Submission
No 15

INQUIRY INTO MANDATORY DISEASE TESTING BILL 2020

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Date Received:	18 December 2020

Submission to the Inquiry into Mandatory Disease Testing Bill 2020

Standing Committee on Law and Justice

Legislative Council, Parliament of New South Wales

Our background and expertise

We are a group of senior academics and practitioners from diverse backgrounds. Collectively we have expertise in law, public health and sociology, in issues of injecting drug use, blood-borne viruses, stigma, discrimination and social policy, and have collectively authored many books, articles and reports on areas of direct relevance to this Inquiry and to the proposed Bill. Our affiliations and expertise are detailed below.

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Overall statement

The health and safety of all Australians, including emergency services personnel and other workers, is of paramount importance. However, protecting the health and safety of workers must be balanced with the health and safety of other members of the community, including those who they service, as well as the rights of these other members of the community. These rights include the right to privacy, the right to bodily integrity and autonomy, and other basic interests linked to health and wellbeing, such as the importance of being protected from stigma and discrimination. In addition, limitations to rights should only be contemplated where there are clear public policy grounds for doing so, and – in accordance with accepted legal principles – where such limitations are proportionate, necessary and the least restrictive means available to achieve the stated goals.

The current Bill does not balance these issues appropriately. First and foremost, this Bill does nothing to protect workers from occupational exposure to blood-borne viruses, but seems to instead focus on protecting workers from stress and worry while they wait for test results. It may fail to achieve this though, including by subjecting them to a potentially unnecessary legal process. The rights violations of others (called 'third parties' in the Bill) do not appear to be necessary for this end given Australia/Victoria already has very good systems in place for preventing occupational exposure (including broad-based HBV vaccination among healthcare workers and universal precautions) and managing potential exposures (e.g. ready availability of post-exposure prophylaxis for HIV). In a related sense, the Bill fails to recognise that existing jurisdictional and national guidelines already set out best practice for minimising the transmission risk of occupational exposures. The Bill also violates several fundamental rights and interests of community members, and does so in the absence of clear and justifiable public policy and/or public health rationales. Introducing a new law to achieve limited ends, as is the case here, is also disproportionate and unnecessary.

For these and other reasons we express our strong opposition to the Bill. In particular:

- Public health and public policy rationales for the proposed measures are insufficient;
- Problems will be generated rather than solved;
- Unclear and imprecise criteria are used, resulting in unpredictability and injustice;
- Inconsistent standards of proof and tests are used, thus introducing the possibility of inconsistency and unjust effects;
- Powers are inappropriately delegated and people without sufficient expertise will make consequential decisions;
- Procedural fairness requirements have not been met;
- Public health efforts regarding blood-borne viruses will be undermined;
- Individual privacy rights are unjustifiably breached and data sharing processes are flawed;
- The privilege against self-incrimination and future liabilities are not properly protected;

- Sanctions are too severe and will create new problems; and
- Monitoring and reviewing processes are inadequate.

We explain these issues in more detail in the sections that follow. We also highlight safeguards that are missing from the current Bill.

Overall, the Bill should not proceed. If the Committee recommends the Bill to Parliament, the various flaws highlighted here should be attended to as a bare minimum, and important omissions identified below should be addressed.

Public health and public policy rationales for the proposed measures are insufficient

The Bill is premised on the potential for some workers to be occupationally exposed to blood-borne viruses if they come into contact with body fluids of members of the community (referred to throughout the Bill as 'third parties') and the assumption that extraordinary measures are needed to ascertain whether transmission has occurred. These measures include mandatory testing of these third parties, the use of reasonable force to assist with testing, and the curtailing of various basic rights. Regarding those rights, the Bill envisages what has been described elsewhere as 'a fundamental shift in the rights of individuals to privacy, to the integrity of their own bodies, and a fundamental change to Australian policy which generally requires consent for HIV testing'.[1]

The general position in Australian law is that informed consent is required for any medical procedure, subject to a small number of exceptions (see for example *Rogers v Whitaker* (1992) 175 CLR 479). In general terms, these exceptions have a strong public policy basis, as where, for instance, an adult is unconscious and requires emergency treatment as a matter of necessity, and that treatment is reasonable in the circumstances. Many of the most ardent proponents of mandatory testing acknowledge that the requirement for informed consent should only be waived in exceptional circumstances such as these, and on strong public policy (including public health) grounds. Such grounds do not exist in the present case.

In its current form, the Bill will not result in a reduction of exposure risk to any worker covered by it. A range of state and national procedures and guidelines already exist that detail best practice in the management of occupational exposures to bodily fluids, which centre on assessing and minimising the risk of transmission. These procedures and guidelines support workplaces to assess whether occasions of 'contact with bodily fluids' constitute actual exposure, categorise the level of risk of the exposure, and detail management of the contact. Importantly, they consider management of the exposure in the instance that test results of the 'third party' are unknown. While these guidelines focus on healthcare workers, the principles of risk assessment and exposure management do not differ in other settings.[2]

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[1] Bambridge, C. & Stardust, Z. (2018) *Mandatory testing of people whose bodily fluids come into contact with police and/or emergency service personnel.* Sydney. Sydney: ACON at p1.

