

Annual Report of Trends in Behaviour 2019: Viral Hepatitis in Australia

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Annual Report of Trends in Behaviour 2019 Viral Hepatitis in Australia

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CSRH

Centre for Social Research in Health

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Abbreviations

ART – antiretroviral therapy

ARTB – Annual Report of Trends in Behaviour

BBV – blood borne virus

CRP – Community Reference Panel

CSRH – Centre for Social Research in Health

DAA – directly-acting antiviral

GCPS – Gay Community Periodic Survey(s)

HBV – hepatitis B virus

HCV – hepatitis C virus

HIV – human immunodeficiency virus

LGBTIQ – lesbian, gay, bisexual, transgender/transsexual, intersex and queer/questioning

NHMRC – National Health and Medical Research Council

NSP – needle and syringe program

OST – opioid substitution therapy

PrEP – pre-exposure prophylaxis

PROM – patient-reported outcome measure(s)

PRM – patient-reported measure(s)

PREM – patient-reported experience measure(s)

STI – sexually transmissible infection

TasP – treatment as prevention

Executive summary

Overview

This Annual Report of Trends in Behaviour (ARTB) focuses on viral hepatitis and provides an opportunity to highlight the contributions of the Centre for Social Research in Health (CSRH) to the rapidly changing landscape of hepatitis C infection and treatment, brought about by universal access to direct-acting antiviral (DAA) treatments. Our research contributes in important ways to this changing landscape; by participating in the monitoring activities that inform prevention, diagnosis and treatment efforts, and by continuing to critique and question the normative assumptions that sometimes underlie research, policy and practice around viral hepatitis. This report continues the structure seen in previous years by presenting material to reflect prevention, care and treatment cascades. Our research in 2018 was wide-ranging, however there are a few key issues that stand out:

- **The continuing need to be innovative with prevention approaches**

While much attention has been focused on DAA treatments, we and others have stressed the continuing need to update and innovate prevention. The initial rush to treatment following the introduction of universal access in 2016 has slowed (from 32,610 individuals in 2016 to 16,110 in 2018) (Kirby Institute, 2019). This suggests not only a need for ongoing efforts to address barriers to treatment but underscores the importance of ensuring prevention measures for those who either do not want or cannot access treatment, or indeed for those who have successfully completed treatment and want to remain virus-free.

Within the shifting context of DAA treatments, there remains the need to continually update harm reduction programs in ways that reflect the social and situated nature of transmission. In 2018, our work in this area showed how the law limits the possibilities for prevention (with peer distribution being a case in point), and how affected communities develop their own prevention practices in particular settings (such as prison), and through particular sets of social relations (such as through sexual and gendered identities). Prisons in particular present unique prevention challenges. There are greatly improved opportunities for prisoners to undertake treatment (which they are doing, in record numbers), yet the absence of prison needle syringe programs means there remains no means of prevention for those who continue to inject, and there is often inadequate continuity of care for those exiting prison. While re-treatment is available and appropriately so, not least within a public health, treatment-as-prevention framework, promoting treatment without providing effective prevention is fraught.

CSRH is also involved in several studies exploring the issue of reinfection in the community. As the numbers of people who undertake treatment grows, the role of social and qualitative research needed in order to understand the issue of reinfection and appropriate prevention will become increasingly important, including peoples' hesitations and/or misunderstandings around the availability of re-treatment.

- **Responsive models of care for viral hepatitis**

With the heightened focus on DAA treatments comes the need to critically explore how models of care are thought about and constructed, and whether they best meet the needs of affected communities. We have made innovative contributions to this area with our focus on peer-delivered models of care. In 2018, a new program of work was established at CSRH, focusing on developing a critical social science of how evidence is made as part of new interventions, technologies and policies in health (such as the implementation of the new DAA treatments). Despite the considerable investment in the development of interventions and research to examine the use and uptake of innovations in health technology, there is relatively little social science research in this domain. We also continue work focusing on *Patient-Reported Outcome Measures*, tools that centrally position the perspectives of service users in the measurement of therapy outcome, and work on the personal, social and systemic barriers and facilitators to treatment, as experienced and understood by people who are affected by hepatitis C.

- **Stigma**

In 2018, we continue our focus on stigma, which underpins many of the analyses in this report. Negative attitudes of health workers towards affected communities, such as people who inject drugs, may act as a barrier to the provision of good quality care and lead to discriminatory practice. We know from previous research, including our own, that experiencing stigma or discrimination in health care settings is correlated with negative impact on health outcomes. We continue to examine the impact of stigma on the capacity of affected communities to navigate treatment systems, offering a range of possible interventions to mitigate its negative impact. We also report on new data arising from the stigma indicators project aimed at monitoring the experience of stigma among key priority populations over time.

Community Reference Panel

The Community Reference Panel (CRP) enables researchers to consult with people who have lived experiences of viral hepatitis, incarceration, sex work, injecting drugs and living with disabilities. The CRP provides specific feedback on various aspects of research projects, ensuring our work remains grounded in and respectful of the experiences and concerns of those most directly affected.

Viral hepatitis prevention

Authorised peer distribution of needles and syringes in NSW: An evaluation of a pilot project

While currently illegal, peer distribution may have numerous harm reduction benefits. Our evaluation of the NSW Users and AIDS Association (NUAA) pilot project revealed that extended distribution of sterile needles and syringes was widespread and undertaken primarily as a way to support safe injecting. We argue that the extensive support for extended distribution among stakeholders in this study, including police, creates meaningful opportunities to further develop the conditions required for legislative change.

Drug use and injection by participants in the Gay Community Periodic Surveys

Nationally, over the last decade, the proportion of men who injected drugs in the six months prior to survey is stable (4% on average), with HIV-positive men more likely to report injecting drug use than HIV-negative men. (Meth)amphetamines and steroids are the substances most commonly injected by gay men, while amyl nitrite was the drug most commonly used by respondents, followed by cannabis.

Crystal methamphetamine use among gay and bisexual men in Perth

During 2017-18, CSRH conducted an interview-based study into crystal methamphetamine use among gay and bisexual men living in Perth, exploring how participants understood crystal, and how they incorporated it into their social and sexual practice. Reported patterns of use varied widely, from daily to occasionally and participants described a range of strategies employed to regulate their use and to avoid HIV infection and other harms.

Crystal, Pleasures and Sex between Men project: Hepatitis C transmission risk factors among gay and bisexual men who use crystal methamphetamine

This three-year, interview-based project examined gay and bisexual men's crystal methamphetamine use in Sydney, Melbourne and Adelaide. In relation to hepatitis C, data indicate that hepatitis C transmission was not perceived as a primary risk, with participants more concerned about other risks, such as losing 'control' over their drug use.

Testing, diagnosis, and lived experience of viral hepatitis

Stigma Indicators Project

In the second phase of this project, surveys were conducted with people who had ever lived with hepatitis C and people who inject drugs to investigate their experiences of stigma. More than four out of five people who inject drugs reported experiencing stigma in the last 12 months related to their injecting drug use. Among people who have ever lived with hepatitis C, 57% reported experiencing any stigma related to their hepatitis C in the last 12 months.

Stigma and discrimination: healthcare and people who inject drugs

People who inject drugs commonly report discriminatory experiences, particularly in health care settings. Our research highlights the role of attitudes toward people who inject drugs in understanding workers' decisions, practices and potential behaviour while also highlighting the importance of education programs to address health workers' attitudes to ensure good quality of care for this community.

Hepatitis B-related stigma among Chinese Australians living in Sydney

This Sydney-based, pilot-study interviewed older Chinese Australians and younger Chinese students to explore their attitudes toward people in their communities living with hepatitis B virus (HBV) infection. Findings highlighted the varying health literacy about viral hepatitis,

and that few older participants had a clear understanding of the risks of transmission, the symptoms, the treatments, and the natural history of HBV infection. A widespread fear of contagion was reported among participants, with ‘distancing practices’ towards those living with infections commonplace.

FUTURE DIRECTIONS – My health, our family: Documenting stories of family life in the context of HIV, hepatitis B or hepatitis C

Extensive qualitative data were collected for this study from people diagnosed with HIV, hepatitis B or C, and their family members. Emerging findings suggest that the effective and tolerable DAA treatments are changing how and when some people disclose hepatitis C infection to family members, because they feel more able to recruit their support in pursuing a cure. However, with no successful cure available, greater barriers exist to openly discussing hepatitis B within families.

Treatment, service engagement and care for viral hepatitis

The Observe Study: Understanding barriers and facilitators to the take up of new direct-acting antiviral hepatitis C treatment

This project collects information from people who inject drugs about their experiences with new DAA treatments for hepatitis C. This study focuses on participant reports of the personal, social and systemic barriers and facilitators to treatment. Findings show that participants were enthusiastic about treatment and that uptake was already high at the sites where we sampled. Participants were well-aware of the opportunities to get treated and those who had not yet taken up treatments reported that such decisions related to their concerns about confidentiality and potential side effects, issues that were linked to a deeper mistrust and suspicion of the medical establishment.

Beyond cure: patient reported outcomes of hepatitis C treatment among people who inject drugs in Australia

The findings of this project suggest that people who inject drugs often seek outcomes ‘beyond cure’, including better physical and mental health, a future free of liver diseases, the creation of a new, non-stigmatised identity disassociated with drug use and disease, better social connections with family and friends, and information and expertise to avoid or manage the possibility of future HCV infections.

Beyond interferon side effects: What residual barriers exist to DAA hepatitis C treatment for people who inject drugs?

The study’s findings showed that many residual barriers to DAA treatment exist for people who inject drugs, at personal, provider and system levels. Among many findings, this study revealed the need for ongoing efforts to reduce stigma and discrimination towards people who inject drugs as this remains a major barrier to care and treatment for many people with HCV infection.

Behind closed doors, no one sees, no one knows': hepatitis C, stigma and treatment-as-prevention in prison

While there is a substantial literature addressing the role of stigma to experiences of living with HCV in the community, scant attention has been paid to documenting how HCV-stigma figures within the distinct sociality of prison life. This article focused on initial, pre-treatment interviews with prisoner participants from the first, real-world trial of HCV 'treatment-as-prevention' in prison: Australia's Surveillance and Treatment of Prisoners with Hepatitis C (SToP-C) study.

Prisoner's perspective of treatment as prevention

The qualitative research from this study, based on the first trial of HCV treatment as prevention (TasP) in the prison setting, reveal a range of concerns raised by prisoners about the potential efficacy of TasP. Among the most common concerns were prisoner movements (transfer between prisons or incarceration-release-incarceration) and vulnerabilities to HCV reinfection following treatment. Suggestions for system-wide efforts to foster TasP efficacy included both education and prison needle syringe programmes.

A policy analysis of hepatitis C risk, prevention, testing, treatment and reinfection within Australia's prisons

This project sought to examine whether state and territorial health and prisoner HCV policies have been responsive to the advent of unrestricted treatment access for HCV, irrespective of drug user or incarceration status. Health and prisoner HCV policies were found to have not kept pace with the test-and-treat HCV landscape, with few jurisdictions having updated or published policies since the availability of DAAs.

