Annual Report of Trends in Behaviour 2018
Viral Hepatitis in Australia

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Abbreviations

AIDS – Acquired Immune Deficiency Syndrome
BBV – blood borne virus
CSRH – Centre for Social Research in Health
DAA – directly-acting antiviral
GCPS – Gay Community Periodic Survey(s)
HIV – human immunodeficiency virus
LGBTI – lesbian, gay, bisexual, transgender and intersex
NHMRC – National Health and Medical Research Council
NSP – needle and syringe program
PROM – patient-reported outcome measures
PREM – patient-reported experience measures
STI – sexually transmissible infection
TasP – treatment as prevention
Executive summary

Overview

This Annual Report of Trends in Behaviour (ARTB) focusses on viral hepatitis and provides an opportunity to highlight our contributions to the rapidly changing landscape of hepatitis C infection and treatment brought about by universal access to direct-acting antiviral (DAA) treatments. It also permits us to showcase some emerging work, in particular a project on hepatitis B and a new program of work exploring ‘evidence-making interventions’.

The introduction of universal access to DAA treatments in 2016 has created both excitement and expectation, and the uptake has been enormous. An estimated 60,000 people have initiated treatment, or about 26% of the Australian population with hepatitis C. Uptake was initially very high, with about 5,000 people taking up treatment each month in the first three months, revealing the number of people who had been waiting for these new treatments to become available. Uptake has become more consistent since, with about 2,000 people initiating monthly in more recent times (Kirby Institute, 2017). We are yet to know how uptake will change over the coming months and years. 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.

Throughout the ARTB we not only interpret the data we have generated, but the methods by which they were obtained, including the need to update questions, measures and approaches. We seek to inform ourselves from a range of perspectives: from remaining abreast of clinical and technical advances in medications and other technologies, to policy perspectives in relation to emerging strategic interests, and especially, to what is important to the variety of communities affected by viral hepatitis, including detailed knowledge of the specific needs of communities and the differences between them.

This ARTB continues the structure seen in previous years by presenting material to reflect prevention, care and treatment cascades. While the wide-ranging nature of the report makes it difficult to present a complete summary, there are a few key issues that stand out:

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

  Our work in the first section of this report shows how viral transmission happens in complex ways that are mediated by the social positions, meanings, identities and relationships of people at risk of acquiring viral hepatitis. Within the exciting context of new generation hepatitis C treatments, there remains the need to continually innovate harm reduction programs in ways that reflect how transmission happens in the everyday. This is especially important to young people and to Aboriginal communities, who continue to be at highest risk...
for acquiring hepatitis C.

- **Stigma**
  We continue our spotlight on stigma, which underpins many of the analyses in this report, be they direct examinations of its impacts or the lens through which we interpret findings. We 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 to arise from the stigma indicators project aimed at monitoring the experience of stigma among key priority populations over time.

- **The continuing need to address prevention**
  Our work on prevention shows how viral transmission happens in complex ways that are mediated by a range of factors, including structural inadequacies in the way prevention services are offered and the social positions, meanings, identities and relationships of people at risk of acquiring viral hepatitis. Within the shifting context of new generation hepatitis C treatments, there remains the need to continually innovate harm reduction programs in ways that reflect how transmission happens in the everyday. In 2017, 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.

**Community Reference Panel**

The Community Reference Panel allows researchers to consult with people who have lived experiences of viral hepatitis, incarceration, sex work, injecting drugs and living with disabilities. The purpose is to provide specific feedback on various aspects of research projects. This feedback from community members is essential to ensuring that the research is grounded in and respectful of the experiences and concerns of those affected by viral hepatitis.

**Viral hepatitis prevention**

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

In the most recent round of this national survey, amyl nitrite was the drug most commonly used by respondents, followed by cannabis. Rates of ecstasy and speed use declined, while cocaine and crystal methamphetamine use remained stable, the latter since 2015. Over the 10-year period since 2008, the proportion of gay men who injected drugs in the six months prior to survey was stable nationally (6% on average), with (meth)amphetamines and steroids the most commonly injected drugs.

**Understanding and preventing hepatitis C transmission within heterosexual couples**

Drawing on interviews with couples who inject drugs in Melbourne and Sydney, alongside focus testing new hepatitis C prevention messages and a fitpack prototype, both intended
for couples, this project highlighted the need for harm reduction strategies that acknowledge the social and intimate contexts of injecting drug use.