[2] See, for example: National Health and Medical Research Council (2019) *Australian Guidelines for the Prevention and Control of Infection in Healthcare.* Canberra: Commonwealth of Australia; Health Protection NSW. (2017) *HIV, Hepatitis B and Hepatitis C – Management of Health Care Workers Potentially Exposed.* Policy Directive, NSW Government; Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (2016). *National guidelines for post-exposure prophylaxis after non-occupational and occupational exposure to HIV*; Communicable Diseases Network of Australia. (2019) *Australian National Guidelines for the*

This Bill allows for workers who come into 'contact with the bodily fluids' of a third party to seek a testing order for the third party. A key concern here is that 'contact' is the threshold for the initiation of a testing order. The bill fails to define 'come into contact with', thus enabling an extremely broad interpretation. Equally, the Bill refers to a standard dictionary definition of bodily fluid. Blood-borne viruses are only contained in transmissible quantities in certain bodily fluids. For example, blood-borne viruses are not typically transmitted through contact with saliva or urine. Blood-borne viruses are transmitted when blood containing virus enters another person's bloodstream. Contact with saliva or urine is not a risk factor for transmission unless there are visible quantities of blood present and the exposed skin or mucosa is broken or damaged. The use of the term 'bodily fluid' is one of many examples of poor drafting and inconsistency, enabling wide interpretation, and likely perpetuating misinformation about blood-borne virus transmission and overestimation of risk.

While a small risk of HIV transmission exists following occupational exposure in healthcare settings, this low risk is essentially confined to needlestick or sharps injury involving parenteral transfer of blood containing HIV virus. On these issues, we recommend to the Committee a position paper produced by Bambridge and Stardust in 2018,[3] including in particular their summary of problematic assumptions about transmission risks, transmission routes and window periods for transmission and their reference to the relevant peer-reviewed literature. When read alongside the Bill, a clear picture emerges in which the Bill proposes a set of extraordinary measures and rights curtailments that are disproportionate to the problems it purports to address.

Of course, as we noted earlier, the health and safety of all workers is of great significance. We do not wish to minimise or dismiss the importance of maintaining safety and protecting workers.

Extraordinary limitations other citizens' rights must be allowed in only exceptional circumstances. This does not include situations where the risk of transmission of a blood-borne virus is negligible or hypothetical.

Problems will be generated rather than solved

A central assumption of the Bill appears to be that testing the third party would lessen the anxiety of workers[4] and give 'peace of mind' to workers who have been potentially exposed. Several observations can be made about this assumption:

- Although it is possible that some workers will feel peace of mind as a result of knowing the serostatus of the third party, this is not a sufficient public policy basis to justify the extraordinary measures established via the Bill including limitations on fundamental rights such as informed consent and privacy;
- Contrary to professional healthcare guidance, the Bill provides no account of what constitutes risk of exposure and instead assumes all bodily fluids are a risk in all circumstances;

Management of Healthcare Workers Living with Blood Borne Viruses and Healthcare Workers who Perform Exposure Prone Procedures at Risk of Exposure to Blood Borne Viruses. Australian Government Department of Health.

[3] Bambridge, C. & Stardust, Z. (2018) *Mandatory testing of people whose bodily fluids come into contact with police and/or emergency service personnel.* Sydney. Sydney: ACON at p2, 8.

[4] See, for example, Department of Communities and Justice (2020). Mandatory disease testing for those who attack frontline workers, press release, 6 November.

- The processes set forth in this Bill regarding the initiation of a testing order do not accord with the object of this Bill 'to protect and promote the health and wellbeing of health, emergency and public sector workers to whom this Act applies.' Any person who sustains an occupational exposure should be directed to appropriate clinical and support mechanisms for the immediate management of the incident. This includes immediate assessment of the level of risk and commencement, where relevant, of HIV post-exposure prophylaxis (PEP) treatment.[5] The national HIV PEP guidelines recommend that in the event of an occupational exposure where the HIV status of the source is unknown and there is other evidence available to indicate risk for HIV, that prophylactic treatments be commenced immediately. This Bill may create a false sense that mandatory testing, and the unknown timeline for the availability of the test results, would change the management of the incident;

- Further, the test results of a third party, if those results are negative, do not rule out risk of transmission in the event of an actual exposure. Currently available tests cannot detect recently acquired infection, so third party false negative test results are possible. Guidelines for the management of occupational exposures recommend that exposed workers are themselves tested to preclude the possibility of infection;

- It is possible that the measures in the Bill will create new stressors for workers, by falsely indicating that their work places them at an elevated risk and requiring them to go through an onerous medico-legal process, including potential court action, in circumstances that may ultimately be of little relevance to determining whether or not they have acquired a blood-borne virus; and

- The Bill is 'uniformly focused on the rights and health of the person who has come into contact with bodily fluids, not the person being tested'.[6] Little consideration appears to have been given to the possibility that the Bill will generate or exacerbate harms for third parties, including by producing stress and uncertainty, especially for those who may be going into the process unaware of their own serostatus. No provision exists in the Bill for pre- or post-test counselling for third parties, aspects of which would be considered best practice under national testing policies such as the *National hepatitis C testing policy, 2020*. These effects are equally important, real and foreseeable, and should be taken into account by the Committee. At a bare minimum, and only in the event that the Bill goes forward, the provision of such counselling should be a requirement.

The Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) has produced advice for emergency services providers and blood-borne viruses.[7] The advice contains information on transmission, and acknowledges that the risk of occupational transmission of blood-borne diseases is very low in many instances. Personal protective measures are recommended, and other risk assessment and management strategies are outlined. We recommend that advice and guidelines such as these should

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[5] See: Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (2016). *National guidelines for post-exposure prophylaxis after non-occupational and occupational exposure to HIV*.

