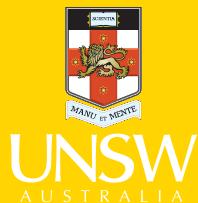




MONOGRAPH 5/2014



Evaluation of NSW Health Aboriginal Hepatitis C Program

Never Stand Still

Arts & Social Sciences

Centre for Social Research in Health

Carla Treloar
Loren Brener
Hannah Wilson
L. Clair Jackson
Veronica Saunders
Priscilla Johnson
Rebecca Gray
Jamee Newland

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Centre for Social Research in Health
Arts & Social Sciences
UNSW Australia



Copies of this monograph or any other publications from this project may be obtained by contacting:

Centre for Social Research in Health

Level 2, John Goodsell Building
Arts & Social Sciences
UNSW Australia
UNSW Sydney NSW 2052 Australia

Telephone: +61 2 9385 6776
Fax: +61 2 9385 6455
Email: csrh@unsw.edu.au
Website: <http://csrh.arts.unsw.edu.au>

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Contents

List of tables	iii
Acknowledgements	iv
Executive summary	1
Introduction	1
The present study	2
Method	2
Ethical consideration	3
Results	4
Recommendations	6
1 Literature review	8
1.1 Introduction	8
1.2 HCV prevalence among Indigenous populations	9
1.3 Risk factors for HCV among Indigenous populations	9
1.4 HCV treatment and care	11
1.5 Barriers to HCV treatment and care	12
1.6 The present study	14
2 Method	15
2.1 Evaluation Team	15
2.2 Survey and in-depth interviews of Aboriginal people living with HCV	15
2.2.1 Sample	15
2.2.2 Recruitment	15
2.2.3 Procedure	16
2.2.4 Data collection instruments	16
2.3 Interviews with key stakeholders	17
2.3.1 Sample	17
2.3.2 Recruitment	17
2.3.3 Procedure	18
2.4 Data analysis	18
2.4.1 Surveys	18
2.4.2 Interviews	18
2.5 Ethical consideration	18
3 Findings	20
3.1 Survey results of Aboriginal people living with HCV	20
3.1.1 Demographics	20
3.1.2 Identification with Aboriginal community	20
3.1.3 Identification with HCV community	21
3.1.4 HCV testing	21
3.1.5 Healthcare and HCV care	23
3.1.6 HCV treatment intention and care	24
3.1.7 HCV Knowledge	28
3.1.8 Physical and mental health symptoms	29
3.1.9 Stigma, perceived discrimination, disclosure and resilience	31
3.1.10 Perceived discrimination and general healthcare	34
3.1.11 Resilience	34
3.1.12 Relationships between stigma, perceived discrimination, resilience and other variables	35

3.1.13	Exposure to HCV health promotion in the last 12 months	36
3.1.14	Variables associated with exposure to HCV health promotion materials	37
3.1.15	Geographical analysis	37
3.2	Living with hepatitis C, decisions about care, and experience of treatment among Aboriginal people in NSW	38
3.2.1	Hepatitis C stigma	38
3.2.2	Perceived challenges in HCV: information and education	40
3.2.3	Diagnosis experience	41
3.2.4	Decisions about care and treatment	42
3.2.5	Choices about health services for HCV care	43
3.2.6	Treatment experiences	44
3.2.7	Examining the experiences of participants who expressed low interest in HCV treatment	47
3.2.8	Hepatitis C campaigns	48
3.2.8.1	Participants who had been treated	48
3.2.8.2	Participants who had not been treated	49
3.3	Key stakeholder interviews	49
3.3.1	Overview	49
3.3.2	Access Coordinators	49
3.3.2.1	General perceptions of the coordinator role	50
3.3.2.2	Shame, stigma and discrimination associated with hepatitis C	50
3.3.2.3	'Where's the shame, love your liver' Campaign	51
3.3.2.4	Experiences within the workplaces	51
3.3.2.5	Timeframe and sustainability	51
3.3.2.6	Re-orienting health services and systems change	52
3.3.3	Managers and supporters of Access Coordinators	53
3.3.3.1	Establishing the role and local input	53
3.3.3.2	Local structures	54
3.3.3.3	Workplace challenges	55
3.3.3.4	Goals of the program, reorienting services and systems change	56
3.3.4	LHD HCV clinical staff	58
3.3.5	Staff of Aboriginal Community Controlled Health Services	61
3.3.6	Stakeholders and other Aboriginal health workers	62
3.3.6.1	Barriers to HCV treatment	62
3.3.6.2	Financial incentives for treatment	63
3.3.6.3	Importance of prison as an access point for treatment	64
3.3.6.4	The story of HCV treatment, peer education and positive speakers	64
3.3.6.5	The burden of HCV-related stigma	64
4	Discussion	67
4.1	Understanding the experiences of Aboriginal people with HCV (using survey and interview data from Aboriginal people and health workers)	67
4.2	Learning from the 4-year program of investment: Interviews with health professionals	72
4.3	Limitations	73
4.4	Concluding remarks	74
5	Recommendations	75
References		77
Appendix 1: Cronbach Alpha for all scales		85
Appendix 2: Correlation Matrix		86

List of tables

Table 1: Demographics	19
Table 2: Identification with the Aboriginal and HCV community	20
Table 3: Time spent with the HCV-positive community	20
Table 4: Reasons for being tested for HCV	21
Table 5: HCV testing experience	21
Table 6: Main place for general and HCV care	22
Table 7: HCV-related attendance at an ACCHS	22
Table 8: Satisfaction with HCV care	23
Table 9: HCV treatment intentions	24
Table 10: HCV care	25
Table 11: HCV knowledge (correctly answered)	27
Table 12: Symptoms experienced in the last six months	28
Table 13: Quality of life and satisfaction with health	28
Table 14: HCV stigma and discrimination	29
Table 15: Cultural stigma and discrimination	30
Table 16: General discrimination in the healthcare sector	31
Table 17: Resilience	32
Table 18: Exposure to HCV health promotion in the last 12 months	33

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Our core research team involved three Aboriginal researchers:

L. Clair Jackson is Ugarapul/Githabal (Jagara Nation, SE Qld) on her father's side and French & German on her mother's side. She has lived mostly in Sydney, working in education, research and the arts, and is now consulting as a Cultural Mentor/Advisor to CSRH.

Veronica Saunders, who was the Aboriginal Liaison Officer for this project, is of Biripi country (Taree NSW) and has worked in nursing and Aboriginal education. She has played leading roles in Local Aboriginal Education Consultative Groups and reconciliation, working closely with Aboriginal and non-Aboriginal people.

Priscilla Johnson is from Cherbourg QLD (Waka Waka & Birri Gubbi) and in addition to working in the CSRH team, also works in the Aboriginal Mental Health Unit, part of the Camperdown Community Health Centre. Priscilla has directed the focus of her work around grief and loss, through healing and mediation.

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Executive summary

Throughout this report we have respectfully used the term Aboriginal to refer to people resident in New South Wales (including participants in this study) and the term Indigenous to refer to national or international populations.

Introduction

As a group, Indigenous Australians face a number of disadvantages in a range of health and socio-economic outcomes and often as a result of unequal access to the same opportunities as non-Indigenous Australians, such as education, employment and healthcare. These patterns are replicated in research on hepatitis C (HCV) among Indigenous populations globally. The Australian Indigenous population is over-represented in both the prevalence of HCV and incidence of newly reported HCV infections.

Despite improvements to HCV treatment, uptake remains low on a global scale. No detailed research is currently available to estimate the number of Indigenous people accessing HCV care or treatment. However, the impact of HCV-related morbidity and mortality is increasingly recognised with an escalating number of cases of advanced liver disease, including liver cancer, and the growing demand for liver transplants. HCV-related ill-health will add to the already inequitable burden of disease experienced by Aboriginal people.

Barriers to HCV care and treatment have been explored in Australia and in other settings. These studies show a range of barriers at personal, provider and systems levels. These barriers often begin with poor diagnosis experiences, with little to no information provided by diagnosing doctors about living and managing HCV, or about available treatment options. Other obstacles to treatment of HCV include fears of the side effects associated with a treatment known to be difficult and demanding, concerns about the impact of treatment on work and family commitments, access to social support and financial strain associated with costs of treatment

where government subsidy is unavailable. Additionally, people with HCV may face competing health and social concerns that impede their access to care and treatment, including poverty, unemployment, lack of stable housing, and comorbidity such as mental health problems and substance use. People with HCV may also experience stigma and discrimination around their HCV-positive status and history of drug injecting. Research suggests that stigma and discrimination may be particularly prevalent in healthcare settings and can lead to a number of negative health outcomes for people with HCV, such as feelings of depression and isolation, and reluctance to seek out healthcare. These negative outcomes may be exacerbated for Indigenous Australians, who are often at higher risk of experiencing these disadvantages than non-Indigenous Australians. Further, it has been suggested that the core challenge associated with HCV among Indigenous people is addressing the issue of shame.

Research suggests that even where people with HCV choose not to undertake treatment or are ineligible to do so, support from healthcare providers is important as it assists them in managing and living with the virus. This support extends beyond treatment to general health and wellbeing. Additionally, research which focuses specifically on Indigenous Australians supports the need for care and support, by suggesting that treatment for HCV will not solve all the issues facing this population, particularly issues of shame around an HCV-positive status. This research further suggests that finding ways for Indigenous people to live well with HCV will achieve more in reducing the HCV burden and is more pressing in the short term than focusing on increasing uptake of treatment.

The present study

To address some of the concerns around HCV treatment and care among the Australian Indigenous population, NSW Health established four programs targeted at supporting care and treatment for Aboriginal people living with HCV in New South Wales (NSW). These programs involved the instatement of Access Coordinator positions in Local Health Districts (LHDs) and Aboriginal Community Controlled Health Services (ACCHS) to facilitate liaison between specialist HCV care and treatment services (such as liver clinics within tertiary hospitals) and organisations that provide general health and social care for the Aboriginal people in NSW (such as Aboriginal Community Controlled Health Services); workforce development for HCV services (aimed at developing services for Aboriginal people); workforce development for Aboriginal health workers (aimed at developing capacity and knowledge in HCV); and community development via a series of arts-based workshops in a series of metropolitan, regional and rural sites. With regard to the Access Coordinator program, six positions were established in five LHDs. A further Coordinator position was established in an Aboriginal Community Controlled Health Service and two additional positions were available, but were not able to be filled (one in the Justice and Forensic Mental Health Network and one in an Aboriginal Community Controlled Health Service).

The goal of the present research was to explore the experiences of Aboriginal people living with HCV in relation to HCV care and treatment. More specifically, this research aimed to evaluate these experiences since the investment in this multi-factorial HCV enhancement program by NSW Health. This evaluation aims to:

1. explore the structural and organisational barriers and facilitators in implementing the program, specifically the role of the HCV Access Coordinators.
2. explore the experiences of Aboriginal people with, or at risk of HCV in engaging with services providing HCV testing, programs supporting self-care and HCV treatment.
3. make recommendations during the research for changes to the role or operation of the HCV care and treatment coordinator and to consider issues relating to the sustainability of this program.

Method

To address these aims a multiple method project was conceived to include: survey and interview with Aboriginal people living with HCV and interviews with key Aboriginal and non-Aboriginal health workers and stakeholders involved in the NSW Health investment.

Survey of and interview with Aboriginal people living with HCV

NSW residents who identified as Aboriginal, were 18 years or above and self-reported as having HCV, were eligible to participate. Recruitment postcards were distributed in relevant services (such as Needle and Syringe Programs, methadone clinics, liver clinics, non-government agencies, Aboriginal Community Controlled Health Services), via personal contacts and referrals from existing participants.

The survey examined participants' quality of care in relation to HCV, engagement with HCV related services, management of HCV and choices around HCV treatment. The survey also investigated participants' knowledge of HCV, contact with HCV health promotion (with a focus on events and programs run as part of the NSW Health investment), quality of life, resilience and experiences of stigma and discrimination. A number of pre-existing measures were used to examine these focal areas. Participants were provided with \$30 to acknowledge their time and contribution.

