Submission No 9

INQUIRY INTO MANDATORY DISEASE TESTING BILL 2020

Organisation: Hepatitis NSW

Date Received: 18 December 2020

Mandatory Disease Testing Bill 2020

Submission

Hepatitis NSW

Hepatitis NSW

Level 4, 414 Elisabeth Street

Surry Hills,

NSW 2010

21 December 2020

Parliament of NSW
Legislative Council
Standing Committee on Law and Justice

Re: Inquiry into Mandatory Disease Testing Bill 2020

Thank you for the opportunity to provide feedback on the *Mandatory Disease Testing Bill 2020*. Please find below a detailed submission in response to the Bill, from Hepatis NSW.

Steven Drew

CEO, Hepatitis NSW

About Hepatitis NSW

Hepatitis NSW (HNSW) is a state-wide, not-for-profit charity started by members of the hepatitis community in 1991, funded by the NSW Ministry of Health. 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 represent 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.

Hepatitis NSW vision is '*A world free of viral hepatitis*'. We are committed to supporting the NSW Government to achieve the elimination of hepatitis B and hepatitis C by 2028.

These elimination targets, set by the World Health Organisation, and adopted by the Australian and NSW Governments, are:

- 90% of people with hepatitis B, and hepatitis C, are diagnosed;
- 90% of people are vaccinated against hepatitis B;
- 80% of people with hepatitis B, and hepatitis C, are on treatment; and
- 65% reduction in hepatitis B, and hepatitis C, deaths.

The key communities we work with to improve health outcomes and help achieve the international, national and NSW elimination target are:

- People living with, at risk of or affected by hepatitis C;
- People living with, at risk of or affected by hepatitis B;
- Aboriginal and Torres Strait Islander people;
- People who inject, or who at risk of injecting, drugs;
- People in custodial settings;
- People from culturally and linguistically diverse backgrounds; and
- People experiencing homelessness.[1]

Our communities will be directly affected and impacted by the *Mandatory Disease Testing Bill 2020*.

About viral hepatitis

Hepatitis B and hepatitis C (viral hepatitis) are blood borne viruses that manifest as liver infections. In NSW, as of 2018, an estimated 80,363 people were living with chronic hepatitis B[2] and an estimated 48,381 people were living with hepatitis C[3].

The hepatitis B virus can live in blood and sexual fluids. Hepatitis B can be a risk if there is blood-to-blood contact with someone with hepatitis B. Unprotected sex can also be a transmission risk for hepatitis B. Hepatitis B can't be passed on through saliva, skin-to-skin contact, or air – so these are not transmission risks for hepatitis B. People with hepatitis B who are diagnosed, in care and treatment can live healthy lives. Vaccination against hepatitis B is available.

Hepatitis C is transmitted through blood-to-blood contact. Hepatitis C is not transmissible through casual contact, spitting, sneezing, coughing, physical contact or kissing. There is no vaccination against hepatitis C, however since 2016 there has been a cure available. The cure rate is successful in 95-98% of cases and can be achieved in 8-12 weeks. It should be noted that in over a quarter of cases, spontaneous clearance occurs. This means that there is no ongoing chronic infection.

[1] Hepatitis NSW. Strategic Plan 2020-24. Sydney: Hepatitis NSW; 2020. p3 see: https://www.hep.org.au/wp-content/uploads/2020/09/2HNSWstratplan_forweb.pdf

[2] Kirby Institute. Hepatitis C Elimination in NSW: Monitoring and Evaluation Report, 2019. Sydney: Kirby Institute, UNSW Sydney; 2020. p5.

[3] Ibid

Preface

HNSW strongly believes that the wellbeing and safety of frontline workers in NSW is vitally important. In terms of wellbeing and safety, we are referring not just to the physical but also to mental and emotional wellbeing. Our frontline workers deserve the community's respect and should not be subject to acts of intimidation, threats or violence in any form. They must be protected as much as is reasonably possible in a high-level occupational risk environment.

In providing that protection, it is essential that the strategies designed and used are scientifically informed, evidence-based and effective in meeting the aim; that they are fit for purpose. Where the issue being addressed is a health issue, the response must be health based, not based on criminalising affected people.

A health informed and based response provides a wholistic, wraparound approach that draws on appropriate health promotion, medical support, interventions and care to the primarily affected person. Force and criminalisation against a third party is punitive and does not provide sanctuary for a victim.

This Bill is a blunt instrument that is wholly incapable of achieving anything other than a perpetuation of fear, loathing, discrimination and privileging that is inconsistent with the inclusive, fair and responsible society and behaviour we would all desire. It will not address the stress and concerns of frontline workers around the exceedingly low risk of infection. Indeed, greater results will be achieved through supporting them with accurate information about risks, addressing their concerns, and providing professional wellbeing, support and counselling.