[6] Cameron, S. (2019). *The System is Broken: Audit of Australia's Mandatory Disease Testing Laws to Test for HIV, HIV Justice Network and the National Association of People with HIV Australia*, at p4.

[7] ASHM (2012). *Emergency Service Providers and Blood-Borne Viruses*, accessed 08/12/20 www.ashm.org.au. See also: *Australian National Guidelines for the Management of Healthcare Workers Living with Blood Borne Viruses and Healthcare Workers who Perform Exposure Prone Procedures at Risk of Exposure to Blood Borne Viruses (2018)* (National Guidelines).

be prioritised as a means of avoiding occupational exposure and that these should be prioritised as the least restrictive means of achieving the objectives of the current Bill.

The Bill will generate new problems and is unlikely to solve the problems it purports to. If necessary, other less restrictive measures such as education of workers about the negligible level of risk should be prioritised as a means of reducing any anxiety they may feel about the unlikely possibility of transmission. These measures can and should be prioritised over mandatory and/or criminal justice responses.

Unclear and imprecise criteria are used, resulting in unpredictability and injustice

Key aspects of the process for deciding whether an order is warranted are unclear, introducing various procedural and legal risks.

Section 9 of the Bill sets out the mechanism for applying for a mandatory testing order. It includes a requirement for a statement from the affected worker that in their opinion the contact with the third party's bodily fluids was as a result of a 'deliberate action'. There are several problems with this requirement:

- The Bill provides for workers who come into 'contact with the bodily fluids' of a third party to seek an order. Here, 'contact' is the threshold for the initiation of a testing order, but the phrase is not defined in the Bill;

- The term 'deliberate action' is also not defined in the Bill. This renders the Bill open to inconsistency, uncertainty and unpredictability. If, for example, a person shouts at a police officer in an emotional context and saliva lands on the police officer's face, does this constitute a deliberate action?;

- Where risk of exposure exists in occupational contexts, this would not be confined to cases involving 'deliberate action', whatever this means. As such, it is unclear why the Bill would utilise this test. To be clear, however, we do not recommend a different test, for the reasons we describe elsewhere in this submission;

- It is unclear whether any basis is required for the worker's belief that a 'deliberate action' has occurred and, if so, what this basis is. The Bill only requires that the worker be of the 'opinion' that it was a deliberate act. This again leaves the Bill open to inconsistent application, and for uncertainty and unpredictability as to when an order would be made.

Some criteria for the making of an order under section 10 are vague. Section 10(5) of the Bill proposes that the senior officer should consider Chief Health Officer-issued guidelines and 'other matters the senior officer considers relevant'. These guidelines are not yet available and it is possible they could introduce new problems or risks.

Regardless, the process outlined in section 10(5) renders the scope of the senior officer's discretion unclear. This lack of clarity creates the potential for inconsistent practice in which senior officers consider vastly different matters 'relevant', leading to unjust outcomes. There is also the possibility, given the lack of precision in drafting and the apparently wide scope of the discretion under 10(5), that decisions will be *ultra vires the Act* and thus be exposed to judicial review.

This is a problem in at least two senses: first, it adds to the general unpredictability of the Bill's operationalisation, and second, it opens up opportunities for discriminatory and stigmatising judgments to be made (which may or may not be considered 'irrelevant considerations' in an administrative law sense). For instance, a scenario is possible where the third party is suspected of having engaged in a deliberate action, and in their defence makes a submission under section 10, noting not only that their action was not deliberate, and that they do not believe themselves to have any blood-borne viruses, making the order unnecessary. They may state that they do not have hepatitis B, C, or HIV and furthermore that they are in a monogamous same-sex relationship where there is no risk of transmission. They might also have had regular tests. The senior officer might nevertheless take the view, based on outdated stereotypes, that men who have sex with men are at heightened risk of HIV. They might therefore consider the third party to be at risk of having a blood-borne virus despite the evidence and take the view that a test is therefore warranted. In speculating on these issues, the senior officer will have: dismissed the third party's evidence, failed to give him an opportunity to respond to the assumptions being made, taken into account arguably irrelevant considerations in an administrative law sense, and potentially unlawfully discriminated against him on the grounds of sexual orientation. The Bill does not protect against any of these events.

At the very least, therefore, the Bill requires much clearer criteria for assessing whether an order is necessary, and for establishing how evidence from workers and third parties will be treated. The potential for stigma and discrimination is real and should be treated as a matter of paramount importance by the Committee as it risks undermining treatment and elimination efforts, as discussed further below. The sanctions for breaching an order also detrimentally impact on already marginalised communities. In all of these respects the Bill risks serious injustices, both for third parties who are the subject of the Bill and for affected workers who seek the benefit of an order.

Justice requires that publics understand with as much confidence as possible how laws will be interpreted and applied and the circumstances in which they may avoid legal consequences for their actions. The law must be as consistent and predictable as possible. As presently drafted, the Bill fails on all counts.

Inconsistent standards of proof and tests are used, thus risking inconsistency and injustice

The Bill does not appear to establish a standard of proof for the making of orders save for the requirement that courts may make orders for vulnerable third parties if it is satisfied 'on the balance of probabilities' (per section 14(2)).