Survey participants were asked whether they could be contacted for a follow-up interview. A selection of those who agreed to be recontacted were invited to participate in an interview. The interview schedule mirrored the topics covered in the survey but allowed participants to tell their story in detail. The three main areas covered in the interviews included HCV history, HCV treatment and care and perceptions of HCV. Participants were provided with \$30 to acknowledge their time and contribution.

Health workers and stakeholders

The sample of key stakeholders consisted of staff of government, non-government and Aboriginal health services from across NSW, who were either involved in the implementation of the NSW Aboriginal HCV Service Access Program or had experience working with Aboriginal people living with HCV in relation to care and treatment. To enable the inclusion of a range of staff perspectives and experiences, the research team actively targeted four groups across the state:

1. Aboriginal Access Coordinators
2. Line Managers of Aboriginal Access Coordinators
3. Senior staff of HCV treatment services linked to the NSW Aboriginal HCV Service Access Program
4. Senior staff of relevant ACCHS

These participants were asked to discuss their experiences and perceptions of the NSW Health investment as well as issues pertaining to unmet need or opportunities with regard to improving care and treatment for Aboriginal people living with HCV. These interviews focused on examining the organisational and system-level influences on the program.

Ethical consideration

This project was overseen by an advisory committee and included sufficient staffing by Aboriginal people to ensure appropriate cultural protocols were followed and that all staff abided by principles of culturally safe research. Since the survey and interview focused on participants' experience of living with HCV, a chronic and highly stigmatized disease, protocols were put into place to support participants during and after the survey and interview were completed.

The study was approved by the Human Research Ethics Committees of the Aboriginal Health and Medical Research Council, UNSW Australia and the Sydney Local Health District. Since this study recruited Aboriginal people and staff from government health services, it was necessary to submit relevant local health districts (LHDs) site specific ethic applications (SSA). A total of 16 SSA were approved across eight LHDs. During this project the structure of the NSW Health ethics and research governance systems continued to change and evolve resulting in significant delays to the project.

The original aim of this project was to conduct two waves of data collection to examine HCV-related knowledge and access to care over time. This was not possible due to the above mentioned delays. Hence, data collection was consolidated to achieve robust samples in each of the three arms of the project.

Results

Surveys of Aboriginal people living with HCV

Of the 203 participants, 117 (57.6%) were male, 84 (41.4%) were female and one was transgendered. The overwhelming majority of the sample identified as Aboriginal; however, seven participants were of both Aboriginal and Torres Strait Islander descent. The mean age of the sample was 38.1 years ($SD = 9.6$) while two-fifths of the sample ($n = 84$) was aged between 36 and 45 years. The majority of the sample, that is around 60% ($n = 116$), had some high school education, but had not completed Year 10. Only 10 participants had a trade certificate or Diploma, and 7 participants had attended university. Very few participants were currently employed (18 participants in either full-time or part-time work), and 179 (88%) participants received Centrelink or financial assistance payments from the Government. Of the 203 participants, 163 or 80% had ever been in prison. The highest number of participants, $n = 82$ (40.4%), were diagnosed with HCV over 10 years ago. The second highest category, $n = 48$ (23.5), was diagnosed within the last 5–10 years while 31 participants (15%) were diagnosed with HCV in the last year.

There are a number of positive findings to note related to knowledge of and engagement with HCV care. Participants show high rates of satisfaction with the HCV care they receive (and this is independent of the site of care). The results from this survey indicate comparable rates of engagement with HCV-related care and treatment in relation to measures of treatment intention, receipt of referral to specialist and uptake of treatment when compared with samples which have not specifically recruited Aboriginal people living with HCV. While these results indicate comparable rates of engagement with HCV care between Aboriginal and non-Aboriginal samples, it is important to note that Aboriginal people experience a proportionally higher prevalence of HCV. Hence, these results should not be interpreted as the 'best that can be achieved'.

Uptake of HCV treatment: Approximately 16.7% of this survey sample had received HCV treatment (6 participants reported currently being on treatment; 28 participants reported having received treatment previously, Table 9). It is also important to note that this result is not related to sampling, as few survey participants were recruited from HCV treatment services.

HCV Treatment intention: Of those who had not received HCV treatment, 55% indicated that they intended to have treatment within the next two years (Table 9).

Receipt of referral to specialist: In this sample, 41% had received a referral to a specialist and of those, 55% had seen a specialist about HCV (Table 9).

HCV knowledge: The knowledge score reported by this sample was a mean of 11.4 (of 16 questions), which shows relatively good knowledge (Table 11).

HCV care: 79% of this sample had seen a GP or other health worker specifically for HCV within the last year (indeed, 63% reported having done this within the last six months) (Table 10).

Changes to lifestyle: The majority of participants reported making some change to their lifestyle since HCV diagnosis (with most common responses indicating reducing/cutting out alcohol (66%), increasing exercise (53%), change to diet (52%), reducing/cutting out illicit drug use (50%) and accessing information about HCV (46%)). Only 8% of the sample indicated that they had made no changes (Table 10).

A number of statistically significant relationships were found between measures of satisfaction with care and quality of life and the various measures of stigma and discrimination. The issue of trust in services forms a core theme which emerged in interview data and will be discussed in more detail below.

Correlational analysis revealed that exposure to HCV health promotion materials and events was associated with some important outcome variables. Exposure to HCV health promotion was related to HCV knowledge in that those who had seen these promotional materials were more likely to have higher HCV knowledge scores.

A second important finding around the exposure to HCV promotional materials was the association of this variable with HCV treatment intent. Correlational data illustrates that those exposed to HCV treatment were more likely to report intent to undertake treatment within the next two years.

Metropolitan and non-metropolitan participants did not significantly differ in their gender or educational attainment. No significant difference was found between metropolitan and non-metropolitan participants in regards to receiving a referral to a specialist, treatment intention, or currently or ever being on HCV treatment. However, metropolitan participants were significantly more likely to have seen or been involved in any HCV health promotion than non-metropolitan participants. Additionally, there was no significant correlation between geographical location and measures of HCV knowledge, satisfaction with HCV care, HCV discrimination, stigma related to HCV disclosure, general healthcare or cultural discrimination.

Interviews with Aboriginal people living with HCV

A total of 38 survey respondents participated in an in-depth interview. Around a third ($n = 15$) of interview participants were female, with one interviewee identifying as transgender. The mean age of interview participants was 40 years. Eleven participants had experience of HCV treatment and one participant was just about to start treatment. Where relevant, analysis was conducted by examining two groups of participants; those who had undertaken HCV treatment and those who had not.

Although there were some dissenting voices, the core issue of HCV stigma dominated the experience of many interview participants. Extreme reactions to diagnosis (such as feeling 'shattered' and 'dirty') and very limited or no disclosure of an HCV-positive status were present within these data. Participants explained that they knew little about HCV when diagnosed and that only limited information to support them in living with the virus was available in Aboriginal communities. Although some participants reported that relationships with family had improved with time and access to information, others reported they still kept their HCV-positive status secret or were isolated from family.

The interview data showed very strong motivations among participants to take steps to promote their health and resilience in seeking information and care despite significant concerns about confidentiality and fear of shame associated with HCV.

Participants in these interviews discussed similar barriers to engaging with treatment which have been discussed in previous research, particularly fear of treatment side effects.

Interviews with health workers and stakeholders

There were different experiences in each LHD in relation to recruitment, retention and activities undertaken by Access Coordinators. Indeed, some LHDs were not able to recruit Access Coordinator positions, or had periods of time in which the positions were not filled. One LHD has continued the Access Coordinator position after the completion of the four year program with an expanded remit.

Issues internal to the work context in which the Coordinator positions were housed were perceived as having more impact on the implementation and achievements of the Coordinator positions than issues between various health systems. Although the issues may vary across the positions involved, a common set of concerns related to the cultural safety

of the workplace, the nature of the role, the background and skill mix or the type of person recruited, and the lack of local input into the development of the Coordinator role.

Despite these critical perspectives, most Coordinators and Managers commented positively on some aspects of the program, particularly the ‘Where’s the shame, love your liver’ community development activities. The endorsement of ‘Where’s the shame, love your liver’ as a means to raise community awareness of HCV was almost universal.

The participants involved in HCV clinical care reported little impact of the Access Coordinator program on their activities. In regional areas, this was related to distance with some HCV services being located at a significant distance to the Coordinator position. Other participants felt that they had experienced no change in demand in relation to the attendance of Aboriginal people at their service.

Few ACCHS agreed to be involved with the project. This may relate to competing demands on the organisations, or the perception that the Access Program was of limited relevance to ACCHS given that the period of funding for the project was limited and that funds were not directed to ACCHS. Engagement with ACCHS was described as difficult by a number of LHD participants. This related to varying issues, but particularly to the already full health agenda for Aboriginal people and services and in some areas, disruption to ACCHS operations. A model of HCV care for Aboriginal people was developed during the course of this project by ACCHS medical staff. The implementation of this model can assist LHD workers in understanding the ways in which HCV is managed in ACCHS. These data would suggest that building partnerships is an important element of a model of care. Other important elements include incorporation of HCV (or more broadly, liver health) in chronic disease programs; community education about HCV; incorporation of HCV care and treatment activities in services where Aboriginal people with HCV are identified (prisons, services for people who inject drugs); other models of care such as support by a peer worker, or a treatment support officer, patient navigator programs, or trials of group models of care.

The importance of the corrections system must be noted. The rate of imprisonment of survey participants, of 80%, is an overwhelming finding. Additionally, a history of imprisonment was associated with lower HCV knowledge. Opportunities for promoting better understanding of HCV among prisoners must be examined. A significant failing of this overall project is that no Access Coordinator position was filled in Justice Health.

Recommendations

- Raise the health literacy of Aboriginal communities in relation to HCV in order to lessen the burden of stigma and discrimination felt by people diagnosed with HCV
- Consider replication of innovative HCV engagement programs (such as ‘Where’s the shame, love your liver’ and the Deadly Liver Mob) in other areas and/or in an ongoing program of activity, ensuring that key principles of local consultation and modification to local context are embedded
- Continue efforts to build relationships and partnerships between mainstream and Aboriginal health services—that is, workers and systems need to be seen as professional, discreet, credible and culturally safe

- Develop an ongoing program of HCV training for staff of ACCHS, or support the ongoing inclusion of HCV modules in other programs (such as programs offered by the Aboriginal Health College or in induction modules)
- Improve the quality of diagnosis via the provision of information in culturally appropriate ways and according to need (such as literacy support)
- Provide referral information for Aboriginal people living with HCV, and at diagnosis, to community organisations (such as Hepatitis NSW and NUAA) to provide anonymous access to information and support
- Promote HCV care and treatment in places where Aboriginal people access services including ACCHS and general practice, noting the over-representation of Aboriginal people in NSPs, drug treatment services and prison. Issues to emphasise include the importance of being tested properly, ease of liver health scan (via Fibroscan, where available), actions that can be taken to better live with HCV, the changing nature of treatments and post-release referral pathways between prisoner health services and ACCHS, or other primary care services
- Support clinicians in high prevalence services to be aware of their important role in raising awareness and recommending care/treatment
- Consider the inclusion of HCV in chronic illness plans, well-person checks and other ways that existing health structures (both ACCHS and mainstream services) can be used to embed HCV care for Aboriginal people in health systems
- Consider building a network of peer workers in the HCV area as there is a growing body of evidence of the added benefits that peer workers bring for marginalised populations
- Develop models of a ‘treatment support officer’ role or ‘patient navigator’ to manage practical and logistical issues regarding testing, treatment assessment and preparation, as well as management during and after treatment, including peer workers within such models
- Emphasise the importance of the local context and consultation process in development of new models of care or implementation of new positions
- Consider trials of incentivised participation in HCV programs (for example, education programs which relate to the State Debt Recovery program, or assessment, or treatment programs) including the development of ethical and culturally safe protocols to support such trials
- Consider the opportunities arising in NSW with the roll-out of activity-based funding protocols such as opportunities to maintain designated positions in HCV treatment programs for Aboriginal people
- (Given the stigma associated with HCV) consider the development of referral and care pathways that minimise the number of times an Aboriginal person with HCV is required to ‘tell their story’ to a new clinician or at a new service