**Sharing knowledge of safer strategies of opioid tablet preparation for injection**

Pharmaceutical opioid (PO) tablets can be prepared using a “hot” or “cold” method, with the latter being safest. Interviews were completed with clients of Sydney’s Medically Supervised Injecting Centre to understand how tablet preparation was learnt. Peers who inject POs were deemed to have the greatest knowledge around preparation. Social connections are valuable for education about safer injecting practices.

**Hepatitis C risk within injecting networks among people who inject drugs in prison**

Prisoners with a history of injecting drug use were interviewed to understand the navigation of hepatitis C risk among injecting networks in prison. Social, economic, and environmental risk factors influenced injecting practices; risk of hepatitis C exposure rarely influenced injecting order. To optimise benefits of DAA therapies, harm reduction strategies should consider the social factors influencing injecting drug use in prison.

**FUTURE DIRECTIONS - Public health and the law - peer distribution of injecting equipment**

Discussions about law reform in relation to peer distribution are ongoing in Australia. With this project we will examine both legislation and case law to critically review the intersection of the criminal law and public health, considering ways in which criminal laws in the drugs field have public health effects.

**Testing, diagnosis and lived experience of viral hepatitis**

**Evaluating the potential for drug law to produce stigma**

The stigma attached to substance use is a growing concern and law reform is seen to be one way in which to address this. This paper reports on a new method to examine the relationship between stigma and the law and establish a framework that can guide and inform future law reform efforts.

**The understanding of liver disease assessment scores among people who inject drugs**

People who inject drugs who received a liver disease assessment score as part of a healthy liver campaign were interviewed to understand how results were understood and whether results influenced health behaviours. People with higher scores expressed surprise; those with lower scores felt encouraged. For people living with hepatitis C, the initiation of DAA therapies provided a clear direction to increase their engagement with healthcare services.

**Stigma and discrimination: healthcare and people who inject drugs**

People who inject drugs commonly report discriminatory experiences, particularly in healthcare settings. Research among healthcare workers reveals the influence of collegial attitudes towards injecting drug use on one’s own behaviour within healthcare settings and the potential of an online training program in changing discriminatory attitudes.
Stigma Indicators Project
In the first phase of this national project an online survey was completed by 123 people who had ever lived with hepatitis C to investigate their experiences of stigma using the stigma indicator. More than half of participants reported experiencing stigma related to their hepatitis C within the last 12 months (56%).

FUTURE DIRECTIONS – Hepatitis B and stigma among Chinese-Australians in Sydney
CSRH is conducting an exploratory qualitative study of Chinese-Australians’ perspectives of hepatitis B virus (HBV) infection to develop a stigma indicator for HBV. This study explores how Chinese-Australians who are living in Sydney understand HBV infection and HBV-related stigma. The study recruits people under 30 years of age and people over 30 years of age, to compare age-based perspectives of stigma between the two cohorts.

FUTURE DIRECTIONS – Sex work and stigma indicators
As part of the Stigma Indicator project, CSRH and Scarlet Alliance have formed a partnership to conduct focus groups with sex workers as a way to inform the development of a survey to be implemented nationally. The survey will ask sex workers to respond to a range of issues relevant to BBVs and STIs and broader issues across other domains of life.

Treatment, service engagement and care for viral hepatitis

Evaluation of the Deadly Liver Mob program
The Deadly Liver Mob (DLM) program is targeted at Aboriginal people who inject drugs and is a composite program encompassing health promotion, peer referral and incentives to improve engagement with testing and treatment services. In its first 12 months at the initial site, DLM engaged more than 400 Aboriginal people in HCV health promotion with subsequent referral of over 300 people to sexual health screening.

Enhancing hepatitis C treatment awareness and uptake among men in prison through increased social capital
Hepatitis C treatment among the prisoner population is low. Social capital, an accumulation of a person’s social resources, can influence health outcomes. Male prisoners living with hepatitis C were interviewed to understand how social capital influenced HCV treatment awareness and uptake in prison. Peer connections positively influenced treatment uptake, and this was further enhanced by engagement with healthcare personnel.

FUTURE DIRECTIONS – Surveillance and treatment of prisoners living with hepatitis C: Perceptions of risk, treatment, reinfection, and management in the prison setting
The Surveillance and Treatment of Prisoners living with hepatitis C (SToP-C) study is trialling treatment as prevention (TasP) towards the elimination of hepatitis C across four correctional centres. Qualitative data collection is currently underway to understand a range of perspectives on hepatitis C risk, treatment, reinfection, and management in the prison setting.
setting.

