

**Submission
No 2**

INQUIRY INTO MANDATORY DISEASE TESTING BILL 2020

Organisation: Centre for Social Research in Health, UNSW Sydney

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Submission by the Centre for Social Research in Health, UNSW Sydney, on the proposed Mandatory Testing Bill 2020, New South Wales

About us

The Centre for Social Research in Health is a national research centre based at UNSW Sydney. We receive federal and state funding, including from the New South Wales Ministry of Health, to conduct social and behavioural research into bloodborne viruses and sexually transmitted infections. We work closely with affected communities to improve their health and wellbeing and reduce stigma and discrimination. One of our key areas of interest is in identifying effective, evidence-based ways to increase the uptake of testing, prevention and treatment related to bloodborne viruses, including by reducing misguided and stigmatising views of these viruses.

Our position on the proposed Mandatory Testing Bill

The Centre for Social Research in Health opposes the proposed Mandatory Testing Bill. We do so for the main reasons that it is unnecessary, poorly defined, violates the principle that testing should be voluntary, and relies on inaccurate and outdated assumptions about the risks of acquiring or managing bloodborne viruses. If passed, we believe the Bill will reinforce stigma and discrimination, contradicting New South Wales' current commitments in both national and state strategies to protect the rights of people affected by bloodborne viruses and reduce the stigma and discrimination related to them.

The Bill is unnecessary

The Bill appears to have been drafted on the premise that there is a substantial risk of infection with bloodborne viruses (HIV, hepatitis B and C) for frontline workers after occupational exposure to body fluids of people with whom they interact as part of their work (third parties). We recognise that frontline workers do a vital job in Australia, and may face challenging and stressful situations in which they are concerned about their health and wellbeing after contact with someone else's body fluids. However, all frontline workers should have received training in infection control and universal precautions which, if followed, render the Bill unnecessary.

The risk of infection through casual or passing contact with body fluids is extremely low. The adult prevalence of HIV, hepatitis B and C in Australia is very low (0.1%, 1% and 1%, respectively), so frontline workers will rarely interact with people living with these viruses (MacLachlan, Allard, Carville, Haynes, & Cowie, 2018; Sievert et al., 2011; The Kirby Institute, 2018). There is no risk of transmission of these viruses if a frontline worker's intact skin is exposed to infected saliva or blood (ASHM, 2012). There is no risk of HIV or hepatitis C transmission from saliva in the mouth or eyes or a bite that breaks the skin, and a very low chance of transmission of hepatitis B in these circumstances (ASHM, 2012). Even contact with infected blood through broken skin, the mouth or eyes poses little risk of HIV or hepatitis C transmission and only a moderate chance of hepatitis B transmission. The highest risk is limited to needlestick or blade injuries in which infected blood is present and the skin is punctured, with hepatitis B being the most likely to be transmitted, if it is present at all (ASHM, 2012). For settings in

which inadvertent exposure is a recognised risk, such as healthcare workers who experience needlestick injuries or punctures related to surgical procedures, there are well established national guidelines to manage risk and actual exposure, and these do not suggest or endorse mandatory testing (CDNA, 2019).

In its current form, the Bill does not clarify that the chance of transmission for frontline workers is very low in most circumstances and that concern about transmission is only warranted in a narrow range of situations. This is likely to cause or exacerbate unnecessary levels of stress and anxiety among frontline workers, their colleagues, and family members, as well as encouraging spurious requests for testing.

The Bill is poorly defined

The concept of 'contact with body fluids' is poorly defined in the Bill and allows too many situations to be considered a risk for transmission, when it is unlikely or impossible (ASHM, 2012). The trigger for a request for mandatory testing in the Bill is when a frontline worker has been exposed to body fluids from a third party due to the 'deliberate action' of that third party. Again, the Bill does not limit these requests to situations in which transmission is possible or likely. The definition of a 'deliberate action' is vague, as it is based on the opinion of the worker in question, without reference to the third party or relevant independent witnesses, suggesting accidental or incidental exposures can be recast as deliberate actions after the event. A 'senior officer' is supposed to assess a worker's request for mandatory testing but it is unlikely all senior officers would be sufficiently knowledgeable or qualified to assess the likelihood of bloodborne virus transmission. We note that whoever is tasked with making determinations or exercising powers in these situations influences whether the outcome is stigmatising or not (Seear, Lancaster, & Ritter, 2017). We therefore think it would be preferable for a qualified medical practitioner to be responsible for assessing if there is a risk of transmission and for suitably qualified personnel to provide support and advice to the worker and the third party.

