
5. Mandatory Hepatitis B vaccination for frontline workers.
6. Transparent data reporting.

Introduction

ACON firmly opposes the Mandatory Disease Testing Act ('the Act') in New South Wales. Forcing someone to be tested just because their bodily fluid touches another person is unfounded and only adds to the stigma against those with HIV and other Blood Borne Viruses (BBVs). This approach goes against local and global guidelines on HIV and BBVs and undermines our unified efforts in NSW that have successfully reduced HIV transmission.

We believe the Act was introduced due to baseless fears and misunderstandings about people with HIV and other BBVs. The Act does nothing to address or change these discriminatory views. Indeed, the Act contributes much to the further discrimination faced by people living with HIV and other BBVs.[3]

The Mandatory Disease Testing Act must be repealed if NSW is truly committed to ending HIV stigma, a goal of the *NSW HIV Strategy 2021-2025*. Failing a full repeal of the Act, there are a number of actions that can minimise the harm the Act causes, and better fulfil the Act's intentions.

The medical evidence leaves no doubt about the risk of occupational transmission of BBVs. All healthcare, emergency service, and law enforcement personnel must be well-informed about this evidence. Such education will decrease the number of unnecessary Mandatory Testing Orders (MTOs) and alleviate the anxiety and fear experienced by those in the emergency services sector.

The risk of emergency service workers in NSW contracting BBVs, such as HIV, on the job is extremely low to non-existent. To put it in perspective, fewer than 0.1% of the Australian population has HIV, and HIV is not easily transmitted. Specifically, there is no chance of transmitting HIV through contact with an HIV-positive person's saliva, even in biting or spitting situations, and even when a small quantity of blood is present in the saliva.[4]

Additionally, the risk of HIV transmission from biting or spitting, when the person has a significant quantity of blood in their saliva, **and** that blood comes into contact with an open wound or mucous membrane **and** the person has a detectable viral load still varies from no risk to negligible risk.[5] In this context it is also important to note that of the fewer than 0.1% of the population living with HIV, just 18% of those have a detectable viral load.[6]

Fewer than 65,000 people in NSW live with chronic Hepatitis C.[7] Since 2016, there has been easy access via the Pharmaceutical Benefits Scheme to a reliable cure. It is estimated that 72,058 people are living with chronic Hepatitis B in NSW in 2021, and hepatitis B notifications have declined in NSW over many years.[8]

The vast majority of emergency services officers are unlikely to encounter HIV or BBVs during their careers, and even if they do, the risk of HIV or BBVs transmission is either non-existent or extremely minuscule.

According to national surveillance data in Australia, there has been no reported instance of HIV transmission in any workplace since 2002, and there has never been a documented case of HIV transmission to a police officer.[9]

Stigma and discrimination or negative beliefs, attitudes, fears and judgments held against people living with HIV and members of groups that are perceived to be associated with HIV, such as gay and bisexual men, people who inject drugs and sex workers, is common. HIV-related stigma and discrimination has

real consequences on the health-related quality of life of people living with HIV. Stigma leads to poorer physical and mental health outcomes. It is a barrier to accessing healthcare and may contribute to incomplete disclosure about health status and medications by patients.

HIV-related stigma hinders efforts to end HIV transmissions for all in NSW. It acts as a barrier to HIV testing, immediate treatment initiation and adherence.

NSW policymakers have also long understood that discrimination based on HIV disproportionately affects already stigmatised and marginalised people. Many laws that were criminalising or stigmatising people living with HIV and priority populations at risk of HIV in NSW have now been removed or changed, and are currently a focus of the National HIV Taskforce. As we have stated, the Act contributes much to the further discrimination faced by people living with HIV and other BBVs.

Fundamentally, mandating a test for HIV on a third party does not change the emergency services worker's risk. It does not protect emergency service workers. The law only serves to perpetuate HIV stigma and misinformation, which negatively impacts the ability to achieve the goal of virtual elimination of HIV in NSW.

Response to Key Questions

1. Have you been directly affected by, or involved in mandatory disease testing? In what capacity have you been affected or involved?

ACON is NSW's largest health organisation, focusing on community health, inclusion, and HIV responses for people of diverse sexualities and genders. For over 35 years, ACON has been the primary organisation offering care, support, and educational resources to individuals living with HIV. ACON's services span NSW, with offices in Sydney, Newcastle, and Lismore and an outreach program that extends its services throughout the entire state.