The absence of a standard of proof elsewhere in the Bill means that there is:

- Uncertainty as to the threshold that must be met/surpassed before an order can be made;
- Insufficient guidance to senior officers and delegates about when and how to make orders;
- A high likelihood that orders will be made inconsistently; and

- Strong potential for discrepancies in the making of orders under Parts 3 and 4, with fewer protections for those who are the subject of orders under Part 3 given the absence of any (or an equivalent) standard of proof.

The drafting of the Bill is also confusing and inconsistent at several points relevant to how and when an order might be made. For example: section 10(5) of the Bill says that in determining an application, the senior officer should consider the Chief Health Officer-issued guidelines and 'other matters the senior officer considers relevant', but at section 10(7) a seemingly different test appears, with a suggestion that a mandatory testing order can be made only if it is 'justified in all the circumstances'. The meaning of this is not defined. This imprecision resurfaces in section 11, where it is said that the senior officer can refuse to make a mandatory testing order if 'on other grounds the senior officer considers appropriate in the circumstances'.

So, on one occasion the order can be made if 'justified', but it can be refused if 'appropriate'; in courts it can be made 'on the balance of probabilities', while outside court there is no stated standard of proof.

For the Bill to be workable and just, its processes, standards and tests should be clear, unambiguous and consistent, and there should be a degree of predictability and certainty for applicants and respondents. The Bill fails in these respects.

Powers are inappropriately delegated and people without sufficient expertise will make consequential decisions

Also of concern is the Bill's delegation of authority for important decision-making to 'senior officers', including police inspectors and other senior officers, Secretaries and Commissioners of various government agencies and departments, and any 'person prescribed by the regulations'. The implication is that the only decision to be made by these 'senior officers' is whether or not a mandatory testing order will be applied. In practice, however, the range of decisions to be made by senior officers is likely to be much more extensive. These likely include determinations regarding the reliability and credibility of witnesses (including the third parties themselves), the meaning of the phrase 'deliberate action', and the evaluation of evidence from third parties, such as evidence that seeks to provide a context or explanation for a purportedly 'deliberate action'. These constitute legal evaluations of evidence and are inappropriate for delegation to a non-expert. In many instances these senior officers will also not have been medically trained and will have no reasonable understanding of the exposure risk. It is possible they will make an assessment based on perceptions of the personal characteristics of the individual, potentially reinforcing the considerable stigmatisation and marginalisation these communities experience. As explained elsewhere in this submission, these evaluations are also not subject to appropriate or adequate review rights, and carry other legal risks (leading to potential liabilities in other legal contexts).

Also of note, section 34 indicates that senior officer and Chief Health Officer powers can be further delegated under the regulations – which are not yet drafted. This raises more questions about the qualifications and expertise of those exercising powers under the Bill, and the possibility that such powers will be inappropriately delegated.

In addition, section 8 of the Bill requires workers to consult with a relevant medical practitioner within 24 hours of the contact that is the subject of the potential application. In the definitions section of the Bill, a relevant medical practitioner is defined as:

(a) a medical practitioner with qualifications or experience in blood-borne diseases, or (b) if a medical practitioner with qualifications or experience in blood-borne diseases is not available at the time the worker requires a consultation under section 8—another medical practitioner.

This scope to nominate 'another medical practitioner' is of concern because blood-borne viruses are a specialised area, within which knowledge and practice is rapidly evolving. It is possible that doctors who are inexperienced in blood-borne viruses may overestimate risk and be more likely recommend testing of third parties.

For the Bill to be just, consistent and predictable, the powers conferred under it should only be exercised by people with the necessary expertise to evaluate complex information and risks and to make consequential decisions. The Bill fails on these grounds.

Procedural fairness requirements have not been met

The Bill has several problems that pertain to procedural fairness. The fundamental requirements of procedural fairness mean that a person affected by a decision 'know the case sought to be made against him [sic] and to be given an opportunity of replying to it'.[8]

Section 10 of the Bill contains information relevant to procedural fairness by, for example, requiring the senior officer to give the third party, parent or guardian an opportunity to make submissions and to consider the submissions received. It is not clear, however, whether the third party gets to first know the case against them as part of this process, or the extent of information provided. We do not know whether all relevant documents (such as the worker's statement) will be provided to the third party. If this is to happen, such protections should be clearly enshrined within the statute. If it is not to happen, there is a very real possibility that the Bill fails on procedural fairness grounds.

The second component of procedural fairness, noted above, requires that a person be given the opportunity to reply to the case being made against them. We have major concerns about this requirement. In our view, any opportunity given to the third party to respond should be both *meaningful* and *practicable*. On this test the Bill fails. The Bill envisages that the senior officer will make a decision about an order within 3 business days of receiving the application (per section 10(2)). This 3 day period thus includes: time for the applicant to receive notification that an application concerning them has been made, time for them to obtain legal advice, time for them or their lawyer to prepare submissions and time for the senior officer to weigh up all the evidence before them. This is an extremely short timeframe likely to be unworkable in practice. There is no conceivable health benefit to it being such a short period of time and extending the time is unlikely to significantly impact the experience of anxiety that may conceivably be felt by the worker, especially in the context of potential false results (referred to earlier). If, in the extremely unlikely case that the worker were to have contracted a blood-borne virus by the deliberate act of a third party, then whether they hear of that's persons status within 3 days or 3 weeks will make no difference to the health protocols that would be followed. The worker would still start PEP if deemed necessary. They would still begin antiretroviral treatment at a time that is clinically relevant.