The Bill violates the principles of informed consent and voluntary testing

National and international guidelines for testing for bloodborne viruses emphasise that testing should be voluntary and conducted with a patient's consent in order to maintain a patient's dignity, privacy and human rights (Commonwealth of Australia, 2020a, 2020b, 2020c; World Health Organization, 2015). The guidelines indicate that testing should only occur when patients are willing and ready to receive a test result, and that mandatory or compulsory testing is not justifiable on public health grounds and should be avoided wherever possible. Testing should be conducted by qualified professionals in a safe environment in which results can be delivered in a supportive way. These principles have been established and proved effective over decades of use and yet the proposed Bill contradicts them without explanation.

We note that one of the Bill's stated aims is to 'protect and promote the health and wellbeing of health, emergency and public sector workers' yet there is no equivalent aim to protect the rights and wellbeing of people who are forced to undergo testing.

We are particularly worried about the Bill's proposed application to people as young as 14 years old. Young people who have regular contact with the justice system, police, emergency health care workers and hospitals suffer significant social marginalisation (Green et al., 2015), and may be particularly vulnerable to the proposed mandatory testing in this Bill. Despite the prevalence of bloodborne viruses in this group being very low (Heard, Iversen, Geddes, & Maher, 2020), marginalised young people who have frequent contact with frontline workers may be subject to the proposed legislation more often. We are concerned that young people may not understand why testing is being

proposed, not be in a position to give or withhold informed consent, and may experience mandatory testing as abusive. This has the potential to do significant harm.

We are also concerned about section 20 of the proposed Bill, which outlines the functions of police and correctional officers when interacting with detained third parties. The use of force to obtain a blood sample from a detained person clearly violates the principle of informed consent and has the potential to be experienced as distressing and punitive by third parties. In addition, the provisions of section 21 of the proposed Bill are not in keeping with principles of confidentiality in medical care. Test results should not be communicated to a frontline worker's medical practitioner before the person subject to the mandatory testing order has been informed about their test results. Test results are private medical data, which ought to be communicated to the person in question by a medical professional, and only shared with others if consent is granted.

The Bill relies on inaccurate and outdated assumptions about the risks of acquiring and managing bloodborne viruses

As noted above, the prevalence of HIV, hepatitis B and C in Australia is very low, and the likely risk of transmission for most frontline workers is also very low. The Bill mistakenly implies that no progress has been made in preventing, managing and treating bloodborne viruses. For all three viruses, significant advances have been made in prevention, treatment or cure that means they should not be feared as unmanageable or life-ending, as the Bill implies.

HIV. While HIV is still currently an incurable infection, the development of highly effective antiretroviral treatments in the mid-1990s means that the majority of people living with HIV in Australia are able to live normal, healthy lives. Since 2015, HIV treatment has been free for all New South Wales residents living with HIV. Research conducted in the last ten years has shown that if a person living with HIV is on treatment and virally suppressed, then the risk of onward sexual transmission is zero (Bavinton et al., 2018; Cohen et al., 2011; Rodger et al., 2016). In Australia, the vast majority of people living with HIV are on treatment and virally suppressed (The Kirby Institute, 2018). There are also additional, effective options for HIV prevention. Post-exposure prophylaxis (PEP), a month-long course of antiretroviral drugs, can be prescribed to an individual within 72 hours of a suspected exposure to HIV and is effective in preventing HIV infection (ASHM, 2012, 2016). It has been available in Australia for decades. PEP can (and should) be offered to an individual without waiting to confirm the HIV status of a suspected or known source, making mandatory testing unnecessary, and offering reassurance to frontline workers that they will not acquire HIV. More recently, pre-exposure prophylaxis (PrEP), the regular use of antiretroviral drugs to prevent HIV acquisition during sex, has been shown to be highly effective and is now available in Australia to anyone at risk of HIV infection (Fonner et al., 2016).

Hepatitis B. Like HIV, hepatitis B is an incurable but treatable bloodborne virus, mainly affecting people from high prevalence countries who contracted the infection at birth or during early childhood (Commonwealth of Australia, 2020a). Hepatitis B is preventable by vaccination, which is available throughout Australia. The vast majority of Australian children are now vaccinated against hepatitis B when they are infants. We note that guidelines already recommend that all frontline workers be tested for and vaccinated against hepatitis B, and indeed, this is a compulsory requirement of employment in many of the settings in which these workforces are located (ASHM, 2012; CDNA, 2019). If a frontline worker is not vaccinated against hepatitis B, post-exposure prophylaxis with vaccination should be offered within 72 hours of a suspected exposure (such as a needlestick injury or exposure to blood on broken skin) (ASHM, 2012). Again, this does not require the known or suspected source person to be tested.