During the 2022-2023 financial year, we experienced a substantial level of community engagement with our HIV programs, including:

- our Ending HIV campaign, accumulating more than 1,396,292 online interactions;
- 23 community forums led by peers, focusing on HIV prevention and treatment information;
- 3,879 instances of counselling and care coordination services to individuals living with HIV;
- as part of our collaborative efforts, we work in partnership with Positive Life NSW to conduct peer-led workshops designed to support individuals newly diagnosed with HIV in NSW;
- we have over 800 peer workers and volunteers delivering our services to people living with HIV and HIV negative gay and bisexual men across NSW; and
- the distribution of 602,788 safe needles and syringes to people in the community through our needle and syringe programs based in central Sydney, Newcastle and Lismore.[10]

Yet, since the introduction of the Act, there have been no reports from any ACON staff, volunteers, or clients indicating that they have been the subject of MTO. This fact remains true despite ACON being the largest and most prominent HIV health and wellbeing organisation in NSW.

We believe that the Act is instead being used to single out and impact marginalised and vulnerable groups, including people experiencing mental distress, people engaging in substance use, sex workers, and people experiencing homelessness. These groups are already disproportionately represented in interactions with police and within the Australian prison system.

We understand that the Act contains provisions for those who are deemed 'vulnerable third parties', however, this definition is narrow and does not practically protect all those who are vulnerable to disproportionate policing.

The human rights of all people impacted by MTOs are paramount; this includes ensuring people have access to appropriate health care and support and have timely access to the appeal and review process for MTOs.

The tight timeframe for the appeal and review process means it is extremely important that third parties are provided with accurate and timely access to information and support, including legal support, in order to be able to apply for a review within the timeframe. We are concerned that information on the appeal process is hard to find, and not readily communicated to those subject to an Order.

Further, the limitations on the appeal and review process make it extremely difficult for a detained person to request an order to be reviewed, as evidenced by the lack of people currently accessing the review process. The Act and the associated guidelines must clarify how detained people can appeal and how the services detaining them must support their right to appeal.

Any person who has been subject to an MTO and tested positive for HIV or another BBV must be connected into clinical care and community support. These marginalised and vulnerable people will require specialist care and support provided by various organisations in the HIV and BBV health sectors. It is of great concern that individuals have been subject to MTOs yet, to our knowledge, none have been referred to specialist HIV and BBV community organisations or legal services.

2. Can you describe what occurred, and the processes you were involved in?

Not applicable.

3. Do you have any concerns about your experience?

ACON is concerned that the Act is not functioning properly. This is evidenced by the lack of clear information that NSW government agencies have provided about the implementation of the Act. No

public information has so far been provided on the number of MTOs issued, the settings they were issued in and to whom, the number of orders that have been denied and why, and the time taken to issue orders.

Key to achieving the purpose of the Act is that the information provided by mandatory disease testing can be used to recommend clinical care for the affected frontline emergency worker in a timely manner. Indeed, if that information is not provided in time, then there is no value in issuing an MTO.

ACON is profoundly concerned about the lack of information about the cost-effectiveness of the Act and its associated scheme. What is the actual number of HIV and BBV infections that have been prevented due to the Mandatory Disease Testing Act? It is likely to be zero. What is the cost of implementing the Act and scheme? What is the effective value of the Act if it is not preventing new infections and is creating more distress, anxiety and worry?

It is critical that the Ombudsman's review provides information on the number of MTOs that have been issued and the circumstances surrounding the order. This includes providing information about how the risk to the worker was determined to be sufficient to warrant an MTO, what information the third party was provided about the Order, including the appeals process, how many were served to someone considered 'vulnerable', how many orders have resulted in a positive result, and how much the implementation of the Act has cost.

ACON is aware that a number of MTOs were withdrawn due to the third party consenting to a test. We are concerned about the information provided to those third parties before they consented. For example, were they made aware of the level of risk (or lack thereof) that the emergency worker was subject to? Did they consent to a test where there was in essence zero risk of transmission, and therefore likely that any MTO imposed upon them would have been overturned on appeal?

The Ombudsman's report must include an analysis of individual cases to ensure that all mandatory testing orders granted met clinically approved guidelines and that appropriate health care was provided promptly to both the frontline emergency worker and the subject of the mandatory testing order.

In addition to the Act not functioning properly, we are also concerned that the Act itself seeks to perpetuate stigma and misinformation, which is contradictory to the goals of NSW and Australia's efforts to eliminate HIV transmission.