1 Literature review

1.1 Introduction

HCV is a significant public health problem, affecting more than 123 million people globally (Global Burden of Disease Working Group, 2004; Perz et al., 2004). Transmission by blood-to-blood contact, through the sharing of equipment for injecting drugs, accounts for the majority of HCV incidences in the developed world (Razali et al., 2007). Transmission of HCV may also occur through the use of unsterile equipment for tattooing and medical procedures, perinatal (mother-to-child) transmission and through needle stick injury. In Australia, it is now estimated that over 300,000 people have been infected with HCV, and over 200,000 people are living with chronic HCV (Kirby Institute, 2011, 2012b). HCV presents a significant economic burden, with a recent evaluation estimating annual HCV-related costs to be at \$252 million to Commonwealth and State governments (Boston Consulting Group, 2012). Over 60% of these costs are medical while much of the remainder is spent on government assistance by the Department of Education, Employment and Workplace Relations and the Department of Families, Housing, Community Services and Affairs (Boston Consulting Group, 2012). For every dollar spent to treat chronic HCV, four more dollars are spent dealing with the failure to prevent, treat and cure the infection (Boston Consulting Group, 2012). Costs of HCV go beyond economic to health consequences for those living with the virus. The Ministerial Advisory Committee on AIDS Sexual Health and HCV Sub-Committee (2006) estimates that nearly 2,000 people with HCV antibodies have died in Australia of HCV-related liver disease since the beginning of the HCV pandemic during the early 1960s (Ministerial Advisory Committee on AIDS Sexual Health and HCV Sub-Committee, 2006). Additionally, around 6,000 people have HCV-related cirrhosis, with research indicating that liver failure occurs in 250 people and hepatocellular carcinoma (liver cancer) in 120 cases every year (Kirby Institute, 2011).

Australia's national response to HCV is guided by the Third National Hepatitis C Strategy 2010–2013 (Australian Government Department of Health and Ageing, 2010a). The goal underpinning the strategy is 'to reduce the transmission of, and morbidity and mortality caused by, HCV and to minimise the personal and social impact of the disease' (Australian Government Department of Health and Ageing, 2010a, p.7). The strategy forms part of a collection of five national strategies, which are all targeted at reducing the transmission of both sexually transmissible infections and blood borne viruses, in addition to alleviating the morbidity, mortality and social impacts caused by these infections (Australian Government Department of Health and Ageing, 2010a). HCV in Australia is also covered by the Third National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy 2010–2013 (Australian Government Department of Health and Ageing, 2010b). This strategy recognises the disproportionate number of the Australian Indigenous population affected by sexually transmitted infections and blood borne viruses.

In NSW, strategies for HCV and an implementation plan for Aboriginal people exist (NSW Department of Health, 2007a; NSW Department of Health, 2007b). The goals of the NSW Hepatitis C Strategy are to minimise the transmission of HCV; improve the health status of people with HCV; and to minimise the negative personal, social and economic impacts of HCV. The implementation plan is a tool for those involved with implementing the NSW Hepatitis C Strategy as it relates to Aboriginal people. The implementation plan is underpinned by a number of principles including community ownership and participation; holistic approach to health; collaboration and partnership; active outreach; evidence-based approach; and development of the workforce.

1.2 HCV prevalence among Indigenous populations

There is limited research on HCV among Indigenous populations globally. In a systematic review of the prevalence of viral hepatitis in the Canadian Inuit and First Nations populations, Riben et al. (2000) noted the difficulties in obtaining data on HCV among these groups due to variations and inconsistencies in methods of data collection. However, available research suggests that there are significant disparities in HCV prevalence across Indigenous and non-Indigenous groups, the greatest of which is apparent among the Australian and Canadian Indigenous populations (Rempel & Uhanova, 2012). In Canada, data collected from the Medical Services Branch and provincial health databases suggests HCV prevalence to be anywhere between 0.4% and 29.3% among the Indigenous population in four regions (Riben et al., 2000). In a more recent systematic review, Minuk and Uhanova (2003) reported serological evidence of HCV to be 1% to 18% among the Canadian Inuit and First Nations populations, which is significantly higher than the 0.5% to 2% prevalence observed among the general Canadian population. Finally, Wu et al. (2007) compared the incidence of HCV among Indigenous and non-Indigenous Canadians using data from the Enhanced Hepatitis Strain Surveillance System. Data from six jurisdictions in Canada were analysed, and findings suggested that the incidence of HCV per 100,000 people aged 15 years and older was 18.9% in the Canadian Indigenous population, compared with just 2.8% in the non-Indigenous population (Wu et al., 2007).

The Australian Indigenous population is overrepresented in both the prevalence of HCV and incidence of newly reported HCV infections. In an Australian study by Maher et al. (2007), participants from culturally and linguistically diverse (CALD) backgrounds, including Aboriginal and Torres Strait Islander participants, had significantly higher HCV seroconversion rates than Anglo-Australian participants. This is despite reporting similar risk behaviours, such as duration and frequency of injecting, and sharing of injecting equipment (Maher et al., 2007). In 2008, the National Centre in HIV Epidemiology and Clinical Research (NCHECR, 2008a) estimated that around 16,000 Indigenous persons were chronically infected with HCV in Australia, representing around 8.3% of the total Australian population living with chronic HCV at the time. Additionally, findings suggested that the rate of HCV diagnosis in 2007 for the Australian Indigenous population was more than double for the age groups 13–19, 20–29 and 30–39 compared with non-Indigenous populations (NCHECR, 2008a). More recent research by The Kirby Institute (2012a) suggests the prevalence of HCV to be substantially higher than previously estimated, with the rate of newly diagnosed HCV in the Indigenous population being 142 per 100,000 as of 2011, compared with a non-Indigenous rate of 40 per 100,000.

1.3 Risk factors for HCV among Indigenous populations

One explanation for the disproportionate number of Australian Indigenous people infected with HCV is the overrepresentation of Indigenous persons in populations identified as a priority by the national HCV strategy (Australian Government Department of Health and Ageing, 2010a), people who inject drugs (PWID), and people in custodial settings. Although prevalence of illicit drug use among Indigenous Australians is not well known due to gaps in data collection (Australian Institute of Health and Welfare [AIHW], 2006; Kratzman et al., 2011), available research suggests that it is high. For example, between 2008–2012, the proportion of Australian Indigenous participants taking part in the Australian Needle and Syringe Program Survey ranged from 11–12% of over 2,000 participants each year (Iverson et al., 2013). Additionally, the Pharmacy Needle and Syringe Survey conducted in Sydney between 2006 and 2008 reported a higher proportion of Aboriginal participants, with 15–20% of the sample identifying as Aboriginal (Bryant, Wilson, Hull, & Treloar, 2010). Sixteen percent of 924 participants from around Australia who reported injecting drugs in the 2012 Illicit Drugs Reporting System identified as

Indigenous (Stafford & Burns, 2013). Finally, Day, Ross and Dolan (2003) conducted three cross-sectional surveys in Sydney among people who inject drugs, and found that Indigenous persons were overrepresented in each survey (17%, 19%, and 15%).

Indigenous status is associated with an earlier onset of injecting drugs (Abelson et al., 2006) in addition to an increased likelihood of sharing injecting equipment, which places Indigenous persons at a higher risk of acquiring a blood-borne virus such as HCV (Correll, MacDonald, & Dore, 2000; Paquette, McEwan, & Bryant, 2012; Ward et al., 2011). Some researchers have proposed that increased likelihood of sharing injecting and tattooing equipment among Indigenous communities may be linked to cultural practices, such as shared use of possessions with kin (Correll et al., 2000; Larson, Shannon, & Eldridge, 1999; van der Sterren & Anderson, 2002). For example, Larson et al. (1999) surveyed 77 Indigenous people who injected drugs and found that most had first injected with a family member, friend or sexual partner. The authors suggested that sharing equipment with these relations may not actually be viewed as 'sharing' (Larson et al., 1999). Additionally, reciprocity may be an important cultural value, thus Indigenous people may feel obliged to share equipment with close relations (van der Sterren & Anderson, 2002).

As a group, Indigenous people face a number of disadvantages on a range of health and socio-economic outcomes. On a global scale, Indigenous people have poorer health than non-Indigenous people, which is associated with poverty, malnutrition and infection and is exacerbated by inadequate healthcare and health promotion (Graeley & King, 2009). Often disadvantages faced by Indigenous Australians are a result of unequal access to the same opportunities as non-Indigenous Australians, such as access to education, employment and healthcare. Additionally, as Hunter (2007) argues, many of these disadvantages are compounded for Indigenous Australians living in rural and remote areas of the country. Health and social issues include poverty, homelessness and mental illness, which may all be linked to the higher prevalence of HCV among Indigenous compared with non-Indigenous Australians. There is empirical evidence to suggest that HCV seroconversion among Indigenous people is associated with denial of shelter, incarceration, mental illness and sex work (Miller et al., 2011; Spittal et al., 2012; Wood et al., 2005; Wu et al., 2007). In relation to mental health, separate findings show the inter-related nature of higher rates of HCV among people with mental illness (Gunewardene, Lampe, & Ilchef, 2010), and higher rates of mental health problems among Indigenous Australians compared with non-Indigenous Australians (Jorm, Bourchier, Cvetkovski, & Stewart, 2012). Indigenous people may additionally be less knowledgeable about the transmission of blood-borne viruses (BBV) than the general community. This may be due to limited access to education and information, especially for Indigenous people residing in rural areas. Paquette et al. (2012) studied knowledge of BBVs among Aboriginal and non-Aboriginal people who inject drugs, and found that Aboriginal people were more likely to share injecting equipment, and were less knowledgeable about transmission and treatment of BBVs than non-Aboriginal people (Paquette et al., 2012).

A further issue to consider is the cumulative toll and intergenerational effects of trauma related to varying practices visited upon Indigenous peoples as a result of white colonisation. In Canada, a direct link between the incidence of HCV infection and having at least one parent attend a residential school has been established (Craib et al. 2009). These writers suggest that:

The forced removal of children from their homes and placement in boarding schools is considered by many researchers, based on testimony given by family and community, to be directly responsible for poor health outcomes among survivors, including the abuse of drugs and alcohol ... As affected communities raise their children and grandchildren, the intergenerational effects of abuse and familial fragmentation become evident. Several Aboriginal HIV/AIDS service providers have suggested that drug use is just one way that people deal with the complex effects of poverty, despair, discrimination, loss of language and traditional territories and the erosion of culture.

For Australian Indigenous communities, the forced removal of children from families (The Stolen Generation), the dispossession of lands, repression of cultural practices, protocol and language, and other racist governmental policies can be read in parallel to the Canadian experience and as contributing to ongoing, trans-generational trauma (Atkinson, 2002).

Indigenous people are more likely to have contact with the criminal justice system, which can negatively affect health. Research indicates that police activity is associated with syringe sharing, rushed injection and reuse of equipment, which may all be risk factors for HCV (Pan et al., 2012). There is also evidence to suggest that incarceration is an independent risk factor for HCV among both Indigenous and non-Indigenous populations (AH&MRC Consultancy Services & Mandala Consulting, 2004). The National Prison Entrants' Bloodborne Virus and Risk Behaviour Survey is conducted every three years to monitor the prevalence of blood borne viruses and sexually transmissible infections among Australian prison entrants. In 2010, the prevalence of HCV among participants in the prison entrants' survey was 22% (Butler, Lim, & Callander, 2011). Indigenous people constitute approximately 27% of the Australian prison population, and are therefore 14 times more likely to be imprisoned than non-Indigenous Australians (Australian Bureau of Statistics [ABS], 2012b). Research suggests that Indigenous people in custodial settings are at higher risk of acquiring HCV than non-Indigenous people. For instance, over 30% of participants in the 2010 National Prison Entrants' Survey identified as being Aboriginal or Torres Strait Islander, and over 50% of these prisoners had HCV antibodies (Butler et al., 2011). Similarly, in a 2007 survey of Canadian prisoners, Indigenous women were at higher risk of both HIV and HCV, with nearly 50% reporting that they had HCV (Zakaria, Thompson, Jarvis, & Borgatta, 2010).

