

## **Insurance discrimination and hepatitis C: Recent developments and the need for reforms**

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### **Abstract**

Current direct-acting antiviral treatments for hepatitis C have the potential not only to cure the disease but to address the discrimination associated with having the virus. However, obstacles remain to the tackling of discrimination in many areas, including in the insurance industry where many insurers still require (a history of) hepatitis C to be disclosed in insurance applications even where it has been cured. This article considers Australian insurance law and practice in the context of hepatitis C. It proceeds in three parts. First, we analyse the case law on insurance and hepatitis C. Second, we examine an Australian-first report on insurance discrimination against LGBTIQ+ populations, including people living with another blood-borne virus, HIV. Whilst there has been no equivalent major Australian study on people with (a history of) hepatitis C, this recent work on HIV, combined with the case law surrounding hepatitis C, raises the possibility that insurance practices and actuarial data regarding hepatitis C are now outdated. We conclude in the third part with a consideration of proposed reforms to insurance discrimination in the Australian Capital Territory and potential law and policy reforms throughout Australia. We argue that assumptions about the risks associated with hepatitis C need to be reconceptualised since the advent of direct-acting antiviral treatments in order to avoid unreasonable discrimination against people with (a history of) the virus.

### **Introduction**

Hepatitis C is a blood-borne virus associated with a range of serious health problems if left untreated, including cirrhosis of the liver and cancer.<sup>5</sup> In recent years, hepatitis C has become more readily curable through the advent of highly effective and tolerable drugs,

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<sup>5</sup> Daniel Webster, Paul Klenerman and Geoffrey Dusheiko, 'Hepatitis C' (2015) 385 (9973) *Lancet*.

known as direct-acting antivirals. Compared to previous regimens, direct-acting antivirals have a relatively high success rate,<sup>6</sup> though patients cured of hepatitis C may still have liver damage like cirrhosis, be at higher risk of liver cancer, and could acquire hepatitis C again.<sup>7</sup> Whilst there have been issues accessing these treatments via health insurers in some other countries, most notably the United States,<sup>8</sup> the Australian Government has listed these drugs on the Pharmaceutical Benefits Scheme since 2016,<sup>9</sup> promising access for all with no restrictions according to disease stage, treatment history or drug use status.<sup>10</sup> This has resulted in almost 90,000 people being treated with these highly curative therapies.<sup>11</sup>

Notably, however, hepatitis C is linked to persistent discrimination, social exclusion and stigma.<sup>12</sup> In part, this is because hepatitis C is commonly linked to injecting drug use. A 2001 report by the Anti-Discrimination Board of New South Wales found that 'hepatitis C related discrimination takes many forms and occurs in many areas of public life.'<sup>13</sup> A later 2004 report by the Australian Senate Community Affairs References Committee found that:

*Hepatitis C discrimination is well documented and has a profound impact on affected individuals. Hepatitis C sufferers have reported discrimination in employment, education, health care, accommodation and insurance. The discrimination is often so*

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<sup>6</sup> European Association for the Study of the Liver, 'EASL recommendations on treatment of hepatitis C 2018' (2018) 69(2) *Journal of Hepatology*; Max Hopwood and Carla Treloar, 'Pretreatment preparation and management of interferon-based therapy for hepatitis C virus infection' (2007) 59(3) *Journal of Advanced Nursing*.

<sup>7</sup> See, e.g., Oluwaseun Falade-Nwulia et al, 'Understanding and addressing hepatitis C reinfection in the oral direct-acting antiviral era' (2018) 25(3) *Journal of Viral Hepatitis*.

<sup>8</sup> Vincent Re et al, 'Disparities in absolute denial of modern hepatitis C therapy by type of insurance' (2016) 14(7) *Clinical Gastroenterology and Hepatology*; Soumitri Barua et al, 'Restrictions for Medicaid reimbursement of sofosbuvir in the treatment of hepatitis C virus infection in the United States' (2015) 163 *Annals of Internal Medicine*; Lauren Canary, Monina Klevens and Scott Holmberg, 'Limited access to new hepatitis C treatment under state Medicaid programs' (2015) 163 *Annals of Internal Medicine*.

<sup>9</sup> Joseph Doyle et al, 'Treatment access is only the first step in hepatitis C elimination: Experience of universal antiviral treatment access in Australia' (2019) 49(9) *Alimentary Pharmacology and Therapeutics*.

<sup>10</sup> Australian Department of Health, *Fifth National Hepatitis C Strategy 2018-2022* (2018).

<sup>11</sup> Kirby Institute, *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia Annual Surveillance Report 2021: Hepatitis C* (2021).

<sup>12</sup> Rui Marinho and David Barriera, 'Hepatitis C, stigma and cure' (2013) 19(40) *World Journal of Gastroenterology*.

