

# Annual Report of Trends in Behaviour 2017: Viral Hepatitis in Australia

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**Publication Date:**

2017-08-10

**DOI:**

<https://doi.org/10.4225/53/597ea9dc4fef2>

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# Annual Report of Trends in Behaviour 2017 Viral Hepatitis in Australia

Edited by:  
Joanne Bryant, Jake Rance, Lise Lafferty, Carla Treloar

## Acknowledgements

We thank our funders, the participants in our studies and the many collaborating organisations and their staff for their invaluable contributions to, and support of, the surveillance and research presented in this report. See the [CSRH website](#) for a list of our partner organisations.

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The Centre for Social Research in Health (CSRH) is based in the Faculty of Arts & Social Sciences at UNSW Sydney. CSRH receives project funding from the Australian Government Department of Health.

Suggested citation:

Bryant, J., Rance, J., Lafferty, L., & Treloar, C. (Eds.) (2017). *Annual Report of Trends in Behaviour 2017: Viral Hepatitis in Australia*. Sydney: Centre for Social Research in Health, UNSW Sydney.  
<http://doi.org/10.4225/53/597ea9dc4fef2>

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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

# Report symbols

The following symbols are used throughout the report to indicate different types of content:



Single study



Trends in behaviour



New development



Commentary

# Executive summary

## Overview

For the first time, the Annual Report of Trends in Behaviour has been divided into three separate reports: viral hepatitis, HIV/AIDS, and sexually transmissible infections. This particular report, focusing on viral hepatitis, provides an opportunity to highlight our contributions to what has been an extraordinary year. The introduction of new, universally available direct-acting antiviral (DAA) treatments for hepatitis C in March 2016 has created excitement around hepatitis C-related research, policy and practice. A remarkable number of people initiated treatment in 2016, demonstrating the significant promise that these treatments hold for both individuals affected by hepatitis C and the broader Australian community. Based on this promising start, governments and other agencies have set ambitious 'elimination' targets. As you will see from the contents of this report, we have contributed in important ways to this current state of affairs, by participating in the monitoring and surveillance 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 Annual Report of Trends in Behaviour 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. While we seek a stable surveillance system, it must be one that is meaningful to the context and fit for purpose. This requires informing ourselves from a range of perspectives: from remaining abreast of clinical and technical advances in medications, to policy perspectives in relation to emerging strategic interests, and especially, to what is important to the variety of communities affected by blood borne viruses (BBVs) and sexually transmissible infections (STIs), including detailed knowledge of the specific needs of communities and the differences between them.

This Annual Report of Trends in Behaviour continues the structure initiated last year 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, a few key issues stand out:

### ▪ The continuing need to address prevention

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.



## ▪ Responsive models of care for viral hepatitis

With the advent of a new generation hepatitis C treatment comes the need to explore the best models of care for affected communities. For a number of years, peer delivered models have been the focus of our work in this area. Over the coming two years we will continue this focus with a series of projects that examine the experience of people who inject drugs with the new generation of treatments, describing the personal, social and systemic barriers and facilitators to treatment, alongside their negotiation of the care system.

## ▪ 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 aimed at health care workers and others to mitigate its negative impact. We also report on the first data to arise from the stigma indicators project aimed at monitoring experiences of stigma among key priority populations over time.

## Community Reference Panel

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. The purpose of this panel is to provide specific guidance and 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

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

Drawing on 22 semi-structured interviews with staff of harm reduction services, this project shows how staff represented couples as either absent from the service or as presenting with needs indiscernible from those of individual clients. The benefits of recognising and working with such partnerships received scant acknowledgement. More effective harm reduction strategies may be achieved by transitioning to a practice framework that addresses the social context of injecting, including the experience of couples.

### Beyond equipment distribution in needle and syringe programs

There is growing evidence regarding the need for BBV prevention efforts to examine strategies beyond equipment distribution. Using self-completed survey responses from 236 needle and syringe program (NSP) clients, we identified three areas of vulnerability: recent risky injection, disadvantage and disability, and drug use milieu. Nearly half of participants (45.5%) could be considered as experiencing double (35.6%) or triple (8.9%) vulnerability, challenging the hepatitis C prevention sector to develop programmes that respond to clients' range of needs beyond those immediately associated with BBV risk.

## Deconstructing injecting risk of hepatitis C transmission

This study highlights gaps in the way that the hepatitis C prevention sector understands and addresses risk. Using survey data from clients of NSPs, it showed that, among those who reported sharing injecting equipment, 'higher' and 'lower' categories of risk were constructed based on hepatitis C status and equipment sharing practices. Being in the higher risk category was associated with perceived difficulty in managing drug use and having less trust in drug and alcohol workers.

## Methamphetamine treatment among gay men

We examined treatment outcomes among gay and bisexual men receiving outpatient counselling at ACON's Substance Support Service. A total of 101 gay and bisexual men receiving treatment for methamphetamine use at the service were interviewed at treatment commencement, and after four sessions and eight sessions. Clients showed reductions in methamphetamine use and improved psychosocial functioning over time, demonstrating the effectiveness of a LGBTI-specific treatment service.

## Young people at risk of transitioning to injecting: What do they know about where to get sterile needles?

This study used cross-sectional survey data collected from 210 young people at risk for transitioning to injecting. The findings suggest that needle distribution policies should focus less on getting 'at-risk' young people to visit primary NSP (since less than a quarter could correctly identify a primary or secondary NSP in their local area), and more on improving services that they already know about, e.g. hospitals and pharmacies, or finding ways of bringing sterile needles to them, such as through peer distribution.

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

As found in previous years, amyl nitrite is the most commonly used drug by men in the Gay Community Periodic Surveys, used by 38%. Use of ecstasy (28% in 2007 to 15% in 2016) and speed (15% in 2007 to 6% in 2016) has declined, however the proportions of men using crystal (from the lowest of 8.8% in 2010 to the highest of 13.2% in 2015) or erectile dysfunction medications (20% in 2007 to 26% in 2016) have increased. Injecting drug use remains uncommon among gay men at about 7% in 2016, but was more common among HIV-positive than negative men. Methamphetamines and steroids were the substances most commonly injected.

## Factors associated with psychostimulant dependence among clients attending the S-Check stimulant clinic

This project evaluated the Stimulant Check-up Clinic located at St Vincent's Hospital. It showed that participants who were categorised as psychostimulant dependent prior to attending a session at S-Check appeared to engage in a greater number of other associated health risks, including those related to hepatitis C and HIV acquisition, compared to those not classified as dependent. The 'dependent' group reported complex drug taking histories, often involving the use of more than one substance, as well as increased engagement in other risk behavior with potentially serious health consequences.

## Testing, diagnosis and lived experience of viral hepatitis

### Care and treatment of hepatitis C among Aboriginal people

A qualitative study was conducted with 39 Aboriginal Australians living with hepatitis C to explore experiences of diagnosis, care, and treatment. Diagnosis experiences were characterised by a lack of information in combination with high levels of stigma. Nonetheless, participants reported being pro-active regarding their health management post-diagnosis. Efficacy and side-effects factored into treatment decision-making. Policies and programmes need to be culturally tailored to address the unique needs and experiences of Aboriginal people living with hepatitis C and their communities.

### Experiences of multiple stigmas among Aboriginal Australians living with hepatitis C

People can experience additional stigma as a result of multiple, marginalised identities. In interviews with 39 Aboriginal people, hepatitis C-related stigma was identified as the primary concern, separate from stigma associated with Aboriginality. Fear of stigma created a barrier in accessing hepatitis C-related healthcare. Participants also reported a lack of support and acceptance of Aboriginal people who inject drugs among some Aboriginal Community-Controlled Health Services when seeking harm reduction services and associated health care.

### Experiences of diagnosis, treatment and care among Aboriginal people living with hepatitis C

This survey of 203 Aboriginal people living with hepatitis C found that participants were generally satisfied with hepatitis C care but were often subject to stigma and discrimination pertaining to hepatitis C status and Aboriginality. Pre- and post-test discussion often did not occur and on-going engagement in specialist care was challenging. Culturally appropriate delivery of diagnosis was experienced positively, highlighting its importance as a means of increasing engagement with care and ensuring positive health outcomes among Aboriginal people affected by hepatitis C.

### Cantonese-speaking and Mandarin-speaking people with liver cancer in Australia: A report of two focus group discussions

Focus group discussions revealed English proficiency was a barrier for accessing Australian health services and understanding the implications of a cancer diagnosis. Recommendations from the study included a directory of Chinese-speaking medical practices and Chinese language interpretation services, the development of Cantonese and Mandarin language health promotional materials, and identifying opportunities to support family doctors and liver specialists.

### Interventions to reduce stigma: A narrative review of the literature

The conclusions of this review noted six key principles of stigma-reduction programs: (i) information-based approaches, (ii) skill-building exercises that entail tangible learning strategies to reduce negative attitudes, (iii) counselling approaches, (iv) social contact-interaction, (v) structural approaches, and (vi) biomedical approaches. The review reported enthusiastic facilitators should be used to model a person-centred approach, with booster

sessions for sustaining positive effects over time.

### **Dimensions of social capital and links to health care among the prisoner population**

Thirty male inmates living with hepatitis C were interviewed to identify dimensions of social capital in the prison setting. Participants described trust in staff members as being interlinked with how they were treated by that person, e.g. as a patient, student, employee, rather than a 'crim'. Informal networks among prisoners were reported to be a source of social support, with agency associated with having others believe in them. The research indicated social capital could foster health care access and rehabilitative program participation among those incarcerated.

### **Social capital among Aboriginal and non-Aboriginal men in prison living with hepatitis C**

Thirty male inmates (27% identified as Aboriginal) living with hepatitis C were interviewed in order to understand cultural differences of social capital among Aboriginal and non-Aboriginal inmates. Aboriginal inmates indicated stronger familial and cultural ties with other Aboriginal people in prison, while non-Aboriginal participants identified other people who inject drugs as those they felt most connected with. Findings suggest bonding social capital should be utilised to promote health and other programs to inmates, particularly Aboriginal men in prison.

### **Evaluation of an online injecting drug use stigma intervention targeted at health providers**

The 'Stigma, Discrimination and Injecting Drug Use' eLearning module was developed for the NSW Health workforce in 2016 to generate discussion around attitudes and behaviours toward people who inject drugs. The module was jointly developed by HETI, the Australian Injecting & Illicit Drug Users League, NSW Users and AIDS Association and NSW Health, and its impact evaluated by the Centre for Social Research in Health. The survey was completed by 139 participants. Health professionals reported less negative attitudes towards people who inject drugs after completing the online module. The majority felt the content was very relevant to them and made a difference to their work.

### **The Stigma Indicators project**

Each of Australia's five national strategies addressing HIV, viral hepatitis and sexually transmissible infections has an objective to eliminate the negative impact of stigma and discrimination on people's health. In this national project, we seek to assess and monitor experiences of stigma among people with BBVs/STIs to feed back to these strategies. The first phase of the project consisted of the inclusion of the stigma indicator in new and existing surveys among people living with hepatitis C, people who inject drugs, men who have sex with men and people living with HIV. A mirrored indicator was also included in a new survey of health workers to monitor the expression of stigma towards people within affected communities.

## Treatment, service engagement and care for viral hepatitis

### Surveillance and treatment of prisoners living with hepatitis C: Perceptions regarding risk, prevalence, and treatment in the prison setting

The Surveillance and Treatment of Prisoners living with hepatitis C (SToP-C) study is a mixed method trial of treatment as prevention towards the elimination of hepatitis C across four correctional centres. Pre-treatment interviews with prisoners were conducted to understand prisoners' perceptions of hepatitis C transmission, risk, and prevention as well as feasibility of treatment as prevention in the prison setting. Additional interviews will be conducted post-treatment, and with correctional officers, health staff, policymakers, and family members of prisoners. It is anticipated that qualitative analysis in conjunction with surveillance will work to identify ongoing behavioural risks of hepatitis C transmission following treatment as prevention efforts.

### Health workers support for hepatitis C treatment uptake among clients with a history of injecting

This study aimed to assess whether health care workers' negative attitudes towards people who inject drugs impacts their support for their hepatitis C clients with a history of injecting drug use to access hepatitis C treatment. Ninety alcohol and other drug workers participated, showing that they reported strong support for their clients to access hepatitis C treatment, particularly if they were no longer injecting drugs. However, support for clients who were still injecting was lower. Furthermore, participants who had more negative attitudes towards people who inject drugs were less supportive of clients with a history of injecting drug use entering hepatitis C treatment, irrespective of whether the client was still injecting drugs.

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

This study is one of a small number of other studies currently underway in Australia examining the uptake of new DAA hepatitis C treatments by people who inject drugs. It offers a unique perspective by focusing on the views and experiences of people who inject drugs, using data collected from them, and focusing on the personal, social and systemic barriers and facilitators to treatment. The study will use an observational cohort design over 12 months at seven NSPs in metropolitan and regional NSW.

### 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

This mixed-method project brings together researchers from King's College London and UNSW Sydney, including a peer researcher, to develop a measure of patient experiences and outcomes in relation to the new DAA therapies for hepatitis C among people who inject drugs. Patient/service-user generated measures are particularly valuable for highlighting differences between the views of professionals and patients and the consequent need for a multiple perspective paradigm on evidence in health care.

# Community Reference Panel



**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 has 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 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.

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 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 among heterosexual couples who inject drugs. While our previous analyses from the study have focused on interview data from the 40 participating couples, this analysis drew on semi-structured interviews with 22 staff of harm reduction services located in Sydney and Melbourne, Australia. Despite injecting-equipment sharing between sexual partners leaving them at increased risk of hepatitis C, there is scant literature available to guide harm reduction workers in their encounters with couples who inject drugs. This article explored workers' understandings of such couples and their accounts of working with them in relation to hepatitis C prevention. Overall, staff represented couples as either absent from the service or as presenting with needs indiscernible from those of individual clients. Responses to questions about hepatitis C and couples were framed primarily in terms of risk. Staff participants questioned 'genuineness' of clients' intimate relationships, instead characterising them as inauthentic and drug-driven. Working with couples was seen to present a number of organisational and clinical challenges. The benefits of recognising and working with such partnerships received scant acknowledgement. Rather, staff tended to perceive couples as being 'impenetrable' to health promotion messaging. The framing and delivery of harm reduction in Australia remains an individualising enterprise with little capacity to recognise the intimate partnerships, including addressing the hepatitis C risks specific to them. More effective harm reduction strategies may be achieved by transitioning to a practice framework that addresses the social context of injecting, including the experience of couples. This would require direct involvement of couples who inject drugs.

Based on our findings from the CUPID project we compiled a series of recommendations for policy and practice. These included the development and implementation of capacity-building strategies to support the harm reduction workforce to strengthen client-centred approaches, and the development and implementation of harm reduction/hepatitis C prevention materials tailored to couples who inject drugs. We recommended also considering other programs within the harm reduction, drug treatment and hepatitis C care sectors that are amenable to including a focus on couples who inject drugs: the provision of couples-oriented detoxification and opiate substitution treatment programs, for example. Similarly, we recommended a review of programs in the broader social welfare field that currently fail to acknowledge couples as 'resources' – or indeed exclude couples as clients – such as drug rehabilitation facilities or crisis accommodation. More focused advocacy for

the reform of relevant laws and regulations around injecting equipment that impact couples, such as restrictions on peer distribution, should be considered. We emphasised the importance of establishing an enabling legal and policy environment (for example, Ottawa Charter principles) for all people who inject drugs, and the imperative of including people who inject drugs in all processes that affect them. In recognising the damage brought about by criminalisation, we recommended researchers, drug-user activists and policy makers work together towards law reform. Finally, we proposed the need for similar research among same sex couples.

Rance, J. A., Fraser, S., Rhodes, T., Bryant, J., & Treloar, C. (2016). *The CUPID Project: Understanding and preventing hepatitis C transmission within heterosexual couples*. Centre for Social Research in Health, UNSW Australia, Sydney. <http://doi.org/10.4225/53/58d1bc317ac54>

Treloar, C., Rance, J., Bryant, J., & Fraser, S., (2016). Harm reduction workers and the challenge of engaging couples who inject drugs in hepatitis C prevention. *Drug and Alcohol Dependence*, 168, 170-175. <http://doi.org/10.1016/j.drugalcdep.2016.09.010>



## 1.2 Beyond equipment distribution in needle and syringe programs

Carla Treloar, Limin Mao

Despite high levels of equipment distribution through needle and syringe programs (NSPs) in Australia, the levels of reuse of equipment among people who inject drugs remain concerning. This paper used an exploratory analysis to ascertain the needs of NSP clients that could be addressed by NSPs to enhance service impact and respond to blood borne virus (BBV) risk practices. People who inject drugs were recruited from six NSP sites in Sydney, Australia, to undertake a self-completed survey. Using the responses of 236 NSP client participants, three factors were identified in an exploratory factor analysis: recent risky injection; disadvantage and disability; and drug use milieu. To understand the distribution of these factors, the standardised factor scores were dichotomised to explore those participants with 'above average' vulnerability on each factor. A small group of NSP clients reported a cluster of vulnerability measures. Most participants (55.5%) reported vulnerability on none or only one factor, indicating that 45.5% could be considered as having double (35.6%) or triple (8.9%) vulnerability. These results challenge NSPs to understand the heterogeneity among their client group and develop programmes that respond to their clients' range of needs beyond those immediately associated with BBV risk. This paper contributes to the growing evidence base regarding the need for BBV prevention efforts to examine strategies beyond equipment distribution.

Treloar, C., Mao, L., & Wilson, H. (2016). Beyond equipment distribution in Needle and Syringe Programmes: An exploratory analysis of blood-borne virus risk and other measures of client need. *Harm Reduction Journal*, 13. <http://doi.org/10.1186/s12954-016-0107-0>



## 1.3 Deconstructing injecting risk of hepatitis C transmission

Carl Treloar, Limin Mao

Current efforts to prevent transmission of the hepatitis C virus focus on the message that all sharing of injecting equipment is risky. This obscures the strategies adopted by people who inject drugs to reduce risk of transmission to themselves and others. This study examined results from a self-complete survey of clients of NSPs in a metropolitan area of Sydney, Australia. Among those who reported sharing injecting equipment, two categories of risk

were constructed based on self-perceived hepatitis C status and self-reported distributive and receptive sharing of injecting equipment. The “higher risk” category contained participants who reported being either hepatitis C-positive and distributive sharing or hepatitis C-negative and receptive sharing. The “lower risk” category contained participants who reported being either hepatitis C-positive and receptive sharing or hepatitis C-negative and distributive sharing. Around a third of the total sample were categorised as “higher risk”. Being in the higher risk category was associated with perceived difficulty in managing drug use and having less trust in drug and alcohol workers. This exploratory study highlights gaps in the way that the hepatitis C prevention sector understands and addresses risk. Further research is required to guide prevention efforts that are meaningful and relate to the strategies that people who inject drugs undertake to reduce hepatitis C risk.

Treloar, C., Wilson, H., & Mao, L. (2016). Deconstructing injecting risk of hepatitis C virus transmission: Using strategic positioning to understand “higher risk” practices. *Drugs: Education, Prevention and Policy*, 23, 457-461. <http://doi.org/10.3109/09687637.2016.1161008>



## 1.4 Methamphetamine treatment among gay men

Toby Lea, Martin Holt

Gay and bisexual men report higher rates of methamphetamine use compared to heterosexual men, and thus have a heightened risk of developing problems from their use. We examined treatment outcomes among gay and bisexual clients receiving outpatient counselling at ACON's Substance Support Service, a lesbian, gay, bisexual, transgender and intersex (LGBTI)-specific, harm reduction treatment service in Sydney, Australia. Gay and bisexual men receiving treatment for methamphetamine use at the service between 2012 and 2015 ( $n=101$ ) were interviewed at treatment commencement, and after four sessions ( $n=60$ ; follow-up 1) and eight sessions ( $n=32$ ; follow-up 2). At each interview, clients completed measures of methamphetamine use and dependence, other substance use, injecting risk practices, psychological distress and quality of life. The median age of participants was 41 years and 56.4% identified as HIV-positive. Participants attended a median of five sessions and attended treatment for a median of 112 days. There was a significant reduction in the median days of methamphetamine use in the previous four weeks between baseline (4 days), follow-up 1 (2 days) and follow-up 2 (2 days;  $p=.001$ ). There was a significant reduction in the proportion of participants reporting methamphetamine dependence between baseline (92.1%), follow-up 1 (78.3%) and follow-up 2 (71.9%,  $p<.001$ ). There was also a significant reduction in psychological distress ( $p<.001$ ), and a significant improvement in quality of life ( $p<.001$ ). Clients showed reductions in methamphetamine use and improved psychosocial functioning over time, demonstrating the effectiveness of a LGBTI-specific treatment service.

Lea, T., Kolstee, J., Lambert, S., Ness, R., Hannan, S., & Holt, M. (2017). Methamphetamine treatment outcomes among clients attending a treatment service for lesbian, gay, bisexual and transgender people. *PLOS ONE*, 12(2): e0172560. <https://doi.org/10.1371/journal.pone.0172560>



## 1.5 Young people at risk of transitioning to injecting: What do they know about where to get sterile needles?

Joanne Bryant, Carla Treloar

Socially marginalised young drug users are recognised as a high-risk group for transitioning to injecting, yet there is very little known about their harm reduction knowledge and practices. Instead, the existing research focuses on young people who are already injecting. This research focused on this under-researched population, characterising their knowledge about NSP prior to any injecting experiences and, in this way, give insight into the context of first injections. We used cross-sectional survey data collected from 210 at-risk young people. While a third (34.3%) of participants thought they knew where to obtain sterile needles, fewer (24.3%) could correctly identify a service and the sources most commonly identified – hospitals (27.8%) and pharmacies (25.0%) – were not specifically needle distribution services. Participants who possessed correct knowledge about where to obtain sterile needles were more likely to report that their social networks contained many people who injected (OR 2.1 95%, CI 1.1-4.0) and they were more likely to report polydrug use in the last year (that is, to have used a wider range of drugs) (OR 2.7 95%, CI 1.4-5.2). Other multivariate analyses identified that recent contact with social and health services had no impact on whether participants knew where to get sterile equipment. This suggests that needle distribution policies might focus less on getting young people to visit primary needle distribution sites, which they know little about, and more on improving services that they already know about - hospitals and pharmacies - or finding ways of bringing sterile needles to them, such as through peer distribution.

Bryant, J., Ellard, J., Howard, J., & Treloar, C. (2017). Young people at risk of transitioning to injecting: What do they know about where to get sterile needles? *Vulnerable children and youth studies* 12(2), 138-146. <http://dx.doi.org/10.1080/17450128.2017.1282071>



## 1.6 Drug use and injection by participants in Gay Community Periodic Surveys

Limin Mao, Martin Holt, Evelyn Lee, Peter Hull, Toby Lea, John de Wit

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.

Table 1 and Figure 1 show that:

- Amyl nitrite is the most commonly used drug by men in the GCPs. The proportion of men using amyl nitrite (38%) in the previous six months has remained stable over the last decade. The proportions of men reporting recent use of cannabis (31%), cocaine (12%) or GHB/GBH (7%) have also stabilised since 2007. Trends in ecstasy or speed use have declined since 2007. While ecstasy use continued to decline since 2014, speed use was stable in the past three years. In contrast, the proportions of men using crystal or erectile dysfunction medications in the six-month period have increased over the 10-year period although both trends have stabilised in the past three years.

- Injection of non-prescribed drugs remains uncommon 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 (6% 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.

Lea, T., Mao, L., Bath, N., Prestage, G., Zablotska, I., de Wit, J., & Holt, M. (2013) Injecting drug use among gay and bisexual men in Sydney: prevalence and associations with sexual risk practices and HIV and Hepatitis C infection. *AIDS and Behavior*, 17, 1344-1351. <http://dx.doi.org/10.1007/s10461-013-0409-0>

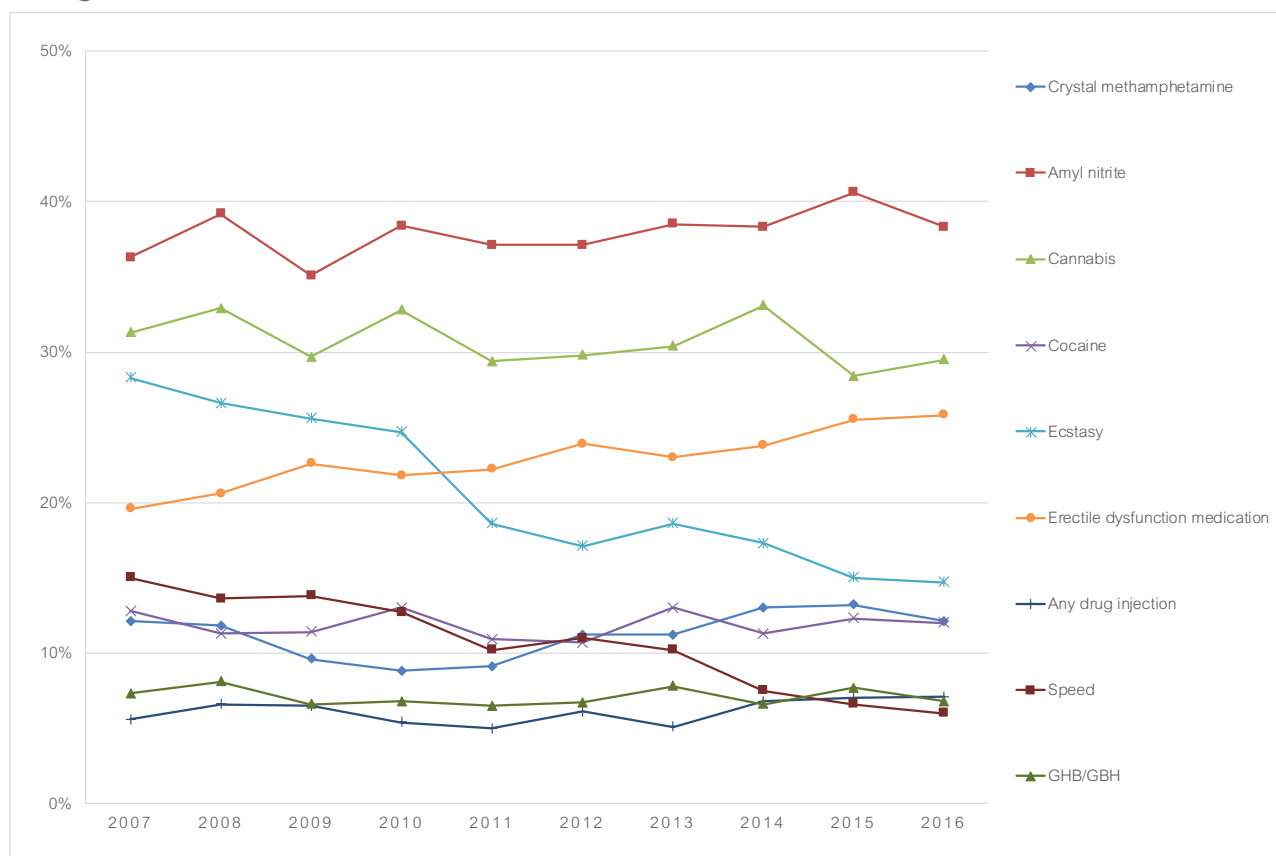
Prestage, G., Jin, F., Kippax, S., Zablotska, I., Imrie, J., & Grulich, A. (2009). Use of illicit drugs and erectile dysfunction medications and subsequent HIV infection among gay men in Sydney, Australia. *Journal of Sexual Medicine*, 6, 2311–2320. <http://doi.org/10.1111/j.1743-6109.2009.01323.x>

**Table 1: Men who reported any use of selected recreational drugs in the six months prior to the survey: GCPS, 2007-2016 (all states and territories)**

	2007 (%)	2008 (%)	2009 (%)	2010 (%)	2011 (%)	2012 (%)	2013 (%)	2014 (%)	2015 (%)	2016 (%)	Overall trend	Trend in last 3 years
Amyl nitrite	36.3	39.2	35.1	38.4	37.1	37.1	38.5	38.3	40.6	38.3	ns	ns
Cannabis	31.3	32.9	29.7	32.8	29.4	29.8	30.4	33.1	28.4	29.5	ns	ns
Ecstasy	28.3	26.6	25.6	24.7	18.6	17.1	18.6	17.3	15.0	14.7	↓	↓
Cocaine	12.8	11.3	11.4	13.0	10.9	10.7	13.0	11.3	12.3	12.0	ns	ns
Crystal	12.1	11.8	9.6	8.8	9.1	11.2	11.2	13.0	13.2	12.1	↑	ns
Speed	15.0	13.6	13.8	12.7	10.2	11.0	10.2	7.5	6.6	6.0	↓	ns
GHB/GBH	7.3	8.1	6.6	6.8	6.5	6.7	7.8	6.6	7.7	6.8	ns	ns
Erectile dysfunction medication (e.g. Viagra, Cialis)	19.6	20.6	22.6	21.8	22.2	23.9	23.0	23.8	25.5	25.8	↑	ns
Any drug injection	5.6	6.6	6.5	5.4	5.0	6.1	5.1	6.8	7.0	7.1	ns	ns



**Figure 1: Men who reported any use of selected recreational drugs in the six months prior to the survey: GCPS, 2007-2016 (all states and territories)**



## 1.7 Factors associated with psychostimulant dependence among clients attending the S-Check stimulant clinic

Loren Brener, Joanne Bryant, Toby Lea, Jake Rance

Harms associated with stimulant use present a public health burden, with significant costs to health care to treat people presenting with stimulant use problems. In Australia, treatment options for stimulant use are limited, as the majority of treatment facilities have traditionally focused on opiates and alcohol. In November 2011 the St Vincent's Hospital Stimulant Treatment Program successfully implemented a three year pilot Stimulant Check-up Clinic. The aim of the clinic is to provide brief strengths-based, bio-psycho-social assessments for people who use stimulants such as methamphetamine, cocaine and ecstasy. The Centre for Social Research in Health (CSRH) was commissioned to evaluate this model of service delivery. The primary method of assessment was through the review of an existing client database consisting of routine information collected from clients at the four clinic sessions.

Two hundred and sixty-six participants made contact with the S-Check service during the study period. This included 186 participants (69.9%) who attended S-Check for at least one appointment, and 80 participants (30.1%) who contacted S-Check via phone but did not attend the service in person. Retention of participants who attended S-Check in person was good (see Table 2). Eighty-one percent of participants who attended session 1 were retained at session 2, 56.5% were retained at session 3, and 58.6% were retained at session 4.



**Table 2: Retention of participants at each S-Check session**

	Attended n (%)	Days elapsed from session 1 Median (IQR)
Session 1 – Psychosocial assessment	186 (100)	-
Session 2 – Medical assessment	151 (81.2)	11 (1-13)
Session 3 – Medical feedback	105 (56.5)	20 (7-21)
Session 4 – Psychosocial feedback	109 (58.6)	29 (13-30)
Completed 3 or 6 month follow-up	14 (7.5)	-

In terms of the data associated with psychostimulant dependence, participants were categorised as dependent if their SDS (Severity of Dependence Scale) score at baseline was greater than 4, consistent with the cut-off used for methamphetamine dependence. A series of bivariate analyses were conducted to examine factors associated with psychostimulant dependence (see Table 3). Participants who were categorised as psychostimulant dependent prior to attending a session at S-Check appeared to engage in a greater number of other associated health risks than those not classified as dependent. For example participants categorised as psychostimulant dependent were significantly more likely to report a current problem with psychostimulant use, have a higher number of unwanted stimulant effects, to have previous experience of alcohol and/or other drug treatment, to have ever engaged in unprotected sex or other risky sexual practices while using psychostimulants, to have ever shared any equipment used for taking psychostimulants, and to have experienced high or very high levels of psychological distress in the four weeks prior to attending S-Check. While not statistically significant, participants categorised as psychostimulant dependent were also more likely to report having injected drugs in the three months immediately before they attended S-Check. It appears that this group have long and complex drug taking histories involving the use of more than one substance, as well as increased engagement in practices that place them at greater risk of more serious health consequences.

**Table 3: Characteristics of participants categorised as psychostimulant dependent at baseline**

	Psychostimulant dependence		
	No (n=40)	Yes (n=146)	p-value
Session 1 overall rating (median, IQR)	98 (91-100)	95 (87-99)	0.06
Source of referral (%)			
Self / family / friend	27.5	35.6	0.02
GP / psychiatrist / psychologist	7.5	21.9	
Criminal justice setting	22.5	8.2	
Other	42.5	34.2	
Previous AOD treatment (%)			
No	65.0	43.2	0.01
Yes	35.0	56.8	
Self-reported problem with stimulant use (%)			
No	52.5	15.1	< 0.001
Yes	47.5	84.9	
Number of unwanted stimulant effects (median, IQR)	3.5 (2-5)	5 (3-7)	0.002
Injected drugs in the past 3 months (%)			
No	80.0	63.7	0.05
Yes	20.0	36.3	
Ever engaged in unprotected sex or other risky sexual behaviours while using			
No	57.5	34.9	0.01
Yes	42.5	65.1	
Ever shared any drug equipment used for taking psychostimulants			
No	52.5	32.9	0.02
Yes	47.5	67.1	

Brener, L., Bryant, J., Wilson, H., Lea, T., & Rance, J. (2016). *St Vincent's Hospital Sydney, Drug and Alcohol Service, S-Check Clinic: Evaluation Report*. Centre for Social Research in Health, UNSW Australia, Sydney. <http://dx.doi.org/10.4225/53/57AA8C9E4A664>

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



### 2.1 Care and treatment of hepatitis C among Aboriginal people

Carla Treloar, Clair Jackson, Rebecca Gray, Loren Brener

Aboriginal people are overrepresented in populations of people living with hepatitis C. However, there remains a paucity of research to inform and guide policy and programme development regarding care and treatment, particularly new direct-acting antiviral therapies.

CSRH conducted a study with Aboriginal Australians living with hepatitis C in NSW to understand the experiences of this population group regarding diagnosis and decisions for hepatitis C care and treatment. Thirty-nine people participated in in-depth interviews. The experience of diagnosis was characterised by a lack of detailed or appropriate information in combination with high levels of stigma. Participants reported low overall knowledge of hepatitis C for themselves and within their communities. However, despite these negative experiences around diagnosis, participants had been pro-active in their response to health management and liver health (particularly through reducing alcohol consumption) since learning of their hepatitis C status. Treatment efficacy and side-effects factored into decision-making processes for treatment uptake. Eleven participants had previously accessed hepatitis C treatment through a variety of care models with a peer worker or in prison.

Policies and programmes should be culturally tailored to address the unique needs and experiences of Aboriginal people regarding hepatitis C diagnosis, care, and treatment. Results from this study indicated further engagement of the primary sector would likely assist in increasing individual and community knowledge regarding hepatitis C. Service models should promote holistic notions of health, healthcare delivery, and health literacy through use of information and communication programmes that are culturally relevant to Aboriginal people.

Treloar, C., Jackson, C., Gray, R., Newland, J., Wilson, H., Saunders, V., . . . Brener, L. (2016). Care and treatment of hepatitis C among Aboriginal people in New South Wales, Australia: implications for the implementation of new treatments. *Ethnicity & Health*, 21(1), 39-57. <http://dx.doi.org/10.1080/13557858.2015.1004870>



### 2.2 Experiences of multiple stigmas among Aboriginal Australians living with hepatitis C

Carla Treloar, Clair Jackson, Rebecca Gray, Loren Brener

People can experience additional (synergistic) stigma for their multiple marginalised personalities (e.g. being Aboriginal and an injecting drug user). This study sought to explore experiences of living with hepatitis C among Aboriginal Australians, a minority population group that has experienced complex issues of stigma and power associated with social,

political, economic, and cultural factors.

The data was derived from a sub-study (n=39), of a larger study (n=203) exploring Aboriginal people living with hepatitis C. This sub-study sought to understand the multiple mechanisms of stigma and the overlap of social, cultural, and historical factors influencing these experiences.

Hepatitis C-related stigma was identified as the primary concern, separate from stigma associated or compounded with Aboriginality. Fear of stigma created avoidance of disclosing hepatitis C status and, in some instances, accessing hepatitis C-related healthcare. Participants indicated perceptions of societal expectations that Aboriginal people would present with stigmatised conditions, such as hepatitis C. It was identified that cultural notions of shame should be explored in notions of stigma. In one instance, a doctor was described as not respecting patient confidentiality in the presence of family who were unaware of the patient's hepatitis C status. In accessing Aboriginal Community Controlled Health Services, the stigma shifted from hepatitis C to injecting drug use, where there existed (in some Aboriginal Community Controlled Health Services) a lack of support and acceptance of Aboriginal people who inject drugs to seek harm reduction services and associated health care. Some participants campaigned against hepatitis C-related stigma, drawing on resilience in doing so.

Treloar, C., Jackson, L. C., Gray, R., Newland, J., Wilson, H., Saunders, V., . . . Brener, L. (2016). Multiple stigmas, shame and historical trauma compound the experience of Aboriginal Australians living with hepatitis C. *Health Sociology Review*, 25(1), 18-32. <http://dx.doi.org/10.1080/14461242.2015.1126187>



## 2.3 Experiences of diagnosis, treatment and care among Aboriginal people living with hepatitis C

Loren Brener, Clair Jackson, Carla Treloar

Aboriginal Australians are disproportionately affected by hepatitis C. Reasons for this include the overrepresentation of Aboriginal persons among high risk groups such as people who inject drugs and people in custodial settings. Little is known about hepatitis C treatment and care for Aboriginal people and few studies have focused specifically on Aboriginal Australians living with hepatitis C. The way in which the hepatitis C diagnosis is delivered may be very important in determining on-going engagement with hepatitis C care. This study aimed to describe their patterns of hepatitis C care and treatment, particularly focusing on the importance of being informed of this diagnosis in a culturally sensitive manner. Two hundred and three Aboriginal people living with hepatitis C were recruited and completed a survey assessing their experiences of hepatitis C testing and care, hepatitis C knowledge, lifestyle changes after diagnosis, perceived stigma and discrimination. Of the total sample, 58% were male, 96% identified as Aboriginal with a mean age of 28 years, and notably 80% had ever been in prison. Nearly all participants reported positive lifestyle changes after their hepatitis C diagnosis. While participants tended to be satisfied with the hepatitis C care they received, they did note experiencing stigma and discrimination related to both their hepatitis C status and Aboriginality. The data also indicated that post-test counselling does not occur often and on-going engagement in specialist care is low and difficult to achieve. Receiving a culturally appropriate hepatitis C diagnosis was found to have positive implications in relation to both experiences of living with hepatitis C such as decreased feelings of hepatitis

C-related stigma; and engagement with hepatitis C care and treatment, that is, increased intentions to seek hepatitis C treatment. Hence these findings confirm the importance of delivering a diagnosis in a culturally appropriate way in increasing engagement with care and positive health outcomes for Aboriginal people living with hepatitis C.

Brener, L., Wilson, H., Jackson, L. C., Johnson, P., Saunders, V., & Treloar, C. (2016). Experiences of diagnosis, care and treatment among Aboriginal people living with hepatitis C. *Australian and New Zealand Journal of Public Health*, 40, S59-S64. <http://dx.doi.org/10.1111/1753-6405.12402>



## 2.4 Cantonese-speaking and Mandarin-speaking people with liver cancer in Australia: A report of two focus group discussions

**Max Hopwood, Carla Treloar**

In a study by CSRH and Cancer Council NSW of Cantonese- and Mandarin-speaking people with liver cancer in Australia, two focus group discussions were conducted to explore the lived experience of primary liver cancer. Bilingual researchers led the Cantonese and Mandarin focus groups. Topics included: participants' experiences of a liver cancer diagnosis; their understandings of investigations, staging and treatment options; and, participants' preferred ways to access liver cancer-related information.

Findings revealed few differences between the two Chinese-speaking populations in our purposive sample, with Mandarin speakers more likely to have travelled to China to seek or augment their cancer treatment than Cantonese-speakers. However, for both groups English language was a major barrier to participants' negotiating Australian health services and to understanding the implications of a cancer diagnosis. Reportedly, participants' main sources of cancer-related information were doctors and specialists.

Study recommendations included: the development of a directory of Chinese-speaking medical practices and Chinese language interpretation services which could be made available through hospitals and at doctors' and specialists' clinics; and, liaising with Chinese community medical practitioners to discuss ways of supporting family doctors and liver specialists to ensure patients receive adequate levels of information about liver cancer, including treatment options. Also recommended was the development of Cantonese and Mandarin language booklets and websites containing information about issues such as the importance of early cancer detection, cancer treatment side-effects, dietary guidelines and psychological support services.

Hopwood, M., Robotin, M. C., Porwal, M., Nguyen, D., Sze, M., George, J., & Treloar, C. (2016). *Cantonese-speaking and Mandarin-speaking people with liver cancer in Australia: A report of two focus group discussions*. [Consultation report for Cancer Council NSW]. Sydney: Centre for Social Research in Health, UNSW Sydney. <http://dx.doi.org/10.4225/53/58d35be5859f2>



## 2.5 Interventions to reduce stigma: A narrative review of the literature

**Max Hopwood**

Using a socio-ecological framework, this literature review identified the key principles of stigma intervention programs where intervention occurs across individual, interpersonal, organisational and structural levels.

In the context of health-related stigma, the key principles and ingredients of stigma-reduction programs were:

- i. Information-based approaches, such as evidence-based written information in brochures and other media, which engage in myth-busting. Such programs emphasise and demonstrate recovery from illness as a key part of their messaging.
- ii. Skill building exercises that entail tangible learning strategies to reduce negative attitudes. Such programs teach skills that help healthcare professionals know what to say and what to do when engaging people with a stigmatised illness.
- iii. Counselling approaches, such as social support groups.
- iv. Social contact-interaction, including testimonials and interaction between people from the general population and people from stigmatised groups. These programs include trained speakers with lived experience of a stigmatised illness, and can employ multiple forms of social contact (e.g. multiple first-voice speakers and a video presentation).
- v. Structural approaches, such as changing discriminatory workplace policies and laws, and increasing healthcare professionals' cultural and structural competency.
- vi. Biomedical approaches, in the context of HIV infection, such as antiretroviral treatment and pre-exposure prophylaxis to reduce new HIV infections.