**FUTURE DIRECTIONS – Developing a patient-reported outcome measure and a patient-reported experience measure related to direct-acting antiviral therapies among people who inject drugs**

The use of patient-reported outcome measures (PROM) and patient-reported experience measures (PREM) helps to centrally position the perspectives of service users. They are important tools for understanding the ways people who are living in marginalised circumstances view the outcomes of new therapies for hepatitis C infection, and their experiences of health care services.

**FUTURE DIRECTIONS – Understanding barriers and facilitators to the take up of new direct-acting antiviral hepatitis C treatment**

This study examines the uptake of new DAA hepatitis C treatments by people who inject drugs. It offers a unique perspective, using survey and interview data, to focus on the views and experience of people who inject drugs, using data collected from them, and focusing on the personal, social and systemic barriers and facilitators to treatment.

**FUTURE DIRECTIONS – ‘Evidence-making interventions' in health**

There has been considerable investment in interventions research that examines the use and uptake of health technologies, including research examining new treatments for hepatitis C. We focus on developing a critical social science to scrutinise how evidence is ‘made’ in this research, by investigating how ground-breaking health interventions are translated into practice and reflecting on the practices and effects of evidence-making linked to implementation science.
Melinda Walker, Kim Beadman, Steve Griffin

The Community Reference Panel consists of three workers: Melinda Walker, Kim Beadman, and Steve Griffin. 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 Sydney. Steve graduated from UNSW in 2012 with a Bachelor of Social Work.

We have a passion for social justice and equality to 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.

The Community Reference Panel 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.
1. Viral hepatitis prevention

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

Limin Mao, Toby Lea, Martin Holt

The Gay Community Periodic Surveys (GCPS) include questions about illicit drug use among gay and bisexual men, permitting analysis of changes in use over time. Figure 1 shows 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 drugs among gay men across the country.

Figure 1 shows 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 38% of men, on average, in the GCPS and its use has increased over the previous ten years (39% in 2008 to 42% in 2017).

• Cannabis is the second most commonly reported drug used by participants in the GCPS (by 31% of men on average) and its use has remained stable since 2008.

• The proportion of participants reporting the use of ecstasy and speed have both declined in the previous ten years (for ecstasy 27% in 2008 to 17% in 2017, p<0.001, and for speed 14% in 2008 to 7% in 2017, p<0.001).

• Cocaine use has been stable since 2008 (12% of men on average).

• Crystal consumption has increased over time, particularly during 2010-15 (from the lowest 8.8% in 2010 to the highest in 2015 at 13.2%, p<0.05) but remained stable in the last three years from 2015-18. 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 a need to provide appropriate harm reduction and treatment services for these men.

• Since 2010, GHB/GBH use has remained stable (7% of men on average).

• The use of erectile dysfunction medications (e.g., Viagra and Cialis) have increased over the last ten years (21% in 2008 to 28% in 2017, p<0.001) but has not changed since 2015. Erectile dysfunction medication is used by gay men to facilitate sex and its use has been associated with an increased risk of HIV seroconversion (Prestage et al., 2009).

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...
since 2008, the proportion of men who injected drugs in the six months prior to survey is stable nationally (6% on average). HIV-positive men are more likely to report injecting drug use than HIV-negative men (Lea et al, 2013). (Meth)amphetamine and steroids are the substances most commonly injected by gay men.

Figure 1: Men who reported any use of selected recreational drugs in the six months prior to the survey: GCPS, 2008-2017 (all states or territories)


1.2 Understanding and preventing hepatitis C transmission within heterosexual couples

Jake Rance, Carla Treloar

The CUPID project is a National Health and Medical Research Council (NHMRC)-funded study concerned with understanding and preventing hepatitis C transmission based on in-depth interviews with 40 heterosexual couples who inject drugs. New hepatitis C prevention messages and a fitpack prototype designed for couples were also focussed tested among participants. In the first of our final CUPID publications we examined how partnerships among people who inject drugs serve as a form of social protection from 'external' threats
such as stigma and other aspects of a hostile social environment in which injecting drug use is heavily stigmatised. While public health research commonly treats intimate partnerships as sites of risk management, including in the management of HIV and hepatitis C transmission, we argued that this risk-infused biomedical approach tends to undermine an appreciation of the emotional and socially situated meanings of care in intimate partnerships. While the care produced in drug-using partnerships is represented as double-edged by participants, we also noted how interview accounts were used to deflect the charge that these relationships represent harmful co-dependency. Taken together, the interview accounts negotiate a 'counter-care' in relation to normalcy, presenting the intimate partnership between people who use drugs as a legitimate embodiment of care.