Facilitators and barrier to uptake of direct-acting antiviral therapy in prison

This study found that there were structural and patient-level facilitators to treatment in prison settings, including on-site and around-the-clock medical care, patient motivation, and availability of time (compared with the competing priorities participants encountered in the community). Barriers included existing high-prevalences of HCV coupled with lack of access to harm minimisation measures, lack of social support when undergoing treatment, and concerns for being 'found out' by their peers of their HCV status when accessing the health clinic.

Evaluation of the Deadly Liver Mob program: Insights for roll-out and scale-up of a pilot program to engage Aboriginal Australians in hepatitis C and sexual health education, screening and care

Deadly Liver Mob (DLM) was a pilot program aimed at improving health promotion and screening for HCV, HIV and sexually transmissible infections (STIs) among Aboriginal and Torres Strait Islander people. Our evaluation presents evidence pertinent to the broader scale-up of the DLM program. Since this project, CSRH have received funding to expand the DLM program to an additional five Local Health Districts across NSW.

Evidence-making controversies: the case of hepatitis C treatment and the promise of viral elimination

We analysed a recent controversy regarding the curative potential of new treatments for hepatitis C; the publication of a systematic review conducted by the Cochrane Collaboration. We analysed this case to illuminate how moments of controversy offer useful sites of evidencing-making investigation for public health research. Our analysis demonstrates how an ‘Evidence-Making Intervention’ approach (as is being developed as part of a new program of work at CSRH) can be used in critical public health research.

Towards eliminating viral hepatitis”: Examining the productive capacity and constitutive effects of global policy on hepatitis C elimination

In 2016 the World Health Organization published the first global health strategy to address viral hepatitis, setting a goal of eliminating viral hepatitis as a major public health threat by 2030. As part of the new ‘Evidence-Making Interventions’ program of work at CSRH, we have been analysing the productive capacity and constitutive effects of target-setting.

FUTURE DIRECTIONS – ‘Evidence-making interventions’ in health

This new program of work focuses on developing a critical social science of how evidence is made as part of new interventions and policies in health. To improve on our understanding of how ground-breaking innovations in health technologies can deliver on their promise, we need a new approach to interventions research which resists taken-for-granted assumptions about how interventions will ‘work’.

Community Reference Panel

Melinda Walker, Kim Beadman, Steve Griffin, Mitchell Beadman, Carla Treloar

The [Community Reference Panel](#) (CRP) was convened in 2016 to allow researchers to consult with people who have lived experiences of viral hepatitis, HIV, incarceration, sex work, and injecting drugs. In 2017, the panel expanded to include people with disability in the areas of physical, intellectual and mental health. The purpose of this panel is to provide specific guidance and feedback on various aspects of research projects. This feedback is essential to ensuring that CSRH research is grounded in and respectful of the experiences and concerns of community members. Being a member of the panel allows for individuals to have a voice and share experiences or highlight issues concerning the target groups.

There are four coordinators for the CRP: Melinda Walker, Kim Beadman, Steve Griffin and Mitchell Beadman. Melinda is enrolled in a Bachelor of Social Work (Honours) and Kim is enrolled in a Bachelor of Psychological Sciences and Criminology, both at UNSW. Steve graduated from UNSW in 2012 with a Bachelor of Social Work. Mitchell is currently undertaking a bachelor in psychological science at UNSW. We have a passion for social justice and equality for all people in the community, particularly Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, as well as people with disabilities.

1. Viral hepatitis prevention

1.1 Authorised peer distribution of needles and syringes in NSW: An evaluation of a pilot project

Joanne Bryant, Loren Brener

One of the current harm reduction debates in Australia concerns the legalisation of the extended distribution of sterile needles and syringes, a practice that is currently unlawful in most Australian settings. Extended distribution occurs when people who inject drugs collect equipment from primary or secondary needle and syringe program (NSP) services and then distribute equipment to their peers. It is a means to service networks of people not otherwise reached by the more traditional harm reduction outlets or routes. Currently within NSW, while it is legal to possess a sterile syringe for the purpose of injecting drugs, it is a criminal offence to pass this equipment on for others to use.

As peer distribution may have numerous harm reduction benefits particularly for those people who inject drugs who do not access NSPs, in 2013 a pilot project was established at the NUAA NSP service to trial the extension of authorisation to clients attending this service to enable them to pass on sterile syringes to their peers without criminal penalty. This research evaluated this pilot and also describes patterns of distribution among attendees participating in this trial.

A cross-sectional survey was completed by 200 clients attending with clients attending the NUAA NSP in South East Sydney and the outreach service NSP situated in South Western Sydney during one week in October 2014. The survey focused on the extent, characteristics, and perceived risks and benefits of extended distribution practices within peer groups. We also conducted in-depth interviews with 22 key stakeholders -service staff, drug users and police - to document the opinions held about the risks and benefits of authorisation, and to analyse the ways in which drug users were understood within these.

The survey findings illustrate that, among this sample, extended distribution is widespread and does not occur in an organised or intentional manner but as a consequence of the daily life activities of injecting drug users. Additionally, as is evident in other research, many drug users were unaware of or confused about the legal status of extended distribution. Those who report that they distribute are similar to those who report that they do not distribute equipment to others which may indicate that extended distribution is something that most drug users engage in at some point in their injecting experiences, perhaps more so when they are injecting with greater frequency. Participants reported willingness to distribute small quantities of equipment to others was higher than willingness to distribute larger quantities, while willingness to distribute was also related to perceived benefits of extended distribution. In terms of the risks associated with extended distribution, a number of participants were concerned that they would be stopped by the police and this was one of the key perceived risks around distributing equipment.

The qualitative interview findings reveal that opinions were strongly in favour of authorising extended distribution, based on the belief that this would reduce the transmission of hepatitis C. However, stakeholders also identified that distributors risked attention from police and some noted that the consequences of this would be borne by distributors themselves and not the services that support them. These opinions rested on specific assumptions about people who inject, some of which reflect negative constructions of drug users as a source of danger to the public or as helpless ‘addicts’ with little control over their risk reduction. But there were other representations that positioned drug users more positively as responsible agents with a strong duty of care to themselves and others whose choices are often limited by inadequate service structures. Staff participants drew on these understandings in careful and strategic ways, arguing for the rationality and expertise of drug users, while also problematizing the individualised approach that any form of authorised extended distribution might take.

This research supports the idea that extended distribution among this sample is widespread and, for the most part, not organised nor intentional. Instead it appears that this practice is undertaken as way to support safe injecting practices. It is an example of drug users acting responsibly to help each other inject safely and to prevent the harms associated with injecting drug use. We argue that the extensive support for extended distribution among stakeholders in this study, including police, creates meaningful opportunities to think about extended distribution and further develop the conditions required for legislative change.

Brener, L., Bryant, J. Cama, E., Pepolin, L., & Harrod, M. (2018). Patterns of peer distribution of injecting equipment at an authorised distribution site in Sydney, Australia. *Substance use and Misuse*, 53(14), 2405–2412. <http://doi.org/10.1080/10826084.2018.1480039>

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1.2 Drug use and injection by participants in Gay Community Periodic Surveys

Limin Mao, Timothy Broady, Martin Holt

The [Gay Community Periodic Surveys](#) (GCPS) include questions about the not mutually exclusive use of a range of drugs. Table 1 and Figure 1 show the use of selected drugs by men nationally (including every participating state and territory) in the six months prior to the survey. Findings illustrate changes in commonly used recreational drugs among gay men across the country.

Tables 1–3 and Figure 1 show that:

- Amyl nitrite (‘poppers’) is the most commonly reported drug used by participants in the GCPS. Amyl nitrite is an inhaled drug which is popular among gay men as both a euphoric and muscle relaxant; it is used as both a ‘party’ drug for dancing and in sexual settings. Use of ‘poppers’ is reported by 37% of men, on average, in the GCPS and the use of ‘popper’ has increased during the 10-year period (35% in 2009 to 43% in 2018, although a stable trend during 2016–18).
- Cannabis is the second most commonly reported drug used by participants in the GCPS (by 31% of men on average) and its use has also remained stable since 2009.

- Proportions reporting the use of ecstasy (26% in 2009 to 16% in 2018,) and that of speed (14% in 2009 to 5% in 2017, rates more than halved) have both declined during the 10-year period.
- Cocaine use has increased since 2009, from 11% to 16% in 2018.
- Crystal meth consumption has increased over time, particularly during 2010–2015 (from the lowest 9% in 2010 rose to 11% in 2012–13, then jumped to the highest in 2015 at 13%,) but remained stable in the last three years (11% in 2018). The use of crystal methamphetamine particularly in the context of sexual encounters and poly drug use (with or without injection) among specific groups of gay men suggests an urgent need to provide appropriate harm reduction and treatment services for these men.
- Since 2009, GHB/GBH use has also slightly increased, from 7% in 2009 to 9% in 2018 (stable during 2016–18)
- The use of erectile dysfunction medications (e.g. Viagra and Cialis) have increased over the last 10 years (23% in 2009 to 29% in 2018) but has not changed since 2016. Erectile dysfunction medication is used by gay men to facilitate sex and its use has been associated with an increased risk of HIV seroconversion.

Injection of non-prescribed drugs for recreational purposes remains relatively rare among gay men although it is more common than in the general population. Over the 10-year period, the proportion of men who injected drugs in the six months prior to survey is stable nationally (4% on average). HIV-positive men are more likely to report injecting drug use than HIV-negative men. (Meth)amphetamines and steroids are the substances most commonly injected by gay men.

Similar information about recreational drug use was also collected from the National Gay Asian Men Periodic Surveys. The overall levels of non-prescription drug consumption among gay Asian men were on par with those of gay men participated in the GCPS. However, relatively smaller proportions of gay Asian men reported use of either cannabis or any erectile dysfunction medications, compared to their GCPS counterparts. Over 70% of gay Asian men reported any alcohol use six months prior to survey.

In terms of service access to HCV testing and vaccination against hepatitis A or B, the GCPS data (unadjusted) shows that, on average, 71% had ever been tested for hepatitis C and of these, about 2% reported either being hepatitis C-positive (between 2013 and 2016) or having chronic hepatitis C to be more precise (since 2017).

The 2018 data from the National Gay Asian Men Periodic Surveys shows that about 53% had ever been tested for HBV, 48% for hepatitis A and 40% for hepatitis C.