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[8] *Kioa v West* [1985] HCA 81 (1985) 159 CLR 550, 582 (Mason J).

Part 7 of the Bill contains a mechanism for seeking a review of the senior officer's decision. Both the worker and the third party may apply, but both have only 1 business day (after being notified of the decision) to do so. This timeframe is also insufficient, especially for third parties who may need to obtain legal advice and representation and/or draft a submission seeking review. The timeframes specified in Part 7 are grossly inadequate and likely to be unfair to affected parties.

These problems continue when one considers that pursuant to section 23(1), a mandatory testing order continues to have effect pending the process and outcome of the review. In effect, this means that the third party is still required to undergo a test pending the review outcome. Significant rights are therefore at stake, including rights to bodily integrity and autonomy. As such, even more stringent and effective procedural fairness obligations should be implemented.

Section 24 of the Bill sets out a process for determining an application for review of a decision. The determination of an application for review is to be made by the Chief Health Officer. This provision is also flawed on procedural fairness grounds and suffers from many of the same problems as section 10, including a 3 day timeframe for review that must include consideration of material from the senior officer and submissions of the third party, their parent or guardian.

We acknowledge that there is a recognised need in the procedural fairness jurisprudence to *balance efficiency with fairness*. However the balance has not been appropriately struck in the present instance, especially because of the short period the third party has to obtain legal advice and representation. Furthermore, when balancing efficiency with fairness, the seriousness of the decision should be taken into account. The threshold for making a decision needs to be high – given the extraordinary rights curtailments in question – and this threshold has not been satisfied in this instance. In addition, this Bill is likely to impact on a vulnerable population, which is further relevant to the way that the balance is to be struck.

Finally, it is unclear whether any of the information relevant to the application, procedural fairness rights or review rights, will be made available in different languages and whether time to secure the services of any necessary interpreters will be provided. The requirements of procedural fairness also necessitate consideration of how this information will be communicated to participants experiencing cognitive impairment, literacy challenges or other relevant barriers including medical conditions for which they were perhaps being treated at the point of contact with emergency services personnel.

The requirements of procedural fairness are not satisfied and there is a genuine risk that the Bill will be open to legal challenge as a consequence. At the very least, the Bill needs additional safeguards than exist in the present proposal.

Public health efforts regarding blood-borne viruses will be undermined

Hepatitis C elimination

As the Committee will be aware, a new generation of hepatitis C treatment (known as direct-acting antivirals) has emerged in recent years. These drugs have the potential to cure large numbers of Australians living with hepatitis C. The Australian government has added these drugs to the Pharmaceutical Benefits Scheme, at an estimated cost of $3 billion over 5 years[9], and adopted the World Health Organization's ambitious goal to

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[9] Rollins A. (2015). *Hep C cure comes with $3 billion price tag.* Australian Medical Association Online.

eliminate hepatitis C by 2030.[10]
These ambitions are echoed in the *NSW hepatitis C Strategy 2014-2020*[11] which includes a target to increase the number of people accessing treatment by 100%.

Although the advent of a cure is welcome, we must not assume that the availability of such drugs can, on their own, eliminate hepatitis C.[12] Indeed, attempts to greatly increase the number of people accessing treatment and to eliminate hepatitis C may be undermined by other laws, policies and practices, along with stigma and discrimination.[13] Blood-borne viruses such as HIV and hepatitis C are linked to persistent discrimination, social exclusion and stigma.[14] With regards to hepatitis C, a key reason for this is the practical and symbolic association between the virus and the heavily stigmatised practice of injecting drug use. As two authors of this submission have previously explained, 'the illicit status of injecting drug use both reflects and contributes to stigmatisation, as well as contributing to the scale and shape of the epidemic'.[15] Recent Australian research has found that more than half of people with hepatitis C experienced hepatitis C-related stigma in the previous 12 months, and that 10% of health workers believed they had discriminated against people living with hepatitis C.[16] Discrimination and stigma increase social isolation and alienation, impede diagnosis and treatment and have been proven to increase the risk of new infections.[17] Put simply, Australia's substantial investment in eliminating hepatitis C by 2030 risks being undermined if stigma and discrimination are not addressed. It would be jeopardised even further by any processes that actually generate and exacerbate stigma and discrimination.

Recognising these issues, both the national and NSW hepatitis C strategies acknowledge the importance of minimising stigma and discrimination. The *Fifth National hepatitis C Strategy* includes as one of its goals the need to 'eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health'.[18] The strategy includes several 'key areas for action', such as: implementing initiatives in the community and health care settings aimed at minimising stigma and discrimination [area 22]; monitoring laws, policies, stigma and discrimination which impact health-seeking behaviour among priority populations, including people who inject drugs [area 20]; working to ameliorate legal, regulatory and policy barriers to appropriate and evidence-based responses [area 20]; improving surveillance of issues that might affect people living with hepatitis C, including stigma and discrimination [area 33]; and the promotion of research from a range of disciplines to better inform all aspects of the response to hepatitis C in Australia [area 34]. The NSW strategy also acknowledges the role that stigma and discrimination play in shaping hepatitis C transmission and prevention. For instance, in her foreword to the strategy, then Minister for Health Jillian Skinner wrote that:

> we have seen that real and perceived stigma and discrimination toward people with or at risk of

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[10] Australian Department of Health. (2018). *Fifth national hepatitis C strategy 2018-2022.* Canberra: Department of Health; World Health Organization (2016). *Combating hepatitis B and C to reach elimination by 2030.* Geneva: WHO.