<sup>13</sup> Anti-Discrimination Board of New South Wales, *C-Change: Report of the Enquiry into Hepatitis C Related Discrimination* (2001) 12.

*distressing that people with hepatitis C have chosen to keep their health status private.*<sup>14</sup>

The report further noted that ‘witnesses stated that they had been unable to obtain travel insurance, loss of income insurance or life insurance because of their hepatitis C.’<sup>15</sup> These reports provided important insights into experiences of discrimination and the contexts within which such discrimination was experienced. Crucially, however, the reports were published before the advent of direct-acting antivirals, and thus before cure became a widespread and predictable proposition for Australians living with hepatitis C. In recent work, we argued for the need to better understand the practices and rationales of insurance companies in this changing environment, and to consider whether updates to existing guidelines on insurance are necessary.<sup>16</sup>

In this article, we examine Australian insurance law and practices in the context of hepatitis C and the advent of direct-acting antivirals. Given Australia offers universal access to this treatment under its Pharmaceutical Benefits Scheme, our focus is not on access to hepatitis C treatment under insurance schemes, but rather on access to insurance coverage for people with (a history of) hepatitis C. In the first part, we consider these issues in the context of relevant case law and, in the second, in the context of a recent report on a related area, insurance discrimination against LGBTIQ+ populations including people living with blood-borne viruses. To conclude, we argue that insurers must keep up to date with developments in hepatitis C healthcare, and that outdated assumptions about the risk posed by the virus are leading to unreasonable discrimination against people with (a history of) hepatitis C. As we will argue, given it has now been six years since direct-acting antiviral treatments became universally available in Australia, insurance practices are lagging and in need of reform, with the risks associated with hepatitis C requiring urgent reconceptualisation.

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<sup>14</sup> Australian Senate Community Affairs References Committee, *Hepatitis C and the Blood Supply in Australia* (2004) 59.

<sup>15</sup> Australian Senate Community Affairs References Committee, *Hepatitis C and the Blood Supply in Australia* (2004) 62.

<sup>16</sup> Kate Seear et al, ‘Beyond a “post-cure” world: Sketches for a new futurology of hepatitis C’ (2021) 94 *International Journal of Drug Policy*; Kate Seear et al, ‘Echoes and antibodies: Legal veridiction and the emergence of the perpetual hepatitis C subject’ (forthcoming) *Social and Legal Studies*.

## Insurance law and the duty of disclosure

No data are available on levels of and access to private health insurance among people in Australia living with hepatitis C. Data from the United States indicate that people with hepatitis C are less likely to have private health insurance than individuals without hepatitis C, and that ‘HCV infection was an independent predictor of being uninsured even after adjustment for demographic disparity of the HCV+ cohort.’<sup>17</sup> Furthermore, many people with hepatitis C inject drugs, which is also likely to affect health insurance coverage.<sup>18</sup> Finally, people with hepatitis C are a diverse cohort, but many are likely to be impacted by disadvantages of various kinds, including criminalisation and discrimination related to intravenous drugs use, which may impact their ability to afford private health insurance. We acknowledge that given the considerable socio-economic disadvantage of populations affected by hepatitis C, purchasing insurance might not be a possibility for many affected people.<sup>19</sup> Our point here, in any event, is that they should still have available to them properly informed and reasonable assessments and products should they wish or need to do so. A lack of insurance coverage matters for several reasons, including because it may create barriers to accessing healthcare.

Until reforms in 2021, Australian insurance law required that those who are – or are to be – insured (‘insureds’) disclose any matter that is material to the nature and extent of the insurance cover to be provided, and enabled the insurer to void the contract if there was a failure to disclose.<sup>20</sup> Insurers were – and still are – granted exceptions to discriminate under Australian discrimination law, but such discrimination must be reasonable in the

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<sup>17</sup> Maria Stepanova, ‘Insurance status and treatment candidacy of hepatitis C patients: Analysis of population-based data from the United States’ (2011) 53 *Hepatology* 737. See also Janus Ong et al, ‘High rates of uninsured among HCV-positive individuals’ (2005) 39(9) *Journal of Clinical Gastroenterology*.

<sup>18</sup> Christine Tindal, Kay Cook and Nena Foster, ‘Theorising stigma and the experiences of injecting drugs users in Australia’ (2010) 16 *Australian Journal of Primary Health* 123.