Table 1: Men who reported any use of selected recreational drugs in the six months prior to the survey: GCPS, 2009–2018 (all states or territories)

	2009 %	2010 %	2011 %	2012 %	2013 %	2014 %	2015 %	2016 %	2017 %	2018 %	Overall trend	Trend in last 3 years
Amyl nitrite	35.1	38.4	37.1	37.1	38.5	38.3	40.6	39.1	42.3	43.3	↑	ns
Cannabis	29.7	32.8	29.4	29.8	30.4	33.1	28.4	28.9	31.5	29.9	ns	ns
Ecstasy	25.6	24.7	18.6	17.1	18.6	17.3	15.0	14.8	16.6	15.8	↓	ns
Cocaine	11.4	13.0	10.9	10.7	13.0	11.3	12.3	12.2	14.1	16.4	↑	↑
Crystal methamphetamine	9.6	8.8	9.1	11.2	11.2	13.0	13.2	12.4	11.2	11.0	↑	ns
Speed	13.8	12.7	10.2	11.0	10.2	7.5	6.6	6.0	7.0	5.4	↓	ns
GHB/GBH	6.6	6.8	6.5	6.7	7.8	6.6	7.7	7.1	9.8	9.0	↑	ns
Erectile dysfunction medication (e.g. Viagra, Cialis)	22.6	21.8	22.2	23.9	23.0	23.8	25.5	26.6	27.5	29.4	↑	ns
Any drug injection	6.5	5.4	5.0	6.1	5.1	6.8	7.0	7.0	4.6	6.0	ns	ns

Table 2: Men who reported any use of selected recreational drugs in the six months prior to the survey: National Gay Asian Men Periodic Surveys (unadjusted data)

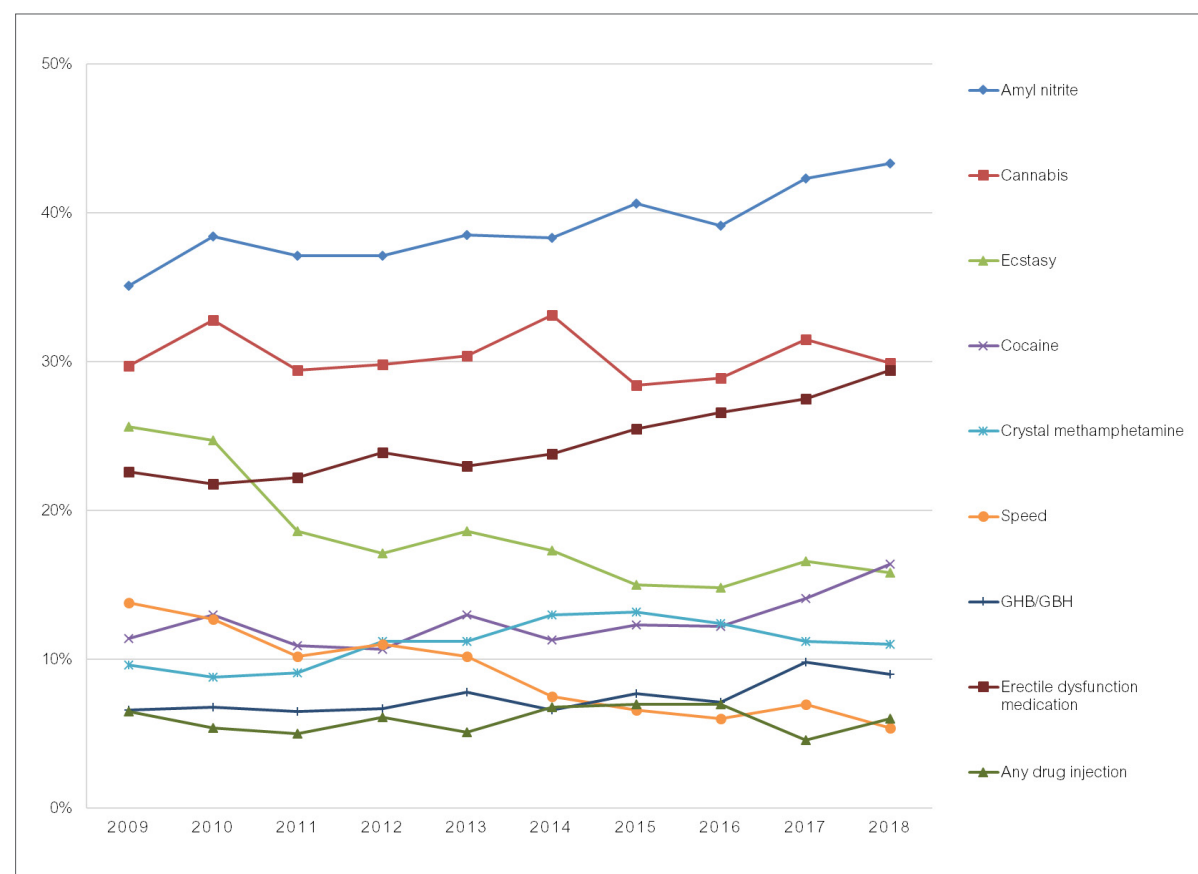
	2015–16* %	2018 %
Alcohol	72.1	77.5
Amyl nitrite	40.2	37.1
Cannabis	15.9	17.4
Erectile dysfunction medication (e.g. Viagra, Cialis)	13.8	19.2
Ecstasy	9.9	13.1
Crystal methamphetamine	8.2	9.5
GHB/GBH	5.2	8.5
Any drug injection	3.7	3.4

*Sydney and Melbourne only

Table 3: Access to hepatitis testing and vaccination: GCPS, 2013–2018 (all states or territories, unadjusted data)

	2013 %	2014 %	2015 %	2016 %	2017 %	2018 %
Ever tested for HCV	73.6	70.8	70.5	70.1	70.2	70.4
Hepatitis C status among those ever tested	*2.2	*1.8	*1.7	*1.6	**2.4	**2.2
Hepatitis A vaccination (ever)						72.5
Hepatitis B vaccination (ever)						77.3

*2013–2016 self-reported hepatitis C positive; **2017–2018 self-reported chronic hepatitis C

Figure 1: Men who reported any use of selected recreational drugs in the six months prior to the survey: GCPS, 2009-2018 (all states or territories)

1.3 Crystal methamphetamine use among gay and bisexual men in Perth

Max Hopwood, Kerry Drysdale, Carla Treloar

In 2017 and 2018, CSRH conducted an interview-based study, funded by the Western Australia Health Department, into crystal methamphetamine (aka crystal) and its use among gay and bisexual men who live in Perth. Building on UK research into 'chemsex', this study aimed to explore how gay and bisexual men understood crystal, and how they incorporated use of the drug into their social and sexual practice. CSRH researchers recruited five key informants from Perth-based non-government organisations to discuss their perceptions regarding crystal use and sexual practice, and the researchers interviewed 16 Perth-based gay and bisexual men who regularly used crystal for sex.

Participants employed coded language/imagery on social media dating apps and websites to find sexual partners who smoked and/or injected crystal (such as 'sunshine on rainy day'). Their sexual partners often belonged to disparate and disconnected networks, and most men that the study participants encountered through the apps were not gay community attached. Reportedly, men who used the apps to look for sex on crystal in Perth often had little interest in socialising within LGBTIQ communities per se. In this study, crystal use was said to bestow a range of benefits for men in Perth: it gave them the confidence to have better social and sexual interactions, it helped men get the sex they wanted, and it made some men feel more comfortable about being gay, or bisexual, and/or HIV-positive.

We were also interested in exploring some of the ways gay and bisexual men managed their patterns of crystal and other drug use in the context of sexual practice. Reported patterns of crystal use varied widely, with men using crystal daily, or weekly, or fortnightly, and monthly to occasionally. A period of intensive crystal use followed by long breaks was common. Reportedly, most men aimed to control their patterns of crystal use to avoid 'addiction', and to avoid becoming dependent on sex on crystal. Despite this, participants' drug use transitioned back and forth between control and functionality, and loss of control and dysfunctionality. Factors which were reported to aid controlled crystal use included: fulltime employment; having diverse social and sexual networks including people who do not use crystal; implementing avoidance strategies such as cutting back on social media use and/or relocating to areas away from Perth; switching between injecting and smoking crystal to reduce injecting; having access to 'friendly' professional support; and, knowing where to access information about safer crystal use. To avoid HIV infection and other harms, biomedical technologies such as antiretroviral therapy (ART) and pre-exposure prophylaxis (PrEP), and negotiated agreements, serosorting, disclosure and personal risk assessments were widely used.

Paradoxically, the folk pharmacology of gay and bisexual men (i.e. how men understand drug effects) constructed crystal as both a drug ideal for sexual activity, and a drug unsuitable for sexual activity. As a sex drug, crystal was believed to facilitate emotional connection, increase confidence, improve stamina, push sexual boundaries, and in BDSM scenes make pain and endurance 'more interesting'. Alternatively, crystal use was perceived by some participants to inhibit sexual activity because it could lead to erectile dysfunction, and some men were said to become impulsive and agitated during sex on crystal. In the

light of these findings, the research team developed wide-ranging recommendations for reducing the harms associated with sex on crystal.

Hopwood, M., Drysdale, K., & Treloar, C. (2018). *'Sunshine on a rainy day': Crystal methamphetamine use among gay and bisexual men in Perth*. Sydney: Centre for Social Research in Health, UNSW Sydney. <http://doi.org/10.26190/5be39b00ad585>

1.4 Crystal, Pleasures and Sex between Men project: How gay and bisexual men who use crystal methamphetamine understand and manage hepatitis C

Kerryn Drysdale, Joanne Bryant, Max Hopwood, Martin Holt, Peter Aggleton, Toby Lea, Gary W. Dowsett, Carla Treloar

The Crystal, Pleasures and Sex between Men research study was a three-year, NHMRC-funded project that sought to examine gay and bisexual men's crystal methamphetamine use, especially when related sexual activity. This research builds on, and intervenes in, recent studies of drug-enhanced sexual practices by examining gay and bisexual men's crystal methamphetamine use in three cities in Australia. One facet of the project explored gay and bisexual men's perceptions of hepatitis C, including the strategies they employed to protect themselves and others from this and other blood borne viruses and sexually transmitted infections.

CSRH researchers conducted 72 interviews in 2017 and 2018 with gay and bisexual men in Sydney (n=28), Melbourne (n=28), and Adelaide (n=16), as well as 25 interviews with key informants working in the health policy, sexual health, harm reduction and blood borne virus prevention fields. Some of the ways that men use crystal, perceive risk and practise risk reduction were dependent on the wider networks they participated in. Interviews with men from different networks revealed how gay and bisexual men generate different risk reduction practices depending on the contingencies and features of their local settings. Their risk reduction practices also include those that may be conventionally understood as risky (for example, turning from smoking to injecting as a mode of administration), but are experienced and understood by gay and bisexual men to be protective (to continue the same example, using injecting as a method of dose-control to prevent the incremental dosing that can happen with smoking). As such, the different approaches to taking drugs for sex can be highly organised and purposeful: gay and bisexual men described how they use specific drugs or combinations of drugs, in specific modes, at particular times and spaces, in order to minimise risk and maximise pleasure.

Data reveal participants were not overly concerned with hepatitis C. Gay and bisexual men either did not report specific concerns in relation to HCV transmission or viewed it as a minor issue that was preventable or treatable. For instance, some men said it was part of the experience of having sex on crystal, to "roll with the punches", or that new DAA treatments meant that it was "less of a concern" now. Generally, men reported that the main way they protected themselves was to use a sterile needle at each injecting event (although they often shared auxiliary injecting equipment, such as tourniquets and water vials). Other strategies gay and bisexual men reported included stockpiling equipment to avoid the need to share or reuse needles and maintaining a safe environment, including adequate lighting to facilitate safe injecting and providing safe needle disposal mechanisms. Only a couple of participants

reported an understanding of, and strategies to prevent, HCV through sexual transmission, including the sharing of sex toys. Overall, participants were less concerned about hepatitis C than they were about other risks, such as developing problematic substance use or becoming dependent on the drug for the type of sex that they want to have.