[11] NSW Ministry of Health. (2014). *NSW hepatitis C strategy 2014-2020.* North Sydney: NSW Health.

[12] Seear, K., Fraser, S., Farrugia, A. and valentine, k. (In press). Beyond a 'post-cure' world: Sketches for a new futurology of hepatitis C. *International Journal of Drug Policy.*

[13] Seear, K., Fraser, S., Farrugia, A. and valentine, k. (In press). Beyond a 'post-cure' world: Sketches for a new futurology of hepatitis C. *International Journal of Drug Policy.*

[14] Marinho, R.T. and Barreira, D.P. (2013). Hepatitis C, stigma and cure. *World J Gastroenterol.* 19(40): 6703–6709.

[15] Fraser, S. and Seear, K. (2011). *Making disease, making citizens: The politics of hepatitis C.* Aldershot: Ashgate at p2.

[16] Broady, T., et al. (2018). Responding to a national policy need: development of a stigma indicator for bloodborne viruses and sexually transmissible infections'. *Aust N Z J Public Health*, vol. 42, 513-15.

[17] Marinho, R.T. and Barreira, D.P. (2013). Hepatitis C, stigma and cure. *World J Gastroenterol.* 19(40): 6703–6709.

[18] Australian Department of Health. (2018). *Fifth national hepatitis C strategy 2018-2022.* Canberra: Department of Health; World Health Organization (2016). *Combating hepatitis B and C to reach elimination by 2030.* Geneva: WHO.

hepatitis C hampers our efforts to prevent hepatitis C and provide health care.[19]

This Bill risks perpetuating stigma and discrimination, however, by:

- Contributing to a perception among workers that blood-borne viruses are more readily transmissible than they are;

- Contributing to a perception among workers that people living with (or perceived to be living with) blood-borne viruses are deserving of fewer rights, including the fundamental rights of bodily integrity and autonomy. These ideas have potential to inform healthcare practices and further the stigma and discrimination of the kind we have described above;

- Contributing to a perception that blood-borne viruses are more readily transmissible than they are;

- Contributing to a perception among third parties (which may include people who live with blood-borne viruses) that they are less deserving of rights. These ideas have the potential to entrench existing feelings of stigma and reduced self-worth, to impact people's help-seeking practices, and to increase the risk of health problems, new infections and other forms of harm; and

- Positioning people who live with blood-borne viruses as especially dangerous and/or reckless.

HIV elimination

We have similar concerns about the implications of the Bill for public health responses to HIV, and for efforts to eliminate stigma and discrimination in that context. An overarching goal of the *Eighth National HIV Strategy 2018 – 2022* is to achieve virtual elimination of HIV within the lifetime of the strategy.[20] In practice, this means eliminating new HIV transmissions within Australia. Achieving this depends on reducing the number of people in Australia who have undiagnosed HIV so they can commence antiretroviral treatment. Regular use of antiretroviral treatment can supress HIV, eliminating the risk that a person can transmit HIV to others via sexual contact. The *National Strategy* aims to increase the proportion of people with HIV (in all priority populations) who are diagnosed to 95 per cent by 2022.

It is known that HIV-related stigma and discrimination is a major barrier to HIV testing, particularly for migrant populations in Australia.[21] HIV-related stigma reduces people's willingness to test due to fear of being diagnosed with HIV as well as fear of judgement or poor treatment by healthcare workers when

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[19] NSW Ministry of Health. (2014). *NSW hepatitis C strategy 2014-2020*. North Sydney: NSW Health at p3.

[20] Australian Government Department of Health (2018). *Eighth National HIV Strategy 2018-2022*. Canberra: Australian Government Department of Health.

[21] Gray, C., Lobo, R., Narciso, L., Oudih, E., Gunaratnam, P., Thorpe, R., & Crawford, G. (2019). Why i can't, won't or don't test for HIV: insights from Australian migrants born in Sub-Saharan Africa, Southeast Asia and Northeast Asia. *International journal of environmental research and public health*, *16*(6), 1034; Hosseinzadeh, H., Hossain, S. Z., & Bazargan-Hejazi, S. (2012). Perceived stigma and social risk of HIV testing and disclosure among Iranian-Australians living in the Sydney metropolitan area. *Sexual Health*, *9*(2), 171-177.

seeking a test.[22] Policies or practice which have potential to increase HIV-related stigma in the general population or within healthcare settings risk undermining the aims of current National HIV Strategy. The importance of reducing HIV-related stigma is recognised in the *National Strategy*, which has a goal to:

> Reduce by 75 per cent the reported experience of stigma among people with HIV, and expression of stigma, in relation to HIV status.[23]

Australia is recognised as a world leader in HIV prevention, in part due to the success of our approach in which human rights and community-engagement have been viewed as a central plank of the public health response to HIV.[24] Successive national HIV strategies have recognised the importance of avoiding punitive measures given they have potential to enhance stigmatisation of already vulnerable populations and dissuade people from HIV testing and treatment.[25] This Bill has potential to undermine the fundamental approach that Australia has taken to HIV-prevention from the very outset of the epidemic, and reduce our standing as a world leader in HIV prevention.