While the health-related benefits of intimate partnership are well documented, little attention has been paid to couples exposed to high levels of social stigma and exclusion. In our second publication we investigated an important site of stigma for partnerships by analysing accounts of changing hepatitis C (HCV) status ('sero-change') among couples that inject drugs. We explored what these participant accounts reveal about the meaning of HCV for these couples, and how this understanding contributes to our collective efforts at prevention and care. While some couples sought greater biomedical understanding as a means of coming to terms with sero-change, others drew on alternative logics or 'rationalities' that sat firmly outside conventional biomedical discourse (privileging notions of kinship, for example). Regardless of which explanatory framework they drew on, participants ultimately prioritised the security of their relationship over the dangers of viral infection.

In our final publication we developed a new fitpack prototype aimed at couples, along with related health promotion messages, and asked 13 couples who inject drugs to examine and reflect on these new objects and messages. Drawing on the work of Bruno Latour to reconceptualise the fitpack, we argued that the fitpack is not inert or neutral in its meaning or effects, that instead it 'affords' particular meanings and actions, such as, for example, that injecting is an individual practice and safety an individual responsibility. Overall, we found a high level of support for the broad idea of couples-oriented materials, as well as for our prototype and associated materials. Participants identified opportunities for improving the materials and commented on implications of the symbols and language used. Together the interviews demonstrated ways in which the new fitpacks and messages could afford couples-oriented safe injecting, and better recognition of relationships that are often dismissed by researchers and health care providers as insincere.


1.3 Sharing knowledge of safer strategies of opioid tablet preparation for injection

Lise Lafferty, Carla Treloar

Injection of pharmaceutical opioid (PO) tablets among people who inject drugs has increased in many countries. The common method for preparing tablets for injection uses heat, resulting in greater particulate matter and therefore increased risk of local infection and damage to veins and organs. A cold preparation process has fewer risks, but this preparation method is not commonly used. This study sought to explore how people who inject POs learn to prepare injections and how health promotion efforts could influence practice. Thirty-three clients of Sydney’s Medically Supervised Injecting Centre (MSIC) who inject PO tablets participated in qualitative interviews between March and December 2013 regarding sources of knowledge and current preparation methods for injection of POs. Participants reported that others who inject POs were the greatest knowledge source around injection of tablets. Heating the solution was reported as the quickest way to administer the drug. Attitudes to the use of wheel filters varied, with some participants reporting that they would use the filters if they were shown how, while others reported a number of barriers to using filters, including availability and complexity of use. Harnessing the power of social connections may provide avenues for education about safer injecting of tablets, including the use of wheel filters. Further work is required to debunk myths about the relative potencies of cold versus hot drug solution. Collaborations between harm reduction workers and peer workers would assist in knowledge dissemination regarding safer injecting practices.


1.4 Hepatitis C risk within injecting networks among people who inject drugs in prison

Lise Lafferty, Jake Rance, Carla Treloar

Hepatitis C (HCV) is most commonly transmitted through shared injecting equipment. Due to the criminalisation of injecting drug use, HCV is highly prevalent among those incarcerated. This qualitative research was undertaken within a larger epidemiological study designed to evaluate the feasibility of HCV ‘treatment as prevention’ among the prisoner population. Using a risk environment framework, this sub-study sought to understand the role of HCV risk within injecting networks in the prison setting. Thirty-two adult prisoners (n=24 men; n=8 women) with a history of injecting drug use participated in semi-structured interviews. Participants were recruited across four correctional centres, including two maximum security prisons, one minimum security prison, and a women’s prison (minimum and medium security). Findings showed that social, economic, and environmental risk factors contributed to injecting practices within prison. Commonly, the person supplying the drugs injected first, with the person owning the injecting equipment going next. HCV did not regularly factor into determining order of injection within networks (i.e., first, second, third), although it was reported that some prisoners claimed not to have HCV in efforts to “jump the queue”. Harm reduction strategies should consider the social factors influencing injecting drug use in the
prison setting, especially to optimise the population benefits of the roll-out of highly effective HCV treatments.


