A study of Aboriginal people in NSW living with hepatitis C
A report to community

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This study was approved by the Human Research Ethics Committees of the Aboriginal Health and Medical Research Council of NSW, UNSW Australia, and relevant health authorities.

We are thankful to the Aboriginal people living with HCV who shared their experiences with us, the many health and other agencies that supported this work and the members of our Advisory Committee.

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Suggested citation
Background and Method

The term "Aboriginal Australians" is respectfully used to refer to Aboriginal and Torres Strait Islander people.

WHY

Hepatitis C (HCV) affects more Aboriginal Australians than non-Aboriginal Australians as measured by new and existing infections. Despite improvements to HCV treatment, uptake remains low internationally and within Australia. No detailed research is available to estimate the numbers of Aboriginal Australians who have appropriate care for HCV or who have had HCV treatment. However, research tells us that the impact of HCV for all Australians is increasing as shown by the growing burden of advanced liver disease, including liver cancer, and the rising demand for liver transplants. The goal of the present research was to explore the experiences of Aboriginal Australians living with HCV to understand their experiences of HCV care and treatment.

HOW

The CSRH developed a specific team to undertake this study including both Aboriginal and non-Aboriginal members. Our team was committed to undertaking research with Aboriginal people that is meaningful and appropriate. Team members included an Aboriginal Mentor who advised the team and oversaw matters of protocol and an Aboriginal Liaison Officer who was involved in developing relationships with Aboriginal and mainstream services.

NSW residents, who identified as Aboriginal, were 18 years or above and self-reported as currently living with HCV, undertaking treatment or recently clearing the virus naturally or through treatment, were eligible to participate in a survey and interview.

The key recruitment strategy for this project was the distribution of postcards. The postcards were distributed in relevant services (e.g. Needle and Syringe Programs, methadone clinics, liver clinics, Aboriginal Community Controlled Health Services), via personal contacts and previous participants. Interested people could contact the Aboriginal Liaison Officer, free of charge, to receive further information about the study.
Method and Participants

This study examined participants’ experiences of HCV care, engagement with HCV related services, management of HCV and choices around HCV treatment. It also investigated participants’ knowledge of HCV, quality of life, resilience and experiences of stigma and discrimination. The survey took on average 30-40 minutes to complete and participants were given $30 to reimburse them for their time and expertise.

All survey participants were asked if they were interested in taking part in an in-depth interview. The interview schedule mirrored the topics covered in the survey but allowed participants to tell their story in detail. Interview participants were given $30 for their time and expertise.

WHERE

The survey was distributed across New South Wales. Most participants (81%) lived in metropolitan Sydney.

WHO

203 Aboriginal Australians living with HCV completed the survey. 58% were male and 41% were female with one transgendered participant. 96% identified as Aboriginal with the remainder identifying as being of both Aboriginal and Torres Strait Islander descent. The mean age of the sample was 38 years (SD=9.6). 40% of the sample was aged between 36 and 45 years. Just under 60% of the sample had some high school education but had not completed Year 10. Most participants received Centrelink or financial assistance payments from the Government (88%) and 80% had ever been in prison. The mean length of time since HCV diagnosis was about 10 years (SD=8.2). 40% of participants had been diagnosed with HCV over 10 years ago; 24% had been diagnosed within the last 5-10 years; 19% were diagnosed with HCV in the last year.

39 people were interviewed about their experiences with HCV. 15 participants were women, 23 were men and one was transgender. The mean age of interview participants was 40 years. 11 participants had experience of HCV treatment and one participant was just about to start treatment.
Culturally appropriate diagnosis

53% of the sample were either satisfied or very satisfied that their HCV diagnosis was given in a culturally sensitive and appropriate way.

Satisfaction with culturally appropriate diagnosis was associated with:

- Higher rates of pre and post test counseling
- Greater satisfaction with HCV care
- Decreased feelings of HCV related stigma
- Decreased feelings of racially based stigma and discrimination in health care
- Less perceived stigma associated with disclosure of HCV status
- Greater intention to have HCV treatment in the future
HCV diagnosis and perceived stigma

Participants spoke about the impact of diagnosis on their feelings. For some people, diagnosis was given with little other information.

"I was a bit depressed at the beginning, not knowing the full extent of it. I didn’t have all the information available so yeah, I didn’t deal with it really good."
(female, late 30s, not on HCV treatment)

55% agreed or strongly agreed
'I feel shame because of my HCV'

66% agreed or strongly agreed
'I am very careful whom I tell that I have HCV'

59% agreed or strongly agreed
'Most people believe I am dirty because I have HCV'

63% agreed or strongly agreed
'Some people act as though it's my fault that I have HCV'

64% agreed or strongly agreed
'I worry that people may judge me when they learn that I have HCV'

Participants spoke about the impact of stigma on their lives

"I was shattered, I felt dirty . . . I still to this day haven’t really, I haven’t told any of my family, haven’t told anyone you know . . . I have just kept it to myself."
(female, 44, currently on HCV treatment)
Resilience is a measure of how people feel they are coping with the hard times in life. Understanding resilience is important to understand living with HCV.

73% agreed that 'I tend to bounce back after illness or hardships' is true nearly all of the time or often true.

Greater resilience was associated with:
- Better quality of life
- Less physical health symptoms
- Stronger sense of Aboriginal community attachment
- Lower perceived stigma in relation to HCV disclosure
- Greater satisfaction with HCV care
- Lower perceived HCV discrimination

72% agreed that 'I think of myself as a strong person' is true nearly all of the time or often true.

A few people were outspoken about stigma and campaigned against it.

"Just don’t have any stigma involved, um don’t shame anyone for having an illness... Not to be ashamed of it and don’t ever let anyone make you feel worthless for having an illness... treat it with as much seriousness as you possibly can but don’t let anyone ever shame or make you feel ashamed of having Hep C."

