Centre for Social Research in Health

UNSW Arts & Social Sciences
UNSW Australia
UNSW Sydney NSW 2052 Australia

T +61 2 9385 6776
F +61 2 9385 6455
E csrh@unsw.edu.au
W http://csrh.arts.unsw.edu.au

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Glossary & report symbols

ARTB – Annual Report of Trends in Behaviour
BBV – blood borne virus
CALD – culturally and linguistically diverse
CLAI – condomless anal intercourse
CSRH – Centre for Social Research in Health
DAA – Directly Acting Antiviral
GBM – gay and bisexual men
GLB – gay, lesbian and bisexual
GCPS – Gay Community Periodic Survey(s)
GPs – general practitioners, medical practitioners working in the community who provide comprehensive health care for people of all ages; in some countries known as family doctors/physicians
HBV – hepatitis B virus
HCV – hepatitis C virus
HIV – human immunodeficiency virus
HIV seroconversion – the process of becoming HIV-positive (confirmed by antibody testing); the appearance of HIV antibodies in the blood serum
HIV status – a person’s antibody status established by HIV testing (e.g. HIV-negative, HIV-positive, or unknown [untested])
MSM – men who have sex with men
n – denotes the frequency of responses or classifications
NHMRC – National Health and Medical Research Council
ns – non-significant
NSP – needle and syringe program, a public health initiative providing sterile injecting equipment to injecting drug users to minimise the spread of blood borne viruses
OST – opioid substitution therapy
sero-concordant – relationship in which both partners are of the same HIV status, either HIV-positive or HIV-negative
sero-discordant – relationship in which both partners are known (as a result of testing) to be of different HIV serostatus (e.g. HIV-positive and HIV-negative)
STI – sexually transmissible infection

Report symbols

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

- Trends in behaviour
- Single study
- Commentary
- New development
Executive summary

Overview

Introduction

The publication of the Annual Report of Trends in Behaviour (ARTB) in 2016 sits within a very dynamic context for hepatitis C. Some of the indicators that we have relied on from the early days are no longer enough to understand these changes and the growing complexity of the field. This complexity generates additional questions to consider and requires ongoing adaptation of surveillance responses in order to capture these advances in biomedical technologies and communities’ evolving practices. We also need to take additional care to unpack and interpret the data we have generated to continue to contribute to the Australian viral hepatitis response.

Throughout the ARTB we make comment on not only the meanings of the data we have generated, but the methods by which they were obtained including the need to update questions and 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 takes significant effort to inform ourselves from a range of perspectives, being abreast of clinical and technical advances in medications, from the policy perspective in relation to emerging strategic interests and especially in relation to what is important to the variety of communities affected by viral hepatitis, including detailed knowledge of the specific needs of communities and differences between them.

This is the most comprehensive ARTB yet. We have reorganised the presentation of material to reflect prevention, care and treatment cascades. The wide ranging nature of the report makes it difficult to present a complete summary. Different audiences will seek information from various sections of the report. But beyond the cascade approach to measuring risk practices and uptake of treatment, is the need to triangulate with data from a range of other sources.

However, in relation to viral hepatitis, a few key issues stand out:

Models of care for HIV and viral hepatitis

A significant proportion of the Centre for Research in Health (CSRH) research program is focused on understanding the decisions made by people living with viral hepatitis regarding engagement with care, and subsequently, how systems of care could be adapted to better meet the needs of their clients. We need to examine how better models of care can be provided to the diverse communities
most affected by hepatitis B. For a number of years, our work has sought to examine new models for hepatitis C care, including peer delivered models. The ways in which health services should be “fit for purpose” will transform again from 2016 with new generations of hepatitis C virus (HCV) treatments available for all.

Stigma
One of the strengths of the CSRH research program across all areas has been the continued spotlight thrown on stigma. Stigma is a key focus of this ARTB and underpins many of the analyses whether these are direct examinations of the impacts of stigma or lens with which we interpret findings. We examine the social positions, meanings and identities of blood borne viruses (BBVs) and sexually transmissible infections (STIs) and communities living with these. We examine the relationships of these social meanings with prevention, care, treatment and broader wellbeing experiences. We have examined the experience of Aboriginal people living with hepatitis C, including the protective effects of community attachment and the impact of stigma on decisions about treatment for HCV. We also flag a future project in which we can report, as an indicator, changes over time in the experience of stigma among key priority populations.

Data summaries

Drug use and injection by participants in Gay Community Periodic Surveys
Amyl nitrite is the most commonly used drug by gay men in the Gay Community Periodic Surveys (GCPS). The proportion of men reporting the use of amyl nitrite has remained stable over the last decade, and was used by around 35%-40% in the six months preceding the survey. The rate of cocaine use has also stabilised at around 10%-13%. The use of other recreational drugs, including cannabis, ecstasy and methamphetamines, has declined since 2006. In contrast, the proportion of men reporting using erectile dysfunction medication, such as Viagra, has increased over the 10-year period, from 21.2% in 2006 to 25.5% in 2015. In the past three years, reported usage of all substances has remained stable, except a decline in ecstasy.

More detailed analysis from the GCPS data focusing on methamphetamine use shows that any use of crystal methamphetamine, but not powder methamphetamines (i.e. speed), in the previous six months has increased slightly since 2010 (9.6% in 2010 to 11.4% in 2014). Mixing crystal methamphetamine use during various sexual contexts, however, is more likely to be adopted by certain sub-groups of gay and bisexual men, placing them at increased risk of both HIV and HCV transmission.

The use of crystal methamphetamine particularly in the context of sexual encounters and poly drug use (with or without injection) among specific groups of gay men suggests an urgent need to provide appropriate harm reduction and treatment services for these men.

Injecting drug use is low but more commonly reported among gay men than in the general population. The 10-year trends have remained stable nationally and across Melbourne, Sydney and Queensland at around 5%-7%. The proportion of gay men reporting any injecting drug use in the previous six months has increased in Melbourne and Queensland and remained stable in Sydney in the last three years.

Sexual identity and substance use in the general Australian population among participants in the National Drug Strategy Household Survey
Gay, lesbian and bisexual (GLB) men and women are more likely to report illicit drug use (non-injection and injection) in the previous 12 months than their heterosexual peers (36% vs 17% for men; 29% vs 11% for women, respectively). GLB men and women are at heightened risk of harms caused particularly by problematic drug use, which calls for more responsive and targeted harm reduction services for this population in Australia.
Hepatitis C risk factors, attitudes and knowledge amongst HIV-positive, -negative and status unknown gay and bisexual men in Australia

Differences were found to exist between HIV-negative, HIV-positive and HIV-untested gay and bisexual men on a range of sexual activities and attitudes associated with HCV. This suggests that HCV education and prevention for gay men may be most effective if tailored according to HIV status.

An online survey conducted in 2013 at CSRH of 405 gay and bisexual men found that increased HCV knowledge was associated with having completed university education, being HIV-positive and a history of drug injection.

Hepatitis C, sex and drug-related risk among Australian gay and bisexual men

Sharing of injecting equipment by Australian gay and bisexual men was associated with crystal methamphetamine use and sexual encounters. In an online survey of 474 gay and bisexual men, of the 71 men who had injected in the previous six months, 41% (n=29) reported sharing ancillary injecting equipment (including needle syringes). This suggests further investigation is needed into the sub-cultural meanings of crystal methamphetamine use, the injection of drugs and the sharing of injecting equipment within social-sexual settings among certain subgroups of gay men in Australia.

Understanding and preventing hepatitis C transmission within heterosexual couples

Couples are a key group to examine for hepatitis C prevention but little attention has been provided to this group. A CSRH qualitative interview study of 40 heterosexual couples who inject drugs found that health promotion efforts should recognise the unique issues that face couples who inject drugs, and that disregarding their partnerships means missed opportunities for understanding decision-making around injecting drug use and HCV prevention.

Peer distribution of sterile injecting equipment

Peer distribution of injecting equipment has been, until recently, illegal in all Australian jurisdictions. CSRH research using qualitative and quantitative methods has demonstrated that peer distribution is relatively frequent and grounded in altruism and concerns for safety. A recent analysis of the legal and regulatory frameworks surround peer distribution conducted by CSRH in collaboration with colleagues at the National Drug and Alcohol Research Centre and Monash University showed that the laws around “peer distribution” of equipment portray people who inject drugs as needing control and oversight. This portrayal undermines the potential to engage people who inject drugs as partners in the prevention of blood-borne viruses. The recent change in three jurisdictions to remove this legal barrier to safer injecting practice is welcome and supported by evidence.

Injecting drug use and BBV risk among Indigenous young people in incarceration

The Goanna study, which included a survey of 2,877 young Aboriginal people, showed a low prevalence of recent injecting, at about 3% of the total sample, although this is a higher proportion than the 1% reported in the general population. We observed a very high rate of receptive needle and syringe sharing (37% of those who had injected) although this is similar to that reported in recent studies of younger injectors. At an average age of 21 years, almost half of the participants in this study who had injected had a history of incarceration.

Pathways to alcohol and other drug care and treatment among young drug users involved with the police in NSW and Victoria

The prevalence of HCV among those incarcerated in juvenile justice facilities is very high. In a project conducted in collaboration with Turning Point Alcohol and Drug Centre, interviews (n=64) were conducted with police, young substance users aged 16-24 years, and staff of youth-focused alcohol and drug services and analysis undertaken of existing survey data. This project showed that understanding how young people can be supported to avoid contact with the criminal justice system is important for the HCV response.
Hepatitis C risk in prison settings

With a range of collaborators, CSRH has been active in commenting on the structural factors affecting hepatitis C risk in prison. Without access to sterile equipment in prison via a formal Needle and Syringe Program, inmates have few means by which to reduce their HCV risk. Programs and policies that can impact this risk include those within the criminal justice system (such as decriminalisation of drug use or alternative, community-based sentencing options for those with drug-related convictions) and within the corrections health system (such as greater access to drug treatment programs).

Knowledge about liver diseases and liver fibrosis assessment among people who inject drugs in alcohol and other drug treatment settings

The LiveRLife study conducted in collaboration with the Kirby Institute and health service partners provided Transient Elastography screening and examined knowledge and attitudes before and after screening. Among 253 people who inject drugs attending drug and alcohol treatment, baseline HCV knowledge scores were moderate, but there were significant gaps in knowledge of HCV antibody testing, factors impacting on HCV disease progression, and response rates to HCV treatment. Transient Elastography as a means to assess liver fibrosis was highly acceptable prior to screening and this acceptability increased after screening.