Australia's approach to HIV has received international recognition for its leadership, collaboration, innovation and human rights focus. The country is well-positioned to become the first nation to reach the global goal of virtually eliminating HIV infections. In 2022 in NSW, there was a 23% decrease in new diagnoses compared to the five-year average.[11]

Under the *NSW HIV Strategy 2021-2025*, "considerable progress has been made towards eliminating HIV transmission in NSW".[12] Collaboration between the government, affected community, clinicians, and researchers continues to be the foundation of our effective response to HIV in NSW.

NSW can lead the way in eradicating BBV transmissions and showcase leadership by adopting a response grounded in evidence. Over the past decade, the NSW Government has spearheaded the Australian HIV response with forward-thinking and adaptable policies. However, we believe the

introduction of the Act has put many of the significant achievements made under the existing and previous NSW and National HIV Strategies at risk.[13]

Laws mandating testing contribute to substantial stigma and discrimination against people living with HIV, hepatitis B, and hepatitis C . This, in turn, hampers the capacity of health services to reach and effectively engage individuals at risk of these BBVs. Implementing the Act risks transforming positive, proactive practices (such as regular and voluntary testing) into a punitive, coercive approach that undermines the existing policies and procedures of the NSW Ministry of Health's response to blood-borne viruses.

Stigma and discrimination are worsened because many of these high-priority populations, such as gay and bisexual men, people who inject drugs, sex workers, those from culturally diverse backgrounds, and Aboriginal and Torres Strait Islander people, already face prejudice and bias based on other characteristics or attributes.

Research indicates the criminalisation of HIV is effective in perpetuating HIV stigma and that "the fear of criminal prosecution hampers people's ability to live openly with HIV infection which manifests in sexual activities such as disclosing less frequently or seeking out anonymous sexual encounters, but that also reduces their quality of life more broadly".[14,15] Efforts to minimise, rather than perpetuate, stigma, are essential if we are to achieve virtual elimination of HIV.

4. Were there positive aspects to your experience? What were they?

ACON has no reported positive aspects of our experience of the Act.

5. Do you think the testing scheme protects and promotes the health and wellbeing of the workers who are able to apply for an MTO? If so, in what way?

ACON believes that the Act fails to safeguard the health and well-being of frontline and emergency workers. Current state and national guidelines outline best practices for managing occupational exposure to bodily fluids, focusing on risk assessment and minimisation.

These guidelines help determine if a 'contact with bodily fluids' is a genuine exposure, gauge the exposure's risk level, and provide strategies for its management. Educating frontline and emergency workers about these guidelines is the most effective way to ensure their health and safety.

Furthermore, ACON believes that the Act offers no reassurance to assault victims. Instead, it likely heightens HIV and BBV transmission fears due to its reliance on outdated and unscientific data regarding transmission risks.

The primary objective of the Act should be reducing anxiety for frontline workers potentially exposed to intentional bodily fluid transfers. Proper education about HIV and BBV transmission risks is far more effective in alleviating these concerns than spreading inaccurate information.

Providing timely expert clinical care to a frontline emergency worker potentially exposed to HIV or BBV will be far more helpful in managing that potential exposure than anything the Act could achieve.

Both the Act and scheme are unnecessary, based on misleading information, and are likely to increase the stress and anxiety of frontline and emergency workers. Further, the Act and scheme likely divert essential resources from providing much-needed accurate and clear information and education on occupational exposure to BBVs to frontline and emergency workers.

Workers who have a genuine risk of exposure to HIV should be offered timely access to post-exposure prophylaxis (PEP), a one-month course of HIV medications shown to prevent the acquisition of HIV. This should be provided to all emergency service workers who have a genuine HIV risk exposure, regardless of any third party test result. HIV tests have a window period, meaning that a negative test result does not always show an individual's actual HIV status. Therefore, PEP is the most appropriate and effective way to prevent HIV acquisition, and no mandatory disease test is required.

Overall, the Act contradicts current evidence and diverges from state, national, and international guidelines. It amplifies outdated fears and fails to educate frontline and emergency workers about modern risks associated with bodily fluids.

6. Do you think the scheme is harmful to individuals or groups subject of an MTO? If so, in what way?

ACON believes that the Act is harmful to individuals or groups subjected to an MTO because of the following:

- *Stigma and Discrimination*: The Act greatly exacerbates the stigma and discrimination experienced by certain groups, particularly those already marginalised or those living with BBVs, such as HIV. The impact of this stigmatisation and discrimination is likely to reduce the willingness of marginalised people to engage in much needed BBV testing and clinical care.
- *Mental and emotional distress caused by being the subject of an MTO:* Those subjected to mandatory testing orders will likely feel their personal and medical privacy is being invaded. They are also likely to be forced into testing, especially when they might not see or understand the need for it, which is likely to cause significant emotional and psychological distress.
- *Distrust in the Health Care System:* As a result of being forced into testing, vulnerable and marginalised people in need of health care and support are likely to feel alienated and distrust the healthcare system due to perceived forceful interventions. The very people who need essential health care are alienated from that system by this scheme.