HNSW has opposed mandatory disease testing since it was first considered following recommendations arising in the 2017 NSW Legislative Assembly Committee on Law and Safety Report. Our position remains unchanged.

Mandatory testing is not in line with the Australian National HIV, hepatitis B or hepatitis C Testing Policies, or supported by global health bodies. The key principles guiding BBV testing in Australia are that testing is conducted ethically, is voluntary and performed with the informed consent of the person being tested.

Mandatory testing does not meet these principles. Mandatory testing laws are not supported by global health bodies such as UNAIDS and the World Health Organisation on the basis that it breaches human rights, compromises public health initiatives and other efforts to eliminate HIV and other BBV transmission.

Introduction

The *Mandatory Disease Testing Bill 2020* provides for mandatory blood testing in the event a prescribed worker comes into contact with the bodily fluids of a third party as a result of a deliberate action and the prescribed worker is at risk of contracting a blood-borne disease. Application of the Bill extends to young people in the 14- to 18-year-old age group.

The Bill fails the public health, natural justice and good practice tests required to justify the resources allocated to date, as well as the time and resources required for its application should it progress through parliament and receive assent.

Work Health and Safety laws should be guiding the designed environment, policies and strategies in workplace settings, with appropriate information provision, policies and procedures, including risk identification and mitigation, training, vaccination, physical workspace design and provision and use of PPE. To simply test individuals for BBVs rather than develop comprehensive workplace safety approaches is ineffective in prevention, reducing risk and supporting frontline worker's rights at work and does nothing to ameliorate the impact of risks on these valued workers.

Public health – considerations and evidence

Australia's response to public health crises, as demonstrated through the current coronavirus pandemic, is recognised as first class around the world. NSW, in particular, has a long and proud history of our responses being expert led, education based, cooperative and non-punitive. In the case of this Bill, these robust, tested and true defining features are absent.

The evidentiary basis for the Bill is lacking. The prevalence of BBVs does not support the introduction of this Bill.

The prevalence of HIV, hepatitis B and hepatitis C in NSW does not support the creation of this Bill. Specifically, the Doherty Institute's *National Surveillance for Hepatitis B Indicators* report estimates that in 2018, the number of people living with chronic hepatitis B in NSW was 80,363. The Kirby Institute's *Hepatitis C Elimination in NSW: Monitoring and Evaluation Report 2019*, estimates that 48,381 people were living with hepatitis C in NSW. The report also states between 2015 and 2018, the number of people living with hepatitis C decreased from 68,963 to 48,381 respectively due to the rollout of new treatments that provide a cure.

The NSW Government estimated the state's population in 2018 at 7.95 million people. Based on these data, prevalence of hepatitis B was in the same year barely 1%, while the hepatitis C prevalence was 0.6% of the NSW population.

Similarly, the epidemiology of blood-borne virus (BBV) transmission in Australian in professional settings does not support the targeting of the relevant diseases as defined in the Bill. It has been over a decade since the last confirmed transmission of a BBV in a workplace setting, despite millions of individual occasions of service and interactions.

Hepatitis C is transmitted through blood-to-blood contact. You can't contract hepatitis C through casual contact, spitting, sneezing, coughing, non-sexual physical contact or kissing.

The hepatitis B virus can live in blood and sexual fluids. Hepatitis B can't be passed on through saliva, skin contact, or air – so these are not transmission risks for hepatitis B. Hepatitis B can be transmitted through unprotected sex and through blood-to-blood contact. The vast majority of people who contract hepatitis B will clear the infection. Only around 5% of people will remain chronically infected.

Finally, the formulation of the Bill fails to take account of the significant changes in BBV disease morbidity and mortality, as well as the current prevention, management and treatment options which further ameliorate the likelihood of transmission and infection.

A vaccine for hepatitis B has been available since 1986. Since 2000, NSW has pursued a comprehensive newborn hepatitis B vaccination program. Vaccination against hepatitis B is at the centre of the *NSW Hepatitis B Strategy*. Indeed, it has been so successful that NSW has exceeded the international agreed targets, as well as its own. In effect, people under 20 years of age and born in NSW are likely to be immune to hepatitis B due to vaccination.

Beyond the newborn vaccination strategy pursued by NSW Health, it is important to note there has been a comprehensive and determined catch-up vaccination program implemented to further reduce prevalence and transmission of hepatitis B. NSW Health is continuously promoting the screening and vaccination of people at risk and susceptible to HBV infection.