Hepatitis C. In 2016, direct acting antiviral (DAA) treatments which cure hepatitis C infection in over 90% of cases became available for all people living with hepatitis C in Australia, and treatment uptake has been rapid (Scott et al., 2018). Any doctor can prescribe DAAs, with treatment periods typically lasting 12 weeks without serious side effects (Hepatitis C Virus Infection Consensus Statement Working Group, 2020). As the risk of infection during an occupational exposure is low (estimated to be less than 2% after a needlestick injury involving infected blood, and zero for body fluids on unbroken skin) (ASHM, 2012; CDNA, 2019), it has been suggested that repeated testing for frontline workers is an appropriate response rather than mandatory testing of third parties, as the large majority of cases will be negative (Charles, Grayson, Angus, & Sasadeusz, 2003). In the unlikely situation that a frontline worker acquires hepatitis C through workplace exposure, DAA treatment should be offered to clear the virus.

The Bill will reinforce stigma and discrimination

Despite their extremely low prevalence, our research shows that bloodborne viruses like HIV, hepatitis B and C remain highly stigmatised conditions in Australia, with a history of prejudice and discrimination against the people and communities who are disproportionately affected by these infections (Broady, Brener, Cama, Hopwood, & Treloar, 2020; Broady et al., 2018). This persistent social stigma appears to be due to enduring community fears about infectious diseases that are perceived to be more contagious or dangerous than they actually are, and misguided social attitudes about the practices most commonly associated with HIV and hepatitis C transmission (e.g. unprotected sex between men or sharing injecting equipment). Discussing these modes of transmission can still trigger moralising or judgmental attitudes about 'promiscuity' or 'addiction'. The disproportionate burden of these viruses in marginalised communities can also trigger homophobic, judgemental, and racist attitudes. Unfortunately, stigma and discrimination remain common experiences for people affected by bloodborne viruses, particularly people living with HIV, hepatitis B or C, as well as the communities disproportionately affected by these viruses, such as Aboriginal people, gay and bisexual men, people who inject drugs, and some migrant populations (Broady et al., 2020). Our research shows that bloodborne virus stigma and discrimination remain pervasive barriers to people seeking help, using effective prevention methods, engaging in testing or treatment, and remaining in care (e.g. Brener, Wilson, Slavin, & de Wit, 2013; Cama, Brener, Slavin, & de Wit, 2015; de Wit, Murphy, Adam, & Donohoe, 2013; Hopwood, Treloar, & Bryant, 2006; Jin, Brener, & Treloar, 2020; Körner, 2007; Treloar, Rance, & Backmund, 2013).

The proposed Bill appears to reinforce these stigmatising and discriminatory attitudes towards bloodborne viruses, rather than trying to challenge them and reduce their impacts. The appetite for such a Bill suggests that there is a pressing need for frontline workers to receive education and reassurance that bloodborne virus risks are low and manageable through basic infection control procedures, and do not require the mandatory testing of third parties (ASHM, 2012; CDNA, 2019; Charles et al., 2003). Requiring third parties to undergo mandatory or compulsory testing implies that people affected by bloodborne viruses are less deserving of rights, dignity and care than other people, undermining the rights-based response to HIV, hepatitis B and C well established in New South Wales and Australia (Commonwealth of Australia, 2018a, 2018b, 2018c; NSW Ministry of Health, 2014a, 2014b, 2015). The NSW government's own HIV, hepatitis B and C Strategies identify stigma, shame and discrimination as barriers to effective prevention, testing and care (NSW Ministry of Health, 2014a, 2014b, 2015). The proposed Bill is incompatible with the Strategies' aim to reduce stigma and discrimination associated with these viruses, counter misunderstandings about prevention and transmission and improve the quality of life of all people at risk of and affected by bloodborne viruses.

Based on our experience working with communities affected by bloodborne viruses, we believe this Bill is incompatible with the rights- and evidence-based response to HIV, hepatitis B and C in New South Wales and we urge you to withdraw it. We would be happy to further discuss our submission or provide extra information, if that would assist the Committee in its deliberations.

Regards

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