A review of interventions to increase hepatitis B and hepatitis C screening, assessment and monitoring

Complex, multimodal educational interventions appear to cause behavioural changes that increase rates of testing, vaccination, and treatment. As well, community-based interventions have used a variety of theoretically informed and culturally appropriate strategies to increase uptake of screening, including: the use of lay health workers from culturally and linguistically diverse communities; role-plays; physician education; electronic physician prompts; FibroScan (Transient Elastography) in street-based outreach clinics; nurse-led assessment clinics; hepatitis A and B vaccinations; support; and motivational interviewing-enhanced case management assistance.

These interventions have successfully: engaged people who inject drugs with health services; facilitated hepatitis care coordination in opioid substitution clinics; integrated infectious disease programming in mental health settings and increased acceptance of such services among clients; and lowered costs of screening and reduced waiting times. The following interventions were reported as potentially cost-effective: screening all recent arrivals for chronic hepatitis B virus (HBV) and treating recent arrivals; implementing an opt-out, general practitioner HCV case-finding intervention; interventions targeting multiple points along the HCV cascade-of-care; and one-off HCV testing of all people in the birth cohort 1945-1965.

Positive Speaking among people living with hep C

This qualitative study explored the experiences of nine people who were part of the positive speakers program (C-een and Heard) managed by Hepatitis NSW. People who take up positive speaking roles had typically witnessed or experienced hepatitis C-related discrimination, particularly in health care settings. These experiences led speakers to challenge misinformation and negative attitudes and start on a path of advocacy, culminating in participation in positive speaking programs.

The role of Aboriginal community attachment in buffering against stigma and promoting lifestyle changes after hepatitis C diagnosis

In a sample of 203 Aboriginal people living with HCV, those who felt more attached to their Aboriginal community were more likely to show greater resilience, report having a better quality of life and report less HCV-related stigma than those who were not as attached to their Aboriginal community. Attachment to an Aboriginal community was associated with positive lifestyle changes, such as changing their diet, reducing alcohol or illicit drug use, increasing level of exercise and having more regular HCV check-ups after diagnosis with HCV.
Multiple forms of stigma among Aboriginal and Torres Strait Islander people living with hepatitis C

In a qualitative interview study of 39 Aboriginal people living with hepatitis C, another layer of HCV-related stigma was described, which related to the cultural experience of shame, was found to have a profound impact on health and health care outcomes.

The impact of stigma on the provision of health care for people who inject drugs

In a survey of 57 health care workers, participants’ beliefs about their colleagues’ attitudes impacted on whether they would prescribe pain medication to a person who injected drugs. Those who perceived their work colleagues to be more supportive of harm reduction were more willing to prescribe pain medication, whereas participants’ own support for harm reduction had no bearing on their intention to prescribe medication.

Discrimination by health care workers versus discrimination by others: countervailing forces on hepatitis C treatment intentions

In a survey of 416 people who reported having acquired HCV through use of non-sterile injecting equipment, experiencing discrimination from health workers resulted in lower intentions to engage in HCV treatment in the future.

Evaluation of two community-controlled peer services accessing hepatitis C services in OST clinics

In a qualitative interview study (n=42) conducted in collaboration with the Kirby Institute, NUAA (the NSW Users and AIDS Association) and participating health services (part of the ETHOS project), we described the ways in which peer workers may enhance the operation of hepatitis C clinics by engaging clients in education and support, allowing better prepared clients to engage with clinical staff. We conducted interviews with clinic clients (n=31), clinic staff (n=8) and peer workers (n=3) at two clinics in which peer support programs were operating. Although this study was conducted in the era of interferon-based treatments, it is suggested that peer workers remain essential in the era of new treatments to provide ongoing education and support, and to assist in moving the discourse away from the “horror stories” of interferon-based treatments.

Structural barriers and facilitators of hepatitis B and hepatitis C treatment and care in primary care settings: a literature review

This review focused primarily on the structural barriers and enablers to hepatitis B and C treatment and care in primary care settings. The management of HBV within primary health care settings was improved by community outreach programs, community-based education programs, and professional education programs.

Similarly, the management of HCV within primary health care settings could be enhanced through the development of social and structural interventions to promote HCV treatment, including strategies to address: stigma reduction; drug dependence; social support; mental health care; infectious disease; improvements in housing; enhanced geographic access to treatment; offsetting transport costs; overcoming the consequences of the criminalisation of illicit drug use; and sensitivity to cultural and ethnic diversity and gender differences. Primary care services should be promoted as community-based, mobile and/or situated in areas where people who inject drugs live, congregate and access health care and other services.

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.
Part I
BBV/STI Prevention
1 Gay men: other BBV/STI prevention

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

Limin Mao, John de Wit and Martin Holt

The GCPS include questions about the use of a range of drugs. Table S1 and Figure S1 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 S1 and Figure S1 show that amyl nitrite (‘poppers’) is the most commonly reported drug used by participants in the GCPS. Amyl nitrite is an inhaled drug which is popular among gay men as both a euphoric and muscle relaxant; it is used as both a ‘party’ drug for dancing and in sexual settings. Use of ‘poppers’ is reported by over a third of men in the GCPS and its use has remained stable since 2006. Cannabis is the second most commonly reported drug although its use has continued to decline since 2006, mirroring national trends which show generally declining levels of drug use by gay men over the last decade (Lea, Prestage, et al., 2013). The use of ecstasy as well as the use of (meth)amphetamines (‘speed’ or ‘crystal meth’/’ice’) have both declined during the 10-year period. The use of cocaine has been stable since 2006. The use of erectile dysfunction medication like Viagra and Cialis has increased over the last 10 years. 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). In the last three years, the use of all listed drugs has been stable, except the use of ecstasy which decreased.

Injection of non-prescribed drugs for recreational purposes remains relatively rare among gay men although it is more common than in the general population. Table S2 and Figure S2 show the proportions of men from Melbourne, Queensland and Sydney who reported any drug injection in the six months prior to the survey, as well as the national trend. It is important to note that because it is infrequently reported, the rates of drug injection by gay men in Adelaide, Canberra, Perth and Tasmania are not reported separately. Data from these locations, however, have been included in the national rate. Over the 10-year period, the proportion of men who injected drugs in the six months prior to survey is stable nationally at around 5%-7%. In the past three years, however, there has been a continuing increase in the proportion of men who report injecting drugs in Melbourne and Queensland while trends have been stable in Sydney as well as nationally. HIV-positive men are more likely to report injecting drug use than HIV-negative men (Lea, Mao, et al., 2013). (Meth)amphetamines and steroids are the substances most commonly injected by gay men.
Table S1: Men who reported any use of selected recreational drugs in the six months prior to the survey: GCPS, 2006-2015 (all states or territories)

<table>
<thead>
<tr>
<th>Drug Description</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>Overall trend</th>
<th>Trend in last 3 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amphetamines (e.g. ‘speed’, ‘crystal meth’)</td>
<td>25.5</td>
<td>19.7</td>
<td>18.9</td>
<td>17.2</td>
<td>16.4</td>
<td>14.9</td>
<td>16.8</td>
<td>16.7</td>
<td>16.7</td>
<td>16.8</td>
<td>↓</td>
<td>ns</td>
</tr>
<tr>
<td>Amyl nitrite</td>
<td>38.1</td>
<td>36.3</td>
<td>39.2</td>
<td>35.1</td>
<td>38.4</td>
<td>37.1</td>
<td>37.1</td>
<td>38.5</td>
<td>38.3</td>
<td>40.6</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Cannabis</td>
<td>36.4</td>
<td>31.3</td>
<td>32.9</td>
<td>29.7</td>
<td>32.8</td>
<td>29.4</td>
<td>29.8</td>
<td>30.4</td>
<td>33.1</td>
<td>28.4</td>
<td>↓</td>
<td>ns</td>
</tr>
<tr>
<td>Cocaine</td>
<td>13.0</td>
<td>12.8</td>
<td>11.3</td>
<td>11.4</td>
<td>13.0</td>
<td>10.9</td>
<td>10.7</td>
<td>13.0</td>
<td>11.3</td>
<td>12.3</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Ecstasy</td>
<td>30.3</td>
<td>28.3</td>
<td>26.6</td>
<td>25.6</td>
<td>24.7</td>
<td>18.6</td>
<td>17.1</td>
<td>18.6</td>
<td>17.3</td>
<td>12.3</td>
<td>↓</td>
<td>↓</td>
</tr>
<tr>
<td>Erectile dysfunction medication (e.g. Viagra, Cialis)</td>
<td>21.2</td>
<td>19.6</td>
<td>20.6</td>
<td>22.6</td>
<td>21.8</td>
<td>22.2</td>
<td>23.9</td>
<td>23.0</td>
<td>23.8</td>
<td>25.5</td>
<td>↑</td>
<td>ns</td>
</tr>
</tbody>
</table>

Figure S1: Men who reported any use of selected recreational drugs in the six months prior to the survey: GCPS, 2006-2014 (all states or territories)

Table S2: Men who reported any injecting drug use in the six months prior to the survey: GCPS, 2006-2015

<table>
<thead>
<tr>
<th>Location</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>Overall trend</th>
<th>Trend in last 3 years</th>
</tr>
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<tbody>
<tr>
<td>Melbourne</td>
<td>8.0</td>
<td>4.9</td>
<td>6.2</td>
<td>6.7</td>
<td>4.5</td>
<td>4.9</td>
<td>9.5</td>
<td>3.9</td>
<td>8.0</td>
<td>7.8</td>
<td>ns</td>
<td>↑</td>
</tr>
<tr>
<td>Queensland</td>
<td>8.0</td>
<td>2.9</td>
<td>5.1</td>
<td>6.1</td>
<td>5.3</td>
<td>5.9</td>
<td>3.0</td>
<td>4.0</td>
<td>6.2</td>
<td>6.7</td>
<td>ns</td>
<td>↑</td>
</tr>
<tr>
<td>Sydney</td>
<td>6.5</td>
<td>8.4</td>
<td>8.1</td>
<td>7.8</td>
<td>6.9</td>
<td>5.2</td>
<td>5.9</td>
<td>6.2</td>
<td>8.2</td>
<td>6.6</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>All states/territories</td>
<td>7.2</td>
<td>5.6</td>
<td>6.6</td>
<td>6.5</td>
<td>5.4</td>
<td>5.0</td>
<td>6.1</td>
<td>5.1</td>
<td>6.8</td>
<td>7.0</td>
<td>ns</td>
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</tbody>
</table>
1.2 Trend of methamphetamine use among gay and bisexual men

Toby Lea

Gay and bisexual men (GBM) report higher rates of methamphetamine use compared to heterosexual men. The contexts of, and motivations for, methamphetamine use differ considerably between GBM and heterosexual men, which can shape the problems GBM experience from use. For example, many GBM use crystal methamphetamine to enhance sexual pleasure, which has been associated with a higher likelihood of reporting sexual risk practices associated with HIV transmission, such as condomless anal intercourse with casual partners.