1.5. FUTURE DIRECTIONS - Public health and the law - peer distribution of injecting equipment

Kari Lancaster, Annie Madden

Building on previous work conducted by researchers at CSRH, we are continuing to examine the implications and effects of laws prohibiting peer distribution of injecting equipment. While several states and territories have reformed their laws in recent years, in many states it is still illegal to pass on sterile injecting equipment unless licensed to do so (i.e. as an employee of a needle-syringe program). Although this practice is unlawful in most Australian states, the evidence shows that people who inject drugs do nonetheless pass on sterile equipment, and this practice is widely understood to be an essential element in the prevention of blood borne virus transmission. Research has also shown laws prohibiting peer distribution of injecting equipment have a range of deleterious effects. As law reform discussions continue, we will be examining both legislation and case law relating to this prohibition on peer distribution. We will critically examine the intersection of the criminal law and public health and consider the ways in which the effectiveness of criminal laws in the drugs field might be examined not for their ‘deterrent’ but rather for their public health effects.
2. Testing, diagnosis and lived experience of viral hepatitis

2.1. Evaluating the potential for drug law to produce stigma

Kari Lancaster

Alcohol and other drug-related stigma is a growing concern. Many organizations have called for a reduction in such stigma through law reform, but there is little sense of how this might be achieved. This paper reports on a new method to examine the relationship between stigma and the law and establish a framework that can guide and inform future law reform efforts. The new framework developed draws on insights from health law, performativity theory, poststructuralist policy analysis, critical alcohol and other drugs scholarship, as well as existing frameworks on mental health law and stigma, and recent work on Australian intoxication legislation. Applying this new framework can reveal the stigmatizing and/or discriminatory potential of law. This work formed one part of a larger project funded by the Queensland Mental Health Commission, which aimed to understand experiences of stigma and discrimination for people experiencing problematic alcohol and other drug use in Queensland, as well as identify effective ways to reduce stigma and discrimination.


2.2 The understanding of liver disease assessment scores among people who inject drugs

Alison Marshall, Carla Treloar

From May to October 2014, people who inject drugs (n=253) who attended drug and alcohol centres in NSW, received a liver disease assessment score via transient elastography (TE) as part of a healthy liver campaign (LiveRLife). All study participants were also asked to attend a clinical follow-up at 2-16 weeks. The aim of this qualitative follow-up study (November 2015 - February 2016) was to gain a greater understanding of how participants in the LiveRLife campaign understood their TE score in relation to their liver health and whether their result influenced any subsequent health behaviours such as engagement with healthcare services. Persons with or without chronic HCV infection were eligible to participate. There were four recruitment categories: (a) high TE score (≥9.5 kPa)/attended clinical follow-up (n=12); b) high score/did not attend follow-up (n=2); c) low score (<9.5 kPa)/attended follow-up (n=11); and d) low score/did not attend follow-up (n=8). Participants were not reminded of their TE score during recruitment. Findings from the 33 semi-structured interviews highlighted that most participants correctly interpreted their level of liver disease based on their TE score. Participants who received higher TE scores often expressed surprise, and also incorrectly identified drug use as the main reason for their advanced liver
disease. Participants with lower TE scores felt encouraged by their result and spoke more to maintaining health behaviours. For persons with HCV infection, the initiation of DAA therapies helped to provide a clear-cut direction for behaviour change. In contrast, discussions concerning alcohol reduction were much more limited. Findings from this study have considerable implications for healthcare practitioners and preventative health, in particular, helping people who inject drugs understand how to maintain healthy liver behaviours in the post-DAA era.


2.3 Stigma and discrimination: healthcare and people who inject drugs

Loren Brener, Elena Cama, Peter Hull, Carla Treloar

**Pluralistic Ignorance – a report on a different approach to understanding stigma and discrimination**

Research suggests that people's attitudes are shaped by a variety of influences, including the attitudes they perceive their colleagues or peers to hold. This phenomenon is termed pluralistic ignorance (Katz & Allport, 1931) and occurs when group members believe that their privately held attitudes differ from the majority of their peers. In a study assessing evidence for pluralistic ignorance, we found that health care workers in emergency departments in Brisbane perceived that their colleagues held more negative attitudes towards harm reduction services for people who inject drugs (PWID) than they themselves held. More importantly, health workers behaviour towards PWID was predicted by their colleagues' perceived support for health care for PWID, rather than by their own more favourable attitudes. This research illustrates the influence of health workers' perceptions of their attitudes of their colleagues towards PWID in potentially shaping the care and treatment options they offer to their clients. Based on these findings, it may be that a change in the focus of health education and training is required which addresses stigma and discrimination amongst health care workers and emphasizes not only individuals' own cognitions and attitudes, but also their thoughts and feelings about the attitudes of their colleagues.