The high prevalence of HCV among prisoners may be attributable to the overrepresentation of people who inject drugs in correctional facilities. At any one time, as much as 60% of the Australian prison population may inject drugs (Butler et al., 1997; Day et al., 2003). Prisoners are also more likely to engage in HCV risk practices, such as shared use of injecting equipment and use of unsterile equipment for tattooing and piercing (Butler et al., 2011), and may have limited knowledge about the risk and transmission of HCV (Paquette et al., 2012; Van der Poorten, Kenny, & George, 2008). Prison is also believed to be a common point of transition to injecting drug use for both Indigenous and non-Indigenous offenders (Edwards, Frances, & Lenmann, 1999; Lane, 1993). There are currently no needle and syringe programs (NSPs) available in any Australian correctional facility, and the lack of access to sterile injecting and ancillary equipment may assist in explaining the high rate of engagement in risk behaviours and high HCV prevalence among Australian prisoners.

1.4 HCV treatment and care

Currently, HCV is treated using anti-viral combination therapy of pegylated interferon and ribavirin. Sustained virological response occurs in approximately 50% of people treated for HCV, with a higher success rate of 70% for genotypes 2 and 3 (Heathcote & Main, 2005; Hepatitis Australia, 2012). Recent improvements to HCV treatment have increased the efficacy of treatment, with clinical trials suggesting that additions of Boceprevir and Telaprevir will substantially increase chances of sustained virological response (Bacon et al., 2011; Jacobson et al., 2011). In early 2013, the Australian Federal Health Minister, Tanya Plibersek, announced that Boceprevir and Telaprevir are to be listed on the Pharmaceutical Benefits Scheme. Under the scheme, more than \$220 million are to be provided by the Australian government to subsidise treatment using Boceprevir and Telaprevir for people aged over 18 years living with genotype 1 (Minister for Health, 2013). It is believed that these additions will improve sustained virological response rates for those with genotype 1 to between 70–80% (Hepatitis NSW, 2013). These additions will also shorten the length of treatment by about half.

Despite improvements to HCV treatment, uptake remains low on a global scale (Grebely et al., 2009; Iverson et al., 2013; Mehta et al., 2008). Although access to HCV treatment in Australia has nearly doubled since 2004, research suggests that the proportion of people chronically infected with HCV receiving treatment is between 10–12% (Kirby Institute, 2011) or around 3,000–4,000 people receiving treatment annually (NCHECR, 2008b). No research has so far estimated the number of Indigenous people accessing HCV treatment. The Australian Chronic HCV Observational Study (ACHOS) collected information from 24 primary care and tertiary level clinics providing HCV treatment. Of the 1,240 patients recruited between 2008–2009, 52 (4%) identified as Aboriginal or Torres Strait Islander (NCHECR, 2010). Although this proportion is above the population rate of Indigenous Australians (at approximately 2.5%), it is less than the 8.3% estimated prevalence of HCV in Indigenous populations (NCHECR, 2010). Unfortunately, the ACHOS study has not conducted further analysis of these data, except to indicate that identifying as Indigenous was not associated with deferral of treatment in this sample (Gidding et al., 2011). However, some available literature does suggest that Indigenous populations are underrepresented in samples of people with HCV accessing treatment. For example, Cooper et al. (2008) compared baseline characteristics and sustained virological response to HCV treatment among Aboriginal and non-Aboriginal Canadians in a community-based treatment program. Findings suggest that despite similar rates of sustained virological response, Aboriginal Canadians comprised only 1.7% of those eligible for analysis. The Ministerial Advisory Committee on AIDS Sexual Health and HCV Sub-Committee (2006) estimates that uptake of HCV treatment in Australia needs to triple in order to decrease the number of people living with chronic HCV, and curb projections of increases in those with advanced liver disease or cirrhosis.

1.5 Barriers to HCV treatment and care

As well as limits on government subsidy provided for HCV treatment, people with HCV may face a number of barriers to treatment at personal, provider and system levels. These barriers often begin with poor diagnosis experiences, with little to no information provided by GPs about living with and managing HCV and available treatment options (Hopwood & Treloar, 2004; Treloar, Newland, Harris, Deacon, & Maher, 2010). A number of researchers have reported that GPs have limited HCV knowledge and are unaware that specialists prefer referral to occur soon after diagnosis (McNally et al., 2006; Gupta, Puech, & Ward, 2000; Gupta, Shah, & Ward, 2006). Conversely, other studies have highlighted the importance of the role of a GP in supporting links to HCV treatment with significant associations between being told by a doctor to have treatment and reports of attending a specialist and treatment uptake (Grebely et al., 2011). A qualitative study similarly indicated the importance of a doctor's recommendation for promoting treatment:

I'm sure [my doctor] would've said something to me a lot ... if I need treatment or, my liver, or whatever, my hep C was not going too good. I'm sure he would've said something ... but, no, he didn't (Treloar, Newland, Rance, & Hopwood, 2010)

At the individual level, research suggests that barriers may also include fears of the side effects associated with a treatment known to be difficult and demanding (Doab, Treloar, & Dore, 2005; Alavi, Raffa et al., 2013), concerns about the impact of treatment on work and family commitments (Fraenkel, McGraw, Wongcharatrawee, & Gercia-Tsao, 2005; McNally et al., 2006), access to social support (McNally, Temple-Smith, & Pitts, 2004; Wilson et al., 2010), and financial strain associated with costs of treatment where government subsidy cannot be acquired (Evon et al., 2010). Additionally, people with HCV may face competing health and social concerns that impede their access to care and treatment, including poverty (Edlin et al., 2005; McNally et al., 2006; Grebely et al., 2008), unemployment, lack of stable housing (Edlin et al., 2005; McNally et al., 2006; Grebely et al., 2008), and comorbidity such as mental health problems and substance use (Weiss, Alcon, Rabkin, &

Dieterich, 2012). People with HCV may also experience stigma and discrimination around their HCV-positive status and history of drug injecting. Research suggests that stigma and discrimination may be particularly prevalent in healthcare settings, and can lead to a number of negative health outcomes for people with HCV, such as feelings of depression and isolation, and reluctance to seek out healthcare (Evon et al., 2010; Treloar, Rance, & Backmund, 2013). Fear or concern of disclosing an HCV-positive status to healthcare professionals may also act as a barrier to decisions to access HCV treatment (Wilson et al., 2010). These negative outcomes may be exacerbated for Indigenous Australians, who are often at higher risk of experiencing these disadvantages than non-Indigenous Australians.

International and Australian research have found that attending an HCV specialist for assessment and HCV treatment uptake was associated with Aboriginal ethnicity (Alavi, Raffa et al., 2013; Alavi, Grebely et al., 2013; Iversen et al., 2013). As well as the barriers commonly experienced by people with HCV outlined above, Indigenous populations may face a range of additional competing health and social issues which inhibit their access to healthcare, support and treatment. These can include unemployment, poverty, homelessness, increased risk of health problems, substance abuse and early as well as higher levels of mortality (e.g. ABS, 2012a). In a study of Canadian Indigenous people accessing mental health and addictions health services, Smye, Browne, Varcoe and Josewski (2011) found that many participants had a history of violence and abuse, and were living with co-occurring health and substance use problems, such as HIV, HCV and depression. It was also found that ongoing experiences of racism, stigma and discrimination, such as within healthcare settings, led participants to express mistrust in the healthcare system (Smye et al., 2011).

Australian Indigenous people face unequal access to health services due to issues of proximity, availability and the cultural appropriateness of such services (ABS, 2012a). In particular, Indigenous Australians are less likely to utilise healthcare services, and cite barriers to healthcare such as communication and experiences of racism as the reasons (Artuso, Cargo, Brown, & Daniel, 2013; Isaacs et al., 2010). Isaacs et al. (2010) examined barriers and facilitators to utilisation of mental health services among Australian Indigenous people. Barriers to mental healthcare utilisation include a history of discrimination, resulting in a lack of trust in mainstream healthcare, in addition to misunderstandings arising from cultural and language differences (Isaacs et al., 2010). Poor experiences in healthcare have been reported by Indigenous Australians, and these include breaches of confidentiality and trust (McNally & Latham, 2009). McNally and Latham (2009) suggest that the core challenge associated with HCV among Indigenous people is the concept of shame. This concept cannot be understood using traditional understandings of stigma and discrimination due to the distinct cultural meanings that shame has for Indigenous communities, which is also related to the notion of shyness amongst Indigenous people (McNally & Latham, 2009). Shame around HCV is argued to be a significant barrier to engagement with care and treatment as it prevents Indigenous people from talking about HCV with partners and healthcare professionals, and essentially precludes Indigenous people from accessing important information and healthcare (McNally & Latham, 2009).

Arising from some of the barriers associated with HCV treatment, Bova, Ogawa and Sullivan-Bolyai (2010) and Weiss et al. (2012) highlight the importance of a supportive relationship between client and health provider. Competing health and social concerns, such as substance use and mental health issues, make stricter treatment regimens difficult to adhere to (Weiss et al., 2012). Hence, ensuring that appropriate support mechanisms are in place is essential in assisting people with HCV through their treatment journey. Furthermore, research conducted among clients of an integrated HCV service in New Zealand suggests that even where people with HCV choose not to undertake treatment or are ineligible to do so, support from healthcare providers is important in assisting them in managing and living with the virus (Brener, Gray, Cama, & Treloar, 2013). This extends beyond treatment to general health and wellbeing, such as dental and nutritional needs (Brener, Gray, Cama, &

Treloar, 2013). Recent research among Indigenous Australians supports the need for care and support by suggesting that treatment for HCV will not solve all the issues facing this population. The authors highlight that issues of shame around an HCV-positive status and finding ways for Indigenous people to live well with HCV will achieve more in reducing the HCV burden and is more pressing in the short term than promoting informed decisions about treatment (McNally & Latham, 2009). Furthermore, the relationship between general health and chronic illness, such as HCV, highlights the need to address general health concerns among Indigenous people (McNally & Latham, 2009). It is therefore essential that culturally specific and appropriate HCV care for this population be implemented to address health and social issues alongside HCV concerns, including the unequal access to healthcare experienced by Indigenous population (Hepatitis Australia, 2007; McNally & Latham, 2009).

1.6 The present study

To address some of the concerns around HCV treatment and care among the Australian Indigenous population, NSW Health established four programs targeted at supporting care and treatment for Aboriginal people living with HCV in NSW. These programs involved:

1. the instatement of Access Coordinator positions in local health districts (LHDs) and Aboriginal Community Controlled Health Services to facilitate liaison between specialist HCV care and treatment services (such as liver clinics within tertiary hospitals) and organisations providing general health and social care for Aboriginal people in NSW (such as Aboriginal Community Controlled Health Services);
2. workforce development for HCV services (aimed at developing services for Aboriginal people);
3. workforce development for Aboriginal health workers (aimed at developing capacity and knowledge in HCV); and
4. community development via a series of arts-based workshops in a series of metropolitan, regional and rural sites.

With regard to the Access Coordinator program, six positions were established in five LHDs, and a further Coordinator position was established in an Aboriginal Community Controlled Health Service. Two additional positions were available but were not able to be filled (one in Justice and Forensic Mental Health Network, and one in an Aboriginal Community Controlled Health Service).

The goal of the present research was to explore the experiences of Aboriginal people living with HCV in relation to HCV care and treatment. More specifically, this research aimed to evaluate these experiences since the investment in this multi-factorial HCV enhancement program by NSW Health. The evaluation aims to:

1. explore the structural and organisational barriers and facilitators in implementing the program, specifically the role of the HCV Access Coordinators
2. explore the experiences of Aboriginal people with or at risk of HCV in engaging with services providing HCV testing, programs supporting self-care and HCV treatment.
3. make recommendations during the research for changes to the role or operation of the HCV care and treatment coordinator and to consider issues relating to the sustainability of this program.