Much media and political attention has focused recently on an apparent increase in crystal methamphetamine use in the Australian general population. With this in mind, we sought to examine 10-year trends in crystal methamphetamine and powder methamphetamine (‘speed’) use among GBM participating in GCPS.

Speed use in the preceding six months steadily declined between 2005 and 2014: from 25.0% to 10.2%. However, crystal methamphetamine use in the preceding 6 months declined between 2005 and 2009 (from 15.6% to 9.6%), and then had a small but significant increase between 2010 and 2014 (9.6% to 11.4%). While there were no differences between HIV-positive and HIV-negative and untested men in recent speed use in 2014 (11.0% vs. 10.1%), HIV-positive men were much more likely to report recent crystal methamphetamine use compared to HIV-negative and untested men (27.4% vs. 9.9%). In addition, among GBM who reported recent crystal methamphetamine use in 2014, HIV-positive men were more likely than HIV-negative and untested men to report any injecting drug use in the preceding six months (53.8% vs. 21.9%). Crystal methamphetamine use in the previous six months was found to be associated with a range of specific sex and drug use practices, including any condomless anal intercourse (CLAI), drug use in sexual contexts (i.e. chemsex), GHB use, and drug injection in the previous six months.

The findings suggest that crystal methamphetamine use in sexual contexts is adopted by a small group of GBM who are likely to be involved in some sexually adventurous cultures. Responding to crystal methamphetamine use problems among GBM thus requires an understanding of the motivations for and pleasures derived from using methamphetamine in sexual contexts. The high rates of crystal methamphetamine use and injecting among HIV-positive men in particular indicates that these men...
should be a specific focus for harm reduction and treatment services.

Reference

### 1.3 Hepatitis C knowledge among gay and bisexual men

**Toby Lea**

GBM are at an elevated risk of acquiring HCV via the sharing of unsterile injecting equipment as well as sexual risk practices. HIV-positive men are overrepresented among GBM living with HCV, with recent self-reported estimates suggesting that around 10% of HIV-positive GBM in Australia have chronic HCV. The prevalence of HCV among HIV-negative GBM is thought to be similar to that in the general population (around 1%).

While GBM’s health literacy and knowledge about HIV is generally quite good, there is comparatively little known about their knowledge of HCV. A national, online survey was conducted in 2013 that aimed to explore the social dimensions of HCV infection among GBM. Completed questionnaires were received from 405 men. The mean age of participants was 39 years. Most men identified as gay (90%) and had completed a university degree or other tertiary qualification (71%). Forty-one percent of participants reported being HIV-positive and 30% had ever injected drugs.

Knowledge about HCV varied considerably among the sample. Knowledge about HCV transmission was generally good, with most respondents correctly identifying injecting drug use and sex between men as potential transmission routes. Less was known about HCV testing, HCV treatments and the natural history of HCV infection. As this study was conducted in 2013, questions about the new direct-acting antiviral treatments were not asked. Knowledge was highest among participants with a university education, and among men at a higher risk of HCV transmission including participants who were HIV-positive and who reported injecting drug use. Viral hepatitis and HIV organisations, together with other health services should continue to target GBM at a high risk of acquiring HCV with education and health promotion.

Reference

### 1.4 Hepatitis C, sex and drug-related risk among Australian gay and bisexual men

**Max Hopwood**

Illicit drug use is characterised as a valued gay cultural practice. For example, research has found that gay and bisexual men use the drug crystal methamphetamine to enhance sociality and to increase sexual pleasure (Southgate & Hopwood, 2001). Notwithstanding these culturally desired effects, injecting drug use in particular can increase the risk of blood-borne virus transmission when injecting equipment is shared, intentionally or unintentionally.

The sharing of injecting equipment, including ancillary equipment such as swabs, spoons and water phials, is a primary risk factor for the transmission of HCV infection. In Australia over recent years, hepatitis C prevention has become a concern for health promotion aimed at lesbian, gay, bisexual and transgender communities, in part due to the high rate of injecting drug use reported by gay and bisexual men. A recent national, online CSRH study of hepatitis C infection (Hopwood, Lea, & Aggleton, 2015) found that the sharing of injecting equipment by Australian gay and bisexual men was associated with crystal methamphetamine use and socialising for sex. In total, 41% (i.e. n=29) of 71 gay and bisexual men who had injected in the previous six months, reported sharing injecting equipment, including needle syringes, in the six months prior to the study. Most commonly, participants reported
sharing ancillary injecting equipment such as swabs, filters and water phials.

Theoretically, hepatitis C transmission can occur among gay and bisexual men because of poor knowledge about infection risks from sharing injecting equipment, a lack of amenities for safer injecting in sexual settings, and/or specific crystal methamphetamine-related effects that inhibit safer injecting and sexual practices. However, it is currently unknown why gay and bisexual men share ancillary injecting equipment. Some sharing practices are likely to occur within HIV and/or hepatitis C sero-concordant regular relationships. The CSRH study findings suggest that the sharing of injecting equipment might also be a result of ritualised patterns of behaviour. To explore this proposition further, an investigation is needed into the sub-cultural meanings of crystal methamphetamine use, the injection of drugs and the sharing of injecting equipment within social-sexual settings in Australian gay communities. Such a study will generate useful theory regarding the intersection of drug use and sexual practice among gay and bisexual men, and the harms associated with co-occurring sex and drug-related practices.

References


### 1.5 Hepatitis C risk factors, attitudes and knowledge amongst HIV-positive, HIV-negative and HIV untested gay and bisexual men in Australia

Loren Brener

There are increasing reports of sexual transmission of HCV among HIV-positive men who have sex with men (MSM). In contrast, HCV prevalence among HIV-negative MSM is low and comparable to that of the general population. Research suggests that an increasing number of MSM, especially those who are HIV-positive, may be engaging in sexual practices which may in turn place them at risk of acquiring HCV. Given that this group is at increased risk of contracting HCV, it is important to understand the level of HCV knowledge and sexual risk practices of HIV-positive gay and bisexual men compared to HIV-negative and HIV-untested men in order to develop particular education and intervention strategies around HCV transmission.

This research compared HCV knowledge and risk practices among HIV-positive, HIV-negative, and HIV-untested gay and bisexual men in Australia. Participants (n=534) completed an online survey assessing sexual risk practices, HCV knowledge, perceived risk of acquiring HCV, and perceptions of people with HCV and who inject drugs. Findings show that differences exist between HIV-negative, HIV-positive, and HIV-untested gay and bisexual men on a range of sexual activities and attitudes associated with HCV. The HIV-positive group report engaging in a greater number of behaviours that place them at risk for HCV; however, they also believe that they are at higher risk of acquiring HCV and show more positive attitudes towards people with HCV and those who inject drugs than other participants. In contrast, the HIV-untested group reported engaging in fewer risk practices, but had lower HCV knowledge and more negative attitudes towards people with HCV and those who inject drugs than HIV-positive participants. They were also more likely to socially and sexually exclude people with HCV compared with both groups. Findings from this data also indicate that there is an association between negative attitudes towards HCV and HCV testing, with those holding more negative attitudes less likely to be tested for HCV. Hence, these negative attitudes towards HCV may present a barrier to HCV testing. The findings of this research indicate that HIV-positive men engage in greater risk practices than other groups, which includes both sexual and injecting practices, such as sexually adventurous behaviour in the context of drug injecting. Additionally, the findings suggest that HCV education and prevention for gay men may be most effective if tailored according to HIV status.

References

attitudes towards people with hepatitis C and testing for hepatitis C among Australian gay and bisexual men. *Sexual Health, 12*, 268-274.


1.6 Sexual identity and substance use in the general Australian population

Toby Lea

Gay, lesbian and bisexual (GLB) people typically report higher rates of alcohol and other drug use and harms compared to heterosexual people. However, most Australian research in this area has relied on convenience samples, as national population surveys have only recently begun to collect data on sexual identity. To address this gap, in collaboration with the National Drug and Alcohol Research Centre, we analysed data from the 2013 National Drug Strategy Household Survey to compare the population prevalence of alcohol and other drug use between GLB and heterosexual people.

While there were no differences between GBM and heterosexual men in the prevalence of tobacco use (18% vs. 14%) and risky drinking (16% vs. 10%) in the preceding 12 months, GLB women were significantly more likely than heterosexual women to report tobacco use (24% vs. 11%) and risky drinking (8% vs. 3%). Regarding illicit drug use, GBM had 2.3 times the odds of heterosexual men in reporting any illicit drug use in the preceding 12 months (36% vs. 17%), while GLB women had 3.5 the odds of heterosexual women in reporting any use (29% vs. 11%). GLB participants were also more likely to report injecting drug use in the preceding 12 months compared to heterosexual participants (2.4% vs. 0.2%).

Consistent with international research, these findings provide some of the first population level evidence that GLB people are at a heightened risk of substance use and harms from use in Australia, and highlight that GLB women are an important target for tobacco and alcohol interventions. These findings suggest a need for more responsive and targeted harm reduction and treatment services for GLB people in Australia.