For the reasons we have already described, the approaches in the Bill are profoundly damaging and harmful, including to the mental health and wellbeing of people living with blood-borne viruses. It means that the Bill is arguably at odds with other national and state strategies, including the elimination strategies, and other strategies to reduce stigma and discrimination for blood-borne viruses more broadly.

It will also be important to give consideration to the possibility that the Bill will further complicate matters by drawing attention and resources away from organisations set up to help support the health and wellbeing of people living with HIV or viral hepatitis, as these organisations will likely be called on repeatedly to provide advice and guidance to potential third parties.

We endorse the concerns of other organisations, such as Hepatitis NSW, which described the Bill as 'futile and stigmatising'[26] and ACON, which describes the Bill as an 'inappropriate criminalisation' of a health issue that will cause harms to affected communities, cost money and add to pressure to a system currently making strong progress in achieving elimination.[27]

The Bill apparently fails to take account of broader state and national agendas, including blood-borne virus elimination agendas. The Bill undermines these important public health efforts and is thus at odds with current public health goals. One of the ways it does this is by generating and exacerbating stigma and discrimination.

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[22] Bolsewicz, K., Vallely, A., Debattista, J., Whittaker, A., & Fitzgerald, L. (2015). Factors impacting HIV testing: a review–perspectives from Australia, Canada, and the UK. *AIDS care*, *27*(5), 570-580.

[23] 23 Australian Government Department of Health (2018). *Eighth National HIV Strategy 2018-2022*. Canberra: Australian Government Department of Health at p17.

[24] Brown, G., O'Donnell, D., Crooks, L., & Lake, R. (2014). Mobilisation, politics, investment and constant adaptation: lessons from the Australian health-promotion response to HIV. *Health Promotion Journal of Australia*, *25*(1), 35-41.

[25] Cameron, S., & Godwin, J. (2014). Barriers to legal and human rights in Australia in the era of HIV treatment as prevention. *AIDS Education and Prevention*, *26*(3), 202-213.

[26] Hepatitis NSW. (2020). Mandatory disease testing a futile and stigmatising exercise.

[27] ACON condemns introduction of mandatory HIV testing laws in NSW. (2020).

Individual privacy rights are unjustifiably breached and data sharing processes are flawed

Recent Australian research underscores the importance of citizens having trust in digital health systems, and documents the effects of reduced trust/confidence in systems.[28] This research emphasises the need to build more trust in such systems, especially for vulnerable populations (e.g. people living with blood-borne viruses), including through the preservation of basic rights such as the right to informed consent. In a related sense, a considerable body of literature outlines the sensitivities for populations who may be affected by this Bill of disclosure of their medical information. For instance, people living with HIV are often incredibly selective about who they tell about their status, and when. Medical disclosure is the source of great anxiety for many.[29] These issues do not appear to have informed drafting of the Bill. The current Bill allows for disclosure of highly sensitive medical information, without due regard to the implications of this for the individuals so affected, or for public health goals more broadly. The Bill may also reduce trust in digital health systems, with a range of adverse consequences for the health of people at risk of or living with blood-borne viruses, people who use drugs and other priority populations (e.g. Indigenous populations, people experiencing homelessness).

Section 21 of the Bill provides for distribution of the results of the blood test. This provides for the results of the third party's test to be distributed to a medical practitioner authorised by the worker to receive the blood test on the worker's behalf. Private and potentially very sensitive medical information pertaining to the third party will be released without their permission to a medical practitioner. This is a fundamental breach of medical privacy that is not justified on public policy grounds.

The Bill does not set out what will happen with the third party's private medical information once it has been provided to the worker's nominated medical practitioner. Presumably, for the whole process to have any meaning, the medical practitioner will be authorised to pass those results on to the worker. This comprises a second and further breach of medical privacy that is also not justified, including on public policy grounds.

Aspects of how this process will work might be detailed in the Chief Health Officer-issued guidelines that are mentioned in the Bill. The adequacy of those guidelines and any protections therein cannot be assessed, however, until those are released. Moreover, if any procedural issues and/or rights protections are deferred to the guidelines rather than the Bill itself, this is an inappropriate delegation of power to the Chief Health Officer. Workers do not appear to have any legal obligation to protect the third party's medical information once it has been conveyed to them, so that such information is devoid of further protections once passed down the line. The Bill thusly fails to protect fundamental privacy rights and introduces grave new risks for third parties.

Importantly, the Bill does not address the intersection between it and the *Public Health Act 2010*, even though these two Acts would overlap in important ways. If a third party tests positive for a blood-borne virus, the *Public Health Act* provides for a mandatory notification process. HIV is notifiable but the third party would not be identified by name. In the case of hepatitis C, however, the third party *would* be

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[28] Newman, C., MacGibbon, J., Smith, A. K. J., Broady, T., Lupton, D., Davis, M., Bear, B., Bath, N., Comensoli, D., Cook, T., Duck-Chong, E., Ellard, J., Kim, J., Rule, J., & Holt, M. (2020). Understanding trust in digital health among communities affected by BBVs and STIs in Australia. Sydney: UNSW Centre for Social Research in Health. http://doi.org/10.26190/5f6d72f17d2b5

[29] See for example: Evangeli, M. and Wroe, A.L. (2017). HIV disclosure anxiety: A systematic review and theoretical synthesis. *AIDS Behaviour.* 21(1): 1-11.

identifiable by name. As such, mandatory testing opens up the possibility of a mandated identifiable notification being made to NSW Health, without the permission or knowledge of the third party. This is another extraordinary rights breach. It also means that the Bill has mandatory consequences in at least two respects: testing, and notification (if positive).