<sup>19</sup> Notably, United States research has found that people with hepatitis C are less to have a higher education and those without a higher education are even less likely to have private health insurance: Maria Stepanova, ‘Insurance status and treatment candidacy of hepatitis C patients: Analysis of population-based data from the United States’ (2011) 53 *Hepatology* 740-742. We should, however, note that other United States studies suggest that income is not associated with insurance status amongst people with hepatitis C: Janus Ong et al, ‘High rates of uninsured among HCV-positive individuals’ (2005) 39(9) *Journal of Clinical Gastroenterology*. There is no Australian data on the rates and causes of underinsurance of people with hepatitis C.

<sup>20</sup> *Insurance Contracts Act 1984* pt IV, as amended by *Financial Sector Reform (Hayne Royal Commission Response) Act 2020* sch 2.

circumstances and have regard to reasonably reliable actuarial or statistical data.<sup>21</sup> These obligations raise important questions for people with (a history of) hepatitis C: are they still required to disclose their past hepatitis C status; is a history of hepatitis C material to the nature and extent of insurance that might be provided; and might it be reasonable to discriminate against people who have or once had hepatitis C? These questions have not yet been answered in depth in Australia, and there are no publicly available industry-wide guidelines on how the advent of direct-acting antivirals relates to the duty of disclosure or the subsequent actions of insurers.

Some insights can be gleaned from examining the practices of insurance companies and from community organisations. Community organisation Hepatitis Australia advises people who have or previously had hepatitis C that ‘you may need to tell your insurer that you have [...] hepatitis C if your health may impact their decision or the terms and conditions of insuring you’ and that ‘if you don’t tell them, they can void your contract if you need to make a claim.’<sup>22</sup> Insurance questionnaires are rarely publicly available, and we were unable to locate this information despite an extensive search. One hepatitis questionnaire from insurer TAL was available, however, and asks insureds about the cause of their hepatitis C – and then, even if a person declares that they have fully recovered from hepatitis C, asks for information on past dates off work and modifications to duties at work, past complications related to hepatitis C, past treatments, past tests or investigations, and past symptoms.<sup>23</sup> What this suggests is a broader duty to disclose, even if a person has fully recovered from hepatitis C. This could be because hepatitis C can cause lasting liver damage or cancer. Crucially, however, the questions in the TAL questionnaire – the only publicly available insurance questionnaire on hepatitis C – go further than assessing liver symptoms or the risk of liver problems and into broader areas of investigation. In what follows, we consider the impacts of the duty of disclosure on the part of people with (a history of) hepatitis C under case law and then consider the impacts of reforms introduced in 2021 to this duty.

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<sup>21</sup> See, e.g., *Discrimination Act 1991* (ACT) s 28.

<sup>22</sup> Hepatitis Australia, ‘Your rights and responsibilities: Living with hepatitis B or hepatitis C’ <<https://www.hepatitisaustralia.com/Handlers/Download.ashx?IDMF=bd2192bd-7949-4ce4-bf74-b9df586e7b5b>>.

<sup>23</sup> TAL, ‘Life insurance: Hepatitis questionnaire’ <[https://www.myexpand.com.au/\\_doc/eXpand\\_hepatitis/Hepatitis.pdf](https://www.myexpand.com.au/_doc/eXpand_hepatitis/Hepatitis.pdf)>.

In *Stevens v Colonial Mutual Life Assurance Society and Commonwealth Financial Planning*,<sup>24</sup> an insured, Noel Stevens, was diagnosed with hepatitis C and had a history of raised liver function test results, but this had no impact on his day-to-day functioning and capacity to work. When completing an insurance application, he did not disclose having contracted hepatitis C two decades prior. Levy SC DCJ concluded that the insurer was entitled to avoid the policy because of his history of hepatitis C and raised liver function test results. His Honour went on to state:

*I also consider that Mr Stevens' non-disclosure of past Hepatitis C infection had occurred inadvertently without intention to mislead, and occurred as a function of the process by which the proposal was submitted, with limited opportunity for reflection on matters calling for disclosure. The context of that omission was the plaintiff's honestly held belief that he was in excellent health.*

*Unfortunately for Mr Stevens, these non-disclosures must be considered as being material to the nature and extent of the risk sought to be underwritten and that view justified avoidance of the policy.*<sup>25</sup>

A more recent case, *D19-20\027*,<sup>26</sup> concerned an insured who was diagnosed with hepatitis C in 2008 and treated with antiviral medication in hospital over two years. At the end of that period, he was considered hepatitis C negative, and the virus was not detected via pathology tests of his blood samples. Following this, when completing an insurance application, he answered 'no' to a question of whether he ever had symptoms of, been told he had, or received advice of treatment from any health professionals for any form of hepatitis. Upon his death from drug overdose, his spouse lodged a claim with the insurer for payment of the insured's death benefit. The spouse argued that 'Based on all this information, a reasonable person would suspect that they did not have the virus and accordingly [this] was not relevant for disclosure in relation to an insurance policy.' The Tribunal concluded that because the insured had been tested for and diagnosed with

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<sup>24</sup> [2012] NSWDC 94. Appeal dismissed (no appeal from Levy SC DCJ's conclusion that the insurer validly avoided the policy): *Commonwealth Financial Planning v Couper* [2013] NSWCA 444.