Reference

2 People who inject drugs, Aboriginal & Torres Strait Islanders & prisoners: hepatitis C prevention

2.1 Understanding and preventing hepatitis C transmission within heterosexual couples

Carla Treloar

In a National Health and Medical Research Council (NHMRC)-funded study, we explored the practices surrounding injecting drug use in interviews with 40 heterosexual couples. The partnerships of people who inject drugs are based on mutual trust, honesty, and care. People in couple relationships value their own health and that of their partners, and want to ensure the ongoing security of their relationships. Relationships between couples who inject can serve to protect each partner in the couple from ‘external’ threats such as stigma and other aspects of a hostile social environment in which injecting drug use is heavily stigmatised. Couples typically report sharing injecting equipment only when no other sterile injecting equipment can be accessed: it is a ‘last resort’. While people who inject drugs with their partners are motivated to protect each other’s health and the security of the relationship, their decisions about injecting practice may run counter to advice on HCV risk when they try to balance these sometimes competing priorities. For example, caring for a partner and the security of the relationship may mean reusing or sharing injecting equipment to cope with the immediate demands of drug dependence and withdrawal. Couples are not indifferent to HCV risk when reusing or sharing injecting equipment. Many couples engage with biomedical knowledge around HCV and incorporate it into forms of ‘negotiated safety’: organising the reuse or sharing of injecting equipment according to each partner’s serostatus or genotype. Couples who inject drugs are not addressed in existing health promotion work and the harm reduction workforce is not equipped or orientated to engage effectively with couples who inject drugs.

It is possible to develop new approaches to harm reduction that address couples who inject drugs. These could include messages that acknowledge the mutual care and protection within couples and the desire to protect and enhance the health for each partner; i.e. messages that address the emotional basis of the relationship beyond concerns about viral risk. We can also redesign injecting equipment and packaging to promote and support additional discussions about couple-based safety between clients and workers in harm reduction services, and to promote discussion and awareness of practice among couples. There is a need for better recognition of the meanings attached to injecting equipment for couples who inject (such as its role in demonstrating care between partners). It is important to acknowledge the serious impact of unequal gender power relations on some couples, including the occurrence of family and domestic violence. The inequities within such couples may seriously limit the injecting-related choices available to one of the partners.
Failing to recognise the unique issues that face couples who inject drugs and disregarding their partnerships mean missed opportunities for understanding decision-making around injecting drug use and HCV prevention. Failing to acknowledge the strengths of partnerships among people who inject is likely to limit the impact of hepatitis C prevention and health promotion programs.

References


2.2 Peer distribution of sterile injecting equipment: research supports recent change of laws in three Australian jurisdictions

Carla Treloar, Joanne Bryant, Max Hopwood and Christy Newman

The Northern Territory (NT) and Australian Capital Territory (ACT) governments recently announced their intentions to change their laws to allow members of the community to exchange used equipment in efforts to reduce the transmission of blood borne viruses. The availability of sterile needles and syringes is a key component in efforts to prevent transmission of HIV, hepatitis C and hepatitis B. Australia has supported publicly funded Needle and Syringe Programs (NSP) since the 1980s. However, until recently, passing sterile needles and syringes between community members has been illegal in all Australian states and territories.

These laws go against what happens in the community, as has been found through detailed analysis of these practices. Dr Joanne Bryant and Dr Max Hopwood were among the first to document that the practice of providing small amounts of sterile equipment to others was a relatively frequent practice among people attending community pharmacies to obtain sterile equipment. The main motivation for this practice was to support other people who inject drugs in their desire to use drugs in the safest way possible. Although frequently occurring, most people provided only a small amount of equipment to their peers. This was further supported by research undertaken by Dr Jamee Newland, whose PhD project at CSRH showed that a small number of people can distribute thousands of pieces of equipment each year in more formal and organised ways.

Recent research examined the ways in which laws around “peer distribution” of equipment portray people who inject drugs as needing control and oversight. This portrayal undermines the potential to engage people who inject drugs as partners in the prevention of blood-borne viruses. Importantly, these laws have been used in a previous manslaughter prosecution (in NSW) where a person supplied a needle to a second person and that (second) person later died of an overdose. These laws and the use of them in this prosecution could act as a significant barrier to people carrying extra sterile equipment to pass on to those in need, and as a vital cog in the prevention of blood borne virus epidemics.

These changes in the NT and ACT follow changes in Tasmania in 2015 to allow distribution of equipment by those involved in the practice. In doing this, the legal systems of these three jurisdictions have caught up with practices that have long been regarded as normal and vital in the community. These changes mean that it will be possible to properly promote and support peer distribution for improving the cost-effectiveness of the NSP and making the program an even better public health investment. Besides the very practical outcomes, these changes provide the potential to position people who inject drugs as powerful actors in achieving better health outcomes.
2.3 Injecting drug use among Indigenous young people: the role of incarceration in Indigenous injecting and BBV acquisition

Joanne Bryant

The Goanna Project provides the first national profile of risk behaviours, levels of knowledge and the types of health services used by young Indigenous people for sexual health, blood-borne viruses and illicit and injecting drug use. Funded through an Australian Research Council (ARC) Linkage project, it collected data from 40 Indigenous cultural events across Australia resulting in the collection of 2,877 surveys from Indigenous young people aged 16-29 years.

In relation to injecting drug use, the sample offers unique insights compared to other studies of Indigenous people who inject drugs. The sample was young (on average 21 years, compared to the much older participants of the Australian NSP Survey, for example) and thereby better represents current trends in the uptake of injecting among Indigenous people. The data showed a low prevalence of (recent) injecting in the previous 12 months, at about 3% of the total sample, although this is a higher proportion than the <0.5% reported in the general population. We observed a very high rate of receptive needle syringe sharing (37% of those who had injected) in the past 12 months although this is similar to that reported in recent studies of younger injectors, which suggests that the high risk injecting found in the Goanna data may not be specific to Indigenous young people but is a pattern of risk attributable to young people more generally. Moreover, almost a quarter of our participants reported that they had injected methadone, which carries significant risk since it requires specialised injecting equipment that is typically not available at primary NSP.

Importantly, data shows that those who had injected were five times more likely to have been in prison. Incarceration has a recurrent and strong association with substance use among Indigenous people. At an average age of 21 years, almost half of the participants in our study who had injected had already been in prison. Given the known high risk of BBV acquisition in Australian prisons, priority must be given to reducing the numbers of Indigenous young people entering justice settings in the first place, delaying the age at first entry to justice settings through diversion schemes, and reducing the risk of BBV virus acquisition while in justice settings. Prison-based NSP is one practical way in which harm can be reduced for Indigenous young people in custody, but other innovative programs must accompany this, including BBV education, low threshold access to pharmacotherapy, and Indigenous-specific treatment that emphasises connection to country and culture which has been shown to be effective in international settings.

The Goanna Project was conducted with a team of investigators from CSRH, The Kirby Institute, the Australian Research Centre in Sex Health and Society and the School of Public Health and Community Medicine at the UNSW, in partnership with the National Aboriginal Community Controlled Health Organisation.

References


2 People who inject drugs, Aboriginal and Torres Strait Islanders and prisoners: hepatitis C prevention


2.4 Navigating services: pathways to alcohol and other drug care and treatment among young drug users involved with the police in NSW and Victoria

Joanne Bryant

There are significant rates of hepatitis C among young people incarcerated in juvenile justice facilities. Understanding the pathways by which young people may find themselves at the attention of police is important to understand their down-the-track vulnerability to hepatitis C infection. There is a small group of young people in the community who, for a variety of reasons, have recurring contact with the police, and drugs and alcohol are usually implicated in some way. The justice system seeks leniency when they commit offences, especially in relation to drug and alcohol offences. While Australia has comprehensive and often complicated diversion programs for young people who offend, there is still opportunity to improve pathways into treatment, and police play an important first-stage role in determining these pathways.

During 2012-2015, CSRH in collaboration with Turning Point Alcohol and Drug Centre in Victoria, conducted a study that looks at police and their diversion practices in relation to young substance users. The project used a mixed method design: it used existing survey data in NSW (n=219) and Victoria (n=150, 3 time points), together with in-depth interview data collected during the course of the project. Interviews were conducted with police (n=25), young substance users aged 16-24 years (n=23), and staff of youth-focused alcohol and drug services (n=16).

The findings showed that some vulnerable young people become entrenched in the justice system at a young age and that the time between first police contact and incarceration was short. This provided a narrow window of opportunity for therapeutic services to intervene. In addition, the pathways into therapeutic care for young people were not straightforward and shaped significantly by adversarial relationships between young people and police. These relationships were partially a product of harsh policing practices (reported by young people and some police interviewees) which served to exacerbate young people's involvement in the justice system. Similarly, police found their interactions with young people to be emotionally challenging because of the often repeated violent encounters with them, and their beliefs that some young people lacked the capacity to change their behaviour.

At a systemic level, the study found that these negative relationships took place within a highly complicated and inconsistent diversion framework, which often only worked if the individual police officer involved had good knowledge about the available cautions and referrals. Further, the referral system appeared less consistent in NSW compared to Victoria, mainly because Victoria had an e-referral system whereby police could enter a young person's needs (emergency accommodation, drug and alcohol counselling) and this was triaged to a range of social and health support services in order to provide the most appropriate help. This system also had the benefit of notifying police whether a young person had taken up their referrals, providing a feedback system which, at times, countered their view that young people lacked the capacity to change their behaviour.

Reference
2.5 Tobacco free prisons increases tattooing harm

Carla Treloar

Implementing strategies to positively influence the health of prison inmates is challenging. The unanticipated outcomes of important public health interventions must be examined in prisons where the restrictions of the environment impact inmate behaviour in ways that are different to the community. Data from a CSRH project on BBV risks in prisons raises important concerns in relation to recent moves to create “tobacco free” prisons in various Australian jurisdictions.

Rates of tobacco smoking among Australian prison inmates are very high and deserve attention to alleviate the individual and social burden of smoking-related ill-health. Australian prison authorities have moved to implement various programs to reduce or eliminate tobacco smoking among prison inmates and staff. While programs to benefit the health of inmates are welcome, recent data highlight the potential of unanticipated increased risks of blood borne virus transmission via tattooing in prison.

Tattooing in prison remains illegal. However, tattoos are regularly done as inmates acquire and manufacture the relevant equipment and ink from materials within the prison. Analysis of qualitative interview data (conducted by CSRH as part of a NHMRC Partnership Project, HITS-P) highlighted the important role of lighting implements (matches or cigarette lighters that were previously freely available) in the production of ink for tattooing.

A ban on tobacco smoking in prisons also categorises lighting implements as contraband. Hence, ink that may have been manufactured afresh for each tattoo (as access to lighting implements was unrestricted) may now become a more precious commodity that is stored for later re-use or shared between people creating a risk for transmission for blood borne viruses when no (or minimal) risk existed before.

Other jurisdictions in Australia have implemented programs in which inmates are trained to provide tattoos and sterile implements are provided. Such programs could be considered in Australian prisons. In addition, our surveillance systems may need sharpening to be able to record and attribute BBV transmission that occur as a result of this change in policy and practice in an area that targets other aspects of inmates’ health.