The review reported that enthusiastic facilitators should be used to model a person-centred approach (person-first, not pathology-first), to set the tone, and to guide program messaging during intervention. Finally, booster sessions (i.e. with programs using the key principles) are recommended for sustaining positive effects over time.

Hopwood, M. (2016). *Interventions to reduce stigma: A narrative review of the literature*. [Consultation report for the Australasian Society of HIV, Viral Hepatitis and Sexual Health Medicine]. Sydney: Centre for Social Research in Health, UNSW Australia. <http://dx.doi.org/10.4225/53/58d33fea1f316>



## 2.6 Dimensions of social capital and links to health care among the prisoner population

Lise Lafferty, Carla Treloar

Social capital refers to a person's social resources, including trust and safety, informal and formal networks, and agency, and has been linked with improved health outcomes. Social capital has been studied extensively in general society, but has garnered little empirical interest for the incarcerated population.

A study was conducted to identify dimensions of social capital, and how they occur within the prison setting among incarcerated men living with hepatitis C to determine if social capital influenced treatment outcomes among this population group. Thirty male inmates living with hepatitis C participated in the study.

Participants described trust in staff members as being interlinked with how they were treated by the staff person, e.g. as a patient, a student, an employee, rather than a 'criminal'. Informal networks among prisoners were shown to be a source of social support in which participants described as beneficial to their wellbeing while in prison; these networks were often entwined with reciprocity. Agency, or a person's inner drive and motivation, was associated with having others believe in them. This external belief in self was perceived



by some participants to improve their own self-belief and enhance relationships between inmates and psychiatric and healthcare workers. The research indicated social capital could foster health care access and rehabilitative program participation among those incarcerated.

Lafferty, L., Treloar, C., Butler, T., Guthrie, J., & Chambers, G. M. (2016). Unlocking dimensions of social capital in the prison setting. *Health & Justice*, 4(9). <http://dx.doi.org/10.1186/s40352-016-0040-z>



## 2.7 Social capital among Aboriginal and non-Aboriginal men in prison living with hepatitis C

Lise Lafferty, Carla Treloar

Social capital is an accumulation of a person's social resources and has been associated with health outcomes. However, there is limited research exploring social capital among people in prison, particularly those living with hepatitis C.

This study sought to understand cultural differences of social capital among Aboriginal and non-Aboriginal male inmates living with hepatitis C in NSW. Thirty male inmates (n=8; 27% identified as Aboriginal) living with hepatitis C participated.

There were unique cultural disparities among Aboriginal and non-Aboriginal participants with regards to bonding social capital (i.e. connections with peers). Aboriginal inmates indicated stronger familial and cultural ties with other Aboriginal people in prison, through shared cultural connections and a sense of kinship. Non-Aboriginal participants identified other drug users as those they felt most connected with. However, as hepatitis C is acquired through blood-to-blood contact, most commonly through injecting drug use, it is not surprising that incarcerated men living with hepatitis C described a bond with other incarcerated injecting drug users. With regards to linking social capital (i.e. connections with institutions and administrations), non-Aboriginal participants described inmate delegates as being "tokenistic". Aboriginal participants reported greater participation of Aboriginal inmate delegates and greater opportunities to have input into their physical and social environment. The research findings suggest bonding social capital should be utilised to promote health and other programs to inmates, particularly Aboriginal men in prison.

Lafferty, L., Treloar, C., Chambers, G. M., Butler, T., & Guthrie, J. (2016). Contextualising the social capital of Australian Aboriginal and non-Aboriginal men in prison. *Social Science & Medicine*, 167, 29-36. <http://dx.doi.org/10.1016/j.socscimed.2016.08.040>



## 2.8 Evaluation of an online injecting drug use stigma intervention targeted at health providers

Loren Brener, Carla Treloar, Peter Hull

The 'Stigma, Discrimination and Injecting Drug Use' eLearning module was developed for the NSW Health workforce in 2016. The interactive 40-minute module provides a discussion around attitudes and behaviours toward people who inject drugs, with the aim of improving their health outcomes and experiences within health care settings. The module was jointly developed by HETI, the Australian Injecting & Illicit Drug Users League, NSW Users and AIDS Association and the NSW Ministry of Health. The goal of the module is to improve the health outcomes for people who inject drugs.

The impact of the training module was evaluated by CSRH. All NSW Health employees who undertook the training were invited to participate in the evaluation which consisted of short online surveys delivered pre and post training. The survey included brief demographics and work history questions, attitude and behaviour questions and feedback on the content of the module, obtained only at the completion of the module. One hundred and thirty nine participants completed both the pre and post survey. The mean scores for the attitude items pre module and post module show that there was a significant change in participants' attitudes towards people who inject drugs between the pre and post survey. Health professionals had less negative attitudes towards people who inject drugs after completing the online module. Additionally, participants did not endorse the negative behaviours or assumptions depicted in the hypothetical scenarios and a shift occurred on responses to three of the scenarios from the pre administration to the post administration all in a positive direction.

Participants were presented with a brief scenario about a client who is a current injecting drug user attending their service and then asked six questions assessing concerns which may arise (i.e. the client may steal or may become violent). Statistical analysis shows that the responses of participants to these concern items were significantly different between the pre and post survey administration and that participants showed less concern around client behaviours after they completed the module.

As can be seen in Table 4, in terms of the course content, the majority of participants felt that the course content was very relevant to them and made a difference to their work. Participants also felt that they knew how to use the skills and knowledge from this course and that they intended to use this in their work.

**Table 4: Relevance of course content to participants**

	Strongly disagree	2	3	Neutral	5	6	Strongly agree
The content is relevant	3(2.2)	6(4.3)	1(.7)	12(8.6)	20(14.4)	21(15.1)	75(54.3)
Make a difference to my work	2(1.4)	2(1.4)	5(3.6)	16(11.5)	18(12.9)	39(28.1)	57(41)
I have an idea how to use skills and knowledge	3(2.2)	2(1.4)	2(1.4)	15(10.8)	25(18)	41(29.5)	51(36.7)
I intend to use skills and knowledge	3(2.2)	2(1.4)	0(0)	15(10.8)	21(15.1)	37(26.6)	60(43.2)
The course provided thorough cover of subject	3(2.2)	3(2.2)	3(2.2)	11(7.9)	26(18.7)	37(26.6)	54(38.8)

The five items which assessed what participants thought of the course and whether they will use it in their work were summed together to make a scale with higher scores indicative of positive perceptions about the course. Participants' responses on this perception about the course scale were then correlated, with their scaled attitude towards people who inject drugs, their responses to the four scenarios and with the client concerns scale after completing the training module. Correlational data illustrates that those participants who rated the course higher were less likely to endorse negative behaviours towards clients who inject drugs (hypothetical scenarios) and were less likely to show concerns around client behaviours as measured on the client concern scale. There was no correlation between feelings about the course and attitudes towards injecting drug users.