<sup>25</sup> *Stevens v Colonial Mutual Life Assurance Society and Commonwealth Financial Planning* [2012] NSWDC 94 [103]-[104].

<sup>26</sup> [2019] SCTA 153 (Death benefit). This case is further discussed in Matthew Daley, Jane Paskin and Vanessa Pallone, 'Sub-optimal disclosure', *SuperFunds* (5 February 2020).

hepatitis C, the pathology lab had notified the Health Department of the positive test result, and the question in the insurance application asked whether the insured had been told he had hepatitis, the insured had made a fraudulent misrepresentation that voided the insurance contract.<sup>27</sup>

Research suggests that non-disclosure may be based on a fear that, even if the virus is cured, the insured will be refused insurance or subject to a higher premium.<sup>28</sup> Indeed, in *D19-20-027*, the insurer argued that had it been known that the insured had a history of hepatitis C, it would not have offered insurance cover on any terms. In the *Stevens* case, the Court found, on appeal, that had the history of hepatitis C been disclosed, there may have been an increased premium or exclusion.<sup>29</sup> Why the Court found this is unclear, but we have previously speculated that this might be based on 'risk-based assessments or predictions about the possibility of future ill-health, including liver disease.'<sup>30</sup> The fact that a person once had hepatitis C may also be the basis for refusing them cover altogether.

In summary, the case law suggests that even inadvertent and unintentional non-disclosure of a history of hepatitis C in an insurance application can be deemed to be material to the nature and extent of the risk to be underwritten, and effectively voids insurance contracts. However, this approach may change following recent reforms to replace the duty of disclosure with a duty to take reasonable care not to make a misrepresentation.<sup>31</sup> Critiques of the former duty of disclosure argued that it effectively 'requires someone who is applying for insurance cover to have the knowledge of a life insurance underwriter. The person might know what medical conditions they've suffered from but [it] is an entirely different question as to whether those medical conditions are relevant.'<sup>32</sup> It is argued that the new duty to take reasonable care not to make a misrepresentation could require insurers to 'ask specific questions about matters necessary for them to assess risk and not ask questions

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<sup>27</sup> *D19-20\027* [2019] SCTA 153 (Death benefit) [65].

<sup>28</sup> Kate Seear et al, 'Echoes and antibodies: Legal veridiction and the emergence of the perpetual hepatitis C subject' (forthcoming) *Social and Legal Studies*.

<sup>29</sup> *Commonwealth Financial Planning v Couper* [2013] NSWCA 444.

<sup>30</sup> Kate Seear et al, 'Echoes and antibodies: Legal veridiction and the emergence of the perpetual hepatitis C subject' (forthcoming) *Social and Legal Studies*.

<sup>31</sup> *Financial Sector Reform (Hayne Royal Commission Response) Act 2020* sch 2, amending *Insurance Contracts Act 1984* pt IV.

<sup>32</sup> John Berrill, 'Life insurance: Non-disclosure breaches and the royal commission', *Investment Magazine* (5 June 2019).

open to interpretation or “catch all” questions.’<sup>33</sup> For example, an insurer might ask specific questions about liver problems rather than broad questions about (a history of) hepatitis C. However, the insurer may still avoid the contract if the insured breaches their duty to take reasonable care not to make a misrepresentation.<sup>34</sup>

The Australian Financial Complaints Authority provides guidance on its approach to complaints from consumers when an insurer denies a claim on the basis of non-disclosure or misrepresentation.<sup>35</sup> The Authority advises that it considers if the consumer was in a vulnerable situation, though their examples of vulnerability point to the consumer’s inability to comprehend the language of the insurance questionnaire, and it is unclear whether (a history of) hepatitis C would be classified as a vulnerability. Insurer IOOF provides some guidance on what to do if a client does not disclose hepatitis C on an insurance policy that has been in place.<sup>36</sup> IOOF suggests that the client should notify their insurer that they failed to disclose their hepatitis C, and that the insurer should void the policy and give a full refund of all premiums paid. IOOF further notes that a client with hepatitis C will be likely to pay a significant loading if seeking cover from another insurer. This does little to ameliorate the fear of disclosure, as it will still likely subject a person with a history of hepatitis C to a higher loading or a voided contract due to the assumed risk associated with a history of the virus. In the following section, we consider how discrimination law might address this issue.