Reference


2.6 Acquiring hepatitis C in prison: the role of social organisation

Carla Treloar

Establishing that a hepatitis C infection was acquired in prison is difficult to achieve in practice. Australian prisons typically offer screening for blood borne viruses on entry to prison. Subsequent tests must be at the inmates’ request. The Hepatitis C Incidence and Transmission Study in Prison (HITS-P) provided the infrastructure to monitor inmates without hepatitis C throughout the duration of their incarceration and identify incident infections among those continuously incarcerated. A qualitative sub-study was conducted to examine the accounts of those men and women found to have acquired hepatitis C in prison as well as examine accounts of risk of hepatitis C in prison as a result of injecting, tattooing and other blood-to-blood contact.

In a study of 30 inmates, six participants (four men and two women) were interviewed about the individual, social, and environmental circumstances of HCV acquisition in prison. Participants reported that they could not ascertain a change in their routine that would account for hepatitis C acquisition. However, on prompting, two participants did discuss injecting with others outside of a trusted network (in which participants relied on others’ to disclose HCV status) or the use of a pre-mixed “gift” shot of drugs in which he did not have control of the injecting equipment used. Participants were aware of the need and mechanism of cleaning injecting equipment. However, some participants were ambivalent about the effectiveness of cleaning in preventing BBV transmission or were unable to put advice into practice because of limitations in the environment (lack of time, privacy, or fear of detection). Being
diagnosed with HCV resulted in participants feeling angry (at others with HCV) or regretful of their practice, particularly in relation to the cleaning of equipment.

Without access to sterile equipment in prison via a formal NSP, inmates have few means by which to reduce their HCV risk. Programs and policies that can impact this risk include those within the criminal justice system (such as decriminalisation of drug use or alternative, community-based sentencing options for those with drug-related convictions) and within the corrections health system (such as greater access to drug treatment programs). This study is among the first to examine the accounts of people who have acquired hepatitis C in prison and to highlight the complex decisions inmates are required to make to reduce their HCV risk when they do not have access to services equivalent to community standards.

Reference

### 2.7 Prison NSP service provision

Carla Treloar

There is strong evidence of the effectiveness of Needle and Syringe Programs (NSP) and NSP in prisons (PNSP) to reduce sharing of used equipment among people who inject, and in turn, reducing the risk of transmission of blood borne viruses. Despite more than 80 countries implementing community NSP, only eight countries have implemented PNSP. Australia is one of the many countries which has rejected this evidence and failed to protect the health of inmates and the community via the provision of sterile injecting equipment in prison, which is at odds with the standard of care provided in the community.

A commentary in the Medical Journal of Australia examined a range of factors in the Australian context. Advocacy for PNSP comes from endorsements from leading Australian medical and health bodies as well as international agencies such as the World Health Organisations and UNAIDS. Leadership in policy circles has been inconsistent. Prison inmates have been named as a priority population in all four National Hepatitis C Strategies but the current strategy (2014-2017) omits articulation of PNSP as a specific strategy for prevention, despite the previous strategy (2010-2013) making a strong call for trialling of PNSP.

The commentary published in the Medical Journal of Australia also examines local policy and practice with a focus on the ACT where the strongest hope exists for a future trial of PNSP in the Alexander Maconochie Centre. However, the union representing corrections officers has strongly resisted such a trial on the basis of workplace health and safety concerns and that a PNSP can encourage drug use in custody. Neither of these claims has been supported by evidence from PNSP operating in other countries.

Writing as a coalition of researchers and community advocates, this commentary aims to reinforce understanding of the existing evidence and outline the concerns contributing to inertia on PNSP. We have called for the ACT government to show leadership and press ahead with their efforts to implement the trial PNSP. We note that no visible progress towards this goal has been made in the intervening period.

Reference
Part II
Testing, Diagnosis and Lived Experiences of BBVs/STIs
3 People living with HIV & people living with hepatitis C: testing, assessment and living with the virus

3.1 HIV sero-discordance and its influence on patterns of HIV and viral load testing

Asha Persson

Clinical engagement and regular testing are core aspects of the HIV treatment cascade; especially HIV testing by sexually active people and viral load testing by those diagnosed with HIV. The focus of the cascade is generally on individual engagement in care. But how does testing of HIV and viral load work in the context of sero-discordant primary relationships where the two partners require different tests, and ideally repeatedly? There is surprisingly scant available literature on the meanings and practices of testing in such couples.

This question was part of a broader study on gay and heterosexual couples with mixed HIV status in NSW, YouMe&HIV, completed in 2016 and funded by NSW Health. Findings showed that the 25 couples represented in the study were highly engaged with clinical care through the use of HIV treatment and services for monitoring and testing, but with some interesting variations.

Firstly, there was a strong commitment among HIV-positive partners to regularly monitor their viral load. Most did so every three months on average and no less than every six months. Being in a mixed-status relationship was a major motivator to remain actively engaged with clinical care and vigilant around viral load, given the broad awareness around the relationship between viral load and infectiousness. Couples described the monitoring of viral load as highly important to the health of both partners, as well as conducive to a safe and satisfying sex life together.

HIV testing was not seen as of equal importance to the wellbeing of the relationship. About two thirds of the negative partners tested for HIV every 3-6 months, while a third tested less frequently. However, none of the negative partners never tested for HIV; once every two or three years was the minimum. Those who tested regularly explained that the testing was more for reassurance or was part of regular health check-ups, rather than based on any specific concern about HIV transmission. The majority of negative partners felt their sexual relationship was safe in the context of effective HIV treatment, including those who had condomless sex, and perceived any risk as very low or even non-existent. For that reason, some negative partners clearly saw frequent testing as unnecessary. However, most of the negative partners who did not test regularly were heterosexual; hence, it is likely that the absence of a culture of HIV testing among heterosexuals also played a part.

Although some positive partners felt comforted by infrequent partner testing, especially when it was sanctioned by their HIV doctor, positive partners were generally keen for their negative partner to...
test on a regular basis, not only because it provided a sense of relief and reassurance that they were “doing a good job”, but because it was seen as an important marker that their HIV-positive status was safe, that they were not infectious, and that their undetectability rendered sero-discordant sexuality unproblematic.

Understanding the different meanings around testing among couples with mixed HIV status is of great value to ensuring the strength of the treatment cascade and how best to support affected populations in engaging with clinical care in a way that makes sense to them.

References

3.2 Knowledge about liver diseases and liver fibrosis assessment among people who inject drugs in alcohol and other drug treatment

Carla Treloar
This study was led by the Kirby Institute as part of an ongoing collaboration with CSRH and other stakeholders to increase awareness and uptake of hepatitis C treatment among people who inject drugs, with a particular focus on the drug treatment setting. An important part of the cascade of care for people living with hepatitis C is appropriate assessment of liver disease. Transient Elastography (TE) is a non-invasive, painless, ultrasound technique for assessing liver health. This study examined the acceptability of TE assessment among people with a history of injecting drug use attending drug treatment.

The LiveRLife campaign materials were developed and focus tested in close consultation with people who inject drugs. These materials included a recruitment poster, TE results card, website, and a short film. Four clinics were involved in the study and 253 participants were recruited. Participants undertook a baseline survey, TE assessment, follow-up clinical assessment, and a post-survey. While baseline knowledge scores were moderate, there were significant gaps in knowledge of HCV antibody testing, factors impacting on HCV disease progression, and response rates to HCV treatment. TE was highly acceptable prior to TE and this acceptability increased after screening. This study points to the need for continuing efforts to increase the knowledge of people who inject drugs regarding HCV natural history and treatment. The high acceptability of TE in this population suggests that this technology would be useful to include in multi-faceted campaigns such as liver health promotion campaigns.

Reference

3.3 Positive Speaking among people living with hepatitis C

Elena Cama
Positive speakers are people who speak publicly about living with an illness for the purpose of public education. C-een and Heard is a positive speaking program of Hepatitis NSW in Sydney, Australia, using educational presentations by people living with hepatitis C to increase understanding of the
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infection and reduce discriminatory attitudes towards people living with hepatitis C and people who inject drugs among health and community workers. This program has already been shown to positively impact on audience members by reducing stereotyped and discriminatory perceptions of the two groups (Brener, Wilson, Rose, Mackenzie, & de Wit, 2013).

For this paper, data from interviews with nine C-een and Heard positive speakers were used to explore experiences of and motivations to participate in positive speaking, and the impact of the program on speakers. Speakers reported that they had commonly witnessed and experienced hepatitis C-related discrimination, particularly in health care settings. While these experiences were distressing, they led speakers to challenge misinformation and negative attitudes and start on a path of advocacy, culminating in participation in positive speaking. Ultimately, speakers felt empowered by the program as they believed they were making a real difference in changing attitudes among people who may provide health care for future generations diagnosed with hepatitis C. Other positive outcomes included increased hope and self-esteem. The program not only provided speakers with the opportunity to connect with like-minded peers, but also an avenue through which to be supported by audience members and program organisers. This program highlights that, in some cases, people living with a stigmatised condition may reject their stigmatised identity and seek to change public opinion about their community group, such as through advocacy and education, with positive results.

References
Rose, G., & Treloar, C. (no date). Positively C-een and Heard: A review of speakers' perceptions of their participation in the C-een and Heard service of the Hepatitis Council of NSW. Unpublished report.

3.4 The role of Aboriginal community attachment in buffering against the negative consequences of stigma and promoting lifestyle changes after hepatitis C diagnosis

Loren Brener

Attachment to a community and feelings of belonging to this community can perform a protective function for those who belong to a marginalised group (Sellers & Shelton, 2003). Aboriginal Australians have a long history of persecution and experience of ongoing stigma and discrimination in Australia. However, a small body of research has shown that stigma does not always result in negative outcomes, rather the impact of stigma can be a function of the resources that people have to cope with this stigma. A strong attachment to and identification with a community could possibly act as a buffer against the negative effects of stigma. Hence, this research assessed whether Aboriginal people living with HCV who have a stronger attachment to their Aboriginal community would experience less of the negative effects associated with stigma. Two hundred and three Aboriginal people living with HCV were administered a survey assessing community attachment, resilience, quality of life, HCV treatment intent, HCV knowledge, and positive lifestyle changes after diagnosis.