2 Method

2.1 Evaluation Team

The Centre for Social Research in Health (CSRH) developed a specialised team to undertake this evaluation, primarily involving an Aboriginal Mentor who advised and supported the team and oversaw matters of protocol. In addition, a Liaison Officer was centrally involved in establishing the project and developing relationships with Access Coordinators and Aboriginal and mainstream services important to the overall program of investment by NSW Health. A number of casual Aboriginal staff members were also involved in data collection. Three principal Aboriginal researchers were involved in the collection, interpretation and reporting of these data: Clair Jackson, Veronica Saunders and Priscilla Johnson. The team was guided by an ethos of reciprocal learning and investment in continuing development of all team members.

2.2 Survey and in-depth interviews of Aboriginal people living with HCV

2.2.1 Sample

To participate in the telephone survey and in-depth interview, participants had to be aged over 18 years, identify as Aboriginal or Torres Strait Islander, and report to currently be living with HCV, undertaking treatment or recently clearing the virus naturally or through treatment. Approximately 203 people living with HCV were recruited from across NSW.

Of the 203 participants surveyed, 38 were interviewed. Early in recruitment, all survey respondents who volunteered to participate in an interview were interviewed. However, in the later stages of recruitment, to enable the inclusion of a range of perspectives and experiences, the research team actively targeted three groups of participants who were:

- currently on treatment or had ever been on treatment
- interested in treatment in the next 12 months
- not interested in ever being treated for HCV

2.2.2 Recruitment

Community visits to each Aboriginal Access Coordinator were conducted during the early stages of the evaluation. During these visits, informal meetings were held with each Aboriginal Access Coordinator and local Aboriginal community groups to inform key stakeholders about the evaluation, discuss the context of the local area, identify possible recruitment sites and build rapport with the local Aboriginal community. Area specific recruitment strategies were developed for each Access Coordinator based on the collaborative work each had undertaken with local health services. The key recruitment strategy for this project was the distribution of recruitment postcards.

Recruitment postcards were designed to look similar to advertising postcards often displayed in cafes, libraries and movie theatres. The front of the postcard displayed a culturally appropriate design, created by the Aboriginal Mentor, while the back of the postcard briefly described the study without specifically referring to HCV. This was to limit the possibility of involuntary disclosure of people in possession of the postcard. A toll free number was included on the postcard to allow interested people to contact the Aboriginal Liaison Officer, free of charge, to receive further information about the study and, if eligible, book a suitable time to complete the telephone survey.

Recruitment postcards were circulated and distributed at a range of services across the state including:

- ACCHSs
- Liver clinics
- NSPs
- NGOs
- Aboriginal drug and alcohol services
- Drug user organisations

Services were provided a briefing sheet to assist them in distributing the postcards. Staff were asked to only distribute postcards to clients who had disclosed their HCV to them personally, and to inform clients that accepting the postcard did not obligate them to participate in the study. Additionally, services were asked to display postcards in the waiting room where other health promotional pamphlets and booklets are displayed.

Other recruitment strategies included distributing recruitment postcards at community health events and through community contacts, placing a one page advertisement in Users News as well as a small article and one page removable poster in the Network of Alcohol and Drug Agencies bulletin.

2.2.3 Procedure

Potential participants called the provided toll free number and spoke with the Aboriginal Liaison Officer. The Aboriginal Liaison Officer informed interested participants about the aims of the study, what the survey would consist of, and assessed their eligibility. If the person was interested and eligible to participate, the Aboriginal Liaison Officer organised a time, which suited both parties, to complete the survey over the phone. Participants were offered the opportunity to be surveyed by either an Aboriginal or non-Aboriginal researcher. Before the survey was administered, participants were reassured that any personal details or information they provided during the survey would remain confidential. Researchers completed the survey by reading out the question and possible responses to the participant over the phone, and entered the participant's response into a computer software program. The survey took on average 30–40 minutes. At the completion of the survey, \$30 was directly credited into the participant's bank account as reimbursement for their time and expertise.

Additionally, the Aboriginal Liaison Officer, Aboriginal Mentor and Research Officers visited mainstream and Aboriginal services to complete surveys with clients in person. Surveys completed on site were conducted in an interview style to mirror how surveys were conducted over the phone. Hard copies of the survey were then entered into the computer manually. Survey participants were reimbursed \$30 either via direct credit, cash or gift voucher depending on the research protocol of the host service.

All survey participants were asked if they were interested in taking part in an in-depth interview. The interviews were conducted by an experienced CSRH researcher. Similar to the survey, participants were offered the opportunity to be interviewed by either an Aboriginal or non-Aboriginal researcher. Interviews were undertaken only after informed consent was provided by participants. Interviewees were reassured that any personal details or information they provided during the interview would remain confidential. All participants were sufficiently fluent in English to provide informed consent and to participate in interviews with an English speaking interviewer (no interpreting services were available for this project). Most interviews were completed over the phone and lasted on average 30–40 minutes. All interview participants were reimbursed \$30 for their time and expertise in the same manner as described above.

2.2.4 Data collection instruments

The survey examined participants' quality of care in relation to HCV, engagement with HCV related services, management of HCV, and choices around HCV treatment. The survey also investigated participants' knowledge of HCV, contact with HCV health promotion (with a focus on those events and programs run as part of the NSW Health investment), quality of life, resilience, and experiences of stigma and discrimination. A number of pre-existing measures were used to examine these focal areas, some of which have previously been used in research with Indigenous people. Pre-testing was undertaken to identify problems with question content, misinterpretation of individual terms or concepts and problems with the survey design, such as skip patterns.

The interview schedule mirrored the topics covered in the survey, but allowed participants to tell their story in detail. Specifically, three areas were covered in the interviews: HCV history, HCV treatment and care, and perceptions of HCV.

2.3 Interviews with key stakeholders

2.3.1 Sample

The sample of key stakeholders consisted of staff from government, non-government and Aboriginal health services across NSW, who were involved in the implementation of the NSW Aboriginal HCV Service Access Program, or who had experience working with Aboriginal people living with HCV in relation to care and treatment. To enable the inclusion of a range of staff perspectives and experiences, the research team actively targeted four groups across the state:

1. Aboriginal Access Coordinators
2. Line Managers of Aboriginal Access Coordinators
3. Senior staff of HCV treatment services linked to the NSW Aboriginal HCV Service Access Program
4. Senior staff of relevant ACCHS

2.3.2 Recruitment

Individual decisions to participate in the evaluation interviews were entirely voluntary. While there was an expectation that senior staff at participating services would assist with the evaluation process by agreeing to be interviewed, there was no obligation to do so. Healthcare workers (HCWs) were sent an invitation letter which described the aims of the study. HCWs who volunteered to be interviewed were sent a copy of the information statement and consent form. The researcher would then organise a time, which suited both parties, to conduct the interview either over the phone or in person.

Approaches to ACCHS followed agreements with AHMRC ethics committees and recognised protocols, specifically that the ACCHS Chief Executive Officer (or designate) should provide approval for the project to commence. We respected the ACCHS process (such as discussion of the protocol by the ACCHS Board) and honoured each ACCHS decision about participation in the project.

Our Aboriginal Community Liaison Officer (ACLO) undertook to contact each ACCHS within the area where an Access Coordinator was placed. The ACLO explained the project and the need to acquire CEO approval (and very often also the endorsement of the ACCHS Board). The person who was contacted at each ACCHS varied according to the team's relationship and knowledge of ACCHS staff. In addition, a limited number of ACCHS in areas where Access Coordinators were not placed were also approached to participate using the same protocols. Finally, a site visit to a combined meeting of CEOs was undertaken to explain the project and make connections with each ACCHS.

The results of our efforts were:

- CEO approved and staff interviews collected: $n = 5$
- CEO approved but access to staff interviews denied: $n = 1$
- ACCHS declined to participate: $n = 2$
- ACCHS under administration or internal restructure: $n = 4$

2.3.3 Procedure

The interviews were conducted by an experienced CSRH researcher. Interviews were undertaken only after informed consent was provided by participants. Interviewees were reassured that any personal details or information they provided during the interview would remain confidential. All participants were sufficiently fluent in English to provide informed consent and to participate in interviews with an English speaking interviewer (no interpreting services were available for this project). The interview explored the aims, perceptions, difficulties and impact of the NSW Aboriginal HCV Service Access program as well as their perceptions of issues relating to care and treatment for Aboriginal people living with HCV. Most interviews were completed over the phone and lasted on average 30–40 minutes.

2.4 Data analysis

2.4.1 Surveys

Frequency data is presented to outline the demographic profile of the sample. Bivariate analysis including dependent t-tests, and Pearson's and Spearman's rho correlations were conducted on some aspects of the data. Statistical Package for Social Sciences software (SPSS) version 21 was used for all statistical analysis of the quantitative results.

2.4.2 Interviews

Digitally recorded interviews were transcribed verbatim. Transcripts were checked for accuracy against recordings, de-identified (names and other identifying information removed) and cleaned by the Aboriginal Mentor. The data was then read closely by a member of the CSRH evaluation team, and a number of themes were identified as relevant to the research questions. The research team then collaborated on the construction of a 'coding frame'—a set of organising, interpretive themes to aid analysis. This coding frame was then used to organise interview data within NVivo 9, a qualitative software program. Each aspect of the thematic analysis, that is the interpretations and meanings drawn from the interview data, was critically examined and summarised (along with supporting quotes).

For analysis of interviews with Aboriginal people living with HCV, analysis was segmented in relation to engagement with care. That is, analysis of data derived from interviews with participants who had received HCV treatment occurred separately to those participants who had not received treatment. The last step of this analysis was to examine patterns of responses and experience across the groups.

For analysis of interviews with health workers, analysis was similarly segmented. Data from each group of health workers (for example, Access Coordinators, managers of coordinators, health workers from HCV treatment clinics) were each analysed separately followed by an examination of patterns of responses across groups.

2.5 Ethical consideration

This project was overseen by an advisory committee and included sufficient staffing by Aboriginal people to ensure appropriate cultural protocols were followed, and that all staff abided by principles of culturally safe research. Additionally, the draft data collection tools (interview schedules and survey) were reviewed by the Aboriginal project staff to ensure that the issues raised were culturally suitable. The Cultural Mentor assisted in ensuring that Aboriginal research staff had the appropriate level of control over the data collection tools and their implementation.

Since the survey and interview focused on participants' experience of living with HCV, a chronic and highly stigmatized disease, protocols were put into place to support participants during and after the survey as well as at the completion of the interview. Respondents were informed that they could stop the survey or interview at any stage if they were feeling any sort of distress or discomfort. Additionally, the Aboriginal Liaison Officer would refer participants to a range of services, including HCV treatment and care, drug and alcohol, housing and legal aid, depending on the participants' needs. Once the survey was completed, respondents were offered information regarding the knowledge questions they had answered incorrectly.

The study was approved by the Human Research Ethics Committees of the Aboriginal Health and Medical Research Council, UNSW Australia, and the Sydney Local Health District. Since this study recruited Aboriginal people from government health services, it was necessary to submit relevant local health districts (LHDs) site specific ethic applications (SSA). A total of 16 SSAs were approved across eight LHDs. During this project the structure of the NSW health system continued to change and evolve. As a result, LHD HREC and SSA procedures were also changing as the project evolved, which subsequently caused significant additional work as well as delays to this project.