It is NSW Health Policy to identify and vaccinate at risk populations (people in custodial settings, household and sexual contacts of people living with hepatitis B, immunosuppressed people, men who have sex with men, people with HIV or hepatitis C, people who inject drugs, people on an opioid treatment program, refugees, newly-arrived migrants attending intensive English centres, sex workers, clients of sexual health services, unvaccinated children and Aboriginal people of any age). The vaccine is freely available to these groups. Health promotion activities to capture these people occur in all sectors, but primarily in primary care.

The simple fact is, to ameliorate any distress or concern of a prescribed worker about potentially contracting hepatitis B, the worker's employer should require and provide hepatitis B vaccination as a condition of employment. It is understood this is consistent with NSW Health policies and procedures for medical staff.

There is no vaccination for hepatitis C, however since 2016 there has been a cure available. The cure rate is successful in 95-98% of cases and can be achieved in 8-12 weeks. It should be noted that in over a quarter of cases, spontaneous clearance occurs. This means that there is no ongoing chronic infection.

All of these facts are important, as the NSW Legislative Assembly Committee on Law and Safety Report in its findings clearly stated that in the framing of any legislation providing for mandatory disease testing the legislation should clearly define the factual circumstances in which there is the risk of transmission of a BBV. Most importantly, it also stated that any definition should be based on up-to-date medical advice.

In summary, the low prevalence of BBVs in the NSW community means that there is a very low risk of transmission in the case of occupational exposure. In its current form the Bill over-inflates this risk causing unnecessary distress to frontline workers. The focus after an event in which a worker is exposed to bodily fluids should be on supporting them with accurate information about risks, rapid medical assessment of the risk, addressing their concerns, providing professional wellbeing support and counselling.

The requirement for mandatory blood testing for the *third party* will, without doubt, bring greater stigma and discrimination associated with these BBVs, at a time when the NSW Ministry of Health has specific targets to *reduce* stigma and discrimination and to engage more people in testing and treatment. The international literature is unequivocal that stigma and discrimination results in avoidance of disclosure and limits access to health care. The MDT Bill is necessarily at odds with attempts by the NSW Government to better the health of the population through encouraging people to access services to be tested and receive treatment as required.

Premise of the Bill

If the Bill is not based on evidence, then what is the actual intent and outcome that is being sought?

In all discussions to date, fear has been the constant feature. In effect this Bill will criminalise a health issue. It will reinforce stereotypes and misinformation of BBVs, how they are transmitted, the level of risk and appropriate responses to critical incidents that impact the mental health and wellbeing of those involved. It reinforces punitive responses rather than compassionate and individually tailored responses that build resilience and coping skills.

It should be noted that there already exist provisions in numerous pieces of legislation covering the vast majority of prescribed workers to protect and punish third parties who impede or threaten physical safety. There is no need to provide a further piece of legislation.

The NSW Legislative Assembly Committee in 2017 found that there are a number of factors that resulted in violence against frontline workers, in particular in emergency departments. These include drug and alcohol use; distressed and frustrated patients and family members of patients; and confused, disoriented or mentally ill patients. This suggests that in many cases incidents and assaults against frontline workers may be avoidable and preventable.

A key refrain in calling for mandatory blood testing provisions relates to the mental health and wellbeing of prescribed workers. The mental health and wellbeing of all workers is vitally important, particularly in the aftermath of a critical incident. Ensuring the mental health and wellbeing of an affected prescribed worker is best achieved through ensuring proper medical assessment and advice, provision of appropriate treatment and care, as well as ongoing counselling and support. It is not achieved by an interpretation of deliberate intent; threat of withdrawal of personal rights; or punishment of a third party. It will not prevent risks, and may, through requiring testing, expose other frontline workers to risks in managing the accused third party whilst collecting blood samples.

It is also disappointing that the legal obligations of the employing agency to identify and implement a range of strategies to lessen potential exposure to BBV risks has not been given more attention. This is particularly pertinent given all submissions responding to the 2018 Options Papers supported the proposition for improvements to current agency policies and practices.

The proposed legislation may take resources, energy and focus away from immediately assessing and supporting the frontline worker who may have been exposed to a BBV, and instead magnify efforts in managing the third party. Neither the third party nor the frontline worker, their colleagues and workplaces benefit from this legislative model.

Legislative Considerations

While we remain opposed to this legislation, if such legislation is to progress, the following matters of concern require attention and action to address lack of clarity, gaps and reduce the opportunity for inappropriate application.