Findings from this research show that those who felt more attached to their Aboriginal community were more likely to show greater resilience, report having a better quality of life, and report experiencing less HCV-related stigma than those who were not as attached to their Aboriginal community. Most importantly, attachment to an Aboriginal community was associated with positive lifestyle changes, such as changing their diet, reducing or cutting out alcohol, reducing or no longer using illicit drugs, increasing level of exercise, and having more regular HCV check-ups after diagnosis with HCV. Hence, the findings of this study highlight the importance of Aboriginal community attachment as related to positive health outcomes among Aboriginal people living with a stigmatised illness. A strong sense of community attachment may provide positive reinforcement and buffer against the negative health
consequences known to be associated with stigma. In fact, this community attachment appears to promote positive health behaviours, such as lifestyle changes that may serve to modify HCV disease progression, ultimately leading to better health outcomes. As over 80% of this sample had not engaged in HCV treatment, it is clearly very important to establish factors that increase positive changes in health behaviours in order to reduce the impact of HCV.

References


3.5 Multiple stigma among Aboriginal and Torres Strait Islander people living with hepatitis C

Carla Treloar and Loren Brener

The association between the experience of stigma and poorer health outcomes has been well established. What is less well understood is the experience and impact of multiple stigmas, i.e. when people are labelled with more than one stigma-acquiring identity category. For Aboriginal people living with hepatitis C, there is another layer to explore of the cultural experience of shame which has also been described as having profound impact on health and health care outcomes.

Recently, CSRH undertook a study of Aboriginal people living with hepatitis C in NSW. This study included surveys with 203 people (see section 3.4) and qualitative interviews with 39 people. The interview data allowed us to examine the accounts of participants as they related to the overlapping origins of stigma (such as related to perceived injecting drug use, hepatitis C status, and Aboriginal identity) and cultural shame.

While participants' accounts of the stigma associated with living with hepatitis C were similar to those collected in other populations, it was also important to note the entangling of hepatitis C-related stigma and the societal expectations of Aboriginal people. This was described by participants as an “automatic” expectation that Aboriginal people would have stigmatised conditions such as hepatitis C. Further, the linking of hepatitis C, stigma and colonisation requires an understanding of health that is not limited to individualised and biomedical conceptualisations but one which acknowledges historical and intergenerational trauma.

These results present challenges for efforts to reduce hepatitis C related stigma among Aboriginal people. We need to look beyond responses that are based on provision of information and education and acknowledge the links between structural and historical factors (such as racism and colonisation) with current experiences. This means understanding how individual experiences (interlocking stigmatised identities) reflect structural inequalities. This suggests that multi-level approaches to stigma that address structural factors and draw upon the resistance offered by stigmatised communities are required.

Reference

3.6 Evaluating the Deadly Liver Mob Project

Carla Treloar

Over the past two years, CSRH has been working on an evaluation of Deadly Liver Mob (DLM) in two pilot sites. DLM is a health promotion project devised by Local Health Districts aiming to provide hepatitis C education, as well as screening for hepatitis C and sexually transmissible infections. On
the basis of this evaluation and existing collaboration, CSRH has been successful in applying for a
NHMRC Partnership Grant to examine the roll-out of DLM in additional five sites. This new project
aligns with a growing international interest in implementation science. Local Health Districts will
determine how to implement DLM in their site, and the evaluation will examine how new sites adapt
the original protocol to meet the needs of their unique sites in terms of local supporting services,
workforce, and engagement with community. We will use routinely collected data to examine patterns
of attendance at sexual health clinics in the two years prior to and in the period of DLM operation. We
will also collect additional qualitative data from health staff and from community members to examine
how these important stakeholders experienced the DLM project. The overall goal of the project is to
contribute to policy and programming for the NSW Ministry of Health and in Local Health Districts and
to contribute to understanding how programs serving Aboriginal communities can be implemented in
mainstream health services.

3.7 The Stigma Indicators Project

Elena Cama and Carla Treloar

Stigma is well recognised as having a major negative impact on health outcomes among people living
with blood borne viruses and sexually transmitted infections. Experiences of stigma and discrimination
are associated with poorer mental health, social isolation, and reduced health care seeking behaviours
and adherence to treatments. This can have adverse implications for public health initiatives which
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.

The aim of this study is to develop a brief indicator to measure experiences of stigma among
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 (B and C), and people who engage in sex work. The indicator
will be included in existing routine surveys of people who inject drugs and men who have sex with
men, and in new surveys of people living with HIV and hepatitis C. This project also aims to develop
a mirrored indicator that can be used among health care professionals and the general population.
This indicator will be used to measure the expression of stigma, such as discriminatory or negative
treatment of patients or clients in a new survey of health professionals.

Reference

among people living with blood borne viruses and sexually transmissible infections in Australia. Presented at
the Social Research Conference on HIV, Viral Hepatitis and Related Diseases (HHARD), Sydney, Australia, 31st
March – 1st April.
Part III
Treatment, Service Engagement & Care for BBVs/STIs
4 People who inject drugs and young people: hepatitis C treatment

4.1 Evaluation of two community-controlled peer services accessing hepatitis C services in opioid substitution therapy (OST) clinics

Carla Treloar

This study was conducted as part of the ETHOS project, which was led by the Kirby Institute as part of an ongoing collaboration with CSRH and other stakeholders to increase access to hepatitis C treatment for people who inject drugs. This study examined two peer support projects that operated within the ETHOS project, that is NUAA (NSW Users and AIDS Association), the NSW drug user organisation, employed peer workers to support clients at two drug treatment services to engage with the co-located hepatitis C treatment staff. The evaluation of these peer support services involved interviews with clinic clients (n=31), clinic staff (n=8) and peer workers (n=3). Preliminary findings were also discussed in a workshop with current NUAA peer support staff as part of the analysis process.

The conduct and context of the peer support projects is important to note as these programs were designed and delivered wholly within a peer model which is uncommon in the international literature. The peer support programs were well received by staff and client participants and had a clear impact on processes, outputs and outcomes. The trust between clients and peer workers was described as an essential element of the programs’ success. The peer support programs were also described as effecting a number of positive changes in the short-term including those related and those additional to the goals of the ETHOS project. This included peer workers facilitating access to other programs to promote the health and well-being of people who inject drugs (that is, dental programs), acting as mediators in discussions between client and staff, and that the presence of the peer workers changed the “feel” of the clinic space to a “friendlier” space. Finally, the peer support programs were described as facilitating the achievement of the ETHOS project goals in supporting clients into hepatitis C assessment and treatment.

Although there were two distinct models of peer work in operation, the impact of peer support appeared to be more reliant on the ways in which peer workers could demonstrate their credibility as peers and trustworthiness as operating independently of the drug treatment clinic. Peer workers may enhance the operation of hepatitis C clinics by engaging clients in education and support, allowing better prepared clients to engage better with clinical staff. Although this study was conducted in the era of interferon-based treatments, it is suggested that peer workers remain essential in the era of new treatments to provide ongoing education and support, and to assist in moving the discourse away from the “horror stories” of interferon-based treatments.
4.2 The impact of pluralistic ignorance on the provision of health care for people who inject drugs

Loren Brener

Research has shown that people believe that their friends or colleagues may hold more conservative attitudes towards certain groups than they do. A person's thoughts about how others think may have some influence in shaping their own attitudes and behaviour (Ajzen & Fishbein, 1980; Miller & MacFarland, 1991). This psychological phenomenon is termed pluralistic ignorance (Katz & Allport, 1931), whereby group members erroneously believe that their privately held attitudes differ from the majority of their peers and thus behave in ways that endorse public opinion, even though it may be contrary to their own opinion. Consequently, pluralistic ignorance can lead to the perpetuation of particular social norms, even though these may lack private support.

Prior research shows that pluralistic ignorance impacts on behaviours such as binge drinking, drug taking, gambling, and condom use where individuals feel an internal pressure to adopt an attitude or behaviour that they believe is consistent with their peer group. However, no research has examined how pluralistic ignorance may impact on individual's treatment of clients' health conditions in meaningful context such as the provision of health care. This exploratory study aims to assess whether pluralistic ignorance plays a role in the prescription of opiate pain relief to people who inject drugs.

Fifty-seven hospital based health care workers were given a survey to assess their attitudes towards their harm reduction services for people who inject drugs and their perceptions of their colleagues' attitudes. They were then given a scenario in which they were asked to indicate the extent to which they would provide pain relief to people who inject drugs.

The data indicate that participants support harm reduction more than they thought their colleagues supported harm reduction, thus demonstrating the existence of pluralistic ignorance. Interestingly, pluralistic ignorance impacted on participants' behavioural intentions to provide pain relief. The data show that participants’ beliefs about their colleagues' attitudes impacted on whether they would prescribe pain medication to a person who injected drugs. Those who perceived their work colleagues to be more supportive of harm reduction were more likely to say that they would prescribe pain medication, whereas participants own support for harm reduction had no bearing on their intention to prescribe medication. These findings highlight the link between pluralistic ignorance and potential discriminatory behaviour and also provide some rationale for understanding the reported inadequate provision of pain relief for people who inject drugs despite health workers not holding negative attitudes towards this group.

References


4.3 Discrimination by health care workers versus discrimination by others: countervailing forces on hepatitis C treatment intentions

Loren Brener

People with hepatitis C face stigma and discrimination largely as a result of the association of HCV with injecting drug use. Injecting drug use is a highly stigmatised behaviour attracting strong moral condemnation especially given its criminal status (Ahern, Stuber, & Galea, 2007). A large body of research has shown that stigma and discrimination has a negative effect on the health and wellbeing of those who are stigmatised and has been linked to poor mental health, poverty, low social status, physical illness, low self-esteem, and academic underachievement (Link & Phelan, 2006; Major & O’Brien, 2005). Stigma and discrimination towards people with HCV has been associated with health problems ranging from increased depressive symptoms to engagement in risky behaviour (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007). There are numerous documented reports of people with HCV experiencing stigma and discrimination and these appear to most commonly occur within the health care sector.

Experiencing stigma or discrimination in a healthcare setting has been shown to adversely affect the health seeking behaviours of people living with a stigmatised condition such as accessing HCV treatment, seeking testing for HCV, and adhering to medical regiments (Butt, 2008). Based on a Social Identity Theory framework, this research attempted to explore a more nuanced approach to understanding the impact of stigma on HCV treatment uptake. Hence, the research explored whether, as Social Identity Theory would posit, HCV-related discrimination may be associated with attempts to remove the stigma of being HCV positive through treatment intentions. Additionally, it was also hypothesised that the source of the discrimination was important and whether discrimination was perceived as directed at the self or at the group would differentially impact on intention to take up HCV treatment.

This sub-analysis is drawn from a larger cross-sectional study which aimed to evaluate decisions around hepatitis C treatment uptake in NSW. The sample consisted of 416 participants who indicated they had acquired HCV through the use of non-sterile equipment to inject drugs. Findings indicate that discrimination towards the individual ‘self’ is a more powerful predictor of intention to take up HCV treatment than discrimination aimed at the HCV-positive group. Additionally, the source of discrimination is also important as participants indicated that experiencing discrimination from health workers resulted in lower intentions to engage in treatment in the future. These findings demonstrate that the relationship between stigma, perceived discrimination and possible health-related outcomes is complex. Intention to have HCV treatment may be dependent on the source of perceived discrimination and on whether this discrimination is directed at the self versus the group. Those who perceived discrimination aimed at the self, indicated a greater likelihood to engage with treatment in the future. This finding is consistent with Social Identity Theory which states that when boundaries are permeable, or status can change as in the case of HCV through treatment to remove the stigmatised condition, people from stigmatised groups are motivated to change their status by switching groups (Tajfel & Turner, 1986). Data from this study further suggest that this strategy is more likely to occur when people are motivated to change after feeling personally discriminated against by others around them.

References


4.4 Stigma and hepatitis C treatment: a social research agenda for the Directly Acting Antiviral (DAA) era of hepatitis C treatment

Carla Treloar

At the end of 2015, an announcement from the Australian Government set an international precedent. The Australian Government had successfully negotiated an agreement with the pharmaceutical companies producing new generation Directly Acting Antiviral (DAA) hepatitis C treatments that promise effective, tolerable treatments and a means to change the course of the epidemic. The agreement guaranteed “equal treatment access”. In other words, everyone with hepatitis C would be eligible to be prescribed these medicines through the publicly subsided Pharmaceutical Benefit Scheme. The cost of DAA treatments is very high, approximately $100,000 per course. Other countries have developed ways to manage the cost to the public purse of DAAs, including limiting access to those with more advanced liver disease. In contrast, the Australian agreement was designed to allow everyone access, so that people living with hepatitis C do not have to become unwell before they can access treatment.

In the first three months of access to DAAs, approximately 18,000 people or 8% of those living with hepatitis C have been prescribed these new treatments. This is a tremendous achievement and must be personally momentous to those who have been awaiting these medicines for some years.

There is talk that hepatitis C can be eliminated from Australia, or made into a rare disease that the public health challenge of hepatitis dissipates. This is an aspiration that is highly attractive for policy makers as well as the community. However, not one medical technology has been effective over the course of history in achieving such outcomes. The picture becomes more complicated when considering the experiences and social positions of the key priority population (people with a history of injecting drug use).

There are a number of issues that need to be examined in this new era and which generate a range of new research questions to be asked and for which social research is well placed to deliver insights. A key factor to consider within a HCV research agenda is stigma. Stigma and discrimination associated with hepatitis C have been described as central to the experience of living with hepatitis C. We need to understand that people who inject drugs are considered in many corners of society as “failed citizens”, that the act of injecting is antithetical to what we expect of responsible citizenry. How we move from that widely held position to one in which people with a history of injecting can express entitlement and expect unproblematic access to HCV treatment needs to be explored. The broader literature and our own research highlight the mistrust that people with a history of injecting may hold to systems of government, including the health system. We have also documented that clinicians and health workers may anticipate that people who inject are disinterested in their health, that they are not engaged, enterprising health citizens, even when the person is sitting across from the clinician in a health clinic. The experience of being told that you are not worthy of treatment, that your place should be offered to someone who is more deserving profoundly shapes the decision one makes about whether and how to access health care in the future. How these experiences can inform the development of new models of care has been examined to some extent but deserves much more attention and monitoring as hepatitis C treatment evolves.

Beyond models of care, a range of other questions arise. We do not know the best way to communicate these advances in hepatitis C treatment to people who are not already connected to information networks. We do not know how best to fill the gaps in knowledge of those who are already connected to the health system. We do not know who will decline or defer treatment or the reasons behind it. We do not know what society will make of people who defer or decline treatment or those who re-acquire HCV after successful treatment. How will couples or networks of people who inject drugs shape their practice after treatment? We do not know how new understandings of hepatitis C as “easy” to cure will impact on the attitudes of broader society, or the ways in which people who inject drugs will reconfigure notions of risk and prevention. We do not know how the workforce will evolve...
and emerge as treatment access broadens; what do DAA prescribers need to understand to support their work and effectively deliver DAA treatments to people with a history of injecting drugs? And finally, while HCV treatment uptake has been remarkable in this first period, will it be sustained? How do we reach those who have not been waiting, “warehoused”, for these new treatments?

While the promise of DAA treatments for HCV is exciting, there is much to understand to ensure that we can capitalise on the “Australian deal” and work effectively to those ambitious targets of elimination. Social research has a key role to play in answering these questions and contributing to our national goals.

4.5 Interventions to increase hepatitis B and hepatitis C screening, assessment and monitoring: a literature review

Max Hopwood and Carla Treloar

In Australia, the HBV infection mostly affects immigrants from Asian backgrounds, whereas the HCV infection is mostly found among people who inject, or who have injected, illicit drugs. During 2015, researchers at the CSRH were funded by the NSW BRISE Program to conduct a literature review of population level health interventions that have been effective at increasing the number of people tested for HBV and HCV, assessed for liver disease stage, and monitored for liver disease. The Cochrane Database of Systematic Reviews, Medline, Embase, CINAHL, and PsycInfo databases were searched for literature about HBV and HCV screening, vaccination, treatment, and care. Studies were included if they: targeted individuals at risk of, or living with, HBV or HCV infection; were randomised controlled trials; reported large, multiple population level interventions; described an intervention in sufficient detail; and, reported a quantitative evaluation of program effectiveness or patient outcomes relevant to the intervention. A total of 12 articles were included in the review.

Interventions to increase rates of HBV and HCV screening, assessment and monitoring have been trialled in community-based settings, primary health care settings, in other clinical health service settings, such as at opioid substitution treatment clinics, and via combined multi-strategy interventions. Theoretically informed and culturally appropriate interventions have been found to have greatest impact. The review highlighted how complex, multimodal educational interventions seem to cause behavioural changes that increase rates of testing, vaccination (for HBV), and treatment.

The review reported that community-based interventions have used a variety of theoretically informed and culturally appropriate strategies including nurses and lay health workers from culturally and linguistically diverse communities (CALD), role-plays, and the use of a photo-novel as ways of health promotion. Outcomes of community-based studies indicate that HBV-related educational interventions delivered by lay health workers can significantly increase HBV screening rates. However, physicians are also highly influential within Asian immigrant communities and should be central to efforts to increase screening.

Within primary care settings, interventions have included strategies such as electronic health record prompts to remind primary care providers to screen for HBV infection among their patients from Asian backgrounds, and also employed in this context is a strategy of prompting primary care providers to use a clinical reminder sticker attached to patient records to identify patients who were at risk of HCV infection. Outcomes of primary care-based studies indicate that electronic physician prompts were effective in improving HBV screening when delivered alongside HBV education and clinical information (e.g. promoting HBV testing). Similarly, a prompt to use a brief risk-screener via a paper-based clinical reminder was effective in increasing HCV testing in primary care settings.

Other clinical health service-based interventions have included the use of FibroScan (Transient Elastography) in street-based outreach clinics, nurse-led assessment clinics, education, hepatitis A and HBV vaccinations, review of risk behaviours, referrals, support, risk reduction counselling, and motivational interviewing-enhanced case management assistance. US-based clinical settings have successfully addressed the large number of HCV antibody positive patients who did not receive viral testing within six months of a positive antibody test result by: (i) improvements in the patient-centeredness of the screening process in ambulatory patients; (ii) local implementation of the
Outcomes of other clinical health service-based interventions indicate that these interventions have successfully (i) engaged people who inject drugs with health services; (ii) facilitated hepatitis care coordination in opioid substitution clinics; (iii) integrated infectious disease programming in mental health settings and increased acceptance of such services among clients; (iv) reduced costs of screening and waiting times (e.g., FibroScan vs liver biopsy); and, (v) successfully assessed and triaged people who inject drugs and streamlined their pathway through the healthcare system.

Studies using complex, combined interventions across multiple settings have employed theoretically informed and culturally appropriate strategies such as the building of a coalition of alliances among health and support services, education campaigns delivered in a range of formats, citywide mass media campaigns to raise public awareness, outreach clinics for blood-testing, viral hepatitis-related information presented through entertainment, and advocacy efforts. In addition, an internet-based HCV screening and referral intervention has been trialled to engage individuals from hard-to-reach populations with HCV testing and health care. One intervention combined a mass media campaign using television commercials, advertising, and online banners to raise awareness of HCV. The campaign directed people toward a validated internet-based risk-assessment questionnaire and an internet-mediated blood-testing procedure to identify individuals infected with HCV in the general population. Outcomes of combined interventions across multiple settings are difficult to evaluate; however, there are indications that screening for viral hepatitis infections can be increased using combined strategies in a variety of contexts.

Finally, while most intervention trials have not published data regarding their costs, interventions to prevent loss to follow-up after screening have reported attractive cost-effectiveness ratios. A range of studies considered the costs associated with hypothetical interventions, and found that the following are likely to be cost-effective interventions: (from Canada) a screening of all recent arrivals for chronic HBV and treating recent arrivals; (from the UK) an opt-out, general practitioner HCV case-finding intervention; (from the US) interventions targeting multiple points along the HCV cascade-of-care rather than a single point are reported to provide better outcomes including more attractive cost-effective ratios; and (from the US) a one-off HCV testing of all people in the birth cohort 1945-1965 (among whom HCV prevalence is highest).

Reference

4.6 Hepatitis B and hepatitis C treatment and care in primary care settings: a literature review

Max Hopwood and Carla Treloar

A review of the research literature on barriers and facilitators to HBV and HCV treatment and care in primary care settings was conducted by researchers from CSRH during 2015, funded by the NSW BRISE Program. The main focus of the review was on the enablers, or facilitators, to management and care of viral hepatitis at the systems level. References to primary health care settings throughout the review include: Aboriginal Community Controlled Health Services, correctional health services, alcohol and other drug settings, sexual health, and general practice settings. A search was conducted of the international literature published from 2005 to 2015, appearing in the Medline and Google Scholar databases. The literature searches returned a total of 14 articles regarding HBV and 31 articles regarding HCV; however, few articles included information about systems-level barriers and facilitators.

Hepatitis B

Our review of the literature uncovered some practical recommendations for improving the management of HBV within primary health care settings. These included community outreach programs, community-
based education programs, and professional education programs.

a) Community outreach programs

To improve engagement with HBV treatment and care generally among ethnic communities, it is important to address chronic HBV care as a community-wide issue rather than a problem of some individuals. Targeted community outreach programs in NSW should draw upon the influence of ethnic community leaders, including religious organisations and most importantly local primary health care providers, to inform community members about HBV infection and to encourage uptake of testing, vaccination, treatment, and care within primary care. Around the world, systems-level interventions are often complex and expensive to implement. They require time for the barriers to care to be identified and dismantled, and they require careful evaluation of strategies in order to assess their effects.

b) Community-based education programs

Ongoing, culturally appropriate education campaigns that are aligned with community values and endorsed by community leaders are needed to inform affected ethnic immigrant populations about HBV infection, and the means to address it via primary care, within their local communities. Considering the ways in which HBV-related stigma can impede engagement with health care services highlights specific cultural understandings of virus transmission (i.e. via condomless sex). To help overcome stigma associated with HBV infection in affected NSW communities, it may help to ‘rebadge’ HBV in education campaigns as a blood-borne virus in order to modify its image among some communities of being solely an STI. Patients often have competing health priorities that become a barrier to viral hepatitis treatment uptake. To help understand the systems-level barriers to HBV treatment and care among immigrants, the literature suggests that it is important to identify how health services of the host country are perceived by immigrant community members. If health services are held in low regard, or understood to be ‘unfriendly’ and difficult to navigate for specific ethnic population groups, services will be avoided.

c) Professional education programs

It should not be assumed that primary care providers with high caseloads of HBV patients have high knowledge and awareness of HBV treatment and care. Research has identified major gaps in primary care providers’ HBV knowledge despite having high HBV case-loads and a common patient-provider ethnicity. As such, Chinese- and Vietnamese-Australian primary care providers in NSW, particularly those in areas where there is a high Asian-Australian immigrant population, may require ongoing medical education programs about the occurrence of HBV infection among their patients, and how to care for and treat these patients.

Primary care providers experience many competing pressures to meet educational requirements in NSW, which can distract their attention from HBV-related health care, particularly when their patients are asymptomatic. This limits the effectiveness of continuing medical education (CME) programs. Combined cycles of web-based teaching and educational emails (interactive, multi-channelled education), where primary care providers are invited to respond to lessons and receive immediate feedback from tutors, may help to increase the effectiveness of HBV-oriented CME programs. Education and training of medical students via the development of a preclinical service-learning curriculum on HBV, using outreach clinics staffed by students, with clinical mentors, to test, monitor and encourage treatment may be an effective strategy to improve knowledge among future primary care providers and to raise awareness of HBV among affected communities.

Hepatitis C

Given the continuing low rates of HCV care and treatment uptake among people who inject drugs and the difficulties associated with engaging people who inject drugs in contexts such as tertiary treatment centres, and given the identified multi-level barriers to treatment and care, this literature review pointed to a range of key innovations that, if implemented, can lead to improved outcomes. These are presented below.

• Acknowledge the underlying issues of stigma, mistrust and concerns about confidentiality that will remain regardless of the medical regimen or setting of delivery.
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• Include social and structural interventions in efforts to promote HCV treatment including strategies for: stigma reduction; drug dependence; social support; mental health care; infectious disease; improvements in housing; enhanced geographic access to treatment; offsetting transport costs; overcoming the consequences of the criminalisation of illicit drug use; and sensitivity to cultural and ethnic diversity and gender differences.

• Promote HCV primary care services as community-based, mobile and/or situated in areas where people who inject drugs live, congregate and access health care and other services.

• HCV treatment and care will be most effective when taken to the affected populations.

• Sites could include alcohol and other drug settings, needle and syringe programs (NSPs), primary care, homelessness services, Aboriginal Community Controlled Health Services, and correctional health services. Consider NSPs as a site of HCV treatment (with new therapies) given high prevalence of HCV among clients and high levels of client trust in NSPs.

• Consider a telehealth model for regionally/rural based GPs to support uptake of new HCV treatments. This could also include elements to support nursing staff to roll-out nurse-led models in primary care and community health care settings.

• Incorporate input from people who inject drugs in the design and operation of health care services, particularly in relation to their location, opening hours, service provision, and appointment schedules.

• There needs to be a range of user-friendly psycho-social support services available which adhere to strict confidentiality requirements and services should utilise peer support and nurse-led models where possible.

• Advocate for the education and training of primary care providers, addiction specialists, psychologists, psychiatrists and nurses, at both undergraduate and post-graduate levels that addresses morally based misconceptions about people who inject drugs within the health care sector and include specific HCV training and education.

• Monitor uptake of interferon-free HCV treatment in relation to equitable access (given the variability in primary care providers' knowledge and judgement about implementation of new HCV treatment, especially for clients who use drugs).

• Design and implement a coordinated information dissemination program aimed at people living with HCV and primary care providers that emphasises (i) availability (or coming availability) of new treatments; (ii) what people living with HCV can do to prepare for new treatments (HCV assessment); (iii) the rights of people with HCV in health care settings; and, concomitantly (iv) the responsibilities of health workers under anti-discrimination legislation.

• Consider workforce development for all primary care staff, including non-clinical staff that covers issues relating to stigma and structural competency.

Reference

4.7 Surveillance and treatment of prisoners with hepatitis C (SToP-C): enhancing treatment of hepatitis C in opioid substitution therapy (OST) settings (ETHOS-2)

Carla Treloar
The advent of new DAA treatments for hepatitis C brings much promise in terms of radically shifting the course of the epidemic in Australia. Two NHMRC partnership projects, led by the Kirby Institute as part of an ongoing collaboration with CSRH, seek to understand how DAAAs will be implemented in the prison setting and in community services. The goal of the SToP-C project is to implement and evaluate
treatment as prevention of hepatitis C in prisons. Treatment as prevention in prison differs markedly from such efforts in the community. This is partly because the prison setting offers somewhat of a “closed” setting in which efforts to reduce prevalence can have direct impact on incidence. However, technologies to reduce hepatitis C risks, such as Needle and Syringe Programs, are not as readily available in prison as they are in the community. CSRH will lead a qualitative study to examine the perceptions and experiences of a range of stakeholders including inmates, their families, corrections officers, justice health staff, policy makers, and advocates.

The NHMRC Partnership project, ETHOS-2, follows from the successful ETHOS-1 project which evaluated the implementation of co-located hepatitis C and drug treatment services on uptake of hepatitis C treatment (in the era of interferon-based treatments). ETHOS-2 will follow how a range of services (including drug treatment, high case load primary care, and NSPs) adapt to the new era of DAAs. CSRH will conduct a qualitative study to examine the experience of clinicians and clients in selected clinics. We will interview clinicians operating in teams with a range of experience with prescribing DAAs to people with a history of injecting. Clinics to be selected will include those who are early adopters of prescribing DAAs, those which are establishing their protocols and starting prescribing, and those that are yet to incorporate prescription of DAAs into their routine care. We will also interview clients with a range of experience of HCV DAA treatment from those who have decided to delay or defer accessing HCV assessment, to those who have experienced treatment. Given that DAAs are supposed to provide a much more simplified and effective treatment experience, the focus of this project is to examine any residual barriers from the clinician or client perspective.

4.8 My health, our family: documenting stories of family life in the context of HIV, hepatitis B or hepatitis C

Christy Newman, Asha Persson and Joanne Bryant

As the management of blood borne viruses undergoes rapid changes, the families of those affected by HIV, hepatitis B and hepatitis C are also living through and responding to those changes. The forms and meanings of ‘family’ also continue to underg0 considerable social transformation.

Researchers at the Centre for Social Research in Health, in collaboration with the Social Policy Research Centre (SPRC) and Australian Research Centre in Sex, Health and Society (ARCSHS), have received funding from the Australian Research Council to conduct a three-year Discovery Project (DP160100134) to document – for the first time – firsthand accounts of what serodiscordance (mixed infection status) means in the context of everyday family life.

With a focus on New South Wales, we will be interviewing individuals (n=30) and family members (n=60) to understand what families mean in the context of stigmatised infectious disease; what stigmatised infectious diseases mean in the context of everyday family life; and how to build on the contributions of families to enhance the prevention, management and treatment of these infections.

Drawing on further interviews with stakeholders (n=20) in the health and social care sectors, alongside a roundtable of health sociology, family/carer studies, and critical health studies researchers, we will also build a critical theory of serodiscordance in order to extend beyond a biomedical focus on individual health and transmission risk in couples to encompass a broader and more relational understanding of wellbeing.

The research questions we will be exploring through this research include:

a) How do families negotiate any disruptions to everyday life associated with serodiscordance? For example, what strategies are developed (or are already in place) to maintain family obligations, rituals and relationships that overcome (or negate the experience of) difference and disruption?

b) Do issues of shame, stigma and secrecy play a role in families’ management of serodiscordance? For example, how are family narratives constructed and communicated to broader social and community networks, and (how) does serodiscordance figure in these? What role does the criminalised or contentious legal status of particular practices associated with BBVs (e.g. injecting drug use, and sexual transmission of HIV) play in the management of serodiscordance within families?
c) How do families negotiate the range of unfolding responsibilities associated with care and treatment, recognising that there are considerable differences between the treatment options and experiences across these diseases? For example, are different roles performed (or resisted) in relation to medication, clinic visits, and maintaining relationships with health and social care providers? Are care roles and responsibilities in the home influenced by gendered, generational, cultural or legal/criminal scripts?

In addition to academic publications, we will in the final year of the study produce a research report and summary, and host a public seminar on what the findings mean for communities. Policy and practice recommendations will focus on improving the experience of diagnosis, treatment and care for individuals and families, and challenge the silence and stigma that continue to be associated with these infections. All study activities will be conducted in consultation with an advisory committee of peak NSW organisations working to promote the prevention and treatment of infectious diseases and/or family wellbeing.
References


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