3 Findings

3.1 Survey results of Aboriginal people living with HCV

3.1.1 Demographics

The demographic data of the sample is presented in Table 1. Of the 203 participants, 117 (57.6%) were male, 84 (41.4%) were female and one was transgendered. The overwhelming majority of the sample identified as Aboriginal; however, seven participants were of Aboriginal and Torres Strait Islander descent. The mean age of the sample was 28.1 years ($SD = 9.6$). Two-fifths of the sample ($n = 84$) was aged 36–45 years. The majority of the sample, that is just under 60% ($n = 116$) had some high school education, but had not completed Year 10. Only 10 participants had a trade certificate or Diploma, and seven participants had attended university. Very few participants were currently employed (18 participants in either full-time or part-time work), and 179 (88.2%) receiving Centrelink or financial assistance payments from the Government. Of the 203 participants, 163 (80.3%) had ever been in prison. The highest number of participants ($n = 82$, 40.4%) were diagnosed with HCV over 10 years ago. The second highest category ($n = 48$, 23.6%), was diagnosed within the last 5–10 years, while $n = 38$ (18.7%) were diagnosed with HCV in the last year.

Table 1: Demographics

	<i>n (%)</i>
Gender	
Male	117 (57.6)
Female	84 (41.4)
Transgender	1 (0.5)
Cultural identity	
Aboriginal	195 (96.1)
Torres Strait Islander	0 (0.0)
Both Aboriginal and Torres Strait Islander	7 (3.4)
Age [M (SD)]	38.1 (9.6)
18–25	28 (13.8)
26–35	45 (22.2)
36–45	84 (41.4)
46–55	32 (15.8)
55 and older	8 (3.9)
Education	
Primary school	12 (5.9)
Some high school education	116 (57.1)
Year 10	48 (23.6)
Year 12/HSC	9 (4.4)
Diploma or trade certificate/TAFE	10 (4.9)
University	7 (3.4)
Employment	
Full-time	10 (4.9)
Part-time	8 (3.9)
Centrelink/ government financial assistance	179 (88.2)
Supported by others	1 (0.5)
Other	5 (2.5)
Ever been in Prison	
Yes	163 (80.3)
No	39 (19.2)
Time since diagnosis [M (SD)]	9.8 (8.2)
1 year	38 (18.7)
2–4 years	33 (16.3)
5–10 years	48 (23.6)
10 years or more	82 (40.4)

3.1.2 Identification with Aboriginal community

On the whole, participants were more likely to identify with their Aboriginal community than to not identify with it (see Table 2). One hundred and twenty-three participants (60.6%) felt that they belonged to their Aboriginal community either ‘quite a bit’ or ‘a lot’; with the majority of those falling into the ‘a lot’ category. Additionally, 135 (66.5%) felt that they had a lot or quite a bit in common with their Aboriginal community, again with the majority of 86 participants falling into the ‘a lot’ category. The majority of participants, $n = 134$ (66.0%) felt that they interact a lot or quite a bit with their Aboriginal community. The data suggests that overall these participants feelings lie on the ‘greater sense of belonging and commonality’ end of the scale and, on the whole, they tend to be fairly well engaged (interact more closely) with their Aboriginal community.

Table 2: Identification with the Aboriginal and HCV community

	Not much n (%)	Somewhat n (%)	Quite a bit n (%)	A lot n (%)
Aboriginal community				
How much do you feel you belong to your Aboriginal community?	37 (18.2)	43 (21.2)	49 (24.1)	74 (36.5)
How much do you feel you have in common with your Aboriginal community?	27 (13.3)	40 (19.7)	49 (24.1)	86 (42.2)
How much do you interact with your Aboriginal community?	28 (13.8)	40 (19.7)	52 (25.6)	82 (40.4)
HCV community				
How much do you feel a part of a hepatitis C positive community?	82 (40.4)	55 (27.1)	34 (16.7)	30 (14.8)

3.1.3 Identification with HCV community

On the other hand, identification with an HCV community does not appear as strong (see Tables 2 and 3). The majority ($n = 137$, 67.5%), did not feel part of an HCV community; however, a small group of 30 participants (14.8%) did feel very much part of an HCV community (see Table 2). Despite these feelings, most of the sample had friends who had HCV. The three categories —'about half', 'almost all' and 'all' of my friends are HCV-positive—totalled to 133 participants or 65.5% (see Table 3). Free time spent with people with HCV was similar in that the categories of 'about half', 'almost all' and 'all my time' totalled to 103 participants (50.7%). Hence, while participants may not strongly identify with an HCV community it seems that many of their friends are HCV-positive and the majority of their time is spent with people with HCV.

Table 3: Time spent with the HCV-positive community

	None n (%)	Some n (%)	About half n (%)	Almost all n (%)	All n (%)
How many of your friends are hepatitis C positive?	8 (3.9)	57 (28.1)	55 (27.1)	63 (31.0)	14 (6.9)
How much of your free time do you spend with hepatitis C positive people?	31 (15.3)	63 (31.0)	44 (21.7)	40 (19.7)	19 (9.4)

3.1.4 HCV testing

The most commonly reported reason for being tested for HCV was part of routine testing ($n = 86$ or 42.4%) (see Table 4). Given the high number of people who have ever been incarcerated in this sample, 80.3%, it is likely that for many of those diagnosed with HCV through routine testing, were tested while in prison. In 30.5% of cases ($n = 62$), the participant had asked for the test, and in a further 17.7% ($n = 36$) of cases, a doctor or health worker had suggested it. Only three participants had learnt about the importance of having an HCV test through recent community awareness campaigns.

Table 4: Reasons for being tested for HCV

	<i>n (%)</i>
A doctor or other healthcare worker suggested it	36 (17.7)
I asked for a test	62 (30.5)
Part of a routine screening (e.g. antenatal screening, entering the judicial system)	86 (42.4)
I learnt about the importance of having a hepatitis C test through a recent community awareness campaign (e.g. poster, radio advertisement, workshop, stall at a community event)	3 (1.5)
Other	16 (7.9)
Don't know	0 (0.0)

Only approximately one-third of participants were offered some pre- or post-test counselling ($n = 60$ and $n = 66$, respectively, see Table 5). Twenty-five people mentioned that they had never received any HCV information at all. The most common information ever given was on safe injecting practices ($n = 139$, 68.5%), a healthy lifestyle (e.g. diet and exercise) ($n = 133$, 65.5%) and treatments that are available for HCV ($n = 129$, 63.5%).

In terms of whether participants were satisfied that the diagnosis was informed in a culturally sensitive/appropriate way, just over half the sample, or 108 participants (53.2%), were satisfied or very satisfied (see Table 5). However, 56 (27.6%) participants were dissatisfied or very dissatisfied with the cultural appropriateness of the diagnosis, and 37 (18.2%) were neither satisfied nor dissatisfied.

Table 5: HCV testing experience

	<i>n (%)</i>
Offered counselling	
Pre-test	60 (30.0)
Post-test	66 (32.5)
Ever given information about	
Safer injecting practices	139 (68.5)
A healthy lifestyle (e.g. diet and exercise)	133 (65.5)
Treatments that are available for hepatitis C	129 (63.5)
Cutting down alcohol	125 (61.6)
How to access treatment for hepatitis C	109 (53.7)
Possible side effects of treatment for hepatitis C	105 (51.7)
A referral to a healthcare worker (e.g. Aboriginal health worker/counsellor/liver nurse/social worker/Drug & Alcohol worker/nurse)	63 (31.0)
Hepatitis community services (e.g. Hepatitis NSW, hepatitis C telephone counselling line)	56 (27.6)
No information	25 (12.3)
Complementary/alternative therapies including bush medicine and side effects of such therapies	20 (9.9)
Satisfied that diagnosis was informed in a culturally sensitive/appropriate way	
Very dissatisfied	19 (9.4)
Dissatisfied	37 (18.2)
Neither satisfied nor dissatisfied	37 (18.2)
Satisfied	85 (41.9)
Very satisfied	23 (11.3)

3.1.5 Healthcare and HCV care

Seventy-six participants (37.4%) attended an ACCHS for general healthcare and 58 participants (28.6%) chose an ACCHS as the place they were most likely to obtain HCV care (see Table 6). Interestingly, the proportion of participants attending GPs not at ACCHS for HCV care ($n = 61$, 30.0%) was similar to the proportion who chose to attend an ACCHS. Twenty-three participants (11.3%) reported attending an alcohol and other drug service for HCV care and 9 participants (4.4%) attended a liver clinic.

It is relevant to note that while 73 participants (36.0%) reported having ever attended an ACCHS for HCV care, the greater majority ($n = 126$, 62.1%) had never attended an ACCHS to discuss their HCV (see Table 7). These data should not be interpreted as participants choosing one service type over another as there may be a range of factors impacting on choice, such as convenient location of services. This will be explored in the qualitative data section.

Table 6: Main place for general and HCV care

	General healthcare <i>n</i> (%)	HCV care <i>n</i> (%)
ACCHS	76 (37.4)	58 (28.6)
General Practitioner (GP) that is not at an ACCHS	73 (36.0)	61 (30.0)
Outreach services (e.g. pitstops)	21 (10.3)	7 (3.4)
Sexual health clinic	8 (3.9)	12 (5.9)
Alcohol and other drug service	n/a	23 (11.3)
Liver clinic	n/a	9 (4.4)
Other	13 (6.4)	30 (14.8)
I don't have a regular place	12 (5.9)	n/a

Table 7: HCV-related attendance at an ACCHS

	<i>n</i> (%)
Yes	73 (36.0)
No	126 (62.1)

Participants on the whole appear to be satisfied with the HCV care received (see Table 8). The mean score for satisfaction with care was relatively high at 3.8 ($SD = 1.0$), from a range 1–5, with higher scores indicative of greater satisfaction with HCV care. For all 5 items (care, support, information, workers' knowledge and availability of appointments) few participants chose the 'very dissatisfied' option. The majority of participant responses for all 5 items lie on the 'satisfied' or 'very satisfied' end of the scale. Satisfaction with care was not related to whether participants attended an ACCHS or a non-ACCHS GP for their HCV care.

Table 8: Satisfaction with HCV care

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Hepatitis C care	13 (6.4)	23 (11.3)	27 (13.3)	84 (41.4)	51 (25.1)
Hepatitis C health support	14 (6.9)	22 (10.8)	31 (15.3)	74 (36.5)	55 (27.1)
Hepatitis C information provided	12 (5.9)	20 (9.9)	28 (13.8)	88 (43.3)	50 (24.6)
Hepatitis C workers' knowledge	9 (4.4)	18 (8.9)	21 (10.3)	87 (42.9)	62 (30.5)
Availability appointments for hepatitis C care	11 (5.4)	14 (6.9)	30 (14.8)	80 (39.4)	60 (29.6)

3.1.6 HCV treatment intention and care

Eighty-four participants (41.4%) had ever received a referral to a specialist for HCV treatment, while 118 (58.1) had not (See Table 9). Of the people who had received a referral, just over half (54.8 %) had taken up that referral and had gone to see a specialist about their HCV, while 42.9% had not taken up the referral. Six (3.0%) people in the sample were currently on treatment, and 28 (14.3% of those not currently on treatment) had ever been on treatment. Of the reasons cited by participants for not going on treatment, being worried about side effects was cited by 52 participants (31.0%) and currently injecting drugs was rated second with 31 respondents choosing this option (18.5%). Twenty-five participants (14.9%) chose fear of being stigmatised, 26 chose other health problems (15.5%), while 22 (13.1%) participants chose lack of support from health professionals. Twenty-two participants (13.1%) noted lack of knowledge that treatment was available, and 21 (12.5%) felt that they had little information about HCV. Eighty-five participants (50%) cited 'other reason' for deciding against HCV treatment. While further information was collected on this issue, we do note that 'waiting for better treatments' was not included as a response option in the original question. As data was collected mostly in 2013, the changing treatment landscape may have influenced the decision of some participants.

In terms of future intention to access treatment, 99 (55.6%) participants reported intending to take up treatment in the next two years, 35 (19.7%) said not in the next 2 years, and an equal proportion ($n = 35$, 19.7%) reported that they never intended to access HCV treatment.

Chi-squared analysis was used to compare HCV treatment (currently or ever being on treatment vs. never being on treatment) and future intention to access treatment (take up treatment in the next two years vs. at least another two years or never) with main place for HCV care. There was no significant difference between HCV treatment and future intention to access treatment between participants who attended an ACCHS for their HCV care and those who did not.