Bryant, J., Hopwood, M., Dowsett, G. W., Aggleton, P., Holt, M., Lea, T., Drysdale, K., & Treloar, C. (2018). The rush to risk when interrogating the relationship between methamphetamine use and sexual practice among gay and bisexual men. *International Journal of Drug Policy*, 55, 242–248. <https://doi.org/10.1016/j.drugpo.2017.12.010>

Hopwood, M., Cama, E., & Treloar, C. (2016). *Methamphetamine use among men who have sex with men in Australia: A literature review*. Sydney: Centre for Social Research in Health, UNSW Australia. <http://dx.doi.org/10.4225/53/58d4418d0a14b>

2. Testing, diagnosis, and lived experience of viral hepatitis

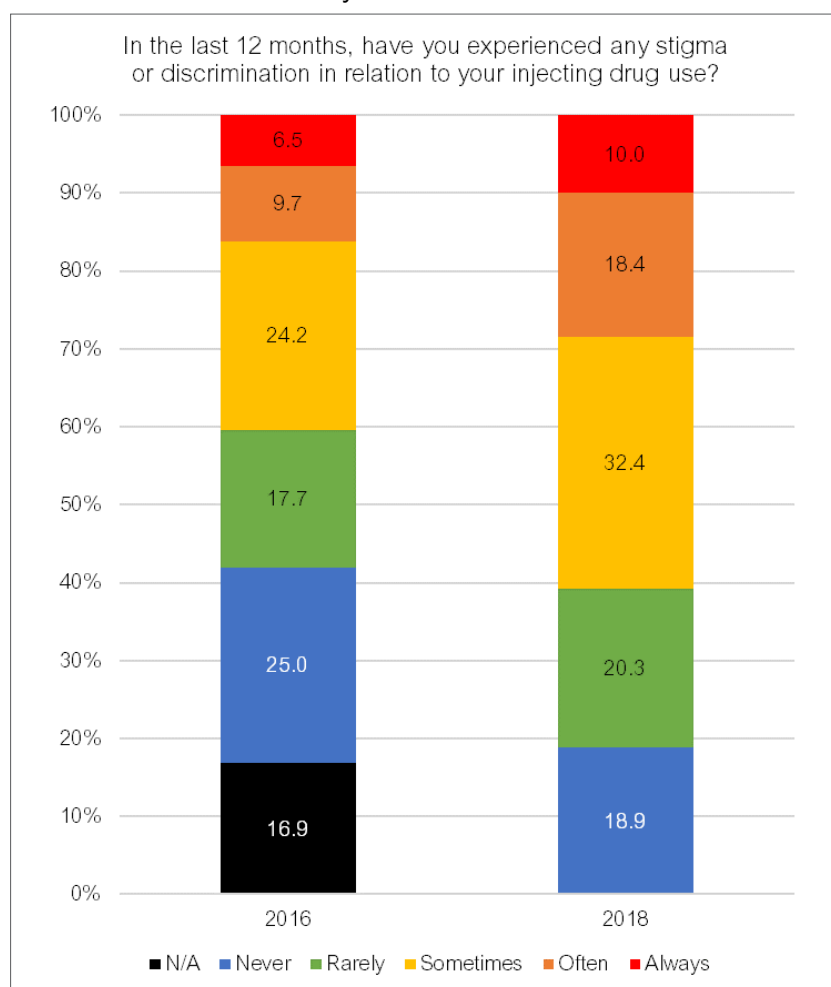
2.1 Stigma Indicators Monitoring Project

Timothy Broady, Loren Brener, Max Hopwood, Elena Cama, John de Wit, Carla Treloar

The aim of this national study is to develop an indicator of stigma amongst priority groups identified by the five national strategies addressing blood borne viruses and sexually transmissible infections, including men who have sex with men, people who inject drugs, people living with HIV, people living with viral hepatitis, and people who engage in sex work.

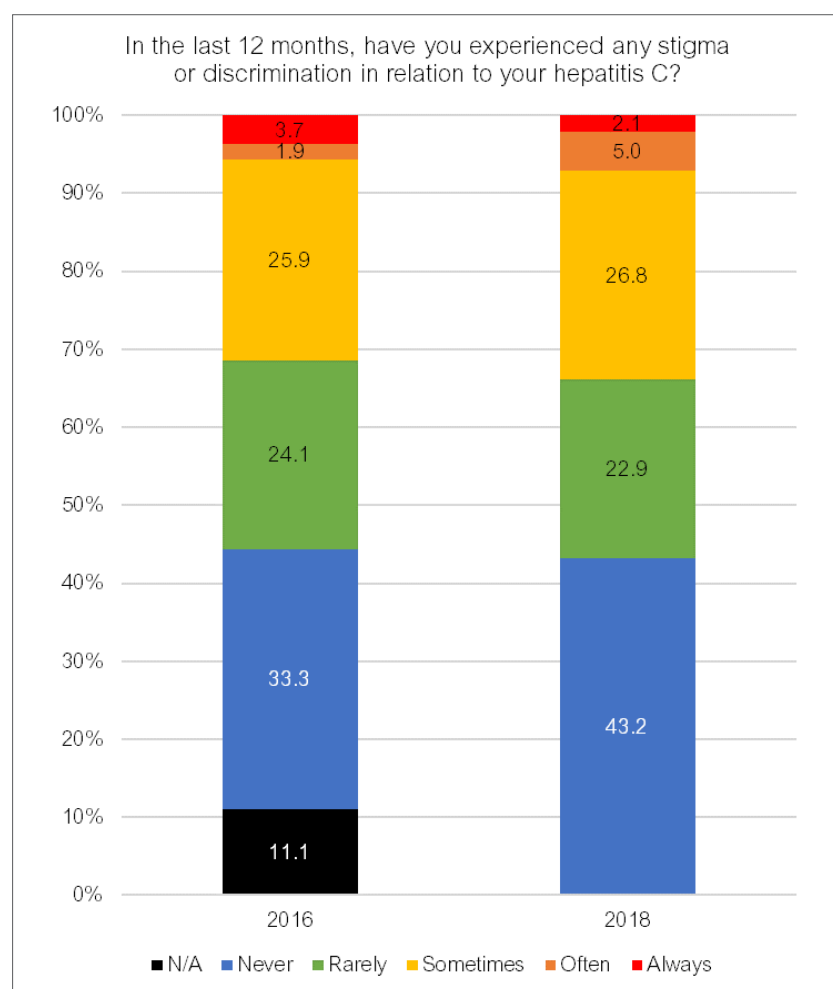
In the second phase of this project, surveys were conducted with people who had ever lived with hepatitis C and people who inject drugs to investigate their experiences of stigma using the stigma indicator. The 'Not Applicable' response option was removed in the second phase, therefore, caution should be used when comparing results between the first and second phase.

In 2018, more than four out of five people who inject drugs (81%) reported experiencing stigma related to their injecting drug use in the last 12 months, with 28% reported that this occurred 'often' or 'always'.



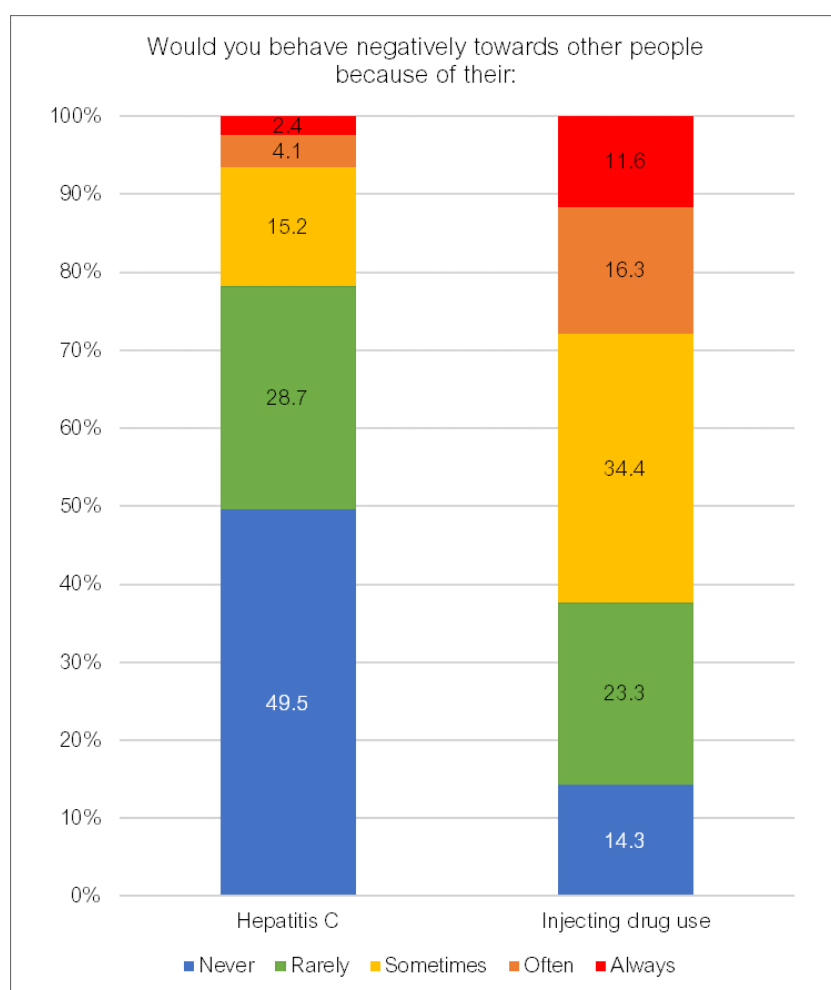
Note: N/A not provided as a response option in 2018.

Amongst people who have ever lived with hepatitis C, 57% reported experiencing any stigma related to their hepatitis C in the last 12 months. A much smaller proportion (7%) indicated that this occurred 'often' or 'always'.



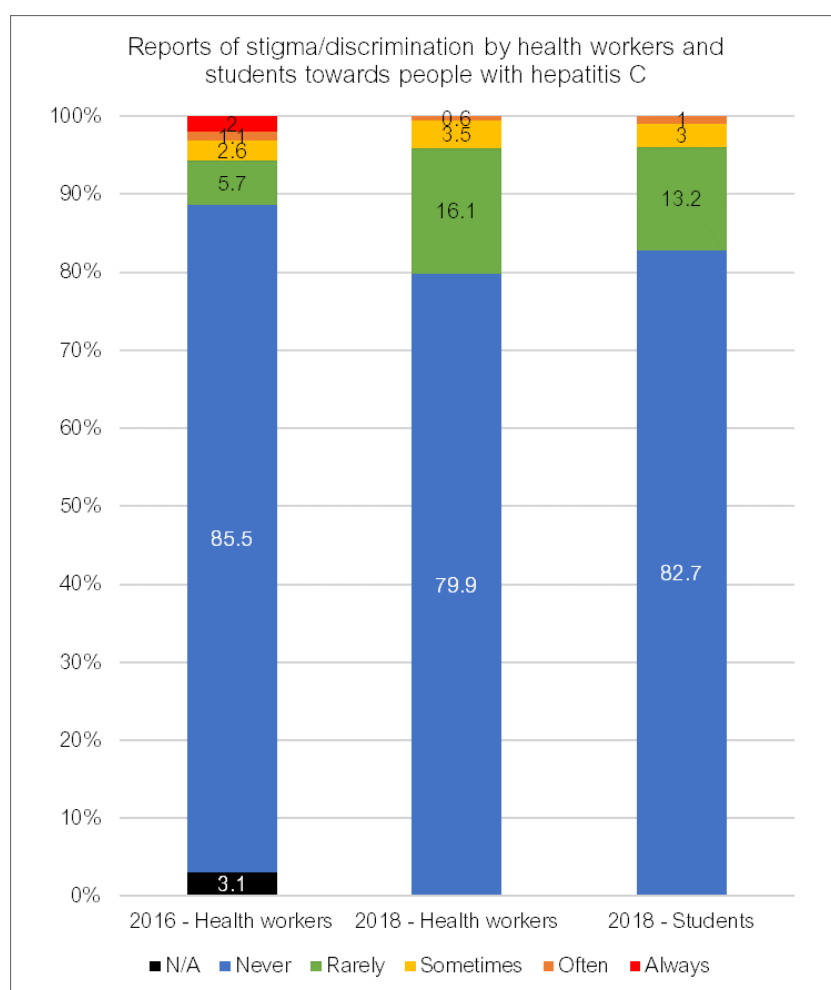
Notes: N/A not provided as a response option in 2018. The 2018 sample combines participants from the 2018 Hepatitis C survey with participants from the 2018 Injecting Drug Use survey who had ever been diagnosed with hepatitis C.

A mirrored indicator was administered to a representative sample of the adult Australian population via the Australian Survey of Social Attitudes. One in two participants indicated that they would behave negatively towards people living with hepatitis C to some extent, while 86% reported that they would behave negatively towards people who inject drugs.



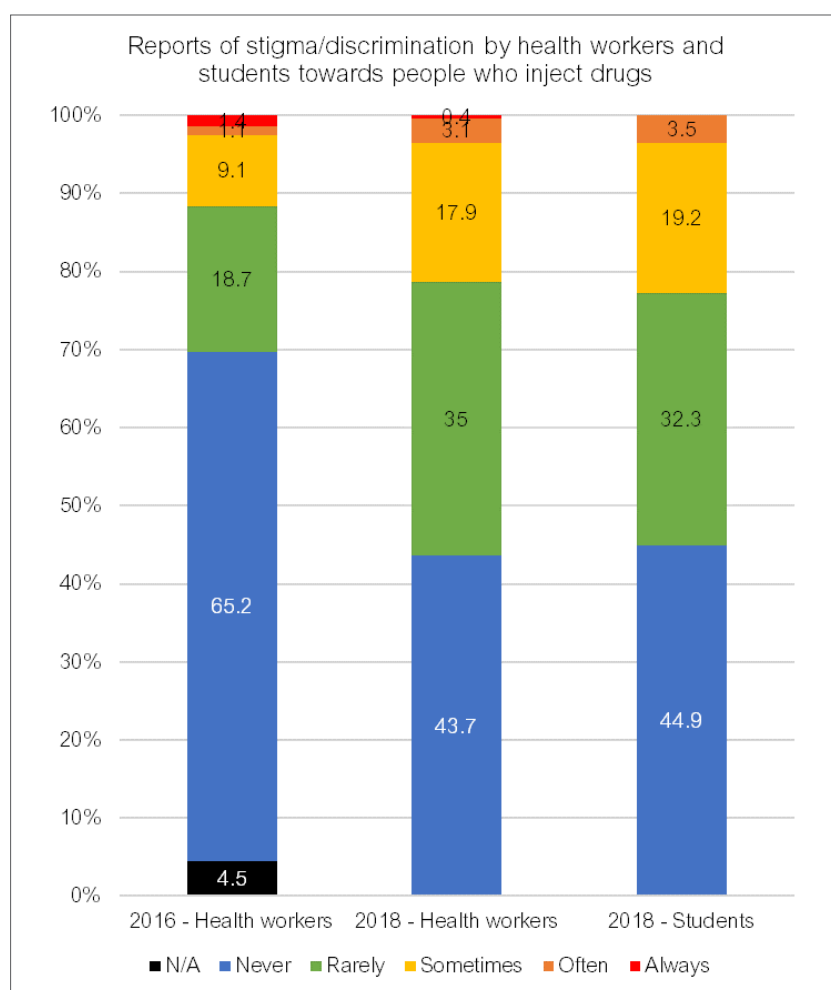
In 2016, a different mirrored indicator was included in a survey of health care workers recruited through the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) to monitor the expression of stigma towards people living with hepatitis C and people who inject drugs. Following consultation with the project advisory committee and health care workers, the wording of the mirrored indicator was revised. In 2018, a mirrored indicator was included in a survey of health care workers and health care/medical students, which recruited participants through paid Facebook advertising, resulting in a more general sample of health workers than was recruited through ASHM in 2016. The mirrored indicator used in 2018 was worded differently to 2016, in order to facilitate comparisons between health care workers and the general public. The 'Not Applicable' response option was also removed from the 2018 indicator. Caution should therefore be used when comparing between 2016 and 2018 results.

In 2018, 20% of health care workers indicated that they would behave negatively towards people living with hepatitis C to some extent, though less than 1% indicated that this would 'often' or 'always' be the case. By comparison, 17% of students indicated that they would display any negative behaviour towards people living with hepatitis C.



Notes: N/A not provided as a response option in 2018. 2016 data combines the original and revised indicators. The wording of the indicator question was different between 2016 and 2018. The 2018 sample represents a more general sample of health care workers than 2016.

Health care workers and students were more likely to indicate that they would behave negatively towards people who inject drugs (56% and 55% respectively). A small proportion (3.5% of each group) indicated that this would 'often' or 'always' occur.



Notes: N/A not provided as a response option in 2018. 2016 data combines the original and revised indicators. The wording of the indicator question was different between 2016 and 2018. The 2018 sample represents a more general sample of health care workers than 2016.

Being able to quantify the experience of stigma within these groups is an important step towards introducing evidence-based strategies to eliminate its negative effects. Future work will continue to monitor stigma using the indicator, particularly alongside any intervention efforts that are implemented.

Broady, T. R., Cama, E., Brener, L., Hopwood, M., de Wit, J., & Treloar, C. (2018). Responding to a national policy need: Development of a stigma indicator for bloodborne viruses and sexually transmissible infections. *Australian and New Zealand Journal of Public Health*, 42(6), 513–515. <http://doi.org/10.1111/1753-6405.12809>

Cama, E., Broady, T., Brener, L., Hopwood, M., de Wit, J., & Treloar, C. (2018). *Stigma Indicators Monitoring Project: Summary Report*. Sydney: Centre for Social Research in Health, UNSW Sydney.

2.2 Stigma and discrimination: healthcare and people who inject drugs

Loren Brener, Elena Cama, Tim Broady, Max Hopwood, John de Wit, Carla Treloar

People who inject drugs are a highly stigmatised group, largely due to the illegality of drug use and reinforced by stereotypes of people who inject drugs as irresponsible, violent, and dangerous criminals. The attitudes of those who provide services to people who inject drugs often reflect those of society more generally, while working directly with this community

may strengthen, rather than diminish, stereotypical notions of people who inject drugs as difficult, complex and aggressive clients. Negative attitudes of health workers towards people who inject drugs may act as a barrier to the provision of good quality care and lead to discriminatory actions. This is important as experiencing stigma or discrimination in health care settings has been shown to have a negative impact on health outcomes for this community. Among other things this study sought to examine whether health workers' attitudes towards people who inject drugs and their concerns about the behaviours of this client group may impact the way they provide care to this community. An online survey was administered to 336 health workers who work with people who inject drugs, assessing contact with and attitudes towards these clients, concerns about these clients, as well as whether health workers feel stigmatised by working with people who inject drugs. Health workers were also asked whether they supported the discriminatory behaviour of a colleague in a series of hypothetical scenarios about working with people who inject drugs. Bivariate correlational analyses revealed that negative attitudes towards people who inject drugs, greater concerns about the behaviour of these clients, not feeling stigmatised by colleagues as a result of working with people who inject drugs, and seeing fewer clients who inject were associated with greater support for discriminatory actions by the health worker in the hypothetical scenarios. Further multiple regression analysis results showed that only attitudes towards people who inject drugs and concerns about the behaviour of clients who inject remain independent predictors of participant support for the hypothetical scenarios.

This research highlights the role of attitudes in understanding health workers' decisions, practices and potential behaviours towards people who inject drugs. It is interesting that health workers' concerns about their clients who inject are linked to stereotypes associated with drug use, for example lying about drug use, pressuring clinicians for medications, and becoming violent. While these may be very real issues that health workers experience when working with people who inject drugs, such fears may also be fuelled by negative media portrayals of drug users. This research highlights the role of attitudes toward people who inject drugs in understanding workers' decisions, practices and potential behaviour, while also highlighting the importance of education programs to address health workers' attitudes to ensure good quality of care for these clients.

Brener, L., Cama, E., Broady, T., Hopwood, M., de Wit, J., & Treloar, C. (2019) Predictors of health care workers' support for discriminatory treatment and care of people who inject drugs. *Psychology, Health and Medicine*, 29(4), 439–445. <http://doi.org/10.1080/13548506.2018.1546018>

2.3 Hepatitis B-related stigma among Chinese Australians living in Sydney

Max Hopwood, Carla Treloar

As part of the Commonwealth Government-funded Stigma Indicator Project conducted by CSRH, a qualitative pilot-study was conducted to explore the attitudes of older Chinese Australians (>50 years) living in Sydney (n=14) and younger Chinese students (<50 years) studying in Sydney (n=8) toward people in their communities who are living with HBV infection. Recruitment to the study was assisted by the Chinese Australian Services Society (CASS), and via a special event at UNSW Sydney to promote HBV screening and awareness among international students. Face-to-face Interviews were held at CASS and at the UNSW

University Health Service during June and July 2018. Interviews were conducted in both traditional and simplified Chinese by male and female research assistants, who were fluent in both language forms. The interviews were transcribed into traditional and simplified Chinese and then translated into English by the research assistants.

The main findings of this pilot-study, while not generalisable to all Chinese Australians in Sydney, highlighted how viral hepatitis health literacy varied widely within and between these two age-cohorts, with few older participants having a clear understanding of the risks of transmission, the symptoms, the treatments, and the natural history of HBV infection. A minority of participants knew that vertical transmission was a primary cause of HBV infection. Furthermore, an association between sexual activity and the risk of HBV transmission was reported by younger participants, whereas older participants in this study did not specifically identify sexual activity as a risk for HBV infection.

A fear of contagion underpinned the stigmatisation of people with HBV infection in this study. Participants were fearful of social interactions, such as sharing food and utensils, and having bodily contact, with affected people. Despite this, viral hepatitis infections were rarely perceived to be stigmatised conditions within Chinese Australian communities, or within China. Distancing practices enacted by participants to avoid contact with people with HBV infection were not considered stigmatising or discriminatory because participants believed it was common sense to protect themselves from infection by reducing personal interactions with affected people. Even younger participants in this study who mostly had a good knowledge of HBV transmission risks, said they felt uneasy about sharing food, utensils or a drink with affected people. Among some younger participants who knew there was no risk of HBV transmission from sharing these items, they nonetheless reported avoiding any close contact with affected people. When prompted, they could not explain the inconsistency between their knowledge about HBV transmission risks and their distancing practices.

The study findings suggested that HBV-related stigma and discrimination is likely shaped by age and level of education, with younger Chinese students reporting more liberal values that made them less inclined to stigmatise and to discriminate. For example, younger participants said they would feel able to discuss HBV infection with family and friends, whereas older participants reported feeling uneasy about discussing HBV infection with anyone, because having an interest in HBV infection and raising it as a topic of discussion could imply they were infected.

Hopwood, M., & Treloar, C. (2019). *Hepatitis B-related stigma among Chinese Australians living in Sydney (Summary report)*. Sydney: Centre for Social Research in Health, UNSW Sydney. <http://doi.org/10.26190/5cfeeed12fb4e>

2.4 FUTURE DIRECTIONS - My health, our family: Documenting stories of family life in the context of HIV, hepatitis B or hepatitis C

Christy Newman, Asha Persson, Kylie Valentine, Myra Hamilton, Jack Wallace, Joanne Bryant, Kerry Drysdale, Rebecca Gray

Publications are forthcoming from the extensive qualitative dataset collected for the 'my health, our family' study, which included 61 interviews with people who have been diagnosed with HIV, hepatitis B or C, and who have supported family members through

those experiences. Some of these papers will explore how the experiences of being diagnosed with a viral hepatitis infection, and making decisions about treatment and care, can be shaped by and influence family relationships. These analyses reveal the embodied and relational dimensions of viral hepatitis, which extends our understandings of how transmission risk and treatment uptake are not just individual practices, but located within particular social contexts. Emerging findings suggest that the effective and tolerable treatments now available for hepatitis C is changing how and when some people will disclose this infection to family members, because they feel more able to recruit their support in pursuing a cure, compared with the fear and uncertainty associated with a diagnosis in the past. HBV is quite different, with no successful cure available, which means that there remains considerable shame and stigma associated with this diagnosis, and greater barriers to openly discussing this condition within families. Fears remained strong among some families that talking openly about these viral hepatitis diagnoses might attract social judgements to the family based in stigma attached to a presumed history of injecting use in the case of hepatitis C, and mother-to-child transmission in HBV.

3. Treatment, service engagement, and care for viral hepatitis

3.1 The Observe Study: Understanding barriers and facilitators to the take up of new DAA hepatitis C treatment

Joanne Bryant, Peter Hull, Lise Lafferty, Rebecca Gray, Limin Mao, Carla Treloar

This project collects information from people who inject drugs about their experiences with new DAA treatments for hepatitis C. People who inject drugs are the main target population for these new treatments, yet virtually nothing is known about the factors that support or prevent their uptake of these treatments. This study focuses on the perspectives of people who inject drugs, using data collected from them, and focusing on the personal, social and systemic barriers and facilitators to treatment as they report them.

The study used an observational cohort design (baseline and 6 months follow-up) at six NSPs in metropolitan and regional NSW to examine: the incidence of taking up treatment, pathways and experiences through the care system, and individual, social and systemic reasons for taking up treatment; for those who do not take up treatment, the range of reasons for not doing so and the individual, social and systemic factors associated with declining treatment, including their opportunities for treatment and experiences with the care system. The study also includes a key stakeholder study in the western and southern regional and rural areas of NSW to examine the pathways and experience of DAA care in these settings.

Our participants

Survey

At baseline, we recruited 293 participants. Of these, $n=155$ or 53%, were ineligible for DAA treatment (because they were HCV-negative, did not know their status, or had cleared the virus previously with interferon treatments). Of the remaining $n=138$ who were eligible to take up treatment $n=82$ had already done so (60%) and an additional $n=56$ had not. At six months follow-up we attempted to recontact the 56 participants who reported that they had not been treated at baseline and we were able to conduct surveys ($n=20$) with approximately one-third of them.

In-depth interviews

We invited follow-up participants to take part in qualitative in-depth interviews and 16 agreed. Of these 7 had begun DAA treatment and 9 had not. These 16 interview participants comprised of three women and 13 men, and ranged in age from 27–62 years with most ($n=9$) aged in their 30s and 40s.

Pathways to treatment among ‘uptakers’

Eighty-two participants had received DAA treatment, either being on it at the time of the survey or completed it prior to the survey date. Of participants who had started their treatment in the last 6 months, over half reported that their first assessment was with a nurse

at a community, NSP or opioid substitution therapy (OST) clinic. For these participants, most (66%) reported that the main reason for starting treatment was that they worried about their future health and/or they wanted to feel healthier. For this group treatment largely happened through the public system (GP, specialist or nurse at an NSP, OST clinic or prison), although over half of medication dispensing happened at community pharmacies.

Qualitative data reveal that participants felt very positive about their treatment experiences, describing treatment as ‘easy’ and that they ‘couldn’t fault it’. Participants were positive about the single tablet regimen, if they were on that, and commented on the ease of being able to collect DAA medications at the same time as their OST medications, if they were on OST. Good relationships with health care providers were an important feature of positive experiences on DAA, from deciding to go on treatment to completing the course:

“It was pretty easy as it was. I don’t know that they could have made it any better... everyone was very lovely and you know, it couldn’t have been better really. I was very happy with it.”

Non-uptakers and the main barriers to treatment

Our survey sample included 56 people who were eligible to take up DAA but had not yet opted to do so. These people were demographically similar to our sample who had already taken up treatment (about 70% were men, about a quarter were Aboriginal, and about half injected daily or more frequently). However, non-uptakers were more likely to report heavy drinking with one-third saying they had seven or more drinks on their last occasion of drinking (compared to only 4% of those treated).

The qualitative data reveal that participants who had not yet taken up treatment were well-aware of the opportunities to get treated, noting the many pamphlets and posters available in NSPs and health clinics: ‘It’s all there you know, all the information on it, so it’s like staring you in the face when you are sitting there waiting to see the methadone doctor.’ Participants were also well-aware of the benefits of DAAs and were generally enthusiastic about them:

‘Now it’s totally different than the old treatment. It takes a shorter period, you don’t get as sick or you don’t get any symptoms or sickness and it’s good’

‘My mates say to me...I’ve got rid of my Hepatitis, my Hep C is gone, you know what I mean. And I look at the smile on their faces and I’m like, good on you, keep it up.’

In the survey sample, knowledge about exclusions for treatment was generally good among participants who had not been treated with, for example, most knowing that being on OST or having depression was not an exclusion (Table 4). Although work may be needed to correct some misconceptions – for example, 24% believed that current injecting was an exclusion for treatment (Table 4).

Participants who had received treatment reported poorer knowledge with respect to some items, compared to participant who had not been treated. For example, they more commonly believed that having already received treatment was an exclusion for being treated again (22% v 10%) (Table 4), which may have important implications for treating reinfections.

Table 4: Characteristics of those who have and have not been treated: knowledge about treatment process and eligibility

<i>Believed that the following makes a person ineligible for treatment:</i>	Received DAA treatment n=82		Not received DAA treatment n=58	
	n	%	n	%
Current injecting	23	28	14	24
Currently on OST	6	7	4	7
Liver cirrhosis	7	9	2	3
Liver failure	10	12	3	5
Heavy alcohol intake	13	16	9	16
Absence of symptoms for hep C	15	18	5	9
Normal liver function test results	8	10	4	7
History of depression	5	6	2	3
Pregnancy	14	17	9	16
Having been on treatment in the past and been cured	18	22	6	10

Table 5: Characteristics of those who have and have not been treated: Fears and concerns related to treatment

<i>Imagine that you are considering DAA treatment. To what extent would you worry about the following:</i>	Received DAA treatment in last 6 months n=28		Not received DAA treatment n=58	
	Not at all	A lot	Not at all	A lot
Talking with a doctor about my injecting drug use	71	18	77	17
The medications involved in treatment	71	21	65	17
The potential side effect of the medications	71	7	52	37
The reaction of people close to me	71	21	81	8
The reaction of others	75	14	81	10
Negative attitudes of staff in treatment services	68	18	77	17
Treatment staff talking about or giving out information about me	71	14	64	25

Scored on a scale, 1 = 'Not at all' to 5 = 'A lot'. For this table the 'Not at all' category includes scores of 1-2 and the 'A lot' category includes scores of 4-5.

We asked participants if they had any worries related to treatment (Table 5) and the most commonly identified worry among those who had not been treated was 'the potential side effect of the medication', by 37%. These participants were also worried about issues related to privacy and confidentiality and the risk of health staff talking about them or giving out information about them (25%).

These concerns about side effects and confidentiality were also evident in the qualitative data, with participants being concerned that 'all nurses talk' and that they did not have health care providers with whom they felt 'safe'. These concerns about confidentiality relate to a deeper mistrust of health professions that was identified by other participants, who used

the metaphor of the guinea pig to describe the vulnerability of drug users within the medical system:

I was sceptical of everything and sometimes I think that I am a guinea pig, do you know what I mean? Do they really have something that's really going to work? Because I don't know, it just seems to me that, well, ok you've got drug addicts, they are already down. They virtually do whatever you want for \$50. They would sell their soul to the devil if they could.

Focus on regional areas: Sub-study of barriers and facilitators to uptake in southern and western NSW

Because of the challenges in applying the survey method to smaller regional settings, we decided to undertake a qualitative key stakeholder study in southern and western areas of NSW, in order to explore the pathways to and experience of DAA treatment in these settings. Recruitment targeted service users and professional stakeholders in Orange, Wagga Wagga and Dubbo, and strategically sought accounts from people who had undergone treatment, and those who had not. In what follows, we outline the barriers and facilitators for treatment, with a specific focus on how living in regional areas of NSW mattered in terms of DAA uptake.

Our Participants

Of the 23 interviews collected, 16 were with service users and seven were from professional stakeholders. Of the 16 service users, eight identified as female and eight male and they ranged in age from 23–54 years. Five had not started DAA treatment and 11 had. The professional stakeholders were clinical staff, including nurses (3), managers (2) and pharmacists (2). Of the seven professionals we spoke to, it is also significant to note that they had often worked in a number of roles and contexts and brought these diverse experiences into their discussions.

Perceived barriers to treatment in regional areas

Long distance travel and the challenges associated with this was one of the key barriers identified. This was not only during treatment period, but also for the required clinical assessments. For example, one participant described how their treatment was delayed due to having to travel for up to two hours to access an ultrasound. For some this meant having to take 'a whole day off work' in order to visit GPs, who often had short opening hours; or needing to make special arrangements for extended childcare. Professionals were aware of the extensive efforts required by consumers to facilitate treatment and adjusted their ways of working wherever possible by organising appointments around the local bus schedule or using videoconferencing for appointments. Professionals felt that co-locating DAA treatment within OST clinics could be a positive solution.

The skills and capacities of local health staff was also identified as a barrier by some consumer participants. This related to their fears about being judged for being an injecting drug user by staff and the fact that communities were small and people and families were often well-known to each other. But it also related to consumers inability to find appropriately skilled health professionals, such as phlebotomist and/or 'friendly' pharmacists. In this regard, one participant described how he had been through three attempts at blood tests and, despite being motivated to start, was wary of further blood testing. These experiences

were consistent with the perceptions and challenges described by professional who describe walking clients up to the local lab where there is a known skilled phlebotomist.

Perceived facilitators to treatment in regional areas

While the nature of small communities brought challenges when accessing treatment, as described above, they also brought supports. Informal peer networks seem to provide a robust pathway through which to disseminate information about the new generation of Hepatitis C treatments, and its greater ease and reduced discomfort. This was somewhat different to what was found in the qualitative data collected in the main part of the study whereby participants talked about keeping their hepatitis C status secret and that treatment was not widely discussed in peer groups. In small communities however, verbal recommendations by friends, family and associates was paramount. Participants also described the key role that allied health staff played in encouraging them, and the importance of a non-judgemental and supportive approach.

3.2 Beyond cure: Patient reported outcomes of hepatitis C treatment among people who inject drugs in Australia

Annie Madden, Max Hopwood, Joanne Neale, Carla Treloar

In recent years, new and highly effective drug regimens have been developed for the treatment of HCV infection. For the first time, DAA drugs provide a real possibility of eliminating HCV infection as a public health threat. In Australia, these drugs have been made available through a universal access scheme, which means they are in theory accessible to all affected people. However, the public health focus on HCV elimination via DAA treatments has led to the idea that a cure is the only important outcome. In this paper, researchers from CSRH and King's College London explored the issues that people who inject drugs PWID considered to be important outcomes of DAA treatment for HCV infection. We wanted to learn whether there were other outcomes from treatment 'beyond cure' that were important to people who inject drugs. We believed this information might be useful for improving the uptake of, and engagement with, DAA treatments among people who inject drugs in Australia.

Data in this study were collected via in-depth, semi-structured interviews. Adopting a participatory research approach, a peer-researcher with experience of both injecting drug use and DAA treatments for HCV infection conducted interviews with 24 participants from Melbourne, Victoria, who had a recent history of injecting. The research team aimed to recruit four different groups of people who inject drugs, namely (1) people who had refused or deferred HCV treatment; (2) people who were actively thinking about, planning and/or about to commence HCV treatment; (3) people currently undertaking HCV treatment; and, (4) people who had recently completed HCV treatment. The results of a thematic analysis of interview data found that people who inject drugs indeed often seek outcomes 'beyond cure', including better physical and mental health, a future free of liver diseases, a better understanding of liver health and infectiousness, having a plan for post-treatment care, the creation of a new, non-stigmatised identity disassociated with drug use and disease, better social connections with family and friends, and information and expertise to avoid or manage the possibility of future HCV infections.

These findings show that while a cure was a desirable outcome, people who inject drugs are seeking change in other areas of their lives from treatment, such as better relationships, less anxiety around future health, and information to help future practice. This study also provided valuable insights for the development of patient reported measures for people having DAA treatments, which is an important step towards more patient-centred approaches to HCV treatment.

Madden, A., Hopwood, M., Neale, J., & Treloar, C. (2018). Beyond cure: patient reported outcomes of hepatitis C treatment among people who inject drugs in Australia. *Harm Reduction Journal*, 15(42). <https://doi.org/10.1186/s12954-018-0248-4>

3.3 Beyond interferon side effects: What residual barriers exist to DAA hepatitis C treatment for people who inject drugs?

Annie Madden, Max Hopwood, Joanne Neale, Carla Treloar

From March 2016 in Australia, highly efficacious and more tolerable treatments for HCV infection, called DAA, became available under a universal access scheme. As a result of therapeutic advances and improvements in access, there has been a rapid increase in the uptake of DAA treatments among people who were living with HCV infection. Despite these positive developments, recent data suggest a plateauing of treatment numbers, indicating that more work is needed to identify and to address ongoing barriers to HCV treatment access and uptake. Researchers from CSRH and King's College London conducted a study that aimed to contribute to our understanding of the ongoing barriers to DAA treatments among people who inject drugs.

Using a participatory research design, the findings of this study drew on in-depth, semi-structured interview data with 24 people from Melbourne, Victoria who had a recent history of injecting drug use. A peer-researcher with direct experience of both DAA treatments and injecting drug use was involved at all stages of the research process. The study's findings showed that many residual barriers to DAA treatment exist at personal-, provider- and systems-levels. Personal barriers to the uptake of DAA treatments reported by participants included being HCV asymptomatic, difficulty in finding the 'right time' to undergo treatment, and poor vein health that limited the drawing of blood for testing. The main provider-level barrier participants reported was concern regarding gaps in continuity of care in health services, where some people had had difficulty locating a DAA prescriber, some general practitioners had refused to initiate DAA treatment because they did not perceive treatment as their 'core-business', and some were concerned about a lack of follow-up care. Systems-level barriers to DAA treatments included the challenges presented by participants' needs to manage multiple health and social priorities and the difficulties they experienced with services that were not coordinated or integrated. It was said that support services did not respond to the broader circumstances in people's lives. Reportedly, participants were also exposed to healthcare-related stigma and discrimination, which made them feel uncomfortable about commencing DAA treatments.

Further efforts to increase access to and uptake of DAA treatment for HCV infection will require a focus on reducing stigma and discrimination towards people who inject drugs as this remains a major barrier to care for many people with HCV infection.

Madden, A., Hopwood, M., Neale, J., & Treloar, C. (2018). Beyond interferon side effects: What residual barriers exist to DAA hepatitis C treatment for people who inject drugs? *PLoS ONE*, 13(11): e0207226. <https://doi.org/10.1371/journal.pone.0207226>

3.4 Acceptability of patient reported outcome and experience measures for hepatitis C treatment among people who use drugs

Annie Madden, Max Hopwood, Joanne Neale, Carla Treloar

Internationally, there is an increasing interest in changing the way in which people's health, and the outcomes of health interventions, are measured. One key area of focus has been in the development of "patient reported measures" (PRMs) which provide a mechanism for patients to provide feedback to healthcare providers about the issues that matter to them. One of the concerns of the PRMs approach is that not all of these measures have been developed with the direct input of patients or service users. Our project developed a PRM for hepatitis C treatment for people who inject drugs. This was done in a participatory design including the engagement of a peer researcher with direct experience of both injecting drug use and HCV treatment with DAAs. We argued that the development of a PRM in this area is important with a focus on elimination efforts given the success of hepatitis C DAA in curing the infection. Other aspects of the treatment experience may not be recognised or valued especially when we know that people who use drugs have typically not been consulted in treatment decision making.

Using qualitative research with people who inject drugs, we developed two new patient reported measures; of treatment experience (PREM) and of treatment outcome (PROM). Issues such as difficulties in drawing blood, transport, stigma and variable interest from clinicians in promoting treatment within health care settings, were incorporated into the PREM. Items for the PROM covered issues such as enhanced physical and mental health, avoiding a need to disclose HCV infection, better social relationships, changes in identity, a positive orientation to the future, and being equipped to manage future health and risk

We asked people who inject drugs to complete and comment on the acceptability of these draft measures. Four focus groups of six people each involved seven women and 17 men ranging in age from 24–58 years. All participants had reported injecting drug use in the previous six months and had completed DAA treatment with a 12-week course. All participants were recruited through the networks of the peer researcher or through the community partner organisations, Harm Reduction Victoria and Hepatitis Victoria.

The typical feedback from participants was that the items within the draft measures resonated with their experiences of HCV treatment and focused on issues 'no-one else had asked them' and which maybe invisible or not important to clinicians. A PRM was also identified as a tool that could help make the voice of people who inject drugs heard in clinical encounters. Several participants spoke quite emotionally about experiencing side-effects from the DAA therapies but felt that their concerns were dismissed or were not validated by their clinicians. Participants identified the value in being able to talk about issues beyond achieving 'a cure' alone including issues that relate more to quality of care and social and family impacts of treatment.

Our findings demonstrated that it is possible to develop acceptable PRMs to represent the experiences and outcomes of HCV treatment for people who inject drugs from their perspectives. The use of a participatory model was important for this project as the social distance between researchers and those who inject drugs and live with hepatitis C can be vast.

Madden A, Hopwood M, Neale N, Treloar C. (2019). Acceptability of Patient-Reported Outcome and Experience Measures for Hepatitis C Treatment Among People Who Use Drugs. *The Patient - Patient-Centered Outcomes Research*, 12(2):259-265.

3.5 Stop-C: Treatment as prevention in the prison setting

Lise Lafferty, Jake Rance, Carla Treloar (on behalf of the SToP-C Study Group)

Prisoner's perspective of treatment as prevention

Globally, there is overrepresentation of hepatitis C among the prisoner population. Access to sterile injecting equipment is restricted in most countries, with access to other harm reduction measures frequently limited. Taken together, high rates of hepatitis C coupled with limited access to harm reduction has equalled higher risk of HCV transmission among people in prison compared with those in the community. The Surveillance and Treatment of Prisoners with hepatitis C (SToP-C) study is implementing the first trial of HCV TasP in the prison setting, i.e., scaling up treatment at sufficient scale to achieve a preventive effect. Qualitative research was undertaken to understand the social and behavioural components underpinning hepatitis C risk behaviours in the prison setting as well as perceptions of a TasP trial to reduce onward HCV transmission. Interviewees were recruited from the broader SToP-C study cohort, with equal participation across the four correctional centres involved in the SToP-C study in NSW, including one women's prison and two maximum security prisons. All participants (n=32) reported a history of injecting drug use (ranging from several decades prior to the day before interview). All participants had been screened for HCV within the previous 6 months; half (n = 16) had chronic hepatitis C; n=2 were awaiting test results. A range of concerns were highlighted by participants relating to the potential efficacy of TasP. Among the most common reported concerns were prisoner movements (e.g. transferred to another prison, or incarceration-release-incarceration) and perceived vulnerabilities to HCV reinfection following treatment. Suggestions for system-wide efforts to foster TasP efficacy included both education and prison needle syringe programmes. Reinfection remained an ongoing concern amid TasP efforts in the absence of increased access to harm minimisation and prevention strategies.

A policy analysis of hepatitis C risk, prevention, testing, treatment and reinfection within Australia's prisons

DAA therapies became available under universal healthcare in Australia in March 2016. This paper sought to critically examine whether state and territorial health and prisoner hepatitis C policies have been responsive to the advent of unrestricted treatment access for all Australians, irrespective of drug user or incarceration status. A total of 18 publicly available health (n = 12) and prison (n = 6) policies were reviewed to assess jurisdictions' policies regarding hepatitis C risk and prevalence, prevention and harm reduction, testing and treatment, and reinfection within the prison setting. Health and prisoner hepatitis C policies were found to have not kept pace with the test-and-treat hepatitis C landscape currently

available, with few jurisdictions having updated or published policies since the availability of DAAs. For example, treatment limitations relevant to previous generation HCV therapies exist in current policies, such as a restriction to the number of prisoner-patients allowed to access HCV treatment at any one time. Without updated policies, the public health benefits of HCV treatment scale-up could be overlooked. These outdated policies amid this new era of highly effective oral medications could potentially hold Australia back as a global leader in HCV elimination.

Facilitators and barrier to uptake of direct-acting antiviral therapy in prison

Hepatitis C is a major public health concern, particularly in the global prison setting where 15% of those incarcerated are HCV-antibody positive (anti-HCV). Whilst HCV treatment is available in a number of jurisdictions internationally, treatment uptake has historically remained low. Drawing on the views of participants enrolled in the Surveillance and Treatment of Prisoners living with hepatitis C (SToP-C) study, this paper examines the perceived barriers and facilitators for the delivery of HCV treatment in prisons. Thirty-two prisoners (including eight women) with a history of injecting drug use participated from across four correctional centres (n = 8 per site). Half of the participants had tested positively for chronic hepatitis C at their most recent test (within previous six months); two participants were awaiting test results. Structural and patient-level facilitators to HCV treatment in the prison setting included on-site and around-the-clock medical care, and patient motivation. Availability of time was viewed as a facilitator for prison-based treatment, compared with the challenges of competing priorities participants encountered when in the community. Structural barriers to prison-based HCV treatment included high-prevalence of hepatitis C within the prison setting coupled with lack of access to harm minimisation measures to ensure against future HCV infection following treatment. Social barriers included a lack of social support from loved ones when undergoing treatment whilst incarcerated as well as a concern for being 'found out' by their peers of their hepatitis C status when accessing the health clinic. Based on these findings, prison-based treatment programmes should implement (or advocate for) patient-centred treatment approaches that protect privacy, provide social support, and promote access to clean needles and substitution therapy to protect prisoners from reinfection.

'Behind closed doors, no one sees, no one knows': hepatitis C, stigma and treatment-as-prevention in prison

While there is a substantial literature addressing the centrality of stigma to experiences of living with hepatitis C in the community, including as a barrier to treatment, scant attention has been paid to documenting how hepatitis C-stigma figures within the distinct sociality of prison life. This article focused on initial, pre-treatment interviews with prisoner participants (n = 32) from the first, real-world trial of HCV 'treatment-as-prevention' in prison: Australia's Surveillance and Treatment of Prisoners with Hepatitis C (SToP-C) study. Drawing on recent developments in stigma theory alongside Goffman's original insights, we understood hepatitis C-stigma as a relational, contingent and political process, materialising across the network of power relations in prison. Participant accounts described a complex picture, with reports ranging from those suggesting the 'normalisation' of hepatitis C to those detailing the potential effects of hepatitis C-stigma, including additional disciplinary attention from officers and/or the rejection from peer networks by fellow prisoners. While acknowledging

the limiting effects hepatitis C stigma may yet have on treatment-as-prevention efforts, we speculated that with committed political leadership, operational investment, sufficient prisoner engagement, interventions such as SToP-C may also afford opportunities for such effects to be challenged, disrupted, and even left behind.

Lafferty, L., Wild, T. C., Rance, J., & Treloar, C. (2018). A policy analysis exploring hepatitis C risk, prevention, testing, treatment and reinfection within Australia's prisons. *Harm Reduction Journal*, 15(39). <https://doi.org/10.1186/s12954-018-0246-6>

Lafferty, L., Rance, J., Grebely, J., Lloyd, A. R., Dore, G. J., Treloar, C., on behalf of the SToP-C Study Group. (2018). Understanding facilitators and barriers of direct-acting antiviral therapy for hepatitis C virus infection in prison. *Journal of Viral Hepatitis*, 25(12), 1526-1532. <https://doi.org/10.1111/jvh.12987>

Rance, J., Lafferty, L., & Treloar, C. (2018). 'Behind closed doors, no one sees, no one knows': hepatitis C, stigma and treatment-as-prevention in prison. *Critical Public Health*. <https://doi.org/10.1080/9581596.2018.1541225>

3.6 Evaluation of the Deadly Liver Mob program

Carla Treloar, Max Hopwood, Elena Cama, Melinda Walker

DLM was a pilot program conducted by mainstream public health services in Western Sydney, Australia aimed at improving hepatitis C health promotion, and screening for HCV, HIV and STIs screening among Aboriginal and Torres Strait Islander (hereafter Aboriginal) people. The program was administered in two sites through co-located NSPs and sexual health clinics. The program aimed to address low attendance at the NSP and sexual health clinic by Aboriginal people in a geographical area with recognised high levels of injecting drug use and low STI screening and very few episodes of care over the immediate preceding years in the adjacent sexual health clinic, despite being one of the most populous areas for Aboriginal people in Australia.

DLM uses an incentive-based, peer-driven intervention model. Aboriginal people who inject drugs are invited to an education session with an Aboriginal worker at the NSP after which participants are offered referral to the co-located sexual health service for STI and blood borne virus (BBV) assessment and screening. The Aboriginal worker accompanies the DLM client to the co-located sexual health service if the client takes up the offer of screening. Sexual health clinic staff manage screening, delivery of results and provision of treatment (if required) as per standard care.

The peer-driven intervention model offers nominal incentives to encourage participants to attend for education then recruit and educate their peers (referred to as peer referral) for which participants receive an incentive. People educated in the community by DLM participants, then attend the DLM program for consolidation of health messages, receive an 'incentive payment' and are then offered screening. The hepatitis C education sessions monitor the quality of peer messages and build on the participants' knowledge while dispelling any myths. An additional incentive is offered for HCV and other BBV and sexual health screening and further incentives are offered for return for results and management, as required.

Our evaluation of the DLM pilot program reports on data about participant attendance in various aspects of the program, and qualitative data from interviews with DLM clients and staff to examine the acceptability of the program as the first step of a scalability assessment

(defined as assessing effectiveness potential reach and adoption, alignment with strategic context and acceptability and feasibility).

A total of 677 and 55 Aboriginal clients attended Site 1 and Site 2 for health education, respectively. Of those attending Site 1 for health education, 79% went on to attend screening, of which 50% returned to receive test results. Of those attending Site 2 for health education, 73% went on to attend screening, of which 48% returned for test results. Both sites reported significant increases in Aboriginal people attending services.

The main theme of the qualitative analysis was stigma: how stigma related to Aboriginality, HCV and injecting drug use acts as a barrier to Aboriginal people's engagement with information and health care services; and, how engagement increased when health-related stigma was minimised via attendance at the DLM pilot program. The qualitative data also supported the assumption that provision of incentives was a key ingredient. However, there were some strong and negative opinions, particularly from staff participants, which would be important to address in scale up plans. For DLM, key elements of context in these two sites were the capacity of the workforce and issues relating to the management of DLM especially in relation to navigating priorities across NSP and sexual health service delivery sectors.

This evaluation presents evidence to consider in the broader implementation, or scale-up, of the DLM program. Significant numbers of Aboriginal people were engaged in the program, acceptability of the program was high among staff and clients and additional resources required to deliver the program (relating to incentive payments) were modest. Some issues need to be clarified in development of an implementation plan: the relationship of DLM with the relevant strategies for HCV and STIs, better support for the workforce to understand the role of incentive payments, additional resources to induct and support workers, and methods to "manage up" in explaining the impact and role of DLM over time.

Since this project, we have received funding to expand the DLM program to an additional five Local Health Districts across NSW and continue with understanding how the model can be used (and adapted) in a range of settings.

Treloar, C., Hopwood, M., Cama, E., Saunders, V., Jackson, L. C., Walker, M., Ooi, C., Ubrihien, A., & Ward, J. (2018). Evaluation of the Deadly Liver Mob program: insights for roll-out and scale-up of a pilot program to engage Aboriginal Australians in hepatitis C and sexual health education, screening, and care. *Harm Reduction Journal*, 15(5). <https://doi.org/10.1186/s12954-018-0209-y>

3.7 DAAs and Politics of knowledge

Kari Lancaster, Tim Rhodes, Jake Rance

In this paper, we analysed a recent controversy regarding the curative potential of new treatments for hepatitis C. The controversy concerned the publication of a systematic review conducted by the Cochrane Collaboration. We analysed this case to illuminate how moments of controversy offer useful sites of evidencing-making investigation for public health research, and to consider how evidence is made through practices. In this paper we reflected on how different experts perform evidence differently, how these evidence performances are in friction yet incorporate one another, and how such evidence-making practice fuses together different knowledge forms within and beyond science. Controversy makes visible the multiplicity and fluidity of evidence which might otherwise be constituted

as singular and robust. This analysis demonstrates how an ‘Evidence-Making Intervention’ approach (as is being developed as part of a new program of work at CSRH) can be used in critical public health research. Further analyses of this hepatitis C case study are underway.

In 2016 the World Health Organization published the first global health strategy to address viral hepatitis, setting a goal of eliminating viral hepatitis as a major public health threat by 2030. As part of the new ‘Evidence-Making Interventions’ program of work at CSRH, we have been analysing the productive capacity and constitutive effects of target-setting. In this paper, we considered how governing is taking place through the mechanism of this global strategy. Drawing on poststructural approaches, we examined the conceptual logics underpinning the HCV elimination goal and targets, and the multiple effects of this policy. We examined how governing takes place through numbers, by analysing ‘target-setting’ (and its accompanying practices of management, quantification and surveillance) as governmental technologies. We considered how the goal of elimination makes viral hepatitis visible and amenable to structuring, action and global management. This critical analysis highlights the ontopolitical effects of governmental technologies such as target-setting, especially for communities ‘targeted’ by these strategies (including people who inject drugs). Further analyses related to mathematical modelling and target-setting in the context of ‘the current ‘viral elimination’ era are underway, building on this foundational piece of work.

Rhodes, T., Lancaster, K., Harris, M. & Treloar, C. (2019). Evidence-making controversies: the case of hepatitis C treatment and the promise of viral elimination. *Critical Public Health*, 29(3), 260-273. <https://doi.org/10.1080/9581596.2018.1459475>

Lancaster, K., Rhodes, T., & Rance, J. (2019). “Towards eliminating viral hepatitis”: Examining the productive capacity and constitutive effects of global policy on hepatitis C elimination. *International Journal of Drug Policy*. <https://doi.org/10.1016/j.drugpo.2019.02.008> (Advance online publication).

3.8 FUTURE DIRECTIONS - ‘Evidence-making interventions’ in health

Kari Lancaster, Time Rhodes, Jake Rance

A new program of work has been established at CSRH, focused on developing a critical social science of how evidence is made as part of new interventions and policies in health. There is considerable investment in the development of interventions research to examine the use and uptake of innovations in health technology. Yet there is relatively little social science research in this domain. Intervention implementation is shaped by complex social relations, including a combination of material, individual, community, institutional, policy and political actors, and social science has a critical role to play in understanding how this process is realised. To improve on our understanding of how ground-breaking innovations in health technologies can deliver on their promise, we need a new approach to interventions research which resists taken-for-granted assumptions about how interventions will ‘work’. This new program of work has two aims: to investigate how innovative or ground-breaking health interventions are translated into practice; and to reflect critically on the practices and effects of evidence-making linked to implementation science. There is a commitment to interdisciplinarity through bringing together social scientists with those engaged in the development, trials and transfer of new health technologies, both in Australia and internationally. While a range of empirical case studies will be examined, the implementation of new treatments and point of care testing technologies for hepatitis C is a primary focus.

Lancaster, K., Rhodes, T., & Rance, J. (2019). "Towards eliminating viral hepatitis": Examining the productive capacity and constitutive effects of global policy on hepatitis C elimination. *International Journal of Drug Policy*. <https://doi.org/10.1016/j.drugpo.2019.02.008> (Advance online publication).

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