**Evaluation of an online injecting drug use stigma intervention targeted at health providers in New South Wales, Australia**

People who inject drugs (PWID) are highly stigmatised and commonly report discriminatory experiences, particularly in health care settings. This paper evaluates an online stigma reduction training module targeting health care providers in NSW working with PWID. A total of 139 participants completed a pre and post survey including attitude items and items depicting hypothetical scenarios and concerns around client behaviours. The findings of this study show that participants' attitudes towards PWID were more positive and they showed
less concerns about client behaviours after completing the online training module. Hence this research highlights the benefits of this online training in reducing discriminatory attitudes towards PWID and improving confidence in working with this client group. This type of intervention also has the additional benefit of being low cost and easy to administer and can reach a large number of people working in the health sector.

**Implicit and explicit internalised stigma: Relationship with risky behaviours, psychosocial functioning and healthcare access among people who inject drugs**

People who inject drugs (PWID) are stigmatised by society and over time they may begin to internalise this stigma. Our research examines how implicit and explicit internalised stigma among PWID relates to health care and treatment access, psychosocial functioning, and engagement in risky behaviours. 115 clients completed the survey measures. To the degree that participants had internalised the explicit stigma about their group, they felt less comfortable attending NSPs, had greater severity of dependence on their drug of choice, and experienced more depressive symptoms. The implicit measure of internalised stigma was related to treatment engagement and needle sharing, although the direction of these effects was unexpected. This research highlights the importance of ongoing research into the implications of internalised stigma for PWID.


### 2.4 Stigma Indicators Project

**Elena Cama, Tim Broady, Loren Brener, Max Hopwood, 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 first phase, an online survey was completed by 123 people who had ever lived with hepatitis C to investigate their experiences of stigma using the stigma indicator. More than half of participants reported experiencing stigma related to their hepatitis C within the last 12 months (56%), although only 6% reported that this occurred ‘often’ or ‘always’.
2. Testing, diagnosis and lived experience of viral hepatitis

Figure 2: In the last 12 months, have you experienced any stigma or discrimination in relation to your hepatitis C status?

![Bar chart showing percentages of respondents experiencing stigma or discrimination.](chart1.png)

Two-thirds of respondents reported at least some instances of being negatively treated by health workers (65%), including 15% who indicated this ‘often’ or ‘always’ happened.

Figure 3: In the last 12 months, to what extent do you agree that health workers treated you negatively or different to other people?

![Bar chart showing distribution of responses to health worker treatment.](chart2.png)

A mirrored indicator was included in a survey of 353 health workers to monitor the expression of stigma towards people living with hepatitis C, with 10% reporting that they may have discriminated against clients living with hepatitis C.

Figure 4: In the last 12 months, do you feel that you may have discriminated against patients/clients because of their hepatitis C

![Bar chart showing distribution of self-reported discrimination by health workers.](chart3.png)
A mirrored indicator was also administered to a representative sample of the Australian population via the Australian Survey of Social Attitudes, with 50% of respondents indicating they would behave negatively towards people living with hepatitis C to some extent.

Figure 5: Would you behave negatively towards other people because of their hepatitis C status?

The next phase of this project will expand data collection with the stigma indicator from people who have ever lived with hepatitis C and health care professionals, with revised surveys being conducted in 2018. Being able to quantify the experience of stigma within this group is an important first step towards introducing evidence-based strategies to eliminate its negative effects.


2.5. FUTURE DIRECTIONS - Hepatitis B and stigma among Chinese-Australians in Sydney

Max Hopwood, Carla Treloar

Chronic hepatitis B virus (HBV) is a serious health condition that causes inflammation of the liver, leading to an impaired quality of life among affected people, and in some individuals, significant morbidity and mortality. While most HBV infections occur through perinatal transmission, HBV is also acquired via sexual contact and through sharing equipment for injecting drug use. The regions in the world most affected by HBV include China, which has a large immigrant community who have settled in Sydney. Currently, little is known about how Chinese-Australians view HBV infection and whether HBV-related stigma is a barrier to health care access for members of this community.

To help develop a stigma indicator for HBV infection, CSRH is conducting an exploratory qualitative study of Chinese-Australians’ perspectives of HBV. This project aims to explore: (i) how Chinese-Australians who are living in Sydney understand HBV infection; and, (ii) their experiences of stigma related to HBV. The study qualitatively compares understandings of HBV infection, based upon two age cohorts: people under 30 years of age and people over
30 years of age, to explore how different age-based perspectives might relate to feelings of internalised stigma and to experiences of public stigma, and to what degree stigma acts as a barrier to health care access among Chinese-Australians.

With the generous assistance of the Chinese-Australian Services Society based in Campsie, 16 people over the age of 30 years were recruited to the study during early to mid-2018 and interviewed by two CSRH doctoral candidates who speak Mandarin and Cantonese. The next stage of the study will involve interviews with Chinese-Australians under 30 years of age. It is expected that preliminary findings of this exploratory study of HBV-related stigma will be available by early 2019.

2.6 FUTURE DIRECTIONS - Sex work and stigma indicators

Carla Treloar

As part of the Stigma Indicators project, CSRH and Scarlet Alliance have formed a partnership to undertake qualitative research with sex workers from across Australia. Focus group discussions were conducted with sex workers from each state and territory. These groups were co-facilitated by a staff member from Scarlet Alliance and CSRH. Analysis of the focus group data will inform the development of a survey to be implemented nationally. The survey will ask sex workers to respond to the stigma indicators as well as respond to a range of issues relevant to BBVs and STIs and broader issues across other domains of life. This is an important project as there have been few examples of partnership between sex workers and researchers.
3. Treatment, service engagement and care for viral hepatitis

3.1 Evaluation of the Deadly Liver Mob program

Carla Treloar, John De Wit, Max Hopwood, Elena Cama, Melinda Walker

The Deadly Liver Mob (DLM) program combines health promotion and education delivered by Aboriginal health workers, a peer referral model of care and incentives to improve engagement, testing and treatment of hepatitis C (HCV), HIV and other sexually transmissible infections among Aboriginal people who inject drugs and their peers. DLM offers nominal incentives to encourage participants to be educated on HCV then recruit and educate their peers, returning to the DLM for consolidation of health messages and an ‘incentive payment’ dependent on the quality of their ‘teaching’. Since 2013, DLM has been running as a pilot project in one publicly-funded Needle and Syringe Program (NSP) in New South Wales and expanded to a second site in 2015. In its first 12 months at the initial site, DLM engaged more than 400 Aboriginal people in HCV health promotion with subsequent referral of over 300 people to sexual health screening, resulting in a 1023% increase in access to sexual health services. During the evaluation period, a total of 677 clients attended Site 1 (2013-2015) and 55 clients attended Site 2 (2015-2016) for education. Figure 1 illustrates the “cascade of care” progression of these clients through the program (e.g. health education, screening, returning for results, additional treatment if required). Of those attending Site 1 for health education (n=677), 79% went on to attend screening, 50% returned to receive test results, and 20% received additional treatment. Of those attending Site 2 for health education (n=55), 73% went on to attend screening, 48% returned for test results, and 5% received additional treatment. The overall proportions of Aboriginal people attending the sexual health services significantly increased during the DLM pilot. In 2016, funding was received for an NHMRC Partnership Project to evaluate the scale-up and implementation of the DLM at additional sites across New South Wales.

Figure 6: "Cascade of care" progression for DLM sites
3. Treatment, service engagement and care for viral hepatitis


3.2. Enhancing HCV treatment awareness and uptake among men in prison through increased social capital

Lise Lafferty, Carla Treloar

Social capital is an accumulation of a person’s social resources and has been found to influence health outcomes. People in prison report greater prevalence of hepatitis C (HCV) compared with the general population, often attributed to the criminalisation of injecting drug use. Although HCV treatment is offered within correctional settings, treatment uptake remains low. Public health strategies informed by social capital could be important in addressing gaps in HCV treatment uptake among those in prison. This study sought to identify the ways in which bonding (connections between peers) and linking (connections with institutions) social capital could enhance treatment uptake among those living with HCV in prison. From Nov 2014 – Mar 2015, 28 men with a history of HCV participated in semi-structured interviews across three correctional centres in NSW. Among them, n=10 participants were either currently receiving HCV interferon-based treatment or had previously completed treatment. The remaining participants (n=18) were HCV treatment naïve. Bonding social capital was found to be an important social resource for men considering accessing HCV treatment whilst in custody. Peer connections provided information, including personal accounts of treatment, and reassurance. Linking social capital, developed through connections with nurses, provided prisoners with education. These findings support peer-based programs within the prison setting as positively influencing HCV treatment uptake and adherence among those who are incarcerated, thereby fostering efforts for HCV elimination. Engagement outside of prison clinics, between prisoners and healthcare personnel, would further enhance opportunities for linking social capital as a mechanism for HCV treatment uptake.