Table 9: HCV treatment intentions

		<i>n (%)</i>
Ever received a referral to a specialist about treatment for hepatitis C	Yes	84 (41.4)
	No	118 (58.1)
Of the people who received a referral (<i>n</i> = 84)		
Ever gone to see a specialist about hepatitis C	Yes	46 (54.8)
	No	36 (42.9)
Of the total sample (<i>n</i> = 203)		
Currently on hepatitis C treatment	Yes	6 (3.0)
	No	196 (96.9)
Of the participants who are currently not on treatment (<i>n</i> = 196)		
Ever been on treatment	Yes	28 (14.3)
	No	168 (82.8)
Of the participants who have never been on treatment (<i>n</i> = 168)		
Reasons against treatment (more than one answer possible)		
Waiting list too long		16 (9.5)
Too far or too difficult to travel to treatment		8 (4.8)
Lack of support from health professionals		22 (13.1)
Lack of support from family and friends		17 (10.1)
Fear of job loss		4 (2.4)
Fear of disclosing my hepatitis C status to others		19 (11.3)
Fear of being stigmatised/ judged about hepatitis C		25 (14.9)
Currently injecting drugs		31 (18.5)
Lack of information about HCV		21 (12.5)
Lack of knowledge that treatment was available		22 (13.1)
Worried about side effects		52 (31.0)
Other health problems		26 (15.5)
Drinking alcohol too heavily		10 (6.0)
Other		85 (50.6)
Of the participants who have never been on treatment or did not complete the full course of treatment (<i>n</i> = 178)		
Plan to go on treatment in the future		
In the next 12 months		57 (32.0)
In the next 1–2 years		42 (23.6)
Not for at least another 2 years		35 (19.7)
Never		35 (19.7)
Don't know		8 (4.5)

As can be seen in Table 10, approximately equal proportions of respondents chose to have their most recent HCV test at ACCHS ($n = 40$, 19.7%) or at non-ACCHS GPs ($n = 42$, 20.7%). The next most frequently reported place of testing was prison ($n = 35$, 17.2%). One hundred and twenty-eight (63.1%) participants had last visited a GP or health worker specifically for their HCV less than 6 months ago, 133 participants or 65.5% had had a PCR or hep C RNA test 12 months ago or less, and 127 participants (62.6%) reported their most recent liver function test was 12 months ago or less. While 47 (23.2%) participants reported that their most recent IL28b gene test was 12 months ago or less, 81 (39.9%) participants stated that they either did not know what an IL28b gene test is, or did not know when their last IL28b gene test was.

The majority of participants reported making lifestyle changes (Horwitz, Brener, & Treloar, 2012) since diagnosis (see Table 10), with only 16 stating that they had made no change. The biggest reported lifestyle change was a reduction in alcohol consumption reported by 134 (66.0%) participants. Of the total sample, 106 (52.2%) had changed their diet while 108 (53.2%) participants reported increasing their level of exercise, and 101 (49.8%) reported reducing or stopping illicit drug use. Additionally, 94 (46.3%) participants reported accessing information about HCV and HCV treatment after diagnosis, and 73 (36.0%) participants had more regular HCV check-ups.

Table 10: HCV care

	<i>n (%)</i>
Location of most recent hepatitis C test	
ACCHS	40 (19.7)
Non-ACCHS GP	42 (20.7)
Hospital	21 (10.3)
Prison	35 (17.2)
Alcohol and Drug service	26 (12.8)
Sexual health clinic	9 (4.4)
Liver clinic	8 (3.9)
Other	9 (4.4)
Have not/unsure if I have received any hepatitis C tests recently	10 (4.9)
Last visit to a GP or other health worker specifically hepatitis C	
Less than 6 months ago	128 (63.1)
6-12 months ago	33 (16.3)
More than 12 months ago	34 (16.7)
I've never seen a GP or other health worker for my hepatitis C	7 (3.4)
Don't know	1 (0.5)
Most recent PCR or hep C RNA test	
12 months ago or less	133 (65.5)
More than 12 months ago	38 (18.7)
Never had a PCR or hep C RNA test	15 (7.4)
Don't know when my last PCR or hep C RNA test was	15 (7.4)
Most recent liver function test	
12 months ago or less	127 (62.6)
More than 12 months ago	28 (13.8)
Never had a liver function test	21 (10.3)
Don't know when my last liver function test was	26 (12.8)
Most recent IL28b gene test	
12 months ago or less	47 (32.2)
More than 12 months ago	15 (7.4)
Never had a IL28B gene test	59 (29.1)
Don't know when my last IL28b gene test was or don't know what a IL28b test is	81 (39.9)
Life style changes since diagnosis (more than one answer could be provided)	
Changed your diet	106 (52.2)
Reduced or cut out alcohol	134 (66.0)
Increased your level of exercise	108 (53.2)
Used any complementary/ alternative medicines for hepatitis C	17 (8.4)
Had more regular hepatitis C check-ups	73 (36.0)
Sought support from hepatitis NSW, drug user organisations or other community groups	39 (19.2)
Used traditional or bush medicine	22 (10.8)
Reduced or cut out illicit drug use	101 (49.8)
Accessed information about hepatitis C and hepatitis C treatment	94 (46.3)
No change	16 (7.9)

3.1.7 HCV Knowledge

Overall the knowledge of respondents was good, with a mean score on the scaled items of 11.41 ($SD = 2.53$), range 1–16 (see Table 11). This mean is above the midpoint of the scale indicating that respondents' knowledge was relatively good.

It is further evident that knowledge on particular items was high. For example, 191 (94.1%) participants knew that there is a treatment for HCV; however, a lower number answered correctly that the treatment can cure HCV ($n = 140$ or 69.0%). A large majority of the sample were aware that alcohol increases a person's risk of complications from HCV, $n = 184$ or 90.6%. Good awareness is also evident amongst the sample of complications which may arise through co-infection with HCV and another disease such as HIV, hepatitis B and diabetes. The sample appeared to have good knowledge in relation to transmission of HCV. One hundred and ninety-one (94.1%) people knew that using new needles/syringes and other equipment reduces the risk of being infected with HCV and that people can get infected with HCV from tattoos and piercings, respectively. One hundred and seventy-eight (87.7%) participants were also aware that HCV could be passed on by sharing an invisible drop of blood. While knowledge was still good for the item on whether people with HCV can safely share their toothbrushes and razors ($n = 170$, 83.7%), it was slightly lower than the other items on transmission. Participants were also somewhat less knowledgeable about the possibility of HCV being transmitted through kissing, $n = 137$ (67.5%). On the other hand, understanding of the different tests for HCV and what these tests mean was limited. For example, very few participants, $n = 61$ or 30.0%, knew that a positive HCV antibody test means the person has been in contact with the virus, but may not be actively infected. While more participants responded correctly that a positive HCV PCR test means you are infected with HCV ($n = 84$, 41.4%), these numbers were still low relative to knowledge on the other items.

Very importantly, correlational analysis revealed that HCV knowledge was associated with being in prison. Those who had ever been in prison had lower knowledge scores than those who had never been in prison. However, there was no significant association between measures of HCV knowledge and participants' education level. Additionally, HCV knowledge was negatively related to cultural discrimination, suggesting that participants who reported greater perceived discrimination on the basis of Aboriginality were more likely to have lower knowledge of HCV.

Table 11: HCV knowledge (correctly answered)

	<i>n (%)</i>
Transmission of HCV	
People with hepatitis C cannot safely share their toothbrushes and razors	170 (83.7)
You cannot catch hepatitis C from kissing	137 (67.5)
Using new needles/ syringes and other equipment reduces the risk of being infected with hepatitis C	191 (94.1)
People can get infected with hepatitis C from tattoos and piercing	191 (94.1)
Hepatitis C can be passed on by sharing an invisible drop of infected blood	178 (87.7)
Natural history	
Hepatitis C does not always cause symptoms	112 (55.2)
Once you're infected with hepatitis C, your body can get rid of the virus on its own without treatment	131 (64.5)
Drinking a lot of alcohol increases your risk of complications from hepatitis C	184 (90.6)
Having a HIV infection increases your risk of complications from hepatitis C	152 (74.9)
Being obese or having diabetes increases your risk of complications from hepatitis C	151 (74.4)
Having hepatitis C for more than 20 years increases your risk of complications from hepatitis C	163 (80.3)
Having hepatitis B increases your risk of complications from hepatitis C	135 (66.5)
Testing and Treatment	
A positive hepatitis C antibody test means you have been in contact with the virus, but you don't know if you are actively infected	61 (30.0)
A positive hepatitis C PCR test means you are infected with hepatitis C	84 (41.4)
There is treatment for hepatitis C	191 (94.1)
There is a treatment which can cure hepatitis C	140 (69.0)

3.1.8 Physical and mental health symptoms

This sample reported a range of physical and mental health symptoms (See table 12). Physical tiredness was commonly reported by this sample with 160 participants or 78.8% of the sample noting that they felt tired. Depression and irritability was also commonly reported with 144 (70.9%) and 143 (70.4%) participants noting that they suffered from depression or irritability, respectively. Less commonly reported symptoms was light/noise sensitive ($n = 77$, 37.9%), diarrhoea ($n = 60$, 29.6%) and a sore throat ($n = 65$, 32.0%). Less than 1 in 10 participants ($n = 12$, 5.9%) reported experiencing no physical and mental health symptoms in the last 6 months. The greatest number of participants, $n = 70$ (34.5%) reported experiencing between 13 and 18 of the 22 physical and mental health symptoms presented.

Table 12: Symptoms experienced in the last six months

	<i>n</i> (%)
Physical tiredness	160 (78.8)
Depression	144 (70.9)
Irritability	143 (70.4)
Mental tiredness	133 (65.5)
Sleep problems	132 (65.0)
Forgetfulness	132 (65.0)
Joint/ muscle pain	123 (60.6)
Poor concentration	113 (58.6)
Weight loss	106 (52.2)
Abdominal pain/ discomfort	104 (51.2)
Night sweats	114 (65.2)
Poor appetite	101 (49.8)
Day sweats	97 (47.8)
Dizziness	95 (46.8)
Breathlessness	89 (43.8)
Nausea	87 (42.9)
Wheeziness	85 (41.9)
Skin problems	75 (36.9)
Light/ noise sensitivity	77 (37.9)
Sore eyes	65 (32.0)
Sore throat	65 (32.0)
Diarrhoea	60 (29.6)

Despite the range of physical and mental health symptoms listed by participants above, participants were still more likely to rate their quality of life as good or very good, $n = 128$ (63.0%), than to rate it poor or very poor ($n = 35$, 17.2%; see Table 13). They were also more likely to say that they were satisfied or very satisfied with their health ($n = 124$, 61.1%) as opposed to dissatisfied or very dissatisfied ($n = 44$, 21.7%). Not surprisingly though, quality of life and health satisfaction were correlated with physical and mental health symptoms, such that those who experienced more symptoms also reported lower quality of life and less health satisfaction (see Appendix 2).

Physical and mental health symptoms were also correlated with a number of stigma and discrimination items. Respondents who reported greater perceived discrimination based on their HCV-positive status and greater perceived stigma in relation to disclosure were significantly more likely to report experiencing a greater number of physical symptoms. Additionally, reporting more physical health symptoms was associated with lower scores on the resilience measure.

Table 13: Quality of life and satisfaction with health

	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
	Very poor	Poor	Neither poor nor good	Good	Very good
Quality of life	10 (4.9)	25 (12.3)	40 (19.7)	99 (48.8)	29 (14.3)
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
Satisfaction with health	9 (4.4)	35 (17.2)	35 (17.2)	95 (46.8)	29 (14.3)

3.1.9 Stigma, perceived discrimination, disclosure and resilience

On the whole, participants tended to perceive that they would experience stigma and discrimination as a result of being HCV-positive (see Table 14). The mean score for the scaled items was 3.1 ($SD = 0.9$) with a response range of 1–5, where higher scores reflect greater perceived stigma and discrimination. Participants were also likely to perceive that they would experience stigma as a result of disclosure of their HCV-positive status. Participants recorded a mean of 3.3 ($SD = 0.9$), with a response range of 1–5, where higher scores reflect greater perceived stigma in relation to disclosure.