(female, 33, not on HCV treatment)
Overall HCV knowledge was good, however there were some gaps.

- There is treatment for HCV (94%)
- There is a treatment which can cure HCV (69%)
- A positive HCV PCR test means you are infected with HCV (41%)
- Being obese or having diabetes increases your risk of complications from HCV (74%)
- Alcohol increases a person's risk of complications from HCV (91%)
- HCV does not always cause symptoms (55%)
- You cannot get HCV from kissing (68%)
- HCV can be passed on by sharing an invisible drop of infected blood (88%)
- People can get infected with HCV from tattoos and piercings (94%)

Participants spoke about not knowing very much about hepatitis C before their diagnosis.

"I haven’t seen anything or come across anyone that has been informed. In the whole 48 years of my life, nobody has come out and told anything. I thought that when I was in gaol, so this is how naïve I was, I thought that the hep shots that I got when I was a kid that that would have stopped me from getting anything. And it doesn’t and I know that now." (male, late 40s, currently on HCV treatment)
Since being diagnosed with HCV...

52% reported changing their diets

36% reported having more regular HCV check ups

66% reported reducing or cutting out alcohol

50% reported reducing or stopping illicit drug use

46% reported accessing information about HCV and HCV treatment

53% reported increasing their level of exercise

Most participants made some changes to their lifestyle to promote liver health, especially cutting down on alcohol:

"I always went on the fact that as long as I look after my liver I will be alright, so that was when I went nil alcohol or anything to make sure my liver was strong — I sort of took the treatment on myself. I always had healthy vegetables, I had a fairly good diet but yeah, I don’t know I just sort of opened my eyes a little bit more, like I am not superman." (male, 45, completed HCV treatment)
Journey to HCV treatment

Of the respondents who had ever received a referral to a specialist about HCV treatment, 55% had gone to see a specialist.

- Never received a referral to a specialist about HCV treatment: 58%
- Received a referral to a specialist about HCV treatment: 41%
- Seen a specialist about HCV: 55%
- Never seen a specialist about HCV: 43%

Of the respondents who had not completed treatment, 56% said they intended to have treatment over the next 2 years.

Of the total sample, 34 participants were either currently on HCV treatment or had previously been on HCV treatment.

- In the next 12 months (32%)
- In the next 1-2 years (24%)
- Not for another 2 years (20%)
- Never (20%)
- Don’t know (5%)

The Liver

These results are similar to those found in other studies.

For some participants, having HCV treatment was important so that they would be healthy to look after their family.

"I have had this disease for about over 20 years now. My liver function is up and down sometimes it’s good and sometimes it’s bad and I just don’t want to die young you know, I am only 42 years old and I don’t want to die at 50 or something you know ... Cos I got a family now and I just don’t want to die and leave them in the lurch you know. ... I just want to get rid of this disease that I have got because it is hanging over my head." (male, 42, completed HCV treatment)
Overall findings

The results of this study were similar to results of other studies. While this is positive, there remains a lot of work to be done in the HCV field for Aboriginal people.

There have already been programs in some Aboriginal communities to raise awareness of HCV (see "Love Your Liver" on the resources page). More information is needed to increase the community's understanding of HCV.

More information needs to be provided to people at diagnosis, and this should be done in a culturally appropriate manner.

Aboriginal people should be able to access appropriate HCV health care in mainstream and Aboriginal Community Controlled Health Services.

People living with HCV need to be treated with respect by health workers, and without stigma or discrimination.
# Resources

## Your decisions about hepatitis C treatment:

Hepatitis C treatment is always changing. If you haven’t had a hepatitis C check-up in a while, find a doctor you can trust to treat you well. With the latest information about treatments, you can make your choice of what is best for you.

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
<th>Contact Information</th>
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<tr>
<td><strong>Hepatitis NSW, Hepatitis Infoline</strong></td>
<td>Peak community-based hepatitis organisation in New South Wales</td>
<td>1800 803 990&lt;br&gt;Monday to Friday, 9am to 5pm&lt;br&gt;www.hep.org.au</td>
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<tr>
<td><strong>Aboriginal Community Controlled Health Services</strong></td>
<td>To find the closest Aboriginal Community Controlled Health Services to you</td>
<td>02 921 247 777&lt;br&gt;www.ahmrc.org.au</td>
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<tr>
<td><strong>Prisons Hep C Infoline</strong></td>
<td>Inmates can access the Prisons Hepatitis Infoline by using the freecall system within their prison. The service can also provide information, support and referrals to people whose family and friends are inside, including sending information packs.</td>
<td>Inmates can call number 3 on the common calls list</td>
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<tr>
<td><strong>Jailbreak</strong></td>
<td>A weekly half-hour radio program for prisoners, their families and supporters that focuses on reducing the risk of transmission of HIV, hepatitis and sexually transmissible infections</td>
<td><a href="http://www.crcnsw.org.au/services/jailbreak">www.crcnsw.org.au/services/jailbreak</a></td>
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<tr>
<td><strong>NSW Users and AIDS Association (NUAA)</strong></td>
<td>Not-for-profit NSW-based organisation advocating for people who use drugs, particularly those who inject drugs. Information about drug use and safer injecting</td>
<td>1800 644 413&lt;br&gt;(country callers)&lt;br&gt;02 8354 7300&lt;br&gt;(Sydney metro)&lt;br&gt;www.nuua.org.au</td>
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<tr>
<td><strong>&quot;Where’s the shame, Love your liver&quot;</strong></td>
<td>Aboriginal Health and Medical Research Council hepatitis C awareness campaign</td>
<td><a href="http://www.loveyourliver.net.au">www.loveyourliver.net.au</a></td>
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