3.3 FUTURE DIRECTIONS - Surveillance and treatment of prisoners living with hepatitis C: Perceptions of risk, treatment, reinfection, and management in the prison setting

Lise Lafferty, Jake Rance, Carla Treloar

The Surveillance and Treatment of Prisoners living with hepatitis C (SToP-C) study is evaluating treatment as prevention (TasP) towards the elimination of hepatitis C (HCV) across four correctional centres in NSW. Mathematical modelling has shown that TasP – treating enough people at sufficient scale to create a preventative effect – is theoretically feasible in reducing transmissions of HCV. The Kirby Institute is conducting ongoing epidemiological surveillance in these four prisons in efforts to identify new transmissions following treatment.
completion and assess TasP efficacy. CSRH is conducting the qualitative components of the study. Post-treatment interviews were recently conducted with prisoners following treatment scale-up at each of the correctional centres to understand prisoners’ experiences of treatment, perceptions of TasP, concerns of (re-)infection, and social and cultural changes in risk behaviours (e.g., changes in injecting networks or injecting practices) following HCV cure. Following treatment scale-up, qualitative interviews were also completed with Justice Health clinic personnel and Corrective Services custodial staff and senior administrators in the four prisons to identify perceptions of HCV risk, treatment, and management in the prison setting. Interviews will be conducted with policymakers to assess policy-level support for HCV TasP efforts in correctional centres. Interviews will be undertaken with advocates to identify barriers which may impact HCV treatment scale-up in the prison setting. Family members of prisoners will be invited to participate in interviews exploring familial supports of prisoners’ access to treatment and perceptions of TasP efficacy. It is anticipated that qualitative analysis in conjunction with surveillance will work to identify ongoing behavioural risks (e.g., injecting networks) of hepatitis C transmission following treatment as prevention efforts.

3.4 FUTURE DIRECTIONS - Developing a patient-reported outcome measure and a patient-reported experience measure related to direct-acting antiviral therapies among people who inject drugs

Carla Treloar, Jo Neale, Annie Madden, Max Hopwood

The use of patient-reported outcome measures (PROM) and patient-reported experience measures (PREM) helps to centrally position the perspectives of service users, including patients having treatments, when evaluating health services. For example, PROM and PREM are important tools for understanding the ways people who are living in marginalised circumstances view the outcomes of direct acting antiviral (DAA) therapies for hepatitis C infection, and their experiences of health care services.

Since 2016, a team of researchers from the CSRH and King’s College London, including a peer researcher, have been developing measures of patient outcomes and patient experiences specific to DAA therapies among people who inject drugs (PWID). Throughout 2017, the research team analysed individual in-depth interview and focus group data to identify key concepts and themes which were important to PWID having, or thinking of having, DAA therapies for hepatitis C infection. These data highlighted participants’ hopes for better physical and mental health after completing DAA therapy, and their need for a fuller understanding of liver health after treatment. As well, participants desired a plan for post-treatment care, which includes having enough information to avoid or manage new hepatitis C infections. Through an iterative process, items regarding DAA treatment experience and outcomes were developed from these findings and refined into short, direct statements for inclusion in a PREM and a PROM instrument.

During 2018, the research team aims to validate the PROM and PREM instruments. Following validation of the two instruments, they will be used to generate measures of DAA treatment
experiences and outcomes which will significantly contribute to a multiple perspective paradigm on evidence in health care.

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

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

This project collects information from people who inject drugs (PWID) about their experiences with new direct-acting antiviral (DAA) treatments for hepatitis C (HCV). PWID 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 is one of a small number of other studies currently underway in Australia examining treatment uptake but offers a different view by focusing on the perspectives of PWID, using data collected from them, and focusing on the personal, social and systemic barriers and facilitators to treatment.

Universal access to DAA treatments was introduced in Australia in March 2016 and an estimated 43,360 people have initiated treatment since that time, or about 19% of the Australian population with hepatitis C (Kirby Institute, 2017). These new treatments hold significant promise for individuals affected by HCV and the Australian community. Gathering information about how to best encourage uptake of these treatments is important to meeting the ambitious targets set by government and other agencies to eliminate HCV.

The study uses an observational cohort design (baseline and 6 months follow-up) at six needle and syringe programs (NSP) 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 study documents: the range of reasons for not doing so, and the individual, social and systemic factors associated with non-uptake of treatment, including participants 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 experiences of DAA care in these settings. Approximately 300 participants have been recruited for baseline, many of whom have already been treated or have advanced some way down the assessment pathway for treatment. Recruitment of these participants for follow-up has begun. In addition, approximately half of the key stakeholders for the regional/rural study have been recruited.

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

Tim Rhodes, Kari Lancaster, Jake Rance

A new program of work is being established at CSRH, which will focus 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 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 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. While a range of empirical case studies will be examined, the implementation of new treatments for hepatitis C is a primary focus.


References