Participants were also likely to report experiences of stigma and discrimination related to their Aboriginality. A modified version of the Group-Based Medical Mistrust Scale (Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004) was used to investigate racial stigma and discrimination in healthcare. The mean score on the scaled items for this measure below (see Table 15) is 3.2 ($SD = 0.8$) with a response range of 1–5 higher scores on the scale reflecting greater experiences of stigma and discrimination. Based on this scale, it is evident these participants feel that Aboriginal people are not afforded the same care as others. Perceived discrimination was particularly evident in relation to feelings of unfair or inequitable medical care of Aboriginal people by medical staff compared with other groups ('agree' and 'strongly agree' categories: $n = 114$, 56.2%), inequitable treatment of Aboriginal people by medical staff compared with others ('agree' and 'strongly agree' categories: $n = 129$, 63.5%), perceptions of not being taken seriously by medical staff ('agree' and 'strongly agree' categories: $n = 111$, 54.7%), not being told all the necessary information by medical staff ('agree' and 'strongly agree' categories: $n = 92$, 45.3%), or being treated like 'guinea pigs' by medical staff ('agree' and 'strongly agree' categories: $n = 90$, 44.3%). Participants also felt strongly ('agreed' or 'strongly agreed') that people of different ethnic groups were not treated equally in hospital ($n = 129$, 63.5%). Participants were asked whether they felt that they had been treated poorly or unfairly by doctors or healthcare workers because they were Aboriginal. Just under half of the sample, 96 participants (47.3%) agreed with this item. However, the majority of participants did not agree that Aboriginal people should not confide in health workers as this information may be used against them ('strongly disagree' and 'disagree' categories: $n = 114$, 56.2%).

These data show a different pattern when the technical capacity of modern medicine and mainstream health workers were considered. The majority of participants did not agree that Aboriginal people should be suspicious of modern medicine ('strongly disagree' and 'disagree' categories: $n = 114$, 56.2%) or suspicious of information from health workers ('strongly disagree' and 'disagree' categories: $n = 100$, 49.2%).

Table 14: HCV stigma and discrimination

	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree
	n (%)	n (%)	n (%)	n (%)	n (%)
Hepatitis C discrimination					
Most people believe I am dirty because I have hepatitis C	14 (6.9)	42 (20.7)	24 (11.8)	91 (44.8)	29 (14.3)
I feel set apart, isolated from the community because of my hepatitis C	15 (7.4)	72 (35.5)	33 (16.3)	64 (31.5)	19 (6.4)
Most people will reject me when they learn that I have hepatitis C	13 (6.4)	62 (30.5)	29 (14.3)	73 (36.0)	25 (12.3)
Most people are uncomfortable around me because I have hepatitis C	11 (5.4)	63 (31.0)	39 (19.2)	68 (33.5)	21 (10.3)
People avoid touching me if they know I have hepatitis C	16 (7.9)	75 (36.9)	26 (12.8)	64 (31.5)	21 (10.3)
People don't want me around their children once they know I have hepatitis C	16 (7.9)	65 (32.0)	35 (17.2)	62 (30.5)	23 (11.3)
Some people act as though it's my fault that I have hepatitis C	14 (6.9)	38 (18.7)	21 (10.3)	90 (44.3)	37 (18.2)
Some family members have rejected me because of my hepatitis C	27 (13.3)	90 (44.3)	19 (9.4)	47 (23.2)	17 (8.4)
I feel shame because of my hepatitis C	19 (9.4)	50 (24.6)	21 (10.3)	79 (38.9)	32 (15.8)
Hepatitis C disclosure					
I could lose my job if my employer learns about my hepatitis C	14 (6.9)	46 (22.7)	38 (18.7)	68 (33.5)	26 (12.8)
In many areas of my life, no-one knows I have hepatitis C	12 (5.9)	39 (19.2)	20 (9.9)	95 (46.8)	36 (17.7)
Telling someone I have hepatitis C is risky	13 (6.4)	49 (24.1)	18 (8.9)	90 (44.3)	33 (16.3)
I work hard to keep my hepatitis C a secret	16 (7.9)	61 (30.0)	23 (11.3)	67 (33.0)	34 (16.7)
I am very careful whom I tell that I have hepatitis C	15 (7.4)	37 (18.2)	17 (8.4)	100 (49.3)	34 (16.7)
I never feel that I need to hide the fact that I have hepatitis C	32 (15.8)	77 (37.9)	22 (10.8)	60 (29.6)	12 (5.9)
I worry that people may judge me when they learn that I have hepatitis C	15 (7.4)	40 (19.7)	18 (8.9)	91 (44.8)	38 (18.7)
I worry that people who know I have hepatitis C will tell others	18 (8.9)	47 (23.2)	23 (11.3)	80 (39.4)	34 (16.7)
I've told people close to me to keep my hepatitis C a secret	20 (9.9)	71 (35.0)	17 (8.4)	66 (32.5)	27 (13.3)

Table 15: Cultural stigma and discrimination

	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree
	n (%)	n (%)	n (%)	n (%)	n (%)
I feel that Aboriginal people do not trust doctors and healthcare workers	7 (3.4)	34 (16.7)	46 (22.7)	85 (41.9)	31 (15.3)
I feel that Aboriginal people should be suspicious of information from doctors and healthcare workers	14 (6.9)	86 (42.4)	38 (18.7)	50 (24.6)	15 (7.4)
I feel that Aboriginal people should not confide in doctors and healthcare workers because it will be used against them	22 (10.8)	92 (45.3)	38 (18.7)	41 (20.2)	10 (4.9)
I feel that Aboriginal people should be suspicious of modern medicine	23 (11.3)	91 (44.8)	29 (14.3)	49 (24.1)	10 (4.9)
I feel that doctors and healthcare workers treat Aboriginal people like 'guinea pigs'	16 (7.9)	66 (32.5)	29 (14.3)	56 (27.6)	34 (16.7)
I feel that doctors and healthcare workers do not take the medical complaints of Aboriginal people seriously	10 (4.9)	36 (17.7)	44 (21.7)	67 (33.0)	44 (21.7)
I feel that Aboriginal people are not treated the same as people of other groups by doctors and healthcare workers	8 (3.9)	32 (15.8)	32 (15.8)	75 (36.9)	54 (26.6)
I feel that Aboriginal people do not receive the same medical care from doctors and healthcare workers as people from other groups	9 (4.4)	43 (21.2)	34 (16.7)	61 (30.0)	53 (26.1)
I feel that in most hospitals people of different ethnic groups do not receive the same kind of care	8 (3.9)	32 (15.8)	32 (15.8)	77 (37.9)	52 (35.6)
I feel that doctors do not have the best interest of Aboriginal people in mind	9 (4.4)	57 (28.1)	43 (21.2)	61 (30.0)	31 (15.3)
I feel that doctors and healthcare workers sometimes hide information from Aboriginal patients	10 (4.9)	60 (29.6)	39 (19.2)	58 (28.6)	34 (16.7)
I feel that I have personally been treated poorly or unfairly by doctors or healthcare workers because I am Aboriginal	14 (6.9)	61 (30.0)	30 (14.8)	55 (27.1)	41 (20.2)

3.1.10 Perceived discrimination and general healthcare

Perceived discrimination and exclusion in the healthcare sector was examined using items modified from Brener, Ellard, Murphy and Callander (2013). In general, participants did not perceive much discrimination in the healthcare sector, as the majority of responses lie at the 'not at all' or 'a little' end of the continuum (see Table 16). This can be seen in the mean score for the scaled items which is 0.5 ($SD = 0.7$) with a response range of 0–4, where lower scores reflect less perceived discrimination. Some participants felt that healthcare workers kept a physical distance to a moderate degree, very much or an extreme amount ($n = 28$, 13.8 %). Similarly some felt that healthcare workers' interactions with them were awkward to a moderate degree, very much or an extreme amount ($n = 36$, 17.7 %), and some felt that healthcare workers took excessive hygiene measures around them ($n = 55$, 27.1 %).

Table 16: General discrimination in the healthcare sector

	Not at all <i>n</i> (%)	A little <i>n</i> (%)	A moderate amount <i>n</i> (%)	Very much <i>n</i> (%)	An extreme amount <i>n</i> (%)
They keep a physical distance	137 (67.5)	33 (16.3)	15 (7.4)	7 (3.4)	6 (3.0)
They are careful not to touch me	132 (65.0)	43 (21.2)	9 (4.4)	10 (4.9)	4 (2.0)
They are indifferent to me	139 (68.5)	24 (11.8)	17 (8.4)	14 (6.9)	4 (2.0)
They interact awkwardly with me	132 (65.0)	29 (14.3)	18 (8.9)	12 (5.9)	6 (3.0)
They avoid interacting with me	147 (72.4)	24 (11.8)	11 (5.4)	9 (4.4)	5 (2.5)
They are overly kind to me	140 (69.0)	35 (17.2)	12 (5.9)	6 (3.0)	3 (1.5)
They behave aggressively towards me	164 (80.8)	24 (11.8)	5 (2.5)	3 (1.5)	1 (0.5)
They take excessive hygienic measures around me	100 (49.3)	43 (21.2)	17 (8.4)	20 (9.9)	18 (8.9)

3.1.11 Resilience

Ten items for the Connor-Davidson Resilience Scale were used to investigate participant resilience (Connor & Davidson, 2003). The majority of participants agreed with many of the resilience items, and marked them as 'often true' or 'true nearly all of the time' (see Table 17). These higher scores of greater resilience can be seen in the mean of the scaled items, which is 2.7 ($SD = 1.0$) with a response range of 0–4, where greater scores reflect more resilience. However, the last three items, 'I can handle unpleasant feelings', 'Under pressure, I can focus and think clearly', and 'I am not easily discouraged by failure' tended to be more evenly spread with an almost equal number choosing 'not true at all' and sometimes 'true' ($n = 71$ or 35.0%, $n = 87$ or 42.9% and $n = 73$ or 36.0% respectively) to 'often true' and 'true nearly all of the time' ($n = 100$ or 49.3%, $n = 91$ or 44.8%, $n = 103$ or 50.7%).

Table 17: Resilience

	Not true at all <i>n</i> (%)	Sometimes true <i>n</i> (%)	True half of the time <i>n</i> (%)	Often true <i>n</i> (%)	True nearly all of the time <i>n</i> (%)
I believe I can achieve my goals	7 (3.4)	37 (18.2)	33 (16.3)	65 (32.0)	60 (29.6)
I think of myself as a strong person	7 (3.4)	29 (14.3)	21 (10.3)	57 (28.1)	89 (43.8)
I tend to bounce back after illness or hardships	6 (3.0)	29 (14.3)	19 (9.4)	61 (30.0)	87 (42.9)
I see the humorous side of things	6 (3.0)	25 (12.3)	13 (6.4)	59 (29.1)	100 (49.3)
I can deal with whatever comes my way	5 (2.5)	29 (14.3)	20 (9.9)	63 (31.0)	86 (42.4)
I believe coping with stress strengthens me	15 (7.4)	32 (15.8)	26 (12.8)	54 (26.6)	75 (36.9)
I am able to adapt to change	11 (5.4)	31 (15.3)	16 (7.9)	58 (28.6)	87 (42.9)
I can handle unpleasant feelings	27 (13.3)	44 (21.7)	31 (15.3)	44 (21.7)	56 (27.6)
Under pressure, I can focus and think clearly	37 (18.2)	50 (24.6)	24 (11.8)	36 (17.7)	55 (27.1)
I am not easily discouraged by failure	30 (14.8)	43 (21.2)	26 (12.8)	34 (16.7)	69 (34.0)

3.1.12 Relationships between stigma, perceived discrimination, resilience and other variables

Correlational analysis revealed a moderate relationship between satