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# HEPATITIS C-RELATED STIGMA AND DISCRIMINATION IN A POST-CURE WORLD

Summary report of project findings  
and recommendations



**LA TROBE**  
UNIVERSITY



Australian Research Centre  
in Sex, Health and Society





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The wedge-tailed eagle (*Aquila audax*) is one of the world's largest.

The Wurundjeri people – traditional owners of the land where the Australian Research Centre in Sex, Health and Society is located and where our work is conducted – know the wedge-tailed eagle as Bunjil, the creator spirit of the Kulin Nations.

There is a special synergy between Bunjil and the La Trobe logo of an eagle. The symbolism and significance for both La Trobe and for Aboriginal people challenges us all to 'gamagoen yarrbat' – to soar.

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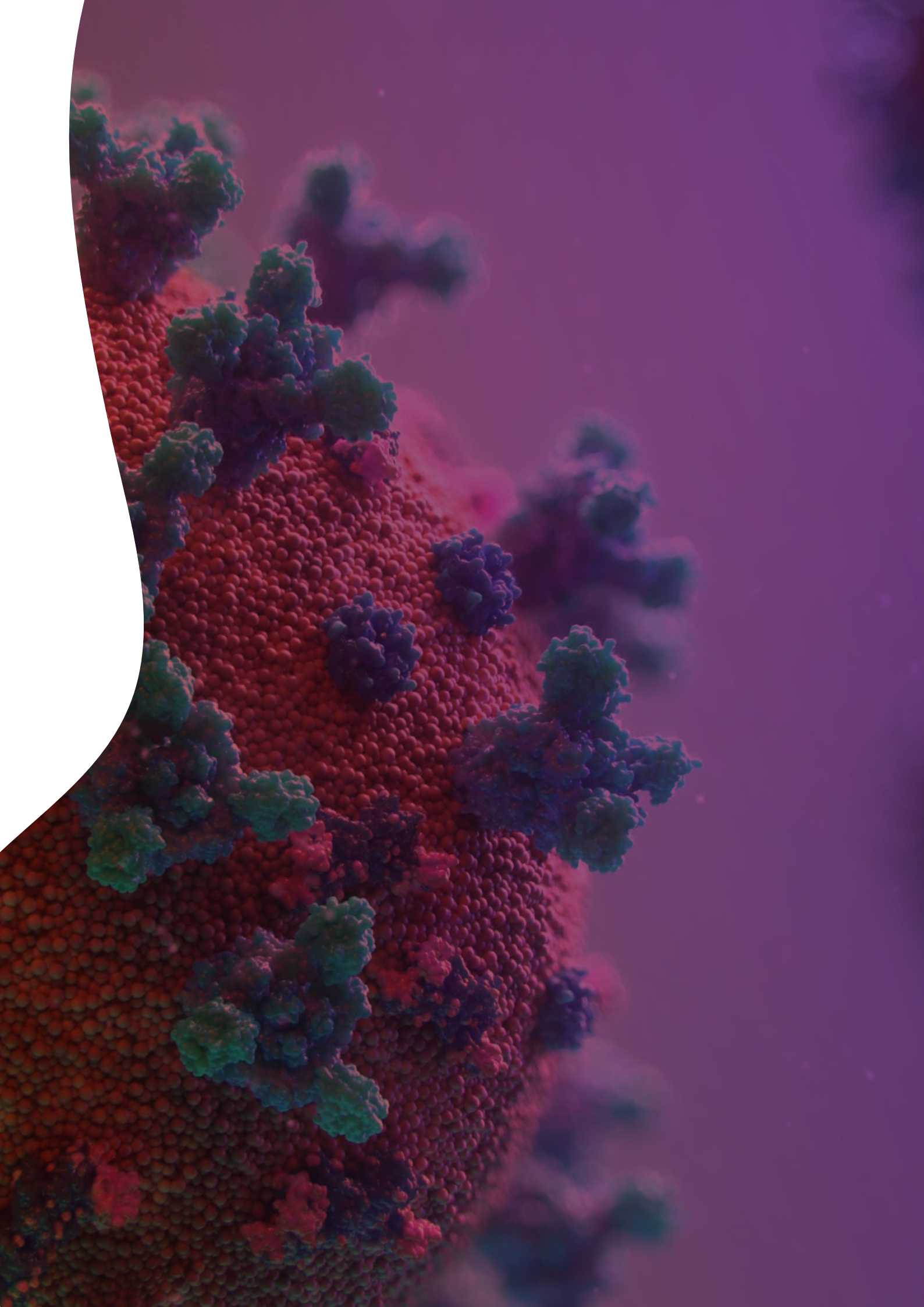
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# NOTES ON LANGUAGE

In this report we use a combination of terms, some of which are direct quotes from research participants or from literature in the field. In other instances, we use person-centred language.

We use the inclusive terms ‘people affected by hepatitis C’ and ‘affected people’ to describe the diverse population of people who are living with, have lived with, are at risk of, or have been treated for hepatitis C. We also use the term ‘people with (a history of) hepatitis C’ to include both those living with the virus and those who have been treated but may have ongoing medical, legal and social needs associated with hepatitis C. ‘People with (a history of) hepatitis C’ encompasses the temporal horizon between living with the virus and post-cure life.

We recognise competing views on the use of language. We also recognise that language has a powerful role in shaping how people understand and experience disease and treatment. As such, we asked participants in this research to nominate their preferred term/s, and, if possible, to explain their preferences. While some had not given this matter much consideration, both people who had undergone treatment for hepatitis C and stakeholders who worked with affected communities tended to be thoughtful or specific about their language choices, and wary of the potential for language to reproduce or reinforce misapprehensions and stigma. Some stakeholders described conversations and debates that had taken place within their organisations about language, particularly in contexts of producing health information communications.

As we explain later in this report, direct-acting antivirals (DAAs) may bring about a sustained virologic response, or SVR, which means that the hepatitis C virus is not detected in the blood 12 weeks or more after treatment. This is the accepted medical definition of ‘cure’. Given the clinical context of ‘SVR’, we rarely used this term in interviews unless specifically addressing the post-treatment blood test, or if participants used it themselves.

The term ‘cure’ was used widely by both stakeholders and people who have undergone

treatment. Among the reasons offered for this preference, participants said they felt it to be straightforward and easily comprehensible. For example, among some stakeholders who work with affected communities, the term was felt to designate a clear and graspable concept for people considering treatment and audiences of health communications. ‘Cure’ was also thought by some to help differentiate DAAs from earlier, interferon-era treatments, which were less effective at bringing about SVR. While DAAs have a cure rate of around 95% (Dore, 2021: 36), interferon-based therapies had a cure rate of between 54% and 63%, depending on genotype and regimen (Feuerstadt et al., 2010).

Some participants questioned the use of ‘cure’ for various reasons, including their feeling that it misleadingly implied immunity from future hepatitis C infections, or that it did not account for the ongoing presence of hepatitis C antibodies, which typically remain detectable in the blood after SVR. Among these people, the preferred terms were ‘clear’ or ‘free of hep C’. For example, P4 (stakeholder in service provision) explained that they would use ‘clear’ in clinical contexts:

*I’d probably hesitate to use the word ‘cure’.  
I’d probably be more likely to say, ‘You seem to have cleared the virus and we think that that will stay, but it doesn’t mean that you can’t get it again’.*

Among people treated for the virus, ‘clear’, ‘cleared’ and ‘hep C free’ were felt to account for the technical state of SVR (e.g., the virus is ‘cleared from my system’) without implying the possibility that they could never pick it up again. In other words, the possibility of subsequent infections after treatment informed some people’s language choices, because SVR was not necessarily assured or permanent among some people we interviewed. In terms of further alternatives to ‘cure’, some

participants said they preferred language with an emphasis on the completion of treatment (e.g., 'treated for hepatitis C', 'completed treatment'). Some stakeholders suggested that this placed an emphasis on (the importance of) treatment adherence, or on a defined clinical encounter after which the process of treatment would be complete.

Most participants explicitly rejected the term 'clean' because of its implication of a binary relationship to 'dirty' and this binary's stigmatising history in descriptions of illicit drug use and chronic illnesses (as 'dirty' practices or conditions). However, some participants who had undergone treatment did claim the term 'clean' to describe their post-cure states, asserting that they did indeed 'feel dirty' living with hepatitis C, and that treatment had made them feel 'clean'.

Importantly, some participants expressed scepticism about the language surrounding new treatment because of its inability to account for the social and other effects of hepatitis C (e.g., stigma and discrimination) that might linger after SVR. Rodney, for example, said:

*I'm not 'hep C free'. Fuck it. I've still got that kind of lived experience of having it. I'm free of the virus, but I still live with it.*

And P3 (stakeholder, policy) said:

*Cure is a physical [...] elimination of the virus, but it doesn't by extension always increase participation in civil society and it [...] doesn't confer an equal access to all things.*

The term 're-infection' was highlighted by some as potentially problematic, with those participants suggesting that the contexts of its use could sometimes imply that avoiding re-infection was the sole responsibility of individuals. They pointed out that this does not recognise factors such as a lack of access to sterile injecting equipment (e.g., in prisons) that support people to avoid re-acquiring hepatitis C after SVR. In the drafting of the *Sixth NSW Hepatitis C Strategy 2022-2025*, the term 'people at risk of infection after cure' was offered as an alternative following consultation with affected communities, and that term is used throughout that Strategy.

**“CURE IS A PHYSICAL [...] ELIMINATION OF THE VIRUS, BUT IT DOESN'T BY EXTENSION ALWAYS INCREASE PARTICIPATION IN CIVIL SOCIETY AND IT DOESN'T CONFER AN EQUAL ACCESS TO ALL THINGS.”**



# REPORT SUMMARY

This report details findings and recommendations from an Australian Research Council-funded project entitled 'Addressing hepatitis C-related legal, policy and practice discrimination in a post-cure world' (DP200100941). This three-year, qualitative research project was undertaken between late 2020 and late 2023, and sought to review the laws, policies and practices that impact people affected by hepatitis C in Australia, particularly after treatment.

The project aimed to generate new knowledge about people's experiences of hepatitis C in the context of new-generation treatments (direct-acting antivirals, or DAAs) and Australia's policy goal to eliminate the virus by 2030. It aimed to better understand whether hepatitis C-related stigma and discrimination persists after cure, in what ways it continues to manifest, what forces shape hepatitis C-related stigma and discrimination, and what opportunities exist to reform law, policy and practice.

To address these aims, research proceeded across four distinct but interlinked stages:

1. **Legal and policy mapping**, including the collection and analysis of legal statutes and case law relevant to hepatitis C in Australia; and the collection and analysis of national and state strategies that guide the prevention, treatment and management of hepatitis C.
2. **Key stakeholder interviews** (n=30), documenting the views of people who work with hepatitis C-affected communities (e.g., policymakers, lawyers, service providers and peers) on latent and emerging issues affecting these communities in the context of new-generation treatments.
3. **Interviews with people treated for hepatitis C with DAAs** (n=30), documenting their post-cure experiences, including experiences of stigma and discrimination and ideas for how to better support people after treatment.
4. **Designing recommendations**, including social, legal and practical interventions aimed at reducing experiences of hepatitis C-related stigma and discrimination and improving the lives of people with (a history of) hepatitis C.

This report presents an overview of findings and a set of recommendations. Additionally, by highlighting the structures and circumstances that affect people after cure, this report aims to support policymakers, peers, advocates, service providers, researchers and others to better address the needs of people with (a history of) hepatitis C. By deepening understandings of the social, legal, administrative and other factors that shape the experiences of people with (a history of) hepatitis C, including stigma and discrimination – and how we may effectively address these factors – this report also contributes to Australia's goal of eliminating hepatitis C by 2030.

The project's findings are summarised in this report across four thematic areas:

1. **Imagining cure and elimination**, which draws on interview data to report on the expectations, hopes and concerns surrounding the availability of DAAs in Australia, both from the perspectives of people who have undergone treatment with DAAs and key stakeholders who work with affected people.
2. **Situating cure and post-cure in strategies and law**, which draws on legal mapping, analysis of state and Commonwealth strategy documents, and stakeholder interviews to outline how hepatitis C figures in Australian legislation and case law, evaluates how key areas of law and legal practice (e.g., discrimination law, migration law, privacy law and insurance law) have adapted to the advent of DAAs, and outlines how Australia's hepatitis C strategies address cure and post-cure life.
3. **The implementation of direct-acting antivirals**, which describes key social and systemic impacts of DAAs in Australia, including people's



treatment experiences and stakeholder perspectives on transformations in policy and practice (e.g., hepatitis C testing, surveillance and care), and the implications of those changes.

4. **Post-cure life**, which describes people's experiences after treatment, including whether stigma and discrimination persist, what forces shape those experiences, and what mechanisms exist to address stigma and discrimination, including complaint processes.

Even in a context where access to effective treatment has been made universal and significant resources have been invested in the expansion of hepatitis C care, numerous forces operate to generate and/or limit ways of living for people with (a history of) hepatitis C. Among these are social, institutional and policy forces, including Australian law and legal practice, which were mapped and analysed in this project for the first time.

## Key findings:

- Stakeholders who work with hepatitis C-affected communities consider the advent of DAAs to have been 'game-changing' for affected people and remain optimistic about new treatments and the impact of efforts to eliminate hepatitis C in Australia. Some suggest that new treatments have the potential to reduce stigma and discrimination by changing the meaning of hepatitis C from one of 'chronicity' to one of 'cure', reducing the sense of punishment associated with treatment, and enabling people to feel a sense of 'pride' in the completion of treatment that alleviates feelings of shame they previously may have had.
- People who have undergone treatment with DAAs reported largely positive experiences of treatment. Some said treatment had positive social effects, including reducing feelings of being an 'infectious person', reducing fears of infecting other people, and strengthening intimate relationships (e.g., with family, partners and friends). However, many continued to experience hepatitis C-related stigma and discrimination after treatment, especially in healthcare settings, and did not feel that treatment had changed that.
- The national and state strategies have begun to address post-cure concerns; however, these remain largely focused on medical surveillance, and the prevention of re-infection. Throughout this project, our research team has advocated for the inclusion of post-cure concerns in national, state and territory strategies. At the time of writing this report, the draft *Sixth National Hepatitis C Strategy* has taken up our recommendations to include a more thorough acknowledgement of post-cure life. Nevertheless, there is scope to further adjust the language used in strategies and policies to better incorporate medical, social and legal challenges that affect people after treatment, as documented in this report.
- Hepatitis C can linger in people's lives after biomedical cure including via administrative systems, legal mechanisms and medical records. Certain legal processes have the potential to 're-make' hepatitis C after cure, meaning individuals may be medically cured and yet legally marked as perpetually 'having' hepatitis C. This means people with (a history of) hepatitis C may continue to experience stigma and discrimination in legal contexts after curative treatment (see Seear et al., 2023a; 2023b). Concerns about this arose in both stakeholder and lived experience interviews, including via reports that hepatitis C antibodies are often misinterpreted for and treated as the virus itself, including in healthcare settings.
- In criminal case law, the distinction between hepatitis C infection and disease is consistently blurred. The criminal law continues to constitute hepatitis C as serious and disabling, despite the advent of cure. This has implications for criminal law sentencing, in which hepatitis C can operate as a mitigating factor leading to reduced sentences for offenders affected by the virus. However, it may also be an aggravating factor in sentencing, particularly where victims are infected or at risk of infection by the virus. Understandings of the virus also have implications for criminal compensation cases, as awards can be increased when victims are either put at risk of contracting the virus or where the virus is transmitted through the offender's act of violence. These legal approaches have implications for the perpetuation of hepatitis C-related stigma, with the virus operating largely as a source of symbolic horror and/or shame for both victims and perpetrators.
- In some legal contexts where cases were heard and decided since the advent of DAAs, people with hepatitis C were no longer conceptualised as 'impaired' or 'disabled'. These shifts in rhetoric and judgment have seen hepatitis C reconstituted as something that can be cleared, via cure, enabling the individual to become 'able-bodied' for legal purposes, and creating the expectation that, once

cured, the virus will no longer affect them. These transformed legal understandings of the virus affect rights and entitlements, including access to residency, social security and other social benefits. At the same time, the stigma associated with the virus can be reiterated – and potentially exacerbated – through the spectacle of telling and re-telling one's status before a court or tribunal. So, although legal rhetoric has in some instances shifted toward recasting hepatitis C as something that may pass, the stigma associated with it may be reinforced by legal processes themselves.

- Insurers may be relying on outdated actuarial data regarding hepatitis C, with reports that chronic hepatitis is still being considered a risk among insurance providers, even after treatment. This means that people with (a history of) the virus may not be granted insurance coverage or may be charged higher premiums. In some instances, this may amount to unlawful discrimination.
- Individual experiences of treatment are extremely diverse. Treatment can be experienced as transformative, life-changing or lifesaving; a huge relief; and/or as disappointing and not living up to hopes and expectations. Discussions of the cost of new treatments to taxpayers and the government have shaped some people's treatment experiences, which some of our participants described as a form of luck, good fortune, or a gift contingent on the beneficence of the state. This suggests that among people treated for hepatitis C, not all feel entitled to health care. These dynamics could inadvertently discourage some people with hepatitis C from accessing treatment, either initially or again in the case of re-infection.
- Stakeholders suggested that the 'democratisation' of access to treatment and other changes to healthcare, including the normalisation of hepatitis C (broadly defined as its expansion into primary health care), had the potential to reduce stigma by 'normalising' the virus.
- However, stakeholders and people who have undergone treatment for hepatitis C remain concerned about ongoing forms of hepatitis C-related stigma and discrimination affecting people after treatment, including the stigma associated with injecting illicit drugs. Both groups shared concerns about several other issues, including aspects of hepatitis C epidemic surveillance (e.g., named notifications and the digitisation of health

records), and how these may continue to affect people with (a history of) the virus, including their ability to access healthcare, their right to privacy and their ability to control the disclosure of their (history of) hepatitis C.

- Novel approaches in hepatitis C policy and health care related to finding and treating people who are undiagnosed or 'lost to follow up' may present risks to people with a (history of) hepatitis C by compromising processes of informed consent to testing.
- In the personal meanings and narratives that people ascribe to treatment, cure is not always conceived of as an end to hepatitis C – the virus may have social and symbolic 'afterlives', including in ongoing experiences of stigma and discrimination. People who have undergone treatment for hepatitis C said they felt that the record of the virus on their medical records led to stigmatising and discriminatory treatment in health care. Additionally, not everyone feels the desire to completely leave hepatitis C behind them after treatment, as some find value in their personal experience of living with the virus.
- Current approaches to hepatitis C care, including the cascade of care, do not sufficiently address the needs of people after treatment, and a range of health-related and other needs remain unmet among this cohort.
- For people who have experienced hepatitis C-related stigma and discrimination, mechanisms for feedback or complaint are flawed. Existing mechanisms pose a significant burden on potential complainants, many of whom do not believe that their experiences are 'worthy' of complaint in the first place. Together, these forces discourage feedback and complaint, and need to be addressed.

## Key recommendations

The following recommendations seek to reduce experiences of hepatitis C-related stigma and discrimination, including among those who have been treated for the virus. To that end, they propose the development of new policies, legal mechanisms and systems, alongside reforms to or improvements of existing ones. While each of these recommendations are targeted to a specific government or non-government organisation or to a specific sector, other relevant organisations or stakeholders may be engaged in these actions.

All these recommendations are prefaced by the **guiding principles** that:

- Their development and implementation involve meaningful partnership with peer and peak organisations and the communities of consumers they represent, with due resourcing of their time and expertise.
- Any new policies, laws and initiatives, and any changes to existing mechanisms must recognise and draw on the individual and collective expertise of people with (a history of) hepatitis C and communities affected by the virus.
- Where relevant, consideration to the specific experiences and needs of priority groups affected by hepatitis C should be given.

In the development and implementation of any of these recommendations, we recommend that responsible bodies consult the priorities outlined in the [Harm Reduction International 2023 Australian Conference Declaration](#).

## Policy recommendations

1. Responsible departments at federal, state and territory levels should work together with relevant consumer and advocacy groups to develop a health data justice framework that balances the benefits of pathways into hepatitis C health care with the risks associated with the use, re-use, and re-purposing of medical and health data to access such care.
2. The Department of Health and Aged Care and its state and territory equivalents should develop stigma-sensitive workforce training and education programs designed for and made available to all people who work with hepatitis C-affected communities.
3. Federal, state and territory hepatitis C strategies and action plans should contain an explicit focus on post-cure life, to ensure they address both the medical and other needs of people cured of hepatitis C. This should include explicit goals to reduce the stigma and discrimination that endures for many people after treatment.
4. The Communicable Disease Network and/or other responsible bodies should review existing national, state- and territory-based systems of hepatitis C notifications, with consideration given to removing name requirements and other personal/identifiable information for new notifications or to introducing opt-in mechanisms for named notifications.

5. The Department of Health and Aged Care should ensure that the National Hepatitis C Testing Policy includes robust, opt-in, informed consent processes on all occasions of hepatitis C testing.
6. Hospitals, health services and research ethics departments should scrutinise new testing and treatment models (including strategies to 'find' undiagnosed or untreated people) for potential breaches of privacy or consent, or other unintended consequences for the health and human rights of people with (a history of) hepatitis C.
7. The Department of Health and Aged Care should ensure that, if human rights are to be acknowledged in the *Sixth National Hepatitis C Strategy*, any reference to human rights should not be limited to specific rights and should incorporate strategies and methods for ensuring that rights are not unjustifiably or unreasonably restricted.

## Legal recommendations

8. All jurisdictions in Australia should legalise the personal use/possession of drugs and decriminalise the use/possession of injecting equipment.
9. Federal, state and territory governments should work together through the National Cabinet to ensure that Australia is meeting its human rights obligations to prisoners, including the obligation to provide equality of health care and harm reduction through the establishment of needle and syringe programs in Australian prisons.
10. The Attorney-General's Department and its state and territory equivalents should consider legislative reform to protect privacy rights over health information, including hepatitis C.
11. The Australian Commission on Safety and Quality in Healthcare or another responsible authority should establish a charter of healthcare rights for people with (a history of) hepatitis C, including provisions for the privacy of health records, the use of hepatitis C notifications data, and the legal requirement to provide informed consent for testing.
12. The Australian Human Rights Commission and its state and territory equivalents should develop guidelines and fact sheets that support individuals to understand their legal rights and support duty holders to understand their legal obligations to prevent and respond to



hepatitis C-related discrimination in workplaces and other settings.

13. The Office of the Australian Information Commissioner and its state and territory equivalents should develop guidance on privacy rights and dealing with unwanted disclosure of hepatitis C.
14. Federal, state and territory governments should undertake comprehensive law reform in recognition of the advent of curative hepatitis C treatments, with particular attention to discrimination law, migration law, insurance law and criminal law.
15. State and territory law reform commissions and/or parliamentary committees should explore the viability of law reform to enable people cured of hepatitis C to remove their history of hepatitis C infection and/or treatment from their medical records or restrict access to that information.

### Practice recommendations

16. Federal, state and territory governments should fund relevant organisations to develop and deliver privacy, healthcare rights, stigma-sensitive practice, and anti-discrimination training for people working with hepatitis C-affected communities in healthcare, legal and other settings.
17. The Australian Health Practitioner Regulation Agency and its state and territory equivalents should introduce or review mechanisms for consumer feedback and complaint in healthcare settings attended by people with (a history of) hepatitis C. These mechanisms should be robust, transparent, accessible and support the provision of quality stigma-free healthcare.

### Other recommendations

18. The Financial Services Council should develop a new guidance note on insurance underwriting for hepatitis C that reflects developments in treatment and with a view to addressing unfair exclusions, increased premiums and policy voiding based on (a history of) hepatitis C as well as stigma-sensitive questioning in insurers' questionnaires.
19. The Department of Social Services and/or other funding bodies should provide support for further research into how the advent of

curative treatment has affected people with hepatitis C who were or are on the Disability Support Pension.

20. The Departments of Foreign Affairs and Trade and of Home Affairs should improve migration decision-making processes in relation to refugees and migrants with hepatitis C by supporting further research on access to hepatitis C treatments in different countries to be included in country information reports.

## Project outputs and outcomes

To date, this project has generated 12 peer-reviewed journal articles and 13 presentations at national and international conferences and other research and practice forums. Alongside this report, these elaborate on project findings and present data in detail. Project findings have also been shared in non-scholarly outputs, including two podcasts: a research showcase to mark World Hepatitis Day 2022, and 'After Cure' (2023), which illuminates experiences of hepatitis C and treatment in the era of DAAs. See Appendix 3 for a complete list of project outputs. The project also coincided with the establishment of the new Gender, Law and Drugs (GLaD) research program at ARCSHS, which reported project findings and outputs in numerous posts on its [website](#).

Additionally, the project dovetailed with several relevant national and state inquiries, legislative debates, law reforms and community consultations, including the development of the *Sixth National Hepatitis C Strategy 2023-2030*. The Draft Strategy took up recommendations from the project, including recommendations to establish baseline measures for legal and human rights issues and a strengthened emphasis on addressing post-cure life. The research team also contributed to the development of the inaugural *National Stigma and Discrimination Reduction Strategy* through its public consultation process; and gave written and oral evidence to the *Inquiry into the New South Wales Mandatory Testing Bill 2020*, expressing opposition to the Bill on the grounds that it undermined efforts to reduce the stigma and discrimination associated with blood-borne viruses (BBVs) and was in tension with public health and disease prevention efforts.

# BACKGROUND AND AIMS

Chronic hepatitis C is associated with a range of major health problems, including cirrhosis, liver failure and liver cancer.

Around 75% of acute hepatitis C infections progress to chronicity (Muller & Hasan, 2021). Combined with cases of hepatitis B, chronic hepatitis C is the primary cause of liver cancer in Australia, which is the country's fastest growing cause of cancer death (MacLachlan & Cowie, 2012). Approximately 117,810 people were living with chronic hepatitis C in Australia at the end of 2020 (Kirby Institute, 2020), and there were 7,990 new known infections that year (Kirby Institute, 2022). However, with the advent of new-generation treatments called direct acting antivirals (DAAs), these problems may become a thing of the past. Widely celebrated as 'revolutionary', DAAs can produce a sustained virologic response (SVR) – the accepted medical definition of 'cure' (Kirby Institute, 2018) – in more than 95% of cases (Dore, 2021: 36). Additionally, their side-effects and administrative complexity are significantly reduced in comparison to previous (interferon-ribavirin combination) treatments, which were notoriously arduous and often involved debilitating side effects, including flu-like symptoms, fatigue, depression, anxiety and insomnia (Biondi & Feld, 2020).

In Australia, DAAs became publicly available in 2016 as part of a globally unique program of unrestricted, nationwide access to treatment for all people with hepatitis C over the age of 18 years, with no restrictions according to disease stage, treatment history or drug-use status (Commonwealth Department of Health, 2018). At an estimated cost of \$3 billion over five years, the Australian government added DAAs to the Pharmaceutical Benefits Scheme (PBS), rescheduling them from S100 to S85 drugs, meaning that the authority to prescribe them expanded from specialists (gastroenterologists, hepatologists or infectious-disease physicians) to general practitioners (GPs), and, more recently, to nurse practitioners (Australian Government Department of Health and Aged Care, 2020). By the end of 2021, approximately 95,395 people with hepatitis C had

received the new treatments in Australia, about 51% of the affected population, and 94% of those treated were cured (Kirby Institute, 2020).

The national target is virtual elimination by 2030, in line with the World Health Organization's ambitious goal to eliminate hepatitis C (World Health Organization, 2016).

Although uptake was initially strong, treatment rates have declined, and there are concerns that Australia may not meet its 2030 elimination goal. Importantly, other issues related to hepatitis C endure, including the ongoing stigma and discrimination experienced by people with (a history of) the virus. Hepatitis C is a heavily stigmatised disease, due in large part to its intimate association with injecting drug use. In Australia, incidence of the virus is concentrated among people who have injected drugs, and the affected population has a high representation of incarcerated people, people from culturally, ethnically and linguistically diverse communities, Indigenous people and people from other disadvantaged groups (MacLachlan et al., 2020). Both local and global research shows that people affected by the virus are habitually subject to discrimination (see Harris et al., 2021 for a synthesis), with healthcare settings the most common place such experiences occur (e.g., Anti-Discrimination Board of NSW, 2001; Treloar et al., 2013). This includes practices such as an unwillingness to administer treatment, reluctance to perform medical procedures, or the use of excessive infection control (Broady et al., 2018). In a 2018 survey of people diagnosed with hepatitis C, the proportion who reported negative treatment by healthcare workers was 71% and 10% of healthcare workers reported that they had discriminated against people living with the virus (Treloar et al., 2018: 12).

It is within this experiential context of persistent stigma and discrimination that people contemplate or undertake treatment with DAAs. Such stigma

# **“WHILE OPTIMISM ABOUT NEW TREATMENTS IS WARRANTED, IT ALSO RISKS OVERLOOKING THE LEGACY OF LAWS AND POLICIES DEVISED IN A PRE-CURE WORLD AND YET TO BE REFORMED.”**

and discrimination matter, as they can operate as a barrier to accessing health care (including diagnosis and treatment of hepatitis C), contribute to social isolation and diminished quality of life, and has been demonstrated to increase the risk of new infections and re-infections (Marinho & Barreira, 2013). In these and other ways, stigma and discrimination threaten to undermine the elimination agenda.

There are also laws, policies and practices relating to hepatitis C that remain unchanged to reflect a post-cure world, and that continue to shape the lives of people affected by the virus, including in discriminatory ways. For example, under the Public Health and Wellbeing Act 2008 (Vic), medical practitioners are obligated to notify government departments when a person is diagnosed with hepatitis C, identifying the person's name and recording the likely transmission route in health record systems. Peer-led organisations working among communities affected by hepatitis C report that people cured of hepatitis C are concerned about these data being kept in their health records, and its potential to expose them to ongoing stigma and discrimination in healthcare settings (Walker et al., 2020). Another example is the Australian law applying to insurance practices.

Here, people applying for health, life and some other insurance products are required to disclose medical conditions or other 'risk' factors, including any history of injecting drug use or hepatitis C, and insurance providers may refuse insurance to people with (a history of) hepatitis C or increase their premiums to account for the perceived risk of future ill health or premature death resulting from the virus. These policies remain largely unreformed despite the advent of new treatments for the virus (see Mulcahy et al., 2022).

Until recently, very little has been known about the range of laws, policies and practices that affect people who have undergone hepatitis C treatment, and how they might be updated to better support people after cure. As the examples mentioned above indicate, a number of such policies, laws and practices continue to affect people who have been cured in deleterious ways, including in ways that may undermine efforts to eliminate hepatitis C. Without, for example, law and policy reforms enabling all priority populations to access harm reduction resources (e.g., sterile injecting equipment), and practice reforms enabling all affected people to access stigma-sensitive health care (including testing and treatment) (Lenton et al., 2021), affected people remain at greater risk of



infection, re-infection, or of not being tested or treated for the virus at all (Day et al., 2019; Seear et al., 2021; Harris et al., 2013). So, while optimism about new treatments is warranted, it also risks overlooking the legacy of laws and policies devised in a pre-cure world and yet to be reformed. These laws and policies may operate as barriers to a revolutionary 'new', 'future' life, where people who once had hepatitis C are no longer subject to stigma and discrimination (see Seear et al., 2021).

The effects of stigma on people living with hepatitis C can be profound. Social research has demonstrated that stigma has harmful consequences for health and wellbeing and often acts as a barrier to accessing health care and social supports (e.g., Farrugia et al., 2019). In part, this can be because those who have either repeatedly encountered discrimination or fear encountering it are less likely to disclose their status (Northrop, 2017). People reluctant to disclose their hepatitis C status for fear of being treated differently in social and healthcare settings may not receive proper medical care. They may even avoid or delay getting diagnosed, for fear of what that would mean for them. Given the growing understanding of stigma's impact on health and wellbeing, key public health policies, such as the World Health Organization's (2022) global health strategy on viral hepatitis and *Australia's Fifth National Hepatitis C Strategy 2018–2022*, explicitly seek to address it. For example, one of the targets of Australia's *Fifth National Strategy* was to 'reduce by 50 per cent the reported experience of stigma among people living with hepatitis C, and the experience of stigma, in respect to hepatitis C status' (Australian Department of Health, 2018: 17).

As researchers at the University of New South Wales pointed out recently, 'unlike DAA therapy, there is no miracle cure for these problems' (Martinello et al., 2020: 363). Alone, improved medical treatment will not resolve the multiple social, political and systemic issues that confront people with (a history of) hepatitis C. Addressing these issues demands that we identify areas in which hepatitis C-related stigma and discrimination occurs and take steps to tackle it. This project addressed these issues, focussing on people's experiences after cure, as well as the laws, policies and practices that shape ongoing hepatitis C-related stigma and discrimination. Its design was premised on two key assumptions: first, that medical cure alone cannot reverse the

entrenched social, political and structural dynamics that drive infections, shape lived experience of the virus, and limit service access; and second, that laws, policies and practices devised in a pre-cure world may continue to impact people with (a history of) hepatitis C and need to be addressed alongside the delivery of DAAs and as part of the aims of elimination.

In summary, the project's objectives were to:

- Better understand the legal and policy dimensions of hepatitis C-related stigma and discrimination and identify laws and policies in need of updating and reform.
- Document the views of stakeholders who work with hepatitis C-affected communities on latent and emerging challenges pertaining to hepatitis C in a post-cure world, including ongoing stigma and discrimination.
- Better understand the experiences of people treated for hepatitis C, including whether they continue to encounter hepatitis C-related stigma and discrimination, and in what settings.
- Identify opportunities for legal, social, policy and practice reform that can address these problems, providing practical strategies and reforms that would reduce hepatitis C-related stigma and discrimination and improve the lives of people affected by the virus.

# METHOD

To better understand the forces shaping post-cure lives and hepatitis C-related stigma and discrimination, a combination of methods were used. Three main data sets were collected and analysed using a range of approaches. The research proceeded through four interlinked stages:

**1. Speculative mapping of legal and policy frameworks**, which sought to identify all statutes, case law, and strategy documents that impact people with (a history of) hepatitis C in Australia.

## Strategy documents analysis

In the first component of this mapping exercise, we investigated how the advent of cure has figured, if at all, within national and state strategies, as well as the extent to which post-cure issues are acknowledged and addressed in these documents. For this stage, we collected state and national strategies published between January 2016 and May 2023. A number of these strategies were expired at the time of collection and analysis, including the *Fifth National Hepatitis C Strategy 2018–2022*, the *Queensland Hepatitis C Action Plan 2019–2022* and the *Hepatitis B, Hepatitis C, HIV and Sexually Transmissible Infections: ACT Statement of Priorities 2016–2020*. These were included in the analysis nonetheless, as they were developed during the DAA era. Tasmania does not have a hepatitis C strategy. The strategies were analysed to identify their handling of issues relevant to post-cure life, and hepatitis C-related stigma and discrimination (including a content analysis of post-treatment concerns and an analysis of the language used to describe these). Mentions of hepatitis C-related stigma and discrimination were coded to identify how the strategies understood the impacts of these and the potential actions needed to address them.

## Legislation and case law analysis

Legislation data were gathered through a variety of means. First, legislation data were gathered by drawing from relevant reports (EC Australia, 2021; Seear et al., 2021), personal knowledge and a search of case law. Second, legislation data were collected through a search for the word ‘hepatitis’ in Australian legislation databases through the open access Australasian Legal Information Institute Collection. Statutes were categorised into different

areas of law, with the most common references to hepatitis C occurring in legislation related to:

- identifiable notifications under public health laws (11 statutes)
- combat sports and discrimination laws (nine each)
- workers’ compensation laws (six)
- mandatory testing and blood donation laws (five each).

Case law data were gathered by a search for the full words hepatitis C in Australian case law databases through the open access Australian Legal Information Institute (AustLII) Collection. Given the scope of this undertaking and given that many cases would be identified, the search was limited to the narrower term hepatitis C rather than hepatitis generally (which was used for the statute search). As a result of this initial search, 1,102 cases were identified (as of 14 January 2021) mentioning hepatitis C (some refer to it as ‘hep C’, ‘HCV’ or ‘hepatitis’). These results were screened for relevance. Of these, we found 232 cases with a substantive discussion of hepatitis C; cases where hepatitis C had no bearing on the outcome or where hepatitis C was mentioned only fleetingly were excluded. Of those cases identified, 55 occurred after DAAs were made available on the PBS in 2016; 177 occurred prior to 2016. Nonetheless, the older cases were documented, as historic case law provides an understanding of how things have changed since the advent of more tolerable and effective treatments.

**2. Interviews with key stakeholders (n=30)**, in the form of in-depth, semi-structured interviews with a diverse sample of people who work with hepatitis C-affected communities across policy, community health, legal, advocacy and other settings in Australia. The experiences and observations of people working in these fields are illuminating because they are often responsible for designing or delivering service and policy reforms and are in a unique position to identify systemic changes underway. Ten stakeholders were recruited from each of the three states with the highest prevalence of hepatitis C and the highest proportion of people undergoing treatment at the time this project received funding

(Burnet Institute and Kirby Institute, 2019).

These states were New South Wales, Victoria and Queensland. Participants were purposively selected to reflect a range of ages, genders and roles in the sector (see Appendix 1 for more detail). We also recruited stakeholders with experience and expertise working with priority populations affected by hepatitis C, including people who use drugs, incarcerated people, Indigenous people, recent migrants, refugees, and other people from culturally and linguistically diverse communities. Some stakeholders self-identified as 'peers', meaning they had personal experience of hepatitis C or other relevant lived experience (e.g., alcohol or other drug use; incarceration). Among other things, the interviews explored participants' views on and experiences of law, policy and service practice relating to hepatitis C in the context of DAAs; the structures or approaches that may continue to expose people with (a history of) hepatitis C to stigma and discrimination; and potential reforms that may address these. The complete stakeholder interview schedule appears at Appendix 2.

Those interviewed in this stage of the research were assigned numbers (e.g., P1, P2, etc.) rather than pseudonyms to obscure their gender alongside other primary markers of identity, and to ensure they remained unidentifiable. In this report and in other publications from the project they are identified by these numbers and one of three generic descriptions of their primary role in the sector ('policy', 'practice', 'legal') at the time of interview, although many of them had varied experience and expertise across a range of relevant concerns and priority populations.

A coding framework was devised by research staff and project investigators that included codes identified in response to existing literature and codes that were developed to account for key themes that emerged from the data. This framework was then applied to the transcripts by Dr Dion Kagan and Emily Lenton, using an iterative process in which coded data were compared and double coded, then reviewed by lead investigator Associate Professor Kate Seear to ensure consistency.

**3. Interviews with people who had undergone treatment with direct-acting antivirals (n=30),** in the form of in-depth, semi-structured interviews with a diverse sample of participants who had undergone treatment with DAAs at least once since they became available in Australia in 2016. Participants were recruited from the same three

states as participants from stage two (New South Wales, Victoria and Queensland). They were recruited through various sources, including needle and syringe programs and community services offering hepatitis C care. They were screened to ensure a variation of experiences, genders, sexualities, locations (urban, regional and rural), ethnicities and treatment experiences, including people who had experienced both interferon-era treatments and DAAs, and people who had subsequent treatment following re-infection (see Appendix 1 for participant details). Those interviewed in this stage of the research were assigned pseudonyms, and in this report and all other published data from the project limited we have limited references to identity markers. Participants were compensated for their time and contribution to the research.

For this stage, a coding framework was devised by research staff and project investigators that included codes identified in response to existing literature on hepatitis C-related stigma and discrimination and codes that were developed to account for key themes that emerged from the data. This framework was then applied to the transcripts by Dr Dion Kagan and Emily Lenton, using an iterative process in which coded data were compared and double coded, then reviewed by lead investigator Associate Professor Kate Seear to ensure consistency.

All interviews conducted were confidential, audio recorded, professionally transcribed verbatim, and then checked for accuracy and de-identified. De-identified and checked transcripts were imported into NVivo 11 for data management and coding. All participants provided informed (written or verbal) consent to participate. The project received ethics approval from the La Trobe University Human Research Ethics Committee (HEC20481).

**4. Development of key recommendations,** which involved using data from stages two and three to update data collected in stage one, and to develop a set of project recommendations, which are included in this report. These recommendations underwent two stages of review by the project advisory board, which included people with lived experience of hepatitis C and treatment, and members of both peak and peer organisations.





# FINDINGS

The following sections discuss the project's key findings and recommendation.

The findings are organised into four parts:

1. Imagining cure and elimination
2. Situating cure and post-cure in law and strategies
3. The implementation of direct-acting antivirals
4. Post-cure life

## Imagining cure and elimination

### Perspectives of stakeholders

Some years since the listing of DAAs on the PBS in Australia, stakeholders who work with people affected by hepatitis C across service, policy, legal and advocacy roles remain largely optimistic about the impact of new treatments and the galvanising effects of Australia's elimination goals. They consistently described DAAs as a 'game changer' and a 'good news story'. A number also suggested that the availability of curative treatments and related developments in hepatitis C care enabled improvements to the social experience of affected people, including by ameliorating the stigma and discrimination they experience.

### Direct-acting antivirals have the potential to reduce stigma and discrimination

New treatments were understood as changing the meaning of a hepatitis C diagnosis from one of chronicity to cure, which some stakeholders regarded as having the potential to reduce stigma and discrimination. This changed meaning was seen as having a particular impact on stigma in the diagnostic setting, where healthcare professionals could now offer a 'good news story' of the availability of effective treatment to people receiving a diagnosis.



Another way stakeholders viewed DAAs as enabling a reduction of stigma was through the 'pride' affected people may experience upon completing treatment, and the potential that they might share their personal story with others. For example, P28 (policy) described treatment and cure as a personal type of 'good news story' that could be shared with others in the community:

*I think the new DAA cures have made a huge difference [...] I can see the pride in people where they're not owning that stigma anymore. They're actually saying, 'Not only have I cured, but I've got that something to share with people, I've got something to tell people' [...] I really feel that stigma is shifting because of the cure, but I mean obviously there's still stigma attached to a lot of other things in people's lives, whether that's ongoing injecting drug use and the illegality of drug use and that sort of thing.*

P28's reflections imply that positive treatment stories and 'pride' can address shame, secrecy and the social discreditation associated with hepatitis C. Importantly, they qualify this when they note that this 'obviously' excludes the stigma 'attached to a lot of other things', including 'ongoing injecting drug use'. This important qualification is discussed further below.

DAAs were also thought to reduce the sense of 'punishment' associated with earlier, interferon-based treatments, which were extremely taxing and widely understood as part of the punitive social experience of injecting illicit drugs and 'addiction' (Fraser and Seear, 2011: 123). The simplified, more effective and less grueling treatment experience was seen as helping to undo the link between treatment and punishment, and therefore to reduce hepatitis C-related stigma and discrimination in that way. As P1 (service delivery) explained, the virus

*can be addressed more quickly and painlessly [and that] has implications for prevalence and people's experiences – you know, not feeling like they have to go through something that is punishing.*

This resounds with other recent social research findings on both hepatitis C and HIV (e.g., valentine et al., 2022c), where improvements to treatments were associated with a reduction of stigma.

Some stakeholders linked new treatments to stigma reduction through Australia's investment in making DAAs universally available. This was viewed as a national policy that strengthened access to health care for affected people, including populations that disproportionately experience obstacles to health care (e.g., people who inject drugs, incarcerated people, Indigenous people). This was viewed as especially significant given that, until 2001, people who inject drugs were restricted from accessing treatment, and after that time eligibility was contingent on psychological testing, secure housing and enrolment in an opioid pharmacotherapy program (Rance, Rhodes and Lancaster, 2022). Although the legacy of these

restrictions continues, with some people who inject drugs still unsure about their eligibility (Wright et al., 2019), stakeholders celebrated the PBS listing of DAAs. For example, P10 (advocacy) viewed the listing as a 'public health victory' in which 'stigma and discrimination' and 'the hierarchy of whose health is valuable and whose health is expendable and disposable was completely refuted'. They described Australia's investment in universal access to treatment as a

*complete 180 to everything else that the Commonwealth and the states have done in relation to health care for highly targeted and imprisoned and criminalised people [...] I can't remember another equivalent commitment which has so precisely addressed those fundamental barriers of structural and other discrimination and stigma and exclusion for a curable and treatable illness.*

Additionally, stakeholders pointed to changes in hepatitis C care and suggested that the democratisation of care could 'normalise' the virus, reducing stigma and discrimination. This was explained as a process that was unfolding through two key, instrumental developments, both of which involved a wider distribution of authority to test and treat for hepatitis C. One of these is public health 'normalisation', in which hepatitis C is incorporated into mainstream primary healthcare contexts and processes. The other is the dispersal of treatment into community settings (e.g., alcohol and other drug treatment services, prison health care, community and linguistically diverse and migrant community health care). We discuss these further below.

### **Perspectives of people with lived experience of hepatitis C**

Many of our participants accessed treatment with DAAs fairly quickly after they became available in Australia, including during trials prior to their listing on the PBS. Several of them were connected to community health organisations where they first heard that new treatments were coming, and they were anticipating their opportunity to get treated. This involved excitement, optimism and waiting. Camille reflected on this time, saying:

*[T]here were different trials going on and stuff like that, and there was sort of an air of excitement [...] and] that excitement grew and*

*that was just sort of really quite phenomenal because stuff was coming out that was alluding to the fact that there may be a cure coming for hepatitis C that was vastly different to what had been before, and that was really, really exciting.*

Participants were asked to recall their aspirations and apprehensions of treatment, including hopes for what it would deliver and how it might change their lives. Many reported hearing that DAAs had reduced side-effects and were hoping this would be true for them, as they had avoided interferon-ribavirin treatments due to their notorious side-effects. Some had been unable to complete earlier treatments or witnessed their debilitating effects on others and were worried that new treatments would be similarly arduous (see also Fomiatti et al., 2022c).

Most people's first and foremost hope for treatment was to attain SVR and to no longer live with hepatitis C, regardless of the progress of the disease. For those with significant disease progression, including cirrhosis, treatment was viewed as something that might save their life. Many participants approached treatment with those primary goals in mind, and with the hope that any side effects would be manageable. For example, Camille said that:

*Clearing hep C was, you know, just about health. Clearing hep C was taking away that thing of living with something that is chronic, that you sort of don't know how it's going to manifest over time and impact on your, you know, your liver and anything else.*

Others reflected on social or interpersonal hopes, including the hope that treatment would reduce experiences of stigma and discrimination. Such hopes tended to be specific and depended on people's lived experience of the virus and broader life experiences and circumstances. Generally, people's hoped-for changes included improvements to relationships, capacity to work and improved emotional wellbeing. For example, Adam described his hope that treatment might 'liberate' him from mental ill health and relationship problems as well as feeling 'judged' in healthcare settings:

*I used the word 'liberation' from hep C because of the mental health costs that I've endured for five years. The stigma I'd endured for five years. So, it wasn't just about having the treatment to get back*



*to those sexual practices and to have an intimate relationship [...] again, but just to get myself through to the point where I didn't have to worry about being in those judged spaces again, and specifically to not be in a position where I'd have another experience like I did at [hospital] because that was [...] hugely damaging [...] So, by the time they [DAAs] came along, it's a case of, you know, finally I can move on from this space.*

## Conclusion

Stakeholders who work with hepatitis C-affected communities considered DAAs to have been 'game-changing' for affected people and remained optimistic about new treatments and the impact of efforts to eliminate hepatitis C in Australia. Some suggested that new-generation treatments could potentially reduce experiences of stigma and discrimination by changing the meaning of hepatitis C from one of chronicity to one of cure, reducing the sense of punishment associated with treatment, and enabling people to feel 'pride' in achieving SVR; and through changes in healthcare,

including normalisation (see 'The implementation of DAAs'). However, stakeholders remained concerned about ongoing forms of hepatitis C-related stigma and discrimination, including the stigma associated with injecting drug use (see 'Post-cure life').

People who have been treated with DAAs reported largely positive treatment experiences. Some said they felt that clearing hepatitis C had positive social or interpersonal impacts, including reduced feelings of being an 'infectious person' who could pass on the virus to others, and that these developments sometimes strengthened intimate relationships. This reflects other recent social research from the era of DAAs, which found that people approach cure with the hope that it will reduce or eliminate stigma and discrimination from their lives (e.g., Harris, 2017; Richmond et al., 2018; Madden et al., 2018; Whiteley et al., 2018; Williams et al., 2019; Goodyear et al., 2021). We discuss these hopes, and whether they were met, in the section 'Post-cure life' below.

**“I CAN'T REMEMBER ANOTHER EQUIVALENT COMMITMENT WHICH HAS SO PRECISELY ADDRESSED THOSE FUNDAMENTAL BARRIERS OF STRUCTURAL AND OTHER DISCRIMINATION AND STIGMA AND EXCLUSION.”**

## Situating cure and post-cure in strategies and law

Laws and legal practices have been slow to respond to the advent of new treatments, and the circumstances and needs of people living post-cure lives. Similarly, post-cure life and the needs of people treated for hepatitis C have, until very recently, gone largely unmentioned in key policy documents, including Australia's state and national hepatitis C strategies. This has implications for affected people, complicating life after treatment. It also suggests the need for significant legal reform, and for more agility in both legal and policy responses to large-scale medical and technological developments. In the case of hepatitis C, this includes DAAs, as well as new and novel public health technologies and strategies aimed at enhancements to testing, treatment uptake, epidemic surveillance and more.

## Strategy approaches to cure and post-cure

State and national health strategies are a combination of actions set out to guide and inform policymakers, researchers and others working in the healthcare sector to prevent, test, treat and manage hepatitis C. Overall, they tend to conceptualise post-cure life in specific ways and to characterise 'post-cure' only in relation to ongoing medical issues linked to the virus, and primarily to the surveillance of liver disease in affected individuals. They make the assumption that hepatitis C-related stigma and discrimination is only experienced by or associated with people while they are living with the virus, and that this concern terminates with treatment.

## Language use

People affected by hepatitis C feature in various different ways in strategy documents. Most commonly, the strategies refer to 'people at risk of' or 'living with hepatitis C', with some variations, such as people 'living with or affected by hepatitis C' (*Fifth National Hepatitis C Strategy; Victorian Hepatitis C Plan 2022–2030*). In this report and throughout our publications, we have used 'affected people' and 'people with (a history of) hepatitis C' (see 'Notes on language'). These terms use person-centred language, are more capacious, and recognise that hepatitis C does not always stop affecting people following SVR. The strategies use the term 'cure', rather than 'hep C free', 'cleared', 'treated' or other language choices

that emerged in our interviews.

There has been advocacy aimed at shifting the use of the phrase 'unsuccessful treatment' in medical, policy and research contexts. Historically, responsibility for treatment that has not progressed to SVR has been accorded to individuals, casting people as 'failed' treatment subjects and blaming them for such failure (see Fraser and Seear, 2011). The most recent and current strategies appear to have addressed this, and now use language including 'successful treatment' and 'people who go through treatment'.

The national and state strategies analysed have started to address post-cure concerns, however they remain focussed largely on medical issues after treatment, with some including concerns about the prevention of re-infection. There is scope to further adjust the language used in strategies and policies to better incorporate medical, social and legal developments and to acknowledge the challenges that people face after treatment, as documented in other sections of this report.

## Post-cure life

Strategy documents often begin with the framing of hepatitis C as one of the largest causes of liver cancer. Discussion of any post-cure issues is focused largely on the medical implications of chronic hepatitis C, both for those treated and untreated. Ongoing surveillance and management of people with cirrhosis is considered a public health priority, and the recent *Victorian Hepatitis C Plan* and the expired *Fifth National Hepatitis C Strategy* note the importance of ongoing surveillance and management in the prevention of liver cirrhosis and hepatocellular carcinoma even if people have been cured. The *Fifth National Hepatitis C Strategy* (expired 2022) also acknowledges the small proportion of people who do not reach SVR following DAA treatment, and that this cohort must also be considered for other treatment options.

The 'cascade of care' model was originally developed to assess the effectiveness of HIV treatment delivery, and is now used for hepatitis C and other chronic communicable diseases. It is represented as a continuum from diagnosis to access and retention in care and treatment, to viral suppression. Its strengths as a model include its capacity to identify stages along the continuum where major gaps occur. Some of the state strategies include calls to follow-up and monitor pre-existing liver conditions if required (e.g., *Western Australian Hepatitis C Strategy 2019–*

2023). The *Victorian Strategy overview and system enabler plan 2022–30* refers to ‘all people living with the possible effects of [hepatitis C] within aged care services and programs, considering the long-term consequences of living with the possible effects of [the virus] as they age’ (2023: 31). Two strategies, the *Northern Territory STI and BBV Strategic and Operational Plan 2019–2023* and the *NSW Hepatitis C Strategy 2022–2025*, include sections on ‘post-cure management’, with the Northern Territory’s plan including an action to provide a pathway for people with ‘continuing at-risk behaviours to access [ribonucleic acid] testing [...] for re-infection and management’ (2019: 17). The *Western Australian Hepatitis C Strategy 2019–2023* addresses post-cure life solely in relation to the need for ongoing medical surveillance and care. The (now expired) *Queensland Hepatitis C Action Plan 2019–2022* does not make any references to post-cure life.

### Infection after cure (re-infection)

Aside from the medical complexities and need for ongoing surveillance and management after SVR, re-infection is the only other post-cure concern addressed in the national and state strategies. The reason for the focus on and importance of re-infection in the strategies is because previous exposure to the virus does not provide immunity (unlike in the cases of hepatitis A and B). The actual number of re-infections is unknown (Hajarizadeh et al., 2020), and this is reflected in most of the strategies. Many strategies make the call for system reforms to enhance the monitoring of re-infection and re-treatment as the current surveillance systems are unable to accurately identify these rates. The likelihood of subsequent infection after cure is occasionally linked to structural factors, such as ‘inequitable access to treatment and harm reduction’, as in the case of the *Fifth National Hepatitis C Strategy* (Commonwealth Department of Health, 2018: 17). Several of the strategies indicate that people should be offered ongoing testing and treatment without stigma and discrimination (*Northern Territory STI and BBV Strategic and Operational Plan 2019–2023*; *NSW Hepatitis C Strategy 2022–2025*). The *Victorian sexual and reproductive health and viral hepatitis strategy: Strategy overview and system enabler plan 2022–30*, the companion document to the tailored plans, draws a connection between ‘finding the undiagnosed’ and decreasing the ‘pool of possible re-infections’ (Victorian Department of Health, 2022: 29). The *Victorian Hepatitis C plan*

2022–2030 makes one mention of re-infection, noting that ‘Victorians know what to do to prevent HCV infection and re-infection and are supported to do so’ (Victorian Department of Health, 2022: 21). The plan links this to health information, education and access to needle and syringe programs.

To address the risk of infection after cure, the strategies identify a number of actions including health promotion and education, regular testing, using new testing technologies such as dried blood spot testing and reflexive testing (automatically testing blood samples that are antibody positive), access to prevention, and case management for people transitioning from prison to community. The *Western Australian Hepatitis C Strategy 2019–2023* acknowledges the connection between transmission risk and opioid-replacement therapies (ORT) and recommends further access to ORT.

### Stigma

All of the strategy documents recognise the importance of reducing the reported experience of stigma and discrimination and the need to address their negative impacts on health and wellbeing. They all acknowledge the connections between hepatitis C and injecting drug use in various ways. People who inject drugs are a ‘priority population’ for the targeting of prevention, treatment and ongoing management. The strategies recognise that stigma and discrimination can have significant negative impacts on health and wellbeing, deter people from seeking health care and other services, and affect other parts of life, including employment and relationships, and can potentially lead to social isolation and compromised mental health. The *Fifth National Strategy* acknowledges that the fear of experiencing stigma or discrimination (as opposed to the actual experience of these) can also impact people’s health in negative ways. Some strategies acknowledge that addressing stigma is complex, requires a range of initiatives including potential reforms to law and policy, the removal of structural barriers and improvements to anti-discrimination protections. The *Western Australian Hepatitis C Strategy 2019–2023* recognises that people should not be subject to ‘stigma and discrimination based on their actual or perceived health status’. All of the current strategies draw on the findings of the UNSW Stigma Indicators Monitoring Project (Treloar et al., 2018) to support the need to address stigma and discrimination.

Some of the strategies include targets for addressing stigma and discrimination. For example,

# “LAWS AND LEGAL PRACTICES HAVE BEEN SLOW TO RESPOND TO THE ADVENT OF NEW TREATMENTS, AND THE CIRCUMSTANCES AND NEEDS OF PEOPLE LIVING POST-CURE LIVES.”

the *Fifth National Hepatitis C Strategy* includes a goal to reduce the reported experience of stigma among people living with hepatitis C by 50% (Commonwealth Department of Health, 2018). The possibility that people affected by hepatitis C will continue to experience stigma and/or discrimination following cure is primarily mentioned in the context of further treatment. The National and NSW Strategies use the exact same wording, and articulate it in this way:

*People at risk of infection after cure should be offered ongoing testing and treatment if required, without stigma or discrimination. (2018: 26; 2022: 17).*

The *Western Australian Hepatitis C Strategy 2019–2023* takes a slightly different approach, which arguably takes post-cure life into consideration. That strategy identifies the need to educate relevant workforces about the delivery of stigma-sensitive care, and

*the delivery of non-stigmatising service throughout all stages of the hepatitis C cascade of care, from testing to diagnosis,*

*treatment to cure, and follow-up and monitoring of pre-existing liver conditions if required (2019: 24).*

Overall, there is scope within the strategies to better address the medical, social and legal challenges that affect people after cure. This includes explicit recognition of ongoing experiences of stigma and discrimination, and measures to monitor and address post-cure challenges. As we noted earlier, during the life of this project there has been some progress on these issues in strategy documents, including the recognition of legal issues and post-cure issues in the *Sixth National Hepatitis C Strategy*, a draft of which was circulated for consultation during the preparation of this report.

## **Legal approaches to cure and post-cure**

Stage one of the project involved mapping legal frameworks impacting on people with (a history of) hepatitis C. This mapping exercise involved the collection of legal frameworks relevant to hepatitis C, including case law and legislation. See ‘Methods’ for more detail on how these were collected.



## Legislation

In total, 59 pieces of legislation were found. Of those, 31 (53%) specifically mentioned hepatitis C. The next step was to assign a 'focus area' to each piece of legislation. This was an exercise designed to establish which areas of law each piece of legislation fell within, noting that some crossed multiple areas (e.g., the Public Health and Wellbeing Act 2008 (Vic) covers both blood donations and identifiable notifications). The most common areas of law were:

- identifiable notifications under public health (11 pieces of legislation)
- combat sports and discrimination (nine each)
- workers' compensation (six)
- mandatory testing and blood donation (five each)

## Case law analysis

Four papers have been produced drawing on data from our legal mapping. These papers cover criminal law (Seear et al., 2023), insurance law (Mulcahy et al., 2022), social security and migration law (Mulcahy et al., 2023), and health privacy law (Mulcahy et al., forthcoming b). Summaries of the findings from these papers are detailed below.

### Criminal law

Of the 232 cases identified, 98 involved criminal law, consisting mainly of criminal cases where an offender was being sentenced (80) or crime compensation cases where a victim was being compensated (18).

In crimes compensation cases, we found that mental or nervous shock due to concern about the possibility of contracting hepatitis C counted as an 'injury' for the purposes of victims of crime compensation (*Morris v Lowe* [2009] QSC 441; *Northern Territory of Australia v Bentham* [1999] NTSC 119), even if that shock only lasted for a short period (*Auton v Northern Territory of Australia* [2022] NTSC 69; *Calcutt v Letondeur* [2006] QDC 78), and even if the possibility of infection was deemed to be low (*Morris v Lowe* [2009] QSC 441; *Harman v Horne* [2001] QCA 349). In the only crimes compensation case decided since DAAs were added to the PBS (*James* [2018] WACIC 12), there was no mention of new DAA treatments or their significance. In addition, the court accepted that potential exposure to the virus resulted in 'psychological trauma' and that the victim should be compensated.

In criminal cases, we found that courts have commonly taken an offender's hepatitis C status into account in sentencing (see, e.g., *Sant v R* [2014]

NSWCCA 261; *R v Prideaux* [2009] VSCA 193; *R v CBK* [2002] NSWCCA 457). In some cases, the fact that an offender had hepatitis C mitigated their sentence (see, e.g., *R v Azar* [2000] NSWCCA 26; *R v Mueller* [1996] NSWSC 232). Historically, this was usually because life expectancy was considered to be reduced by the disease or because it was disabling and would make imprisonment more burdensome for the offender (*R v Johnstone* [2011] VSC 300; *R v Glenbar* [2013] QCA 353; *DPP v Pittard* [2013] VCC 1150; *Sumner v R* [2010] VSCA 298; *Drury v The State of Western Australia* [2010] WASCA 220; *R v Orbach* [2007] VSCA 166). Importantly, this approach to hepatitis C persists now, even after the advent of DAAs (*Mitchell v R* [2018] VSCA 158; *DPP v Mitchell* [2017] VSC 423). In several other cases, the offender's positive hepatitis C status was treated as an aggravating factor during sentencing, particularly where there was an assumed risk of transmission (*R v Leighton* [2014] QCA 169; *Police v Carter* [2002] SASC 48; *R v BBK* [2008] QCA 2; *DPP (Acting) v Poole* [2015] TASCAA 10). Other cases confirm that actual transmission is not required for the virus to be considered an aggravating factor (*R v Robinson* [2007] QCA 349; *R v Sparks* [2010] NSWSC 1512; *Moore v Commissioner of Police* [2013] QDC 59; *Maslin v Police* [2006] SASC 333; *DPP v Gholikani* [2016] VCC 2032).

The only case that grappled with the advent of DAAs in any depth was the widely publicised criminal case known as *Peters v R (No 2)* [2019] VSCA 292. The *Peters* case confirmed that the apparent biomedical significance of these treatments is of little consequence under criminal law. That is, even if victims acquire hepatitis C and can then be cured with DAAs, it is possible for the law to still treat the initial infection as a grave or 'serious' injury for the purposes of sentencing the offender. This approach appears to be based on public policy grounds in the criminal law; namely, that the criminal law treats injuries as serious without regard for how those injuries might be subsequently treated (i.e., through DAAs). This approach ensures that offenders are punished for the potential consequences of their actions, regardless of any steps that victims might later take to limit the extent of those injuries.

Our research found that hepatitis C can be an aggravating factor when the offending occasions an assumed risk of transmission to a victim, but it can be a mitigating factor when it impacts the health and wellbeing of the offender with hepatitis C in prison, and that the advent of DAAs had no legal or

practical significance to legal outcomes. Put simply, even after the advent of DAAs, the law retains its longstanding view of hepatitis C as an extremely serious disease.

### **Insurance law**

While no data are available on levels of and access to private health insurance among people in Australia with (a history of) 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 (Stepanova, 2011; Ong et al., 2005). A lack of insurance coverage matters for several reasons, including because it may create barriers to accessing healthcare.

Our research found that even inadvertent and unintentional non-disclosure of (a history of) hepatitis C in an insurance application can be deemed material to the nature and extent of the risk to be underwritten and can effectively void insurance contracts (*Stevens v Colonial Mutual Life Assurance Society and Commonwealth Financial Planning* [2012] NSWDC 94; D19-101027 [2019] SCTA 153 (Death benefit)). However, this approach may change following recent reforms to replace the duty of disclosure that applicants for insurance have, with a duty to take reasonable care not to make a misrepresentation, though an insurer may still avoid the contract if the insured breaches their duty to take reasonable care not to make a misrepresentation (*Financial Sector Reform (Hayne Royal Commission Response) Act 2020*). Moreover, a person with (a history of) hepatitis C is still likely to have to pay a higher premium due to the assumed risk associated with (a history of) the virus.

Australian discrimination law allows insurers to discriminate so long as any discrimination is reasonable in the circumstances and has regard to reasonably reliable actuarial or statistical data (see, e.g., *Disability Discrimination Act 1992* (Cth) s 46). Our research raised concerns about whether insurance companies are relying on up-to-date statistical or actuarial data and found that there is a lack of transparency about the data relied on in both the formulation of insurance policies and in insurance practices.

However, the potential for discrimination against people with (a history of) hepatitis C may be ameliorated by new laws in the Australian Capital Territory, which 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 actuarial or statistical data upon which any discrimination is based (*Discrimination Amendment Act 2023* (ACT) s 8). This applies to all insureds in the ACT, not just those with (a history of) hepatitis C. Our research argues for other jurisdictions throughout Australia to follow the ACT's lead and swiftly enact reforms to ensure insurance discrimination decisions are transparent (such that they can be shown to be proportionate and justifiable), and that insureds be given access to actuarial or statistical data upon which any discrimination is based. This should lead to the replacement of any blanket exclusions of people with (a history of) hepatitis C, reduce premiums or waiting periods, give consumers greater information with which to challenge insurance discrimination if it occurs or is suspected, promote reliance on higher quality data when making insurance decisions, and narrow the exceedingly broad exceptions insurers currently use to discriminate, while still respecting their right to do so provided it is justifiable, proportionate and based on publicly available actuarial and statistical data. Our research also argues for insurers to ensure that policies and questionnaires around hepatitis C are necessary, based on up-to-date local actuarial and statistical data, and that questions are posed in sensitive, non-stigmatising ways.

### **Social security and migration law**

Of all cases analysed, 84 took place within the Administrative Appeals Tribunal, and a significant proportion of these fell within the areas of social security claims and refugee or migration matters. Our research examined these cases and found a shift in rhetoric surrounding hepatitis C in these contexts: from a permanent, impairing disability to a temporary, curable illness that aligned with the introduction of curative treatment. Our research also found that, while hepatitis C is recast in post-cure cases as temporary, the stigma associated with it – and perhaps exacerbated through the telling and retelling of one's experiences with the virus before a court of law – may be more lasting, and that the mark of hepatitis C is still present after curative treatment, at the very least in the legal documents in which the lives of people affected by the virus are recorded.

Our analysis of social security decisions raised important questions about whether hepatitis C can be classified as an 'impairment' for the purposes of

accessing the disability support pension, and whether it affects a person's capacity to work. We found that applicants with hepatitis C are placed in a double bind: hepatitis C is only regarded as an impairment for the purposes of the disability support pension if it has been treated, but once it is treated successfully, it is no longer an impairment.

Our analysis of migration and refugee decisions found that difficulties accessing treatment for hepatitis C in a home country may be considered in decisions about visa cancellation and refoulment (*PBPZ v Minister for Home Affairs (Migration)* [2019] AATA 18). However, asylum seekers with hepatitis C have not been held to be a particular social group for the purpose of refugee claims (*SZRIR v Minister for Immigration* [2012] FMCA 1006; N95/09330 [1996] RRTA 3259), and in some cases, have been told that they will not face discrimination if returned to their home country so long as they keep their hepatitis C status private (1208444 [2012] RRTA 883).

#### **Health privacy law**

Our research found that the race to elimination of hepatitis C has led to novel methods of finding cases of the disease whereby eligible health practitioners, including nurses, sift through health records to identify people who fall into a risk category for hepatitis C and subsequently follow up with them (Horwood et al., 2020). A broader push is also underway to increase the availability of and access to electronic health records.

Given concerns about privacy, we argue that these novel approaches raise important questions, including about how health information and data should be handled, and that there is a need to improve health information sharing to reduce stigmatisation and discrimination against people with (a history of) hepatitis C. This includes improving health providers' use of health information in ways that increase the confidence of people with (a history of) hepatitis C that their privacy will be protected and respected and handled in ways that reduce the stigma that attaches to a record of hepatitis C; simplifying the process for accessing and correcting health records; and providing a clearer and more accessible complaints mechanism for breaches of health information privacy. We conclude that health information needs to be collected, kept and shared in ways that do not further stigmatise people with (a history of) hepatitis C.

## **Conclusion**

Law and legal processes can shape stigma and discrimination experienced by people with (a history of) hepatitis C, with the capacity to both reduce and reproduce it. Historically, national, state and territory strategies have neglected issues affecting people after treatment, including legal issues; however, the draft *Sixth National Hepatitis C Strategy* has begun to remedy this by more thoroughly addressing post-cure life, with particular attention to stigma, discrimination, legal and human rights issues. We have found that legal approaches towards hepatitis C after cure are inconsistent. In some cases, the virus continues to be treated as 'serious' or 'grave' and operates as a source of symbolic horror and/or shame; in other cases, hepatitis C is constituted as something that can be cleared and is accompanied by an expectation that people will simply 'move on' after treatment. In further cases, attitudes towards hepatitis C remain outdated, meaning that people with (a history of) the virus remain exposed to discriminatory treatment. These findings suggest that approaches to hepatitis C across different areas of law are variable and unpredictable and not always or consistently shaped by developments in biomedicine and healthcare. This has implications for the treatment of people with (a history of) hepatitis C, and the stigma and discrimination they may face.