### **Discrimination law and actuarial and statistical data**

Australian discrimination law allows insurers to discriminate but requires that any discrimination be reasonable in the circumstances and have regard to reasonably reliable actuarial or statistical data.<sup>37</sup> Actuarial data are, broadly speaking, the statistics used by insurers to make risk assessments. According to available guidance from the Australian Human Rights Commission, the following matters are relevant to determining whether it is

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<sup>33</sup> John Berrill, ‘Life insurance: Non-disclosure breaches and the royal commission’, *Investment Magazine* (5 June 2019).

<sup>34</sup> *Insurance Contracts Act 1984* s 29.

<sup>35</sup> Australian Financial Complaints Authority, ‘The AFCA approach to non-disclosure and misrepresentation’ <<https://www.afca.org.au/sites/default/files/2020-07/AFCA%20Approach%20-%20Non-disclosure%20and%20misrepresentation.pdf>>.

<sup>36</sup> IOOF, ‘Technical insurance guide’ <<https://silo.tips/download/ioof-techconnect-technical-insurance-guide-adviser-use-only>>.

<sup>37</sup> See, e.g., *Disability Discrimination Act 1992* (Cth) s 46.



reasonable to rely on data: data must be up to date;<sup>38</sup> data should preferably be from an Australian source;<sup>39</sup> underwriting manuals with detailed information regarding the nature and degree of risk associated with insureds with a particular condition may be relied upon insofar as the manuals themselves are based on relevant and up to date actuarial or statistical data;<sup>40</sup> and any other relevant data must also be considered.<sup>41</sup>

A recent report by the Victorian Pride Lobby – a community-based advocacy group that works to advance the rights of lesbian, gay, bisexual and same-gender attracted people in the state of Victoria – examined insurance discrimination against LGBTIQ+ people, including people living with HIV. The report found that ‘it is difficult to tell whether insurance companies have updated their policies around HIV since the advent of new treatment’ and, despite calls from peer organisations for underwriting policies to be based on up-to-date scientific information, ‘reinsurers will generally only revisit actuarial data every decade or when new treatments arise.’<sup>42</sup> The report also found that questions about HIV status, sexual practices and risks were not always asked in a sensitive manner – with some insurers asking invasive questions about sexual activities, monogamy, sex work, injecting drug use, and sexual partners – and that the process of asking such questions could be off-putting and even distressing, reproducing HIV-related stigma.<sup>43</sup> The stigmatising questioning process may increase the likelihood that people with HIV will not disclose their status, which puts them at risk of losing coverage (for the same reasons we discussed above, the same may apply in the context of hepatitis C). The report recommended that questions about HIV be asked in a sensitive manner, and that insurers review their actuarial or statistical data in line with current medical advice to enable any exclusions or increased pricing to be as minimal as possible.<sup>44</sup> In response to the report, the Insurance Council of Australia’s Chief Executive Officer, Andrew Hall, stated:

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<sup>38</sup> *Xiros v Fortis Life Assurance* [2001] FMCA 15.

<sup>39</sup> *Kors v AMP Society* [1998] QADT 23.

<sup>40</sup> Australian Human Rights Commission, *Guidelines for Providers of Insurance and Superannuation under the Disability Discrimination Act 1992 (Cth)* (2016) 9-10.

<sup>41</sup> Australian Human Rights Commission, *Guidelines for Providers of Insurance and Superannuation under the Disability Discrimination Act 1992 (Cth)* (2016) 7.

<sup>42</sup> Victorian Pride Lobby, *Worth the Risk: LGBTIQ+ Experiences with Insurance Providers* (2022) 19.

<sup>43</sup> Victorian Pride Lobby, *Worth the Risk: LGBTIQ+ Experiences with Insurance Providers* (2022) 16-17.

<sup>44</sup> Victorian Pride Lobby, *Worth the Risk: LGBTIQ+ Experiences with Insurance Providers* (2022) 17-19.

*I think areas like HIV need to be reconsidered. I think we need to look at them very carefully because it's clearly now a chronic disease, and perhaps some of these areas haven't been updated for a number of years. And I think it's something that insurers should take a look at.*<sup>45</sup>

Although dealing with a discrete set of issues and a different blood-borne virus, the research conducted by the Victorian Pride Lobby is instructive as it suggests that insurance practices can lag well behind medical and scientific developments, and that insurance practices may not be updated for many years. Antiretroviral treatments for HIV have been available since 1996 – well before the advent of direct-acting antivirals for hepatitis C. Whilst there has been no equivalent major Australian study on people with (a history of) hepatitis C, in our recent research on legal issues pertaining to hepatitis C, we conducted interviews with stakeholders, including lawyers, policymakers and drug-user organisation representatives.<sup>46</sup> Several interviewees raised concerns about insurance discrimination, ranging from denial of coverage to heavy premiums even for people that have undergone treatment. These issues – and the recurrence of them in the interviews – suggest concerns about the practices of insurers on the part of key stakeholders and a need for much more work in this area. The issues also suggest the possibility that actuarial and statistical data devised in a pre-cure era of hepatitis C are even further out of date than data used in risk assessments for people affected by HIV, which could be because antiviral treatments for hepatitis C are comparatively recent (even though these treatments go even further than those for HIV, in that they are curative) or because there is less attention on insurance access for people with (a history of) hepatitis C.