- *Erosion of Patient-Clinician Relationship*: Enforcement of the Act will contribute to the erosion of trust between patients and clinicians if medical professionals are seen as enforcers of a potentially controversial law rather than healthcare providers.

The emotional and psychological impact of being the subject of an MTO on marginalised and vulnerable people, including people experiencing mental distress, people who use drugs and alcohol, sex workers, and people experiencing homelessness, is likely to be devastating and lasting. The Act and the associated scheme provide little or no support for these people and is likely to alienate them from much-needed clinical care and support.

7. Do you have any views as to whether the mandatory testing scheme could be improved?

Frontline emergency workers regularly risk their lives to save others. Ensuring their safety against potential disease transmission during service is paramount. The Act falls short of achieving that goal because it is based on a misunderstanding of the risks of transmission of HIV and other BBVs.

The Mandatory Disease Testing Act should be repealed. If the Act and its associated scheme are to continue, then important changes need to be made to the Act to minimise the detrimental impacts of the legislation.

1. **Increased education and information for frontline emergency workers.**
   Emergency workers should have detailed, up-to-date information about various BBVs, their transmission routes, and preventive measures. Ongoing training needs to be provided to provide awareness of risks to frontline emergency workers and how to respond. This education and information must be provided in a clear and accessible format for emergency settings. Importantly, it must provide a clear and accurate assessment of the risks for workers so that they can make immediate risk assessments and identify the most effective response.

2. **Implementation of accurate and practical risk assessments.**
   Before granting an MTO, qualified specialist staff must conduct a systematic risk assessment. This would determine the actual risk faced by the emergency worker based on the nature of exposure, the type of fluid or substance involved, and other contextual factors. Only genuine high-risk exposures (which are very rare) should lead to mandatory testing.

3. **Strengthening of independent review and oversight processes.**
   The process to appeal to the Chief Health Officer to review an MTO must be strengthened and made more accessible. The current review process is opaque, inaccessible and functions poorly. It is difficult to find information on the process and nearly impossible to initiate a review of an MTO within the timeframes given. Marginalised and vulnerable people, likely the subjects of MTOs, would find it extremely difficult to access the current review process.

Timely and effective assessments are critical to the success of the review process. The vulnerable and marginalised people who are the target of MTOs must be provided with accessible, easy-to-understand information on how to access the review process.

This information must be provided promptly to ensure all parties affected by a MDT order have their rights and needs met. Importantly, this includes providing access to the review process for people within outside and within custodial settings.

4. **Development of clear guidelines on risk based on the "Chief Health Officer's Risk Matrix".**
   The Chief Health Officer's guidelines provide evidence-based information on what constitutes a genuine risk of transmission. This information is essential in making informed decisions swiftly without being clouded by panic or prejudice. This information should be made clear, accessible, and as simple as possible for all frontline emergency workers as it is likely to be used in highly charged and stressful circumstances. This information and the review process must be clearly communicated to all parties involved in MTOs.

5. **Mandatory Hepatitis B Vaccination.**
   Since Hepatitis B is one of the most transmissible BBVs, it's essential to make Hepatitis B vaccination compulsory for all frontline emergency workers. This would provide an added layer of protection against potential exposures and remove the need for many MTOs.

6. **Transparent data reporting.**
   Maintaining a clear, transparent record of the scheme's implementation is crucial for frontline emergency service workers and community acceptance. This includes data on the number of tests conducted, the number of MTOs initiated, withdrawn, appealed, and proceeded, the rationale for initiating and/or serving an MTO, including in instances where the risk is low to none, demographic details of the people subject to MTOs (including age, location, Aboriginal and Torres Strait Island status, for example), in what settings the MTO was issued (i.e., custodial setting, police, emergency ward, etc.), by whom was it issued (i.e., police officer, corrections officer or another type of emergency services worker), and any subsequent actions taken.

   Making such data accessible (while respecting privacy) is essential to building public trust in the system. All government agencies must provide this data to the community promptly and efficiently.

If it will not be repealed, the current Act and the associated scheme must be reformed. Only by strengthening the review process and guidelines, providing accurate and assessable education and appropriate clinical care, ensuring transparency of the system and data, and a more holistic supportive approach, can we ensure our frontline emergency workers, as well as the most marginalised and vulnerable members of our communities, are protected and kept safe.

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