## The implementation of direct-acting antivirals

This section describes findings related to the public rollout and distribution of DAAs, including how people treated with DAAs felt about their experiences and what changes have emerged in policy and practice as new treatments and the elimination agenda were implemented. Although some of the findings we explore in this section relate to experiences of 'pre-cure' life, they have implications for life after cure and the elimination agenda. This is because, as we have argued elsewhere, there can be an 'indivisible flow' between pre- and post-cure life, with what happens pre-cure shaping post-cure experiences, and vice versa (Seear et al., 2021). For instance, the willingness of people affected by hepatitis C to take up treatment might be informed in part by expectations about cure and the extent to which they see its promises being fulfilled among others undergoing treatment. In addition, stigma and discrimination after treatment can increase social isolation and alienation. The likelihood of re-infection may also increase, especially where people are stigmatised or discriminated against and socially excluded, as these forces can drive drug use underground and undermine optimism about access to mainstream life.

### Experiences of treatment

For some of our participants, DAA treatment was felt to be life-changing or literally lifesaving. For those who were less concerned about their hepatitis C diagnosis to begin with, treatment was generally felt to be less transformative, and in some cases merely something on people's 'to do' list. On the whole, participants reflected positively on treatment experiences, describing limited or negligible side-effects from the medication, supportive relationships with trusted healthcare and other service workers (especially peers), and positive feelings upon completion, including amazement, gratitude and relief.

For example, Cassie lived with hepatitis C for many years but had deliberately avoided earlier, interferon-era treatments because of the side-effects she observed in others. When she was eventually treated with DAAs, she said she was 'amazed' at the simplicity of treatment and 'elated' when she cleared hepatitis C.

*I was really amazed at how easy it was, one tablet a day, and I had no side effects, none*

*whatsoever. And then to find out that I was clean, I'll never forget it, because so many of my friends were dying from it and had been really sick from it and had such disastrous things going on [...] I was elated. I think it was just because I didn't have to go through all the shit that my friends had gone through [with interferon-era treatments] I'd already been brutalised by stigma, and I was just happy to be free of it and it was so easy.*

Jenna reiterated this sense of awe and surprise at how easy and swift the process was. Treatment had loomed as an administratively daunting prospect on Jenna's personal 'to do' list for some time, so it felt especially manageable when it eventually took place:

*If I spoke to somebody else who had been treated, we would just be like marveling at how effective and how easy the treatment was and how [...] relatively simple, you know, the whole process was, considering how serious the virus is, to get treated, and considering how hard it used to be or how bad the treatment used to be. Yeah. So, I've had a few conversations like that, like 'Yeah, me too, I've been treated'. 'God! Isn't it amazing? It's so quick and it's so easy'.*

For some, treatment could be viewed in a positive light, but, at the same time, as not living up to hopes and expectations. Daniel, for instance, was treated in his late fifties after living with the virus for over two decades and anticipating the arrival of new-generation treatments with some urgency, as he had been unable to complete earlier treatments due to their side-effects. He recalled feeling deeply fortunate when the time finally arrived, and yet the immediate aftermath was a surprisingly difficult time, as he recalled:

*It took a while for things to change [...] Bloods ended up being perfect [...] and then a whole other sort of thing happened because as the months went by, I just sort of sunk deeper and deeper into depression because, you know, I was still divorced, I still didn't feel well, I'm still looking after mum and I'm thinking, 'Why hasn't my life changed? You know, I'm not a leper anymore.' And it took about three years before I really felt like 'I'm back' [...] I went through a whole bunch of antidepressants and stuff and I think I did*



*a lot of harm by not getting myself the right mental health treatment earlier [...] When they cured me, it took a little bit longer than just to say 'You're cured' to feel good.*

Although Daniel felt treatment had been extremely valuable, he reported realising further down the track that he had needed support with a 'whole lot of burden[s]', including his mental health, relationships, financial matters and caring duties. He pointed to an unmet need for compassionate, stigma-sensitive health care and social services (see Lenton et al., 2021) for people with (a history of) hepatitis C, accessible after treatment completion, and that offered support for a range of things without stigmatising judgement. He said:

*It's like you give them the cure, the \$70,000 cure or whatever, but there's nothing else, so you're still on your own. You're still, you know, having to do that fight [...] After years of feeling a bit outside, for me, I needed a manager or a smile I recognised or something to be there with help [...] I would say, honestly, that being beaten up in a sense by the whole hep C and pain management issues, that you go into these places [e.g., social services and health care] wary of [...] more of that sort of treatment.*

Stigma shaped many people's accounts of treatment and its impact, including how they reflected on living with hepatitis C. Simion provided an example of this when he described completing treatment as enabling him to no longer feel 'dirty':

*I was just elated. I was so happy, you know. I felt clean. I felt [laughs] like actually clean. I didn't feel like a dirty diseased scumbag, you could say, because when you have a virus and it's a drug-related virus, you feel dirty and you are. You're infectious, you know. All these negative things that people talk about and then you find yourself in that position, it's very hard to not feel that way about yourself.*

**"IT'S LIKE YOU GIVE THEM THE CURE, THE \$70,000 CURE OR WHATEVER, BUT THERE'S NOTHING ELSE, SO YOU'RE STILL ON YOUR OWN. YOU'RE STILL, YOU KNOW, HAVING TO DO THAT FIGHT."**

## Treatment as a gift

Participants often articulated their access to hepatitis C treatment through notions of luck, like winning the 'lottery', and many described it as a 'gift', a 'present' or a gifted 'opportunity' – sometimes explicitly from the state. For example, Dana said she

*just felt so lucky that I got the call, that this stuff worked and I got it for free [...] I just felt like I'd won the lottery.*

Many expressed an awareness of the cost of treatment, and recalled the precise unsubsidised cost printed on the label of their medication. Importantly, the notion of treatment as a gift was often accompanied by an expression of personal responsibility. Patti, for example, said:

*Because I saw how expensive it was I felt like I owed, you know, my body and, you know, people who were sick who have to pay \$23,000 or whatever to, you know, try and eat well and do everything [...] I'm a firm believer in, you know, if you're going to do something, you shouldn't be allowed to just, you know, waste government's money over and over again.*

Extending this idea of treatment as part of a 'gift' economy, some people used metaphors of a 'debt' they 'owed' to the state and/or described concerns not to 'waste' the opportunity, either by damaging their prospects of achieving SVR, or by (putting themselves at risk of) acquiring the virus again after cure. Elena expressed some of these themes when she reflected on the high cost of treatment and described people who access retreatment as an 'abuse':

*I mean, this hep C treatment is \$300,000 a pop, each human, each person, the course. It's a lot of money, you know, and we're lucky to have that for free sort of thing if you're eligible and, you know, some people I know have abused that and have used the new meds a number of times. Other people have just done it once and that's it, they have never used again, like myself, you know, just got clean and stopped and moved on in my life.*

While many participants approached treatment with the promise of renewed health and reduced stigma in mind, cost loomed large for people

treated with DAAs, even in a context of universally subsidised access. This may in part be attributable to discussions of cost-effectiveness and other cost-related issues in media coverage of new treatments and of the elimination agenda in Australia, and discussions of the significance of the national policy to invest in unsubsidised treatment (see Farrugia et al., forthcoming). It may also be informed by the comments of treatment and other healthcare providers, as Evie suggests when she reflected that it was:

*really impressed upon me about what an opportunity this was, and it was, you know, a real gift and not to basically fuck it up [...] I felt a lot of pressure to make sure that this golden opportunity that I'd been given wasn't wasted.*

These themes of cost, luck, gratitude, treatment as a gift, and the need to make the most of the opportunity and not to 'waste' it might be suggestive of a compromised relationship to health care among some people with (a history of) hepatitis C (see Farrugia, et al., forthcoming). It suggests that among people who have undergone treatment there are those who do not view themselves as citizens intrinsically entitled to treatment or worthy of public investment in their health, but rather as an additional burden on the Australian healthcare system and the government and taxpayers that fund it. In other words, they see their inclusion in Australian healthcare through the provision of DAA treatment as exceptional rather than routine.

## System changes

DAAs and the investment in elimination have stimulated significant transformations to the delivery of hepatitis C care in Australia, with implications for affected people's access and experiences. Before DAAs, hepatitis C care was only available through specialist tertiary-based services (Richmond & Wallace, 2018). Now it is increasingly available in nurse-led community clinics, prisons, alcohol and other drug treatment settings, pharmacies that administer opioid pharmacotherapy and other non-hospital settings (Bajis et al., 2017). Treatment has also become more widely available in general practice, with GPs prescribing 43.6% of courses of DAAs in 2020 (MacLachlan et al., 2020: 5). The integration of hepatitis C care into primary health care is part of a broader public health policy of decentralisation and the "democratisation" of access' to care (Harris & Rhodes, 2018: 30), as set

out in Australia's *Fifth National Hepatitis C Strategy* (2018: 25). It is enabled, in large part, by the less administratively and medically complex treatment sequence offered by DAAs, which has allowed care to expand beyond its traditional province of specialist, hospital-based management by gastroenterologists and hepatologists.

Several stakeholders pointed to the enhanced accessibility of treatment, and a tantamount reduction in administrative and other barriers, and suggested that these have the capacity to reduce structural stigma, in which formal or informal organisational roles either deliberately or inadvertently create and maintain social inequalities (Knaak et al., 2020: 4). For example, P23 (policy) suggested that:

*Things like [community-based care models] are really good opportunities to address stigma [... It] can be challenging for someone to go to a hospital-based clinic [...] hospitals often have good public transport and things like that, but the referral process might not be that clear or you know actually walking into a cold hospital-type clinic, you know doesn't work for everybody.*

The movement of hepatitis C care into spaces beyond specialist and hospital contexts was seen as particularly important, and to have implications for stigma and discrimination. P18 (policy) described this transformation:

*DAAs [... have] allowed non-liver clinic specialists to test and treat their patients, so it has sort of empowered alcohol and other drug clinicians, nurse practitioners and GPs to feel like they can do this [...] it does sort of, for me, suggest that maybe it minimises how big hep C is as a problem. You know, this person doesn't necessarily have to go off to a specialist and is brought back into some of these services, it could reduce the size of it.*

A number of stakeholders celebrated the movement of hepatitis C care into specific and needs-tailored community health care and other services, reflecting recommendations in other recent international research that has endorsed offering hepatitis C care in such settings, and in models that are peer-led, peer-informed and/or co-delivered with or linked to other relevant services, including harm reduction (e.g., Richmond & Wallace, 2018; Von den Hoff, et al., 2021; Biondi & Feld, 2020).


Several stakeholders cited the role of GPs in this transformation, including P27 (service delivery) who noted that they were 'seeing more [providers] in primary care less reluctant to prescribe and more GPs [that are] more likely to be prescribing out in the community'. They saw this as a form of institutional stigma reduction. The ability for GPs to prescribe treatment for DAAs reduces barriers, as they explained:

*DAAs have also gone a long way in that respect as well in being able to reduce some of the stigma from that angle too, because if you've got a GP who's then got to work with a specialist and the interferon and all of that sort of thing, that can mean more work for them. So, that can lead to a level of stigma at [...] the coalface.*

### Normalisation

A key development in the delivery of hepatitis C care is its increased normalisation, which was highlighted by stakeholders and posited by some as a development with implications for ameliorating stigma and discrimination. Broadly speaking, normalisation refers to the integration of hepatitis C testing, treatment and surveillance into general preventative healthcare processes, settings and contexts in order that these become 'normal, routine public health practices' (Hindmarch & Orsini, 2021: 100). P13 (policy) described hepatitis C normalisation as a movement from 'boutique' care to 'whole-of-population efficiencies'. They suggested that while BBVs and sexually transmitted infections (STIs) have customarily been 'seen as boutique or bespoke or a specialist kind of content area within health care', DAAs enable hepatitis C to become a 'mainstream conversation' in health care, 'no different from dealing with obesity' and 'no different from any other health priority areas'. P3 went on to explain how healthcare normalisation may function to reduce stigma. As they said, hepatitis C is increasingly becoming part of a

*normalising conversation in healthcare and in primary community care, like it's no different from – in fact it's easier to deal with than – diabetes these days. I think from a service delivery point of view, it's taken hep C out of the kind of contagion shadows, associated maybe with HIV, and it's alongside management of diabetes, or it's alongside*



*other things in general practice now, and so I think [DAAs] are beginning to reduce a sense of stigma associated with living with the virus as it become a more normalised option within primary community care.*

Some stakeholders advocated for the policies that would lead to further normalisation of hepatitis C as a strategy to specifically address stigma and discrimination. For example, P24 (policy) suggested that, via normalisation,

*We can mainstream the treatment in a sense now. That's [...] the route to stigma reduction, is through normalisation. Normalisation is getting treatments into places, and*

*getting our frontline health professionals comfortable with asking the screening questions and offering the treatment. So, I think that's probably the — it's probably already underway, I guess, is what I'm trying to say. The fact that it's moved from being a specialist prescriber to being something that's more widely available to be prescribed is probably the biggest stigma reduction strategy that you could have hoped for in the last little while.*





Because normalisation may include a focus on supporting and training GPs to tackle hepatitis C as a 'normal', 'routine' part of their work, it was thought that it could help address the reported unwillingness of some GPs to provide hepatitis C care. It was suggested that such reluctance, implicated as it is with stigmatising assumptions about people with (a history of) hepatitis C, can be overcome by further normalisation. For example, P18 (policy) speculated on the reluctance of some GPs to treat people

with (a history of) hepatitis C being based on assumptions that they are people who inject drugs, and therefore they are 'complex patients'. P18 suggested that normalisation could help overcome those assumptions among GPs. As they explained:

*people who inject drugs are [imagined to be] very complex and may not, you know—they're going to make this clinician's life harder, whether it's because they're not going to come to their appointment; or they will you know, ruin some reputation of the GP waiting room [...] they're going to have a lot of other health problems that the GP has to look into and just, you know, overall it's not going to be worth their time [...] I think overall,*

*it being more complex, is what I hear. I don't know if it's so much of judging that person for injecting itself, but it's about 'oh well, that person injects drugs, so they must also have this other tidal wave of things to deal with'.*

This suggests something of a double bind in which normalisation appears to support a reduction of barriers to health care and to potentially reduce hepatitis C-related stigma and discrimination, but only where patient's needs are relatively straightforward, and healthcare consumers do not present as 'complex'. Therefore, there may be limits to the promise that normalisation will alleviate discrimination and stigma and this highlights the entrenched dimensions of the stigma process surrounding hepatitis C (see Kagan et al., 2023).

While normalisation was viewed as a means of bringing hepatitis C into the space of routine, mainstream healthcare practice, stakeholders indicated that injecting drug use is stubbornly fixed in the space of the exceptional, and remains heavily stigmatised. Thus, normalisation carries risks, including that it might actually reinforce stigma and discrimination, thereby generating or exacerbating social isolation and alienation for people with (a history of) hepatitis C. These processes, in turn, increase the risk of re-infection, as we noted earlier. And, while hepatitis C normalisation might bring more people with a history of injecting drugs into the purview of general practice, the DAA treatment process itself does not require discussion or disclosure of (a history of) injecting illicit drugs. This has mixed implications: on the one hand, this may give healthcare consumers more control over whether they discuss any (history of) injecting drug use, which may give some people more of a sense of agency to avoid experiences of stigma and discrimination; on the other hand, eliminating the need to address (a history of) injecting drugs means doctors and other healthcare workers can test and treat hepatitis C but are not compelled to extend their practice to address specific other needs that may affect people who inject drugs, including harm reduction information and resources.

### Finding the 'missing millions'

As mentioned above, the goal of achieving hepatitis C elimination by 2030 has inspired new approaches to finding, diagnosing and treating people with the virus who have themselves not presented for testing or treatment. This includes

case-finding projects that aim to identify undiagnosed people, and/or to contact those who have been previously diagnosed but are 'lost to follow-up'. These operate through at least three different approaches: 1. actively recalling people by searching health records; 2. using jurisdictional hepatitis C notification data to contact either the testing clinician to encourage PCR testing, or the person tested to offer further testing and treatment; and 3. emergency department screening for hepatitis C, which is happening in England, Ireland, Canada and Australia. Many of these approaches have ethical infrastructures in place, and/or are embedded in settings attended by affected people, including people who inject drugs. In some of these settings, important relationships of trust (between healthcare professionals and people with a history of hepatitis C) are established. However, some of these novel approaches to finding the undiagnosed or untreated raise legal and ethical questions, particularly concerning informed consent. For example, in some pilot projects and settings, there has been a shift towards the use of 'opt-out' methods for obtaining consent, raising concerns about the implications for people affected, and the legal status of such moves (see Seear & Lenton, 2021). There has also been a broader shift in the terminology used to describe policy and practice priorities, with references to the need for 'testing and diagnosis' beginning to give way to references to the need for 'screening and retrieval'. Our research has also found some language in use that may position individuals and their rights (including the right to informed consent) as a potential impediment to testing and treatment, or a barrier to desired (treatment) outcomes. Other recent research (e.g., Fomiatti et al., 2022a; 2022b) suggests that a range of forces might influence a decline in rates of testing and treatment, or the reasons people become 'lost to follow up', including experiences of stigma and discrimination, and fears of legal, employment and other repercussions if a person is found to have hepatitis C.

Healthcare practices including those that take place prior to cure are inextricably linked to post-cure life. For instance, one possibility is that new approaches to testing and treatment may help locate people affected by or at risk of hepatitis C in circumstances where they were not previously aware of treatment options. This could generate goodwill and gratitude towards healthcare workers and systems who have enabled them to acquire important healthcare knowledge and/or be cleared of hepatitis C. On the other hand, such practices

risk undermining confidence and trust in healthcare systems, which is a particularly important issue for those with (a history of) hepatitis C, given their historic and ongoing marginalisation, criminalisation and stigmatisation. Thus, novel approaches have the potential to generate or exacerbate mistrust in healthcare systems, which may lead to social isolation, and introduce additional medical, legal and social risks. These possibilities suggest that there is a need for caution with novel or new approaches to finding and treating the so-called 'missing millions', and that all such approaches must be evaluated for their wider impacts, including for post-cure life.

### Data-driven approaches

Changes in technologies of patient data management are making it feasible to use hepatitis C clinical data for large-scale automated surveillance and monitoring, including case finding. Case finding is also made possible through the re-use of departmental notifications and contact tracing. Hepatitis C elimination goals have created a strong mandate for the expansion of data-driven approaches. These methods are increasingly being pursued to reach elimination targets, especially in light of the aforementioned decline in treatment uptake.

While there was some enthusiasm for data-driven interventions among those we interviewed, stakeholders were also suspicious of the use of data collection processes and systems, or believed that people with hepatitis C were. As we describe in the next section, people who had undergone treatment had ongoing concerns that the record of their history of the virus on medical records enabled stigma and discrimination in healthcare settings, and acted as a significant and ongoing obstacle to accessing healthcare. Some stakeholders expressed concerns about the sharing of people's health data without informed consent or prior knowledge, and worried that while systems offer putative protections for patient rights, maintaining these protections depends on a high level of legal, health and data literacy. Concerns that data-driven approaches could perpetuate hepatitis C-related stigma and discrimination were also raised (see valentine et al., forthcoming).

### Conclusion

The advent of DAAs have been transformative for many people who have undergone treatment. Perhaps unsurprisingly, they have been less effective at addressing hepatitis C-related

stigma and discrimination, including hepatitis C's association with injecting illicit drugs, which is a highly stigmatised practice and remains criminalised in all Australian jurisdictions. Similarly, while system changes and other developments associated with the rollout of DAAs, including the 'democratisation' of access to and provision of treatment and the normalisation of hepatitis C care, are viewed as changes with the potential to reduce stigma and discrimination, there are concerns that both existing and new approaches to hepatitis C work to reproduce or exacerbate stigma and discrimination. For example, both people with (a history of) hepatitis C and stakeholders who work with them remain concerned about medical records, including state notifications and digital health record systems, and their potential to affect people with (a history of) the virus, as well as their ability to access healthcare, their right to privacy and their ability to control the disclosure of their (history of) hepatitis C.

## Post-cure life

### Positive experiences of post-cure life

In interviews, people who had undergone treatment with DAAs shared numerous positive experiences of life after treatment, and there were widely shared sentiments of feeling happy and grateful to no longer have the virus. These feelings were especially prominent among those who had been living with hepatitis C for many years; for those who had experienced significant disease progression, treatment was experienced as transformative. Patricia described this feeling as one that, for her, remained ongoing:

*I haven't got hepatitis C anymore, and the change is remarkable and brilliant and wonderful and there is [...] not a day that goes past where there's [not] at least a moment where I'm just really aware of what it is to be alive and what it is to be free of the disease.*

Hepatitis C was described by some participants as a catalyst for other improvements. For example, Alice said that

*a lot of things started going good and I would like to think that that was one of the beginning parts to my life changing [...] I was healthier and able to live my life a bit better.*

Dana, who completed DAA treatment as part of trial in 2015, echoed a number of participants when she described the relief of no longer feeling like an infectious person:

*I felt like I had clean blood again and, you know, I was no longer Typhoid Mary. Not that I felt seriously like Typhoid Mary, but I was constantly aware that I had to— and then after that, when I cut myself, I just look at my blood and say, nothing to see here, just normal blood.*

This sense of relief at no longer needing to constantly worry about infecting others reflects the findings of other research on experiences of hepatitis C treatment (e.g., Guggisberg et al., 2022). Several of our participants also linked this relief to positive changes in relationships, including among family. For example, Angus said:

*It made me feel a lot easier and comfortable around people again. [...] I'm more at ease and I feel more comfortable with friends and family again.*

**“I’VE HAD PEOPLE DOUBLE GLOVE THEMSELVES. EVEN NOW, IT’S STILL AN ISSUE. EVEN THOUGH I SAY, ‘NO. I’M HEP C FREE’, STILL NOTHING CHANGES. NOTHING’S CHANGED.”**



### The persistence of hepatitis C after cure

Some participants experienced ongoing pathogenic effects of having lived with the virus for many years, particularly if it had progressed to liver damage or liver cancer. Some were therefore continuing to grapple with major and even life-threatening health complications. Additionally, many reported that they continued to experience the social burdens of hepatitis C, including stigma and discrimination, after treatment. These experiences largely occurred in healthcare settings. In the following sections, we outline some of these social 'afterlives' of the virus (see Kagan et al., 2023).

### Stigma and discrimination persist in healthcare settings

A number of those we interviewed reported experiencing stigma and discrimination after cure, with those experiences disproportionately manifest in healthcare settings, where it was felt that the knowledge among health workers of their history of hepatitis C led to assumptions about (a history of) drug use. Problems that people reported included:

- Delays to diagnosis, and diagnostic experiences that seemed unnecessarily complex and protracted
- Feeling as if healthcare workers were treating them with suspicion or not taking complaints of pain and other symptoms seriously
- Being accused of lying
- Being accused of drug seeking
- Being subject to assumptions that medical complaints of various kinds were the results of drug use, rather than something else
- Being denied treatment, especially pain treatment
- Receiving unusual or experimental pain (and other) treatment combinations that were ineffective or that triggered onerous or debilitating side-effects
- Practices of unnecessary infection control, such as double gloving
- Being subjected to rude and stigmatising comments.

These experiences occurred across the gamut of healthcare areas, including in pathology, dental care, obstetric and gynaecological care, pain management, surgery, anaesthesia, general practice and more.

Elena, for example, described these experiences in ways that reflect our earlier description of a 'indivisible flow' (Seear et al., 2021) between pre- and post-cure life. She said that: 'Since I've been treated, I still get the same rhetoric'. Echoing the comments of

others, Elena highlighted the role of medical records in enabling these experiences, stating:

*[I]t's on my [dental] record that I had it [hepatitis C]. Now whether they've got [an] updated record, they still ask, and I tell them 'No', [but] the rhetoric doesn't change. Their mannerisms or anything like that doesn't change. It's still, 'Okay, we've got to be ten steps away from you, arm's-length away', and I've had people double glove themselves. Even now, it's still an issue. Even though I say, 'No. I'm hep C free', still nothing changes. Nothing's changed.*

These experiences raise the concern that, alongside disclosures of (a history of) the virus, medical records and/or antibodies may be viewed by practitioners 'as indistinguishable from other factors and forces sometimes entangled or conflated with hepatitis C, including HIV, sexual practices, hygienic practices and dirt' (Seear et al, 2023b: 14–15) or, sometimes, as 'synonymous with having the virus and disease' operating 'as a kind of incriminating evidence of past hepatitis C status and/or injecting drug use' (16) that makes people vulnerable to ongoing stigma or discrimination in healthcare.

Several participants said they had become cautious about disclosing, or no longer disclosed, their history of hepatitis C to healthcare professionals. For example, Evie said she preferred:

*not to disclose to doctors that I have been hep C positive or that I'm on 'done [methadone] because it really does skew— I don't know whether I'm self-stigmatising or whether they're stigmatising, but something changes in the dynamic. I don't feel like I'm taken seriously with my issues.*

This aligns with findings from other recent research (e.g., Richmond et al., 2018; Madden et al., 2018: 4), where people treated with DAAs reported an ongoing reluctance to disclose a history of hepatitis C in healthcare settings for fear of a stigmatising response, delays or disruptions to care, or withheld treatment. Indeed, some of our participants who have undergone treatments with DAAs said that reducing or removing a need to disclose their (history of) the virus, and therefore potentially avoiding instances of stigma and discrimination in this way, was one of the most prized outcomes of treatment.

For some, becoming 'hep C free' promised the ability to shrug off the 'drug user' label – however, the deployment of such labelling was also often felt to be outside their control. In other words, while treatment was seen as an end to chronic hepatitis C among participants who have undergone it, several felt that its presence in medical records would mean they were permanently marked as people with the virus. Elena used the metaphor of a 'red dot', saying:

*That red dot is on your file. That red dot won't ever get off your file in terms of health.*

Stakeholders expressed parallel concerns that affected people continued to confront stigma and discrimination across settings, including after cure. They suggested that the stigma surrounding hepatitis C remains heavily associated with – and hard to disentangle from – attitudes to injecting drug use (e.g., Fraser and Seear, 2011); and, as in the findings of earlier research, stigmatising and discriminatory practices most commonly occurred in primary healthcare settings, including GPs, outpatient hospital departments and mental health services. Stakeholders believed that healthcare practitioners' assumptions that people with (a history of) hepatitis C are people who use drugs, and therefore are 'complex patients' presenting with multiple health problems would persist if a person's previous hepatitis C status remained on their medical records. Stakeholders also speculated that even among people cured of hepatitis C, past negative, stigmatising and discriminatory experiences often meant that they may continue to avoid primary healthcare settings. As P4 (service provision) put it:

*It doesn't just go away for people when they've had those kinds of experiences and, you know, [have been] treated as an infectious person.*

Both sets of interviews we conducted suggest that a strategy of non- or guarded disclosure remains a key coping mechanism among people after cure.

These accounts suggest that while achieving SVR is widely touted as transformative and promises to eliminate hepatitis C, the stigma and discrimination experienced by people in healthcare and other contexts may remain unaltered by cure, and people may remain marked by hepatitis C in medical records or in other ways, with implications for their ability to access health care and other social services.

### **Intimate experiences of stigma can persist**

Treatment may not always function or be understood by individuals as a neat enactment of closure that resolves the biographical disruption brought about by diagnosis (Bury, 1982), enabling them to leave hepatitis C behind. For some of our participants, aversive personal feelings surrounding hepatitis C and injecting drug use, which were enmeshed before treatment, continued afterwards. Relatedly, the language and metaphors some people used to describe their post-cure selves sometimes appeared to resist both a sense of closure to chronic illness, and the restoration of a former ('healthy', 'normal') self. For example, rather than describing herself as 'cured' or 'cleared' or 'treated', Jenna, whose treatment experience was mentioned earlier in this report, described herself as 'at risk'. She said:

*I would absolutely say that I'm still in the high-risk category and that, you know, it is 'never say never' because of that.*

Rather than the definitive end typically implied by 'cure', some people described their post-cure selves in more provisional or temporary ways. Hepatitis C was in their past, but there was no certainty it would not be in their future. Participants also highlighted the stigmatising behaviour of family, friends and healthcare workers/professionals that continued to label them as infectious, or to imply that they couldn't be trusted to remain free of hepatitis C (see Kagan et al., 2023b).

### **The hepatitis C antibody test can be misinterpreted**

Stakeholders reported that one issue that was ongoing since the emergence of DAAs was the misunderstanding of the meaning of positive hepatitis C antibodies in a person's blood test results. According to several stakeholders, positive antibodies were sometimes (mis)understood to mean that a person 'has hepatitis C' and that there may be a risk of onward transmission. These misinterpretations of antibody test results were said to arise in medical, employment and other settings, and to remain prevalent. As we also noted earlier, research has identified legal, actuarial and other administrative contexts in which hepatitis C antibodies and other records of the virus were treated as 'synonymous with having the virus and disease' (Seear et al, 2023a: 14-15). Such treatment was echoed by our lived experience participants, and identified as an ongoing problem,

particularly in the context of medical records. For example, Sandy said that in encounters with medical and other professionals who might have access to information that she had hepatitis C in the past, she was still 'classed' as somebody with hepatitis C. She said that

*people don't define all the differences, they really don't. Hep C is hep C. You had it, you have it. You've cleared it, you're still classed as had it.*

Sandy said she didn't feel that a 'distinction' was made between having or clearing the virus, and that healthcare workers effectively regarded her as a person with hepatitis C either way.

### The stigma of re-infection

The issue of re-infection and the challenges it poses to Australia's elimination goals was raised in some interviews, especially among stakeholders. Among other things, they were concerned about re-infection's capacity to activate or exacerbate feelings of shame, self-blame or failure among individuals who might be re-infected, particularly considering the cost of treatments (see 'Treatment as a gift'). For example, P13 (policy) said:

*They often feel as though they've failed, and they know we've invested time and energy and, I guess, taxpayer's money [...] when they come back reinfected, they feel as though that's a failure.*

Some stakeholders suggested the need to revise the language used around 're-infection' and 're-treatment', in order to address these feelings of shame, responsibility or self-blame (see 'Notes on language').

### Other barriers remain

While many of the stakeholders we spoke to were supportive of the impetus and resources galvanised by Australia's elimination agenda, a number worried that it narrowed the focus of policy and activity to testing, treatment and ways to enhance treatment uptake. For some people affected by hepatitis C, their experience of the virus was bound up in a broad swathe of issues, including homelessness, unemployment, other chronic health/mental health conditions and more, and treatment alone could not address these challenges. As one stakeholder (P16, policy) put it:

*The free, easy-to-take, super-effective treatments that will cure your hep C in eight weeks do nothing about these systemic factors [...] For someone who is homeless and has no safe place to store medication, an eight-week course of tablets is just as inaccessible as a six-month course of interferon injections.*

Other concerns that emerged from these conversations included the impact of elimination efforts on harm reduction, access to needle-syringe programs and opioid substitution therapy, and efforts to decriminalise illicit drug use.

### Life after cure remains poorly understood

Stakeholders also expressed concerns that post-cure lives were not adequately understood or addressed by current approaches. A number of those we talked to across a range of roles suggested that people may have specific needs after treatment, but that post-cure lives were not adequately addressed in the hepatitis C cascade of care and other social and public health approaches. For example, P18 (policy) said:

*Once you are cured, we are done with you in a public health sense. That space post-cure and any attendant stigma and discrimination [...] hasn't come up in policy discussions at all.*

And P3 (policy) said:

*We have survivorship pathways for cancer post-cure, but we don't have that comparable aftercare pathway for hepatitis C. That's interesting [...] what does that look like or could that look like? Is there a role for the health system in there? Is that more about wellbeing and less about health care, and if so then what's required? I think it triggers interesting thinking about not just stopping our efforts at a cure.*

## The forces shaping stigma and discrimination (after treatment)

Our participants identified several forces that they felt shaped stigma and discrimination, and thus, several ways in which stigma and discrimination might be able to be reduced or eliminated.

### Healthcare access and equity of care

As noted above, Australia's early adoption of and significant investment in DAAs was celebrated as a major policy success, in which life-saving treatment would be provided without restriction, including to many groups of people who had historically experienced major obstacles to health care. Both stakeholders and people who had undergone treatment reflected that this commitment to treat everyone, and the decentralisation of treatment were significant changes, with positive implications for hepatitis C-related stigma and discrimination. The announcement of Commonwealth funding for DAAs very soon after their approval by the Therapeutic Goods Administration was a significant change in how policymakers and the health workforce approached hepatitis C treatment delivery. Here P3 (policy) reflected:

*It was like 'this is our polio moment'. In public health terms it's miraculous that there is this virus that now can be eliminated by medical intervention and we have a generational opportunity [...] to significantly improve health outcomes for people living with hepatitis in this country. And really, the first time I was ever able to have a policy elimination conversation: What does that look like? How do we achieve that? What are the pathways? What do we need to do?*

Alongside this announcement, there was some concern about the redirection of funding from prevention to treatment (Harris et al., 2015). While there does not appear to have been a reduction of funding to prevention, there remains limited access to prevention and harm reduction in custody and detention (i.e., an absence of any needle and syringe programs in Australian prisons), and this was raised by multiple stakeholders – and some lived experience participants – we interviewed. For example, P10 (legal) said:

*the failure to do proper harm minimisation and hep C prevention and any BBV prevention in prison means that the goal of elimination in one generation [...] is absolutely*

*put in jeopardy [...] and the fact that you can go through treatment and then re-criminalise, go to prison and be re-infected, you know, it could have been used as a really profound point of leverage to say that 'this money, these resources, these medications come with a requirement to do comprehensive harm minimisation and mitigation'.*

Additionally, many stakeholders advocated for more meaningful involvement of peers, and that they undertake more than health promotion – this was viewed as central to undermining stigma.

### Shifting testing and treatment from tertiary to primary and community healthcare settings

Co-locating treatment with services that consumers were already accessing and are trusted (e.g., alcohol and other drug services, needle and syringe programs, etc.) with the opportunity for nurse-led and peer-led models of testing and treatment were identified as forces that reduce instances of stigmatised or discriminatory healthcare (see Cunningham et al., 2023; Overton et al., 2019). Where such models are already in place, they were also identified as opportunities to provide ongoing testing and treatment in the event that a person re-acquires hepatitis C after treatment.

### Peer-led and consumer partnerships

Meaningful involvement of affected communities in the delivery of testing and treatment for hepatitis C and more broadly in program design and delivery was of major importance to all those interviewed. Participants routinely emphasised that meaningful peer involvement operated as a force to reform stigma in health care, including for people living post-cure lives. Stakeholders identified numerous opportunities and levels of involvement to elevate peer models of care and partnerships, from the design of the services and programs to service delivery itself.

For example, P20 (service) detailed the benefits of peers in service delivery, particularly for reducing stigma and discrimination and for post-cure life:

*there's a growing understanding of the need to incorporate and to build mechanisms to involve peers above and beyond consultation [...] It's kind of really partnering with peers and making their role really explicit and valued, you know putting some resources behind [...] And once you get a service with that kind of dialogue, [it] means that when*



**“THE FAILURE TO DO PROPER HARM MINIMISATION AND HEP C PREVENTION AND ANY BBV PREVENTION IN PRISON MEANS THAT THE GOAL OF ELIMINATION IN ONE GENERATION [...] IS ABSOLUTELY PUT IN JEOPARDY.”**

*the treatment experience finishes, people have a reason and a meaning to maintain a relationship with the service and the people that work within that service.*

Several of our lived experience participants had taken up peer and lived experience roles – with some explicitly identifying their personal experiences of stigma and discrimination as motivations for taking up these roles. As Elena explained:

*Stigma and discrimination does drive me a lot and it needs to change. That's what really drives me with the [health organisation] part, why I'm involved with the consumer committee, because that's where the consumer is going to be heard, where language matters and, you know, language is a thing where it can break or make a person regardless of your opinion.*

Others spoke about the meaningful involvement of peers and the need for healthcare settings that foster and communicate trust and safety. To be effective, employing peers needs comprehensive and embedded organisational reform, not simply

having one peer to represent all people's needs. Stakeholders identified several systems that needed to be developed to ensure that the meaningful involvement of peers was effectively implemented, including through:

- The provision of appropriate orientation processes
- The use of formal mechanisms to support peers and to provide supervision to peers/consumers
- Communication systems that facilitate peer engagement with external stakeholders, management and staff. This extends to the design of new projects and to the improvement of the physical space of services (all understood to potentially contribute to or reduce stigma).

Some participants expressed concern about the role of peers in the future, calling for assurances that funding be maintained beyond the hepatitis C elimination agenda. Some were concerned about a lack of funding for peer-led and civil society services to engage in advocacy that would seek to address structural, organisational and individual forms of stigma, noting that this lack of resources might be viewed as a form of stigma itself. For example, funding for Australian Injecting and Illicit Drug Users League (AIVL) and the state peer

organisations are for health promotion activities, which limits their capacity to undertake advocacy that could help support the elimination agenda and the needs of a large (and growing) population of people living post-cure lives.

#### Disclosure post-cure

While disclosure of hepatitis C is required by law only under very specific circumstances, our interviews revealed that people continued to feel an obligation to disclose their history of hepatitis C, especially in medical settings. Other recent literature on post-cure life (e.g., Madden et al., 2018) found that not needing to disclose was a valued outcome of cure, and that disclosing in social and medical contexts after treatment remained a force of stigma and discrimination for several of our participants. For out participants with lived experience, disclosing, talking about and reliving their hepatitis C history could continue to evoke strong emotions such as anger, guilt and shame. As such, autonomy and choice surrounding disclosure matters, operating as both a potential site of stigma production and a force to help reduce it.

#### Medical records and privacy

Medical records and privacy breaches were identified as key sources of stigma and discrimination both pre- and post-cure. Given hepatitis C is both a highly stigmatised virus and a chronic health condition, decisions on whether and when to disclose it in healthcare settings was not clear cut. For example, Grant's experiences illustrated the tensions of disclosing in medical settings:

*I really only go through the liver clinic at [a hospital]. They know my history there and they've got all the records there and it's easy because I don't have to give them any background or history to it. So, if ever I get any test done through them, it's built upon the records that are there already, but if I went somewhere else, let's say I moved interstate and I went to a new doctor, I would give them my UR [unit record] number, which I believe would have access to all of my tests and all the information, and I would have to probably tell them the full story again.*

This concern may have been ameliorated to some degree with the introduction of electronic health records, which enable freer sharing of health information and reduce the burden on individuals having to repeat their medical history to each new health provider, with the discomfort and potential stigmatisation that follows disclosure. However, participants remained unsure, for instance, whether to opt in to the Australian My Health record system (an online government health records system that allows individuals and their healthcare providers to securely access that individual's health information) and allow their medical records to be shared between providers. As Grant's account showed,

**“LANGUAGE MATTERS AND, YOU KNOW, LANGUAGE IS A THING WHERE IT CAN BREAK OR MAKE A PERSON REGARDLESS OF YOUR OPINION.”**

records may list a particular condition, such as hepatitis C, but not 'the full story' behind it, and the people we interviewed felt the need to provide additional information or further context to their healthcare providers. If personal health records are to be accessed by people with whom an individual does not have a relationship of trust, this may expose the person to stigma or discrimination. Concern that this may happen shapes how people with (a history of) hepatitis C conceptualise privacy and approach access to their health data.

### Human rights

In stakeholder interviews, the potential of human rights as a framework for addressing hepatitis C-related stigma and discrimination was raised as a question or a prompt (see Appendix 2). Some stakeholders suggested that the absence of human rights protection was responsible for deficiencies in the treatment of people with (a history of) hepatitis C, and some specifically condemned the absence of national human rights protections in Australia, noting the benefits that a national bill of rights might have for those affected by stigma and discrimination. For instance, as P17 (service) asserted:

*the bill of rights should be a fit, it should be a nationally available document and it should be available to all citizens in Australia, it's that simple. We don't have that instrument. There is the Victorian [Charter of Rights] but as far as I'm aware, there's no real bill of rights actually existing from a national point of view in an Australian context.*

P27 (service) explained that the state of Queensland had recently introduced its own Human Rights Act, noting that the Act had increased awareness of the rights of all consumers, while also improving structures and systems for health care. P27 reported that the Act:

*has been really positive and I think that people could be better educated around what the Human Rights Act means for [...] consumers and [...] I think services have really looked at that in a lot of respects. How are we going to comply and it's had a positive effect in relation to the provision of services [...] if they're not provided with the services they should be provided with [...] then they do have a recourse through that framework.*

For these stakeholders, human rights protections might act as a force to reduce stigma and discrimination by offering overarching protections for all Australians in areas of relevance to hepatitis C. These include issues addressed in other parts of this report that are important to consider from a human rights perspective, such as informed consent, and equity of access to care through needle and syringe programs in prisons.

### Re-infection

As previous exposure/s to hepatitis C does not confer immunity, re-infection among people who use drugs is possible. For many stakeholders, re-infection and subsequent re-treatment was a key concern, and this has not changed since the implementation of DAAs in 2016. Stakeholders highlighted re-infection's potential to activate or exacerbate feelings of shame and failure, and they described the prospect of re-infection as something that may discourage testing and treatment (despite universal access and access to re-treatment). This was among their concerns, as were reinfections in custodial settings.

Knowledge of re-infection among people with a (history of) hepatitis C was largely high, however a number of people were unaware of the possibilities and logic of re-infection. Most were aware that previous infection did not provide immunity, but a small number were unaware that if exposed to infected blood, they could pick hepatitis C up again.

Ideas about re-treatment are both a potential factor in stigma production and reduction. Two participants explained that they were treated at sites that were caring, supportive and non-judgemental and were encouraged to return if they were exposed to hepatitis C again, which made them feel 'grateful'. On the other hand, some reported 'condescending conversations [...] like a dressing down that a mother would give a child' (Erik), and imperatives to not use drugs again rather than information about prevention. Two participants reported that while they were aware that they could access treatment again, there were 'no excuses' for further infection. Feelings of guilt and concern about the possibility of re-infection were also described in relation to ongoing injecting drug use (see Kagan et al., 2023).

These accounts suggest that re-infection is a potential source of stigma and discrimination, including through negative commentary about the cost of re-treating people, or through perceptions about agency and responsibility in re-infection.

It is therefore important to ensure that re-infection is not located as a problem of individuals but of wider forces including those that we have identified in this report.

### The possibility of complaint

An important issue to emerge concerned the role of complaint mechanisms to address experiences of stigma and discrimination, both before and after treatment. One of the challenges of complaint is the need to articulate, identify and describe – often in great depth – an experience of stigmatising behaviour or discrimination. When prompted, many interviewees struggled to recall and describe specific stigmatising or discriminatory experiences, as these had been so pervasive and recurrent. Eddy observed that:

*It all becomes so common, that's the problem. That you forget.*

The relentlessness of these experiences led to feelings of helplessness for many, and a sense that it was neither possible or productive to make a formal complaint. Camille explained that because stigma happened so often, 'I couldn't do anything about it really'. Cassie 'never questioned it or tried to fight it'. Others used discourses of 'resilience' to explain how they overcame these experiences, noting that they had 'thick skin' (Heather), were 'pretty savvy' and 'articulate' (Patricia), were 'courageous' or 'fearless' (Dana). Others said that they had endured stigma for decades before, finally, 'not caring' (Daniel), or learning to 'handle it because I'm who I am and it doesn't affect me anymore' (Elena).

Our participants identified specific problems with the nature and logic of complaints mechanisms themselves, including the need for individuals to pursue complaints through often daunting, sometimes complex and convoluted or costly complaints processes, which they feared were not sensitised to the needs of those affected by hepatitis C and/or those symbolically or literally adjacent to injecting drug use. Some spoke on the difficulty of formalising a complaint. It takes time and can be laborious to make a formal complaint. In addition, power relations between practitioners and patients can be pronounced. As Nicole suggested, it can be difficult for some people with a history of hepatitis C to be confident that their concerns were valid or would be taken seriously:

*She's a doctor, she should know more than me, that's what I would have thought. She would know more about it than I did and not to discriminate against anybody that's got hep C [...] it was unfair the way she treated me [...] I should have spoken up then and there, but I didn't have the confidence to do that.*

Although this did not mean that our participants were not often powerful advocates for their own interests, acutely aware of deficiencies in the quality of their care, few had ever lodged an official complaint of any kind (see Lenton et al., forthcoming).

### Complaint mechanisms

A key theme to emerge from both groups of interviewees was the difficulty of seeking to address stigma and discrimination after it had taken place, and the importance of preventative measures. While complaints occasionally proceed into and through legal systems our data suggest that many do not proceed. For instance, as P5 (policy) explained:

*There are laws around discrimination in websites and all of that kind of thing, but the trickle-down effect of that, you know, once someone's being discriminated against in the workplace, yes, it may give them some recourse to complain, to report, to what have you, and that's really important, but it still happened. So, how do you [...] yeah, it's so tricky.*

Many of the key stakeholders we interviewed had decades of experience working with people affected by hepatitis C. They too identified the barriers to formalising complaints, such as time, effort and the possibility of being exposed to further stigma and discrimination. P1 (service), who had worked supporting hundreds of people over several years said that, in their experience, complaints were rare. They said that complaints were 'just tiring, it was tiring, it's that one person versus an organisation'.

P15 (legal), who had experience representing complainants with hepatitis C, often in employment law contexts, felt that legal action was rarely pursued, in part because potential payouts were low and associated costs were prohibitive. Recalling a case where 'there would have been reasonable prospects to appeal', they noted that the complainant affected by hepatitis C-related discrimination decided that 'the process was too



stressful for him. He didn't want to go through another round of hearings and everything for that, he was just happy to leave it as it was.'

P12 (service) recalled a breach of confidentiality that occurred in the process of case finding. This breach was not the subject of a formal complaint, despite P12 offering to support the affected person through the process. According to P12 (service), the complainant declined to proceed, saying that:

*I have lost all trust with the health system, so I'm not going to trust them with more. It's already had too much of an impact on me.*

When asked what mechanisms were available for people to make a complaint against healthcare services, P7 (policy) said

*I think that opens up a whole other Pandora's box, which is the calibre of our complaint systems and certainly the work that we have done show[s] that [...] whether their complaints process is within clinics or at the health commission level or at the upper level, if it comes to professional misconduct, [these processes] are [a] total failure for consumers.*

Arguably, to make a complaint, the complainer needs to trust that the institution managing the complaints process will properly manage their complaint. The issue of trust (and lack of trust) in public and private institutions has been taken up by multiple researchers and commentators in recent years, including in the context of hepatitis C care (e.g., Harris et al., 2013; Treloar et al., 2013; Newman et al., 2021). Alongside the deficiencies of complaint mechanisms, lack of trust in institutions may be a significant disincentive to speaking up about experiences of stigma and discrimination.

## Conclusion

For people who have undergone treatment for hepatitis C, the virus may linger in social and symbolic 'afterlives', including in ongoing experiences of stigma and discrimination – especially in healthcare settings. A range of factors and forces were identified as shaping people's experiences of stigma and discrimination after treatment, including inequitable access to health care, confidentiality and privacy (notably in relation to medical records), understandings and misunderstandings of disclosure requirements, and figurations of re-infection as an individual concern. Current approaches to hepatitis C care,

including the cascade of care, do not sufficiently address the needs of people after treatment, and a range of health-related and other needs remain unmet among this population. Few people who have experienced hepatitis C-related stigma and discrimination pursue redress through existing feedback or complaint mechanisms. Importantly, the meaningful involvement of peers and the affected communities was identified as a significant and essential development to address stigma and discrimination.



## RECOMMENDATIONS

This report has outlined key findings from an Australian Research Council-funded project exploring the legal, policy and practice mechanisms that shape people's lives after treatment for hepatitis C. The findings are based on the collation and analysis of a detailed legal dataset; interviews with 30 key stakeholders who work with hepatitis C-affected communities in policy, practice, law and service provision; and interviews with 30 people who have undergone treatment for hepatitis C with direct-acting antivirals.

Among our participants with lived experience of hepatitis C and treatment there were people from groups identified as 'priority populations' or from 'priority settings', including women affected by hepatitis C, Aboriginal and Torres Strait Islander peoples, sex workers, people from culturally, ethnically, and linguistically diverse communities, people at risk of/living with hepatitis B co-infection, and people at risk of/living with HIV co-infection. We also spoke to stakeholders who work with people in these communities/settings. Apart from people who use (or have a history of using) illicit drugs, and apart from legal findings that specifically affect members of these groups (e.g., migration law), our research has not yielded findings that are specific to the needs of people in these groups. We therefore suggest that more work, including targeted research, is needed to better understand the post-cure needs of people in these communities and settings.



## Key recommendations

This research has informed a set of recommendations for policy, practice and law reform. These recommendations seek to reduce experiences of hepatitis C-related stigma and discrimination, particularly for those who have been treated for the virus. To that end, they propose the development of some new policies, legal mechanisms and systems, alongside specific reforms to and enhancements of existing ones. These draw on project findings and were developed in consultation with the project's advisory board, including members of peak and peer organisations representing hepatitis C-affected communities. The recommendations also draw on suggestions from the 60 interviews we conducted. While each of these recommendations are targeted to a specific government or non-government organisation or to a specific sector, other relevant organisations or stakeholders may be engaged in these actions.

All these recommendations are prefaced by the guiding principles that:

- Their development and implementation involve meaningful partnership with peer and peak organisations and the communities of consumers they represent, with due resourcing of their time and expertise.
- Any new policies, laws and initiatives, and any changes to existing mechanisms must recognise and draw on the individual and collective expertise of people with (a history of) hepatitis C and communities affected by the virus.
- Where relevant, consideration to the specific experiences and needs of priority groups affected by hepatitis C should be given.

In the development and implementation of any of these recommendations, we recommend that responsible bodies consult the priorities outlined in the [Harm Reduction International 2023 Australian Conference Declaration](#).

## Policy recommendations

1. Responsible departments at federal, state and territory levels should work together with relevant consumer and advocacy groups to develop a health data justice framework that balances the benefits of pathways into hepatitis C health care with the risks associated with the use, re-use, and re-purposing of medical and health data to access such care.
2. The Department of Health and Aged Care and its state and territory equivalents should develop stigma-sensitive workforce training and education programs designed for and made available to all people who work with hepatitis C-affected communities.
3. Federal, state and territory hepatitis C strategies and action plans should contain an explicit focus on post-cure life, to ensure they address both the medical and other needs of people cured of hepatitis C. This should include explicit goals to reduce the stigma and discrimination that endures for many people after treatment.
4. The Communicable Disease Network and/or other responsible bodies should review existing national, state- and territory-based systems of hepatitis C notifications, with consideration given to removing name requirements and other personal/identifiable information for new notifications or to introducing opt-in mechanisms for named notifications.
5. The Department of Health and Aged Care should ensure that the National Hepatitis C Testing Policy includes robust, opt-in, informed consent processes on all occasions of hepatitis C testing.
6. Hospitals, health services and research ethics departments should scrutinise new testing and treatment models (including strategies to 'find' undiagnosed or untreated people) for potential breaches of privacy or consent, or other unintended consequences for the health and human rights of people with (a history of) hepatitis C.
7. The Department of Health and Aged Care should ensure that, if human rights are to be acknowledged in the *Sixth National Hepatitis C Strategy*, any reference to human rights should not be limited to specific rights and should incorporate strategies and methods for ensuring that rights are not unjustifiably or unreasonably restricted.

## Legal recommendations

8. All jurisdictions in Australia should legalise the personal use/possession of drugs and decriminalise the use/possession of injecting equipment.
9. Federal, state and territory governments should work together through the National Cabinet to ensure that Australia is meeting its human rights obligations to prisoners, including the obligation to provide equality of health care and harm reduction through the establishment of needle and syringe programs in Australian prisons.
10. The Attorney-General's Department and its state and territory equivalents should consider legislative reform to protect privacy rights over health information, including hepatitis C.
11. The Australian Commission on Safety and Quality in Healthcare or another responsible authority should establish a charter of healthcare rights for people with (a history of) hepatitis C, including provisions for the privacy of health records, the use of hepatitis C notifications data, and the legal requirement to provide informed consent for testing.
12. The Australian Human Rights Commission and its state and territory equivalents should develop guidelines and fact sheets that support individuals to understand their legal rights and support duty holders to understand their legal obligations to prevent and respond to hepatitis C-related discrimination in workplaces and other settings.
13. The Office of the Australian Information Commissioner and its state and territory equivalents should develop guidance on privacy rights and dealing with unwanted disclosure of hepatitis C.
14. Federal, state and territory governments should undertake comprehensive law reform in recognition of the advent of curative hepatitis C treatments, with particular attention to discrimination law, migration law, insurance law and criminal law.
15. State and territory law reform commissions and/or parliamentary committees should explore the viability of law reform to enable people cured from hepatitis C to remove their history of hepatitis C infection and/or treatment from their medical records or restrict access to that information.



## Practice recommendations

16. Federal, state and territory governments should fund relevant organisations to develop and deliver privacy, healthcare rights, stigma-sensitive practice, and anti-discrimination training for people working with hepatitis C-affected communities in healthcare, legal and other settings.
17. The Australian Health Practitioner Regulation Agency and its state and territory equivalents should introduce or review mechanisms for consumer feedback and complaint in healthcare settings attended by people with (a history of) hepatitis C. These mechanisms should be robust, transparent, accessible and support the provision of quality stigma-free healthcare.

## Other recommendations

18. The Financial Services Council should develop a new guidance note on insurance underwriting for hepatitis C that reflects developments in treatment and with a view to addressing unfair exclusions, increased premiums and policy voiding based on (a history of) hepatitis C as well as stigma-sensitive questioning in insurers' questionnaires.
19. The Department of Social Services and/or other funding bodies should provide support for further research into how the advent of curative treatment has affected people with hepatitis C who were or are on the Disability Support Pension.
20. The Departments of Foreign Affairs and Trade and of Home Affairs should improve migration decision-making processes in relation to refugees and migrants with hepatitis C by supporting further research on access to hepatitis C treatments in different countries to be included in country information reports.

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# APPENDICES

## Appendix 1: Participant tables

Stakeholders	(n=30)
<b>State</b>	
New South Wales	10
Victoria	10
Queensland	10
<b>Core practice at time of interview</b>	
Legal	3
Policy	8
Service provision	19
<b>Gender</b>	
Male	15
Female	14
Non-binary	1

People treated with direct-acting antivirals	(n=30)
<b>State</b>	
New South Wales	10
Victoria	10
Queensland	10
<b>Location*</b>	
Major City	19
Inner regional	2
Outer regional	7
Remote	1
Very remote	1
<b>Age</b>	
26–34 years	2
35–44 years	5
45–54 years	6
55–64 years	11
65–74 years	6
<b>Gender</b>	
Male	17
Female	13
<b>Cultural and ethnic background<sup>†</sup></b>	
Northern & Western European	5
Southern & Eastern European	3
Australian	19
Aboriginal & Torres Strait Islander	3

**People treated with direct-acting antivirals (n=30)**

<b>Employment<sup>†</sup></b>	
Employed full time	2
Employed part time	3
Employed casual	1
Unemployed	16
Student	2
Caring duties	3
Student	2
Retired	2
Volunteer	8
<b>Likely route of hepatitis C transmission</b>	
Intravenous drug use	25
Sexual transmission	1
Tattoo	1
Unsure	3
<b>Number of times treated</b>	
Once	22
Twice	8
<b>Types of treatment experienced</b>	
Interferon & DAAs	7
DAAs only	23
<b>Year treated with DAAs<sup>§</sup></b>	
2015	8
2016	8
2017	5
2018	5
2019	2
2020	0
2021	1
Unsure	1

\* Reporting of location follows the Australian Bureau of Statistics (ABS) Remoteness Area Region (2016), which divides Australia into five classes of remoteness on the basis of a measure of relative access to services.

† Reporting of cultural and ethnic background follows the Australian Standard Classification of Cultural and Ethnic Groups, developed by the ABS. Cultural and ethnic background was classified according to self-reported identification, participants' birthplace and/or parents' birthplaces.

‡ Employment figures do not add to 30 because some participants occupy more than one category.

§ Estimated in some cases.

## Appendix 2: Interview guides

### Interview guide – stakeholders

1. Can you briefly describe your work to me?  
Tell me a bit about what your job involves?  
**Prompt:** What is your disciplinary/relevant/professional background?
2. As you know, the specific focus of this study is hepatitis C. Can you explain to me how hepatitis C is involved in the kind of work that you do?
3. I want to ask you about hepatitis C-related stigma and discrimination. As you will know, people sometimes distinguish between these two things.
  - First of all, can we ask you what does hepatitis C-related stigma look like to you?
  - And what does hepatitis C-related discrimination mean to you?
4. We'd like to learn more from you about hepatitis C-related stigma and/or discrimination. Based on your expertise and experience, can you tell us about some of the ways that hepatitis C-related stigma and/or discrimination comes up?
  - Are there any groups in your opinion who seem to be most at risk of stigma and/or discrimination? Why do you think they are most at risk?
  - Have you personally experienced any hepatitis C-related stigma and/or discrimination in your work? Can you explain?
  - What do you think are the main forces that shape hepatitis C-related stigma and/or discrimination?
5. We are interested in talking to you about the advent of new treatments for hepatitis C. Australia was one of the first countries to offer universal access to direct acting antivirals.
  - What was your initial impression when you first heard of direct acting antivirals?
  - Did you have expectations for those new treatments? What expectations did you hold?
  - Did you have any concerns about those new treatments? What were they?
  - Did you have a view about the relevance of new treatments to stigma and discrimination? What was your view?
6. You mentioned earlier that your overall impression of the new treatments was [XXX]. Have the new treatments lived up to your expectations? How so/not?
  - Have your concerns been realised? Can you say a bit about this?
  - Treatment rates have plateaued in recent times. Do you have any thoughts on why this might be happening?
7. Reflecting on your role, how have direct acting antivirals affected how your work, or changed things in your field?
  - Have you had to develop or change your approach, or shift focus in notable ways? Can you tell us a bit about that?
  - *[If working directly with people with hep C, either pre- or post-treatment]* Have the needs of your clients/community members/patients changed? How have you adjusted to those changes?
  - Have your needs changed? Are they being met/supported?
8. We now want to ask you some questions about people's lives after treatment. Do you have a preference for what language is used when describing people who have achieved SVR [sustained virologic response] (e.g., 'cure' or 'clear')? Can you tell us a bit about why you prefer that language?
9. You said earlier that your experience of hepatitis C stigma and/or discrimination is [XXX]. Have you found that this occurs even for people who have been cured?
  - In what ways is hepatitis C-related stigma and/or discrimination still a problem for people who have been cured?
  - Can you tell me some of the reasons for your view?
  - What are the main challenges that people continue to face?
  - In which settings?

10. Are there any laws, policies or legal mechanisms of any kind that you are aware of that have the potential to contribute to hepatitis C-related stigma and/or discrimination?

- What are they?
- Can you tell us a bit about how they are relevant?

**Prompts, if needed:** Medical records; mandatory notifications; contact tracing

11. Are there any laws, policies, public health, legal mechanisms or other initiatives (of any kind) that you are aware of that help alleviate or minimise hepatitis C-related stigma and/or discrimination?

- What are they?
- And what is it about them, in your view, that makes them helpful in reducing stigma and/or discrimination?

12. Are there any areas of law or policy (including state or national strategies) that you would like to see amended so as to minimise hepatitis C-related stigma and/or discrimination?

- What are they?
- What potential arrangements would you like to see instead?

13. Do you think human rights principles have any utility in this context, and could help to minimise hepatitis C-related stigma and/or discrimination? Can you tell us a bit about that?

14. In your view, do current strategies (at state and national levels) adequately address the needs of post-cure life?

- If not, what do you think those strategies should focus on? What isn't being adequately addressed?
- What would you like to see put in place to address these challenges more adequately?

15. Apart from those things you've mentioned already, what do you think are some of the main challenges in overcoming hepatitis C-related stigma and/or discrimination?

**Prompts if needed:** The elimination agenda; Models of testing and treatment; processes of policy and strategy development; the hepatitis C workforce; the public health system/ legal system/education

16. Is there anything we've missed, or any other issues surrounding hepatitis C-related stigma and discrimination that you wanted to describe?

17. That concludes our set list of questions. Is there anything else you would like to add?



## Interview schedule – people treated with direct-acting antivirals

1. I want to start by asking you about your experience of being diagnosed with hepatitis C.
  - Can you tell me when and how old you were when you were first diagnosed? Where were you diagnosed?
  - Do you have an idea of how long you'd had hep C before being diagnosed?
  - How did you feel and how did you respond to the diagnosis at the time?
  - Do you have any idea how you picked up hep C?
  - Had you experienced any obvious symptoms?
  - Do you recall what you were told at the time about how hepatitis C may affect you?
  - Did you tell anyone about it? What was their reaction/s?
2. Did your life change after being diagnosed with hepatitis C? Can you tell me how?
3. Now we are moving on to your experiences of treatment. Did you undergo treatment using the old drugs that were available (e.g., combination therapy/interferon)? (If no, then ask: what did you hear about the old treatments, and can you tell me why you didn't try it? If yes, then ask):
  - Do you remember when that was?
  - What were your expectations when undergoing the old treatment?
  - Can you tell me about your experience of the old treatment?
  - How was your life after the old treatment? (e.g. relationships with others, work experiences)
4. Next, I want to ask you some questions about DAAs.
  - First of all, do you remember how you first heard that there were new drugs available for the treatment of hepatitis C? What were you hearing about it?
  - How and where were the treatments first offered to you? How did it come up? Did you ask for it?
  - What did you discuss/what were you told about the new treatments/ and what questions did you ask?
  - What was your impression of those treatments at that time, before you had them?
5. Can you talk us through how you came to make the decision to try the new treatments?
  - What were your expectations?
  - Was stigma or discrimination relevant to your goals in any way?
  - Can you tell me about your experience of the new treatment?
  - Do you know what the outcome of your treatment was?
  - Was there any discussion about if you picked up hep C again? What was said about this, and how did it make you feel?
6. Did treatment live up to your expectations? Can you tell me a little bit about why
  - Did your life change once you'd had treatment? Prompts: Employment, health care; relationships/family; legal
7. As you know, the specific focus of this research is hepatitis C-related stigma and discrimination, with a focus on life after treatment. I want to ask you about hepatitis C-related stigma and discrimination. As you will know, people sometimes distinguish between these two things and sometimes don't.
  - First of all, what does hepatitis C-related stigma look like to you?
  - And what does hepatitis C-related discrimination mean to you?
8. Thinking back to when you had hep C, were you ever treated differently because of your hep C? Can you tell me a bit about those experiences?
  - In which settings did this occur (e.g. health care) and what happened?
  - How did you feel? Did you feel listened to and cared for? Did you feel you were trusted and believed?
  - Do you have any thoughts on why people were treating you differently?
  - Were you able to get what you wanted or needed (e.g. health care)? Did you feel it could have been better? In what ways?
  - Did this impact you or your approach in any way (e.g. accessing services or help-seeking in general; how entitled you felt to ask for things; whether you disclosed your status?)
  - Are there other examples that come to mind?

9. Does your past hepatitis C status ever come up now? Or do you worry that it could come up? (If yes, then ask: Could you please tell me a bit about that?)
  - Does it come up among family, friends, intimate relationships or at work?
  - Does it come up in healthcare settings, legal settings
  - Has it come up on in personal records or information, like in medical records, for example?
10. Now that you have undergone treatment, do you still feel you are ever treated differently because of your hep C? Can you tell me about those experiences?
  - Where were you (e.g., at a doctors' rooms/with family), and what happened?
  - How did this make you feel? Did you feel listened to and cared for? Did you feel trusted and believed?
  - Were you able to get what you wanted or needed (e.g. health care)? Did you feel it could have been better? In what ways?
  - Have you heard about this or similar things happening to others?
  - Are there other examples that come to mind?
11. I'm interested in hearing about how you identify now that you have been through the new treatments.
  - First of all, what language would you use to describe yourself or your hep C status, now that you've been through treatment? (e.g., 'cured'; 'hep C free'; 'cleared hep C')
  - Do you ever still think about hep C? How do you think/feel about hep C now?
  - Earlier you said your hopes for treatment were [xx]. Were those hopes realised?
  - Was it important for you to leave hepatitis C behind, and do you feel that you have?
12. What do you think needs to change to reduce hepatitis C-related stigma and discrimination?
  - Who are your allies, or who do you think could make this happen?
13. Are you aware of Australia's goal to eliminate hepatitis C by 2030? [If yes, ask:]
  - What are your thoughts about this goal?
  - How could Australia achieve this?
  - What are the barriers to achieving this?
14. That concludes our set list of questions. Is there anything else you would like to tell me about your experiences, or other thoughts about stigma and discrimination, why it occurs and what could be done to reduce people's experiences of it? Or anything else important we have missed?

## Appendix 3: Project outputs

### Book chapters

Seear, K. (2023). Illicit Drugs. In Bennett, B. & Freckelton, I., *Australian Public Health Law: Contemporary Issues and Challenges*. Federation Press, Australia. 405–409.

### Refereed journal articles

Lenton, E., Kagan, D., Seear, K., Mulcahy, S., Farrugia, A., valentine, k. Jeffcote, D. & Edwards, M. (author order TBD). Troubling complaint: Addressing hepatitis C-related stigma and discrimination through complaint mechanisms. (forthcoming).

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valentine, k., Lenton, E., Seear, K., Fraser, S., Kagan, D., Farrugia, A. & Mulcahy, S. (under review). Hepatitis C data justice: The implications of data-driven approaches to the elimination of hepatitis C. Farrugia, A., Lenton, E., Seear, K., Fraser, S., Kagan, D., valentine, K. & Mulcahy, S. (under review) 'We've got a present for you': Hepatitis C elimination, compromised healthcare subjects and treatment as a gift.

Kagan, D., Seear, K., Lenton, E., Farrugia, A., valentine, k. & Mulcahy, S. (2023b) 'I'm not hep C free': Afterlives of hepatitis C in the era of cure'. *Medical Humanities*. Advance online publication. <http://dx.doi.org/10.1136/medhum-2023-012653>

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Seear, K., Fraser, S., Mulcahy, S., Kagan, D., Lenton, E., Farrugia, A. & valentine, k. (2023b) Echoes and antibodies: Legal veridiction and the emergence of the perpetual hepatitis C subject. *Social and Legal Studies* 32(2): 216–236. <https://doi.org/10.1177/0964663922111569>

Seear, K., Mulcahy, S., Kagan, D., Lenton, E., Fraser, S., valentine, k. & Farrugia, A. (2022) Complicating cure: How Australian criminal law shapes imagined post-hepatitis C futures. *Sociology of Health and Illness*. 45(1): 179–195. <https://doi.org/10.1111/1467-9566.13562>

Seear, K. & Lenton, E. (2021). Becoming posthuman: Hepatitis C, the race to elimination and the politics of remaking the subject. *Health Sociology Review* 30(3): 229–243. <https://doi.org/10.1080/14461242.2021.1971102>

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Kagan, D., Lenton, E., Mulcahy, S., Seear, K., Farrugia, A., valentine, k., Edwards, M. & Jeffcote, D. (2023). *Hepatitis C-related stigma and discrimination in a post-cure world: Summary report of project findings and recommendations*. La Trobe University, Bundoora.

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Seear, K., Lenton, E., Mulcahy, S., Fraser, S., valentine, k., Moore, D., Farrugia, A., Kagan, K. and Bourne, A. (2022). Submission to the consultation on the: *Draft National Stigma and Discrimination Reduction Strategy*.

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### Inquiries/law reform – oral evidence

valentine, k. (2020). Inquiry into Mandatory Disease Testing Bill 2020. Standing Committee on Law and Justice, Legislative Council, Parliament of New South Wales.

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Seear, K. *Are we compromising cure? Examining the elimination agenda against post-cure life and human rights*. [keynote presentation]. HIV Coinfection and Viral Hepatitis Elimination Conference, Brisbane, Australia, 22 July 2023.

Lenton, E. *Troubling complaint: The legitimate subject and hepatitis C-related stigma*. [paper presentation]. Contemporary Drug Problems Conference, Paris, France, 6–8 September 2023.

Lenton, E. *Hepatitis C data justice: The implications of data-driven approaches to the elimination of hepatitis C*. [paper presentation]. 27th Harm Reduction International Conference, Melbourne, Australia, 18 April 2023.

Kagan, D. *‘I’m not hep C free’: The persistence of hepatitis C after cure*. [paper presentation]. ARCSHS Research Seminar Series, Bundoora, Australia, 15 February 2023. Available at: [www.youtube.com/watch?v=5wWDnLzK9zE](https://www.youtube.com/watch?v=5wWDnLzK9zE)

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Kagan, D. *Cured bodies in flux: Living with/out hepatitis C in the era of viral elimination*. [paper presentation]. The Australian Sociological Association Conference, Melbourne, Australia, 1 December 2022.

Seear, K. *Stigma undermining the elimination of hepatitis C*. [Keynote presentation]. Australian Stigma Conference, Canberra, Australia, 17 November 2022. Available at: [facebook.com/watch/live/?ref=watch\\_permalink&v=495570829203545](https://facebook.com/watch/live/?ref=watch_permalink&v=495570829203545)

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### Select media

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