Overarching observations

As outlined in detail earlier, the Bill does not take account, or reflect, current medical and scientific knowledge around infectious diseases and specifically blood-borne viruses. It also does not, and will not, address evidence-based risks and concerns regarding BBV transmission.

This is reflected most glaringly in the proposed definition of '*bodily fluid'* which is defined as 'blood, faeces, saliva, semen or other bodily fluid or substance prescribed by the regulations'. All diseases proposed to be tested for under the Bill are transmitted only via blood or semen. There is no medical or scientific reason to include faeces or saliva. Nor is there a reason to make provision to expand the definition via regulation.

Regulations and definitions relating to medical conditions and transmission risks must, be necessity, match those used by the medical profession, and should not be amended without oversight from the Chief Health Officer.

Also, it is telling that in seeking a mandatory testing order (MTO), the provision of documentation that outlines the advice provided by the treating medical practitioner is not required to be submitted as part of the application to be considered by the senior officer. In effect this removes medical professional oversight of the assessment of risk at the first instance, implying that the Bill's implementation is not based on medical evidence or genuine care for the health of the frontline worker.

That the Bill is to apply to young people 14-18 years of age is very concerning and extremely difficult to justify on scientific or medical grounds. In 2018, excluding Justice Health data, there were 159 hepatitis C notifications among young people in the 15-24-year-old age group[4]. In Justice Health settings in 2018, there were 173 hepatitis C notifications among people [5]. This represents a miniscule proportion of the total NSW population that are being potentially targeted for no evidence-based purpose.

It should be noted that from 1 April 2020, on advice of the Pharmaceutical Benefits Advisory Committee (PBAC) age restrictions from all PBS listings of Direct Acting Antiviral (DAA) regimens – the cure for hepatitis C – were lifted. This made access to DAAs available to young people aged 12 years old and above. As time goes by and more people are being treated and cured, less young people will have or acquire hepatitis C.

Similarly, with hepatitis B vaccination rates of more than 95% in newborn babies for close to twenty years, the vast majority of young people are immune, and will never be exposed to or acquire hepatitis B. In fact, the youth cohort pose an ever-decreasing, virtually non-existent risk for viral hepatitis as health programs reach toward the elimination targets.

A major concern is that the Bill provides for a mandatory testing order (MTO) to be sought on the basis of the belief of a prescribed worker that the act of the third party was deliberate. There is no objective test and no recourse for the third party to put an alternative perspective. This is not procedural fairness and doesn't reflect community expectations of our justice system.

Another issue of note that is not addressed in the Bill is the education and training of senior officers in the application of the Chief Health Officer guidelines and the implementation of the legislation.

Specific issues and concerns

Lack of definition – 'deliberate actions'

In the preliminary section of the Act, reference is made to 'deliberate actions'. Despite this, the term is not defined in the Dictionary. This is not a reasonable or acceptable arrangement. Failure to define such a critical term opens up the opportunity for subjective assessment by the frontline worker or the MTO being used as a form of extrajudicial punishment.

Definition of 'bodily fluid'

As highlighted earlier, the definition used in the Bill does not reflect the science in relation to the transmission of blood borne viruses. It is essential that the legislated definition of *'bodily fluids'* only include those fluids that may transmit blood borne viruses. There is no reason to include faeces or saliva.

Application of legislation to young people

[4] Ibid. p55.

[5] [5] Ibid. p56.

As outlined previously, the application of the proposed legislation to people 14-18 years age is inappropriate, unacceptable and totally lacking in any scientific reasoning. The minimum age of application for this legislation should be 18 years.

Prevalence rates for hepatitis C in people aged under 18 are exceptionally low.

Given a vaccine for hepatitis B has been available since 1986 and NSW has pursued a comprehensive newborn hepatitis B vaccination program since 2000, the number of young people living with hepatitis B under 18 years of age is negligible. Further, NSW Health implemented a comprehensive and determined catch-up vaccination program to further reduce prevalence and transmission of hepatitis B.

Concerningly, the Bill does not recognise or provide for parental or guardian involvement in relation to the mandatory testing process. This is unacceptable and inappropriate and does not reflect community expectations.

While requiring a court order to proceed with a MTO may be a safeguard, it does not change the material evidence that application of the legislation to 14-18 year old people is not justified.

Process timeline for worker assessment

To ensure the mental health and wellbeing of a frontline worker who may have been exposed to the risk of transmission of a blood borne virus, we believe it is essential for the inclusion of a requirement for an urgent appointment with a medical professional who can discuss treatment, prevention and transmission risks.

To this end, anyone who makes a request for an order must visit a medical professional within 24 hours for assessment and counselling, or referral to an emergency department or infectious diseases expert. Transmission of some BBVs is completely preventable if appropriately treated within this timeframe. The guidelines for such incidents should be those devised and used for exposure prone health workers.