**Table 5: Inter-correlations of variables (n=139)**

Variable	1	2	3	4	5	6	7
1. Course Good							
2. Scenario A	-.27**						
3. Scenario B	-.33**	.52**					
4. Scenario C	-.19**	.54**	.41**				
5. Scenario D	-.34**	.64**	.66**	.61**			
6. Client Concerns	-.23**	.56	.38**	.50**	.57**		
7. Stigma Scale	-.15	.35**	.32**	.36**	.44**	.38**	

\*  $p < .05$  \*\*  $p < .01$

Brener, L., Treloar, C., & Hull, P. (2016). *Stigma, Discrimination and Injecting Drug Use HETI eLearning Module for NSW Health Staff: Evaluation Report*. Sydney: Centre for Social Research in Health, UNSW Australia. <https://csr.h.arts.unsw.edu.au/research/projects/heti-elearning-module-evaluation/>



## 2.9 The Stigma Indicators project

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

Stigma is recognised as being a critical barrier to effective responses to blood borne viruses and sexually transmitted infections. Among affected communities, stigma is associated with mental health issues, social isolation, and can discourage people from accessing essential health care and medical treatment, including uptake and adherence to medications. This can have adverse implications for public health initiatives that target prevention and management of infection. Australia currently has a suite of five national strategies addressing HIV, viral hepatitis and sexually transmissible infections. Each strategy contains a clear objective to eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health. Despite this, there is currently no system in place to assess and monitor experiences of stigma among people with BBVs/STIs to feed back to these strategies.

CSRH has received funding from the Australian Government Department of Health to develop an indicator of stigma among priority groups identified by the national strategies. The first phase of the project consisted of the inclusion of the stigma indicator in new and existing surveys among people living with hepatitis C, people who inject drugs, men who have sex with men and people living with HIV. A mirrored indicator was also included in a new survey of health workers to monitor the expression of stigma towards people living with hepatitis B and C, people who inject drugs and people living with HIV. Funding has now been awarded to continue monitoring stigma and discrimination in the abovementioned groups and to expand this research to include the experiences of people living with hepatitis B and sexually transmitted infections, and the expression of stigma among social service providers and the general population.

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



### 3.1 Surveillance and treatment of prisoners living with hepatitis C: Perceptions regarding risk, prevalence, and treatment in the prison setting

Lise Lafferty, Jake Rance

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 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 hepatitis C. CSRH is conducting the qualitative components of the study. Pre-treatment interviews with prisoners were conducted to understand prisoners' perceptions of hepatitis C transmission, risk, and prevention as well as feasibility of TasP in the prison setting. Ongoing epidemiological surveillance will be undertaken by the Kirby Institute to identify new transmissions following treatment completion and assess TasP. Post-treatment interviews will explore prisoners' experiences of hepatitis C treatment, identify any social and cultural changes in hepatitis C risk (e.g. changes in injecting networks following prison-wide treatment), and perceived risks of reinfection. Correctional officers and health staff members will also be interviewed to identify perceptions of hepatitis C risk, treatment, and management in the prison setting. Interviews will be conducted with policymakers to assess policy-level support for hepatitis C TasP efforts in correctional centres. Family members of prisoners living with, or recently treated for, hepatitis C will be invited to participate in interviews exploring familial supports of prisoners living with hepatitis C to access 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.



### 3.2 Health workers support for hepatitis C treatment uptake among clients with a history of injecting

Loren Brener, Max Hopwood

Hepatitis C virus is a highly stigmatised illness because of its association with injecting drug use. Health workers' attitudes and behaviours are increasingly recognised as related to quality of care and in determining client health outcomes. People who inject drugs make up the overwhelming majority of hepatitis C cases, hence it is important to assess how health worker's attitudes towards people who inject drugs may impact on their support for hepatitis C positive clients accessing hepatitis C treatment. This study aimed to assess whether health care workers' negative attitudes towards people who inject drugs impacts

their support for their hepatitis C positive clients with a history of injecting drug use to access hepatitis C treatment. Ninety alcohol and other drug workers completed a survey assessing their attitudes towards people who inject drugs and their support for hepatitis C treatment for three different client scenarios: one who stopped injecting; one on methadone maintenance; and, one who continues to inject. Health care workers showed strong support for their clients to access hepatitis C treatment, particularly in the two scenarios where they were no longer injecting drugs. Support for the client who was still injecting to engage in hepatitis C treatment was lower. Furthermore, participants who had more negative attitudes towards people who inject drugs were less supportive of clients with a history of injecting entering hepatitis C treatment, irrespective of whether the client was still injecting drugs. The findings of this study highlight the influence that health workers' attitudes have in providing appropriate care and services for people living with a stigmatised illness such as hepatitis C. The study also illustrates that it is important for health workers to be aware of any potential biases they may have towards particular groups such as people who inject drugs and to understand how this may impact on the way they work with these clients.

Brener, L., von Hippel, C., Wilson, H., & Hopwood, M. (2016). Health workers' support for hepatitis C treatment uptake among clients with a history of injecting. *J Health Psychol*, <http://dx.doi.org/10.1177/13591053166420>



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

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

This project will collect information from people who inject drugs about their experiences with new direct-acting antiviral (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 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 people who inject drugs, using data collected from them, and focusing on the personal, social and systemic barriers and facilitators to treatment.

DAA treatments were introduced in March 2016 and, between March and December 2016, an estimated minimum of 30,390 people initiated treatment, representing about 13% of the total Australian population with hepatitis C (Kirby Institute, 2017). These new treatments hold significant promise for individuals affected by hepatitis C 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 hepatitis C.

The study will use an observational cohort design over 12 months (baseline and two follow-up points) at seven 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. Approximately 300 participants will be recruited at baseline with an expected 70% retained at 12 months. Participants will be aged 18 years or older, have received a positive antibody test for hepatitis C (self-report) and be treatment naïve.

The Kirby Institute (2017). *Monitoring hepatitis C treatment uptake in Australia* (Issue 6). UNSW Australia. Retrieved from: <https://kirby.unsw.edu.au/report/monitoring-hepatitis-c-treatment-uptake-australia-issue-6-february-2017>



## 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**

Until recently, the experience and outcomes of health care have been conceptualized and measured from the perspective of clinicians or researchers. While important, these measures may obscure or miss issues that are of central relevance to the experience of the patient. The growing literature and use of “patient-reported outcome measures” (PROM) and “patient-reported experience measures” (PREM) seeks to position the service user perspective as central to measurement and evaluation of health services. This change of perspective is especially important for acknowledging and understanding the healthcare experiences and outcomes of patient groups experiencing significant marginalisation from mainstream health services.

A mixed-method project currently underway at CSRH brings together researchers from King’s College London and UNSW, including a peer researcher, to develop a measure of patient experiences and outcomes in relation to the new DAA therapies for hepatitis C among people who inject drugs. This work builds on expertise developed in King's College London in a collaborative project of international significance.

This project will produce a variety of outcomes including the production of a PROM and a PREM to describe and account the engagement of people who inject drugs with health services during DAA therapy. This project will develop externally facing dissemination tools and activities, using the exemplar of co-produced knowledge, to engage affected communities, health workers and health policy makers. The project will also provide evidence of a track record to support a grant application to further this work, including establishing a research method that can be applied to measure the outcomes and experiences of health care among other marginalized groups. Patient/service-user generated measures are particularly valuable for highlighting differences between the views of professionals and patients and the consequent need for a multiple perspective paradigm on evidence in health care.



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