These extraordinary rights breaches matter for several reasons. Among these, they:

- Add further to the sense that people with blood-borne viruses and associated populations (e.g. people who inject drugs, men who have sex with men) are entitled to fewer rights and protections than the general public, thus entrenching stigma and risking further discrimination;

- Pose potentially special risks to people from particular communities, including culturally and linguistically diverse communities who may have additional sensitivities regarding their serostatus and/or concerns about medical privacy; and

- Raise concerns about how sensitive medical data will be shared, including whether data will be shared with other government departments or used for punitive purposes (e.g. in child protection cases, or for the purposes of law enforcement). Even if these data are not used in such a way, the perception that one's private and sensitive medical information can be collected and shared so readily risks undermining public confidence in medical systems, and furthering distrust in healthcare systems at a time that trust is important, including for the purposes of elimination strategies.

If individuals are properly informed about the full range of consequences that may follow mandatory testing, including the notifications process, some may refuse to comply with mandatory testing orders, given anxieties about the overall consequences for them. These fears are predictable and even understandable, given the historic treatment of populations that may be affected by the Bill. These concerns have not been acknowledged in this Bill, however; instead, those who refuse to comply risk criminalisation and imprisonment (discussed further below).

The Bill unjustifiably breaches fundamental individual privacy rights and fails to give proper consideration to the consequences of data sharing that will result from new notifications. These processes further entrench stigmatisation, marginalisation and vulnerability at the exact time that governments have committed to eradicating such problems.

The privilege against self-incrimination and future liabilities are not properly protected

Section 30 of the Bill affords some rights to the third party by limiting the circumstances in which evidence collected under the proposed Act would be admissible in other proceedings. However, the wording may be too narrow to provide adequate protection in all instances.

The Bill states that evidence would not be admissible in proceedings against the third party if it were information given 'for the purposes of an application for a mandatory treatment order or the determination of the application'. Does the protection extend to information collected or produced for the purposes of a review by the Chief Health Officer under Part 7? If not, the protections are insufficient and risk undermining the operation of the entire Act including the review rights ostensibly afforded in Part 7. Further, there are some protections against civil and criminal liability in section 31 but these do not appear to extend to third parties themselves.

Fundamental rights (e.g. against further incrimination or future liability) should not be removed without adequate justification, and they should be consistently afforded across each element of the process. There is no sufficient justification for eroding these rights.

Sanctions are too severe and will create new problems

Under section 17, the failure to comply with an order carries a penalty of 100 penalty units (currently $11,000) or imprisonment for a period of 12 months or both. The financial limb of the penalty is relatively severe when assessed within the hierarchy of offences; it is equivalent for example to penalties for several sex offences under the NSW *Crimes Act 1900*. We strongly oppose criminalisation under the Bill.

Sanctions in the Bill are far too severe, and risk further criminalising and, indeed, imprisoning, populations already likely to be marginalised, stigmatised or vulnerable in some respect (e.g. homeless people who are intoxicated in public, Indigenous or First Nations people).

Monitoring and reviewing processes are inadequate

Writing about the use of coercive public health and human biosecurity laws in Australia generally, David Carter of the Faculty of Law, University of Technology Sydney, has argued that:

> The power wielded by public health officials through the public health Acts is potentially immense, and the use of those powers should be acknowledged, lawful, transparent, auditable and justified.[30]

The Bill fails on this account, including because processes for monitoring and reviewing the Bill are inadequate. Section 12 of the Bill requires a report to the Ombudsman regarding orders made under the Bill, and section 25 requires the Chief Health Officer to report any decisions to the Ombudsman. The Bill requires them to report to the Ombudsman about any determinations made and the 'reasons for the determination'. Beyond this it is not clear whether the:

- Privacy rights of workers and third parties are protected; and
- Ombudsman will receive information on issues such as: how many people are ordered to provide tests and how many occupational exposures or transmissions occur.

If the Ombudsman is to be granted monitoring powers, the Bill should ensure that the Ombudsman has adequate information to assess the operation and effectiveness of mandatory testing orders, any unintended consequences, potentially discriminatory measures, and so on. These matters should be clearly articulated within sections 12, 25 and 35 so as to ensure proper accountability in decision-making.

Section 36 of the Bill stipulates that the Minister is to review the Act to assess whether the problems that it purports to respond to (including occupational transmission) are actually realised and whether the provisions that it puts in place to deal with these purported problems are and remain appropriate.

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[30] Carter, D. (2020). The use of coercive public health and human biosecurity law in Australia: an empirical analysis. *UNSW Law Journal.* 43(1): 117-154, at p.150.

The Act is to be reviewed by the Minister, as opposed to an independent office or office-holder, and the matters that they are to take into account as part of this review (apart from any reports from the Ombudsman) are not clearly articulated.

Accountability measures are insufficient and the Ombudsman lacks adequate powers for the purposes of monitoring the Bill. If the Bill is to be introduced, these matters ought to be rectified at a minimum.

Conclusion

We thank the Committee for the opportunity to make this submission and for their time and consideration and can be contacted via the corresponding author if any further details are required on our submission.

Yours sincerely,

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