Testing order application documentation

The proposed legislation requires various content to be included when making an application for an MTO. In a peculiar oversight, it does not require a copy of the medical advice of an expert to be included in the application. Ensuring a senior officer has the most appropriate and factual information available in considering an application for an MTO is essential. Therefore, a copy of the medical advice must be provided by the medical practitioner to the applicant and must be required documentation for inclusion with the application to be considered by the senior officer or their delegate.

Notwithstanding this, we are concerned that a decision about whether a MTO is necessary is placing a decision about medical science in the hands of a non-medically trained person. These decisions should be vested with a medically trained health practitioner. The requirement for the senior officer to take account of any Chief Health Officer guidelines is not rigorous enough to ensure an informed and evidence-based decision is made.

Submissions by the Third Party

A reasonable expectation must be placed on the senior officer to seek out submissions from the third party. Efforts to obtain such a submission must be documented in the event the third party is unable to be located.

Setting of regulations

It is posited that the primary purpose of the Bill is about the health and wellbeing of frontline workers, however the legislation is vested not with the Health Minister, but with the Police Minister. Given this, the use of Regulations should be highly restricted. Indeed, it is preferable and appropriate for guidelines and provisions to be included in the legislation itself. Failing this, as a bare minimum no Regulations should be made without the full agreement of the Minister for Health.

Refusal of an Application

In the event a third party cannot be located, a senior officer should be required to refuse an application. Currently, the legislation allows discretion in relation to refusing an application on these grounds. It is unfair that a person who has not had access to their grounds of recourse to be subject to a test.

Oversight of legislation

External oversight of this proposed legislation by the Ombudsman is welcome. To assess the impact of the legislation, and to identify whether it is disproportionately affecting particular population groups or community, it will be important to ensure appropriate information is collected and provided.

Detained Third Parties
We are very concerned around transportation, detention and the use of force of people in police custody who are subject to a MTO, especially possible extended detention in the event a testing facility is not readily accessible.

Review by Chief Health Officer
The inclusion of a thorough review process, overseen by the Chief Health Officer is welcome.

Review request timeline
We are concerned at the inclusion of 1-day timeframe to submit an application for review. This is particularly pertinent for people who may be in custody given the challenges in making a written application for review. One day is not a reasonable timeframe for many people to take in and process their options, seek advice and guidance, as well as lodge an appeal. Such a short time frame has the potential to significantly restrict access to the review process.

Any MTO must include mechanisms that facilitate lodgement of a review application within a reasonable timeframe. There must be clear instructions to assist the third party. Provision of a pro-forma review application should be part of documentation provided to a third party against whom a MTO has been issued. A no disadvantage rule to accommodate those vulnerable people – such as people living with mental illness, cognitive or intellectual impairment, etc – needs to be included.

Effect of application for review
Under Section 23 (1), an application for review requires a third party to comply with a MTO regardless. That is, the MTO continues to have effect. In the event the Chief Health Officer sets aside the decision, the results of mandatory testing will not be provided to prescribed parties.

It is unacceptable that a person who has appealed a decision is still required, and indeed may be forced to undergo, a mandatory test pending the outcome of the appeal that would have disallowed the test. This is a gross violation of civil liberties. This section must be removed, with provision for the test to proceed in the event the Chief Health Officer upholds the decision of the senior officer.

Delegation
We are concerned that senior officers can delegate their functions to other public service staff. For the most effective application of the legislation in terms of assessing a MTO, it is essential that the person undertaking the process has the necessary education and training to do so. Any senior officer implementing such legislation would be expected to have training on the application of the legislation. It follows therefore that any delegate of the senior officer must also be able to demonstrate successful completion of such training.

The legislation needs to make clear that a senior officer may not delegate the decision in relation to an application to any officer or staff involved in, or connected to, the incident that is the subject of the application. This is a significant gap in the legislation in its current form.

Conclusion

NSW has a long and proud history of leadership in bipartisan, evidence-based, considered public policy responses that balance public health and individuals' rights.

HNSW strongly supports decision making and public policy responses on mandatory testing based on medical and scientific evidence. This should include considerations based on the prevalence of Blood Borne Viruses (BBVs), the methods, thresholds and likelihood for transmission and the testing windows for results. On all these counts, provision of expert medical and mental health assessment and support will be far more effective than mandatory disease testing.

In progressing any mandatory blood testing legislation, it is essential that medical and scientific evidence is at the heart of a fair, just and respectful process. Under no circumstances should it be driven by motivations of fear and retribution.