Moreover, the case law we noted above suggests that insurance practices regarding hepatitis C may require revision given the stigma attached to disclosing hepatitis C. It should also be considered whether disclosure of a history of hepatitis C is in fact necessary for making assessments of risk after someone has been treated with direct-acting antiviral treatments or whether, as discussed above, insurance questionnaires should ask more

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<sup>45</sup> Rhiana Whitson, 'One in two LGBTQIA+ people report discrimination or exclusion in insurance', *ABC News* (9 June 2022) <<https://www.abc.net.au/news/2022-06-09/lgbtqia-people-report-discrimination-from-insurance-industry/101128494>>.

<sup>46</sup> Kate Seear et al, 'Echoes and antibodies: Legal veridiction and the emergence of the perpetual hepatitis C subject' (forthcoming) *Social and Legal Studies*.

specific questions about liver problems rather than potentially assuming a correlation between (a history of) hepatitis C and liver damage or cancer. Some insurers may have updated their underwriting guidelines since the advent of direct-acting antiviral treatments, but information on this is hard to find through public searches and, therefore, lacking in transparency. We also made multiple direct inquiries with insurers to share their underwriting guidelines publicly to no avail. Furthermore, there are not (and never have been, as far as we are aware) industry-wide, publicly available guidelines on insurance for people with (a history of) hepatitis C since the advent of curative treatments, unlike that for HIV.<sup>47</sup> Some insurers may still have excessive waiting periods in place post-treatment. For those that have not updated their underwriting guidelines, it could be that the collation of up-to-date actuarial data on viruses such as hepatitis C is considered a low priority in comparison to other areas where there are more claims. This means that reinsurers (that is, companies that provide financial protection to insurance companies) are less likely to update their guidelines even with the advent of more reliably curative treatments. Access to data and the accompanying underwriting guidelines is essential to assess whether insurance practices reflect current medical understandings of the risks associated with (a history of) hepatitis C. A lack of transparency and clarity creates concerns about these practices and their legitimacy and may dissuade people with (a history of) hepatitis C from purchasing insurance products.

In any event, direct-acting antiviral treatments clearly necessitate a review of the risks associated with hepatitis C. As our previous research has noted, despite the availability of treatment there remains a misconception that chronic infection automatically equals cirrhosis and liver failure.<sup>48</sup> These misconceptions around the assumed risks of the virus can lead to ongoing and unreasonable discrimination against people with (a history of) hepatitis C. However, the Anti-Discrimination Board of New South Wales has held that ‘there is no justification for refusing to insure people on the basis of their hepatitis C antibody status’ as people who are otherwise hepatitis C negative are not at risk of symptoms associated with

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<sup>47</sup> Financial Services Council, ‘HIV/AIDS underwriting guidelines’ <<https://www.fsc.org.au/web-page-resources/fsc-guidance-notes?limit=20&limitstart=20>>.

<sup>48</sup> Kate Seear et al, ‘Echoes and antibodies: Legal veridiction and the emergence of the perpetual hepatitis C subject’ (forthcoming) *Social and Legal Studies*.

the virus.<sup>49</sup> In the next section, we consider how law reform, including to require justification for insurance discrimination, might address this issue.

### **Law reform on insurance discrimination**

Ongoing discrimination against people with (a history of) hepatitis C may be challenged by proposed new laws in the Australian Capital Territory. The ACT Government has released an exposure draft Discrimination Amendment Bill 2022 as part of its agenda to modernise discrimination law to promote equal opportunity, respect for diversity and social inclusion. If enacted, the Bill would require that insurance discrimination (that is, exceptions that allow insurers to discriminate in the provision of insurance products) be proportionate and justifiable, and that insureds be given access to the actuarial or statistical data upon which any discrimination is based.<sup>50</sup> This would apply to all insureds, not just those with (a history of) hepatitis C. In what follows, we consider these two aspects of the proposed reforms.

#### ***Proportionality and justifiability in insurance discrimination***

The first part of these proposed reforms is a requirement for proportionality and justifiability in insurance discrimination.<sup>51</sup> The ACT Law Reform Advisory Council noted that the current reasonableness test is ‘imprecise’,<sup>52</sup> and recommended a requirement for proportionality and justifiability as this is more consistent with the test in the ACT’s *Human Rights Act 2004* for limiting the right to non-discrimination.<sup>53</sup> According to the ACT Law Reform Advisory Council this would necessitate an assessment of ‘the purpose of the discriminatory conduct and its importance; the nature of the discriminatory conduct; the relationship between the discriminatory conduct and its purpose; and whether there was any less restrictive means reasonably available to achieve the same purpose.’<sup>54</sup>

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<sup>49</sup> Anti-Discrimination Board of New South Wales, *C-Change: Report of the Enquiry into Hepatitis C Related Discrimination* (2001) 80.

<sup>50</sup> Minister for Human Rights (ACT), *Exposure Draft: Discrimination Amendment Bill 2022 (ACT)* (‘Discrimination Amendment Bill 2022 (ACT)’).

<sup>51</sup> Discrimination Amendment Bill 2022 (ACT) cl 7, inserting *Discrimination Act 1991* (ACT) s 28(1).

<sup>52</sup> ACT Law Reform Advisory Council, *Review of the Discrimination Act 1991 (ACT): Final Report* (2015) 118.

<sup>53</sup> *Human Rights Act 2004* (ACT) s 28.

<sup>54</sup> ACT Law Reform Advisory Council, *Review of the Discrimination Act 1991 (ACT): Final Report* (2015) 119.

In short, the proposed test requires a consideration of whether discrimination is *demonstrably* justified and proportionate, placing a higher onus on insurers to demonstrate that discrimination is necessary, having regard to any less restrictive means that are reasonably available and the need and most proportionate means to address any hardship on the part of the insurer. For example, insurers may need to replace blanket exclusions for people affected by specific conditions (such as hepatitis C) with premiums or waiting periods. Even increased premiums and waiting times may not be justifiable, however, given the advent of direct-acting antivirals has reshaped the implications of the virus.

### ***Availability of data in insurance discrimination***

The second part of these reforms includes a requirement for availability of data in insurance discrimination. This would require an insurer, upon request, to do one of the following: give the consumer a document containing the data being relied on by the insurer; make a document containing the data available for inspection at a reasonable time and place; or give the consumer a document containing a meaningful explanation of the data.<sup>55</sup> In explaining these reforms, the ACT Justice and Community Safety Directorate has argued that:

*The complex nature of the insurance industry can create asymmetries of information and power between providers and consumers. An option to address this would be to require insurance or superannuation providers to give the consumer access to the data on which a decision about them is made, upon written request [...] Requiring some transparency may also promote reliance on higher quality data from the outset.*<sup>56</sup>

Some laws require disclosure of data to consumers, but most do not.<sup>57</sup> Various other reviews of insurance discrimination have raised issues with the availability of data. For example, the Public Interest Advocacy Centre found in its recent report on mental health discrimination in insurance that insurers are ‘reluctant to provide detail regarding the data they have relied on.’<sup>58</sup> The Victorian Equal Opportunity and Human Rights Commission

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<sup>55</sup> Discrimination Amendment Bill 2022 (ACT) cl 7, inserting *Discrimination Act 1991* (ACT) s 28(2).

<sup>56</sup> ACT Justice and Community Safety Directorate, *Inclusive, Progressive, Equal: Discrimination Law Reform – Discussion Paper 1: Extending the Protections of Discrimination Law* (2021) 40.

<sup>57</sup> *Sex Discrimination Act 1984* (Cth) s 41(1)(e); *Equal Opportunity Act 1984* (SA) s 89.

<sup>58</sup> Public Interest Advocacy Centre, *Mental Health Discrimination in Insurance* (2021) 68.

similarly noted concerns from advocacy groups about ‘the failures of insurers to provide consumers with access to the statistical and actuarial data relied on in making decisions.’<sup>59</sup> The Australian Law Reform Commission found that ‘the current system offers limited independent oversight of whether insurers are basing decisions on reasonable actuarial or statistical data.’<sup>60</sup> The Tasmanian Anti-Discrimination Commissioner noted that ‘explanations for unfavourable underwriting decisions would create greater transparency and provide avenues for decisions to be contested where appropriate’,<sup>61</sup> and also ‘allow for more informed public debate about discriminatory provisions in insurance products.’<sup>62</sup>

Insurers have expressed concerns about disclosing data, arguing that it would infringe intellectual property rights and may impact insurers’ competitive advantage (noting that the unique possession of data can confer the ability for insurers to differentiate themselves from other providers), and also that any data may be difficult to interpret by most consumers.<sup>63</sup> That is perhaps why some laws require disclosure of data to Commissions instead of consumers.<sup>64</sup> This requirement of disclosure to consumers may require insurers to provide a meaningful explanation of the data to consumers, and also give consumers greater information with which to challenge insurance discrimination. In our view, any reforms that would lead to greater transparency in decision-making processes by insurers will have the corollary benefit of ensuring that processes are more human rights compliant; in particular, compliant with the right to equality and non-discrimination.<sup>65</sup>

## Conclusion

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<sup>59</sup> Victorian Equal Opportunity and Human Rights Commission, *Fair-Minded Cover: Investigation into Mental Health Discrimination in Travel Insurance* (2019) 27.

<sup>60</sup> Australian Law Reform Commission, *Access All Ages – Older Workers and Commonwealth Laws: Final Report* (2013) 139-140.

<sup>61</sup> Tasmanian Anti-Discrimination Commissioner, *Volunteers, Age and Insurance: Investigation Report* (2013) 94.

<sup>62</sup> Tasmanian Anti-Discrimination Commissioner, *Volunteers, Age and Insurance: Investigation Report* (2013) 96.

<sup>63</sup> Australian Law Reform Commission, *Access All Ages – Older Workers and Commonwealth Laws: Final Report* (2013) 141.

<sup>64</sup> *Age Discrimination Act 2004* s 54(2); *Disability Discrimination Act 1992* s 107(1).

<sup>65</sup> Victorian Equal Opportunity and Human Rights Commission, *Fair-Minded Cover: Investigation into Mental Health Discrimination in Travel Insurance* (2019) 2-3; Tasmanian Anti-Discrimination Commissioner, *Volunteers, Age and Insurance: Investigation Report* (2013) i.

A turn of the century inquiry found that ‘people with hepatitis C are being routinely refused insurance or dissuaded from applying for insurance.’<sup>66</sup> While treatments for the disease have improved enormously since then, problems with access to, and fair conditions for, insurance remain. Even today, community organisation Hepatitis Victoria advises that ‘chronic hepatitis is considered a “risk” to many insurance providers, and you may not be approved for a policy or the costs may be increased.’<sup>67</sup> The issue of insurance discrimination against people with (a history of) hepatitis C needs to be addressed urgently through law and policy reform. In terms of law reform, the ACT Legislative Assembly – and other parliaments throughout Australia – should swiftly enact reforms to require that decisions about insurance discrimination be transparent (such that they can be shown to be proportionate and justifiable), and that insureds be given access to actuarial or statistical data on which any discrimination is based. This should lead to the replacement of any blanket exclusions of people with (a history of) hepatitis C and the reduction of premiums or waiting periods. It would also give consumers greater information with which to challenge insurance discrimination if it occurs and promote reliance on higher quality data when making insurance decisions. Indeed, at present it is not even possible to clarify whether matters beyond the physical effects of the disease (such as assumed connections with hepatitis C, intravenous drug use and risks of overdose) are contributing to actuarial calculations. Finally, it would narrow the exceedingly broad exceptions insurers currently use to discriminate, whilst still respecting their right to do so provided it is justifiable, proportionate, and based on publicly available actuarial and statistical data.

Policy reform to insurance industry practices and decision-making is also necessary in two respects. Insurers should adopt new policies both on how they assess actuarial data as relevant and on how they design and deliver questionnaires. First, insurers should ensure that any decisions and related decision-making tools that exclude or increase premiums for people with (a history of) hepatitis C are based on up-to-date local actuarial and statistical data. Second, insurers should review their questionnaires around hepatitis C to ensure that the questions they ask are both necessary and posed in sensitive ways that are not

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<sup>66</sup> Anti-Discrimination Board of New South Wales, *C-Change: Report of the Enquiry into Hepatitis C Related Discrimination* (2001) 80.

<sup>67</sup> LiverWELL, ‘Stigma and discrimination’ <<https://liverwell.org.au/liver-conditions/stigma-discrimination/>>.

stigmatising, such as questions that suggest that hepatitis C affects capacity to work, questions that demand an unreasonably extensive medical history, or questions that assume connections between hepatitis C and liver conditions or intravenous drug use. As we have argued, such questions may encourage non-disclosure. If a person fails to disclose a history of hepatitis C, insurers should consider whether this was based on the stigma associated with hepatitis C, such as that produced through insensitive insurance questioning practices, rather than a fraudulent intent, especially in circumstances where the person did not have any signs of disease associated with the virus. When complaints are made against denial of a claim due to non-disclosure, complaint authorities such as the Australian Financial Complaints Authority should consider the impact of voiding an insurance policy based on non-disclosure and adopt a more expansive conception of vulnerability to consider what the effects of this may be for stigmatised population groups such as people with (a history of) hepatitis C. It is through a combination of such law and policy and practice reform that insurance discrimination against people with (a history of) hepatitis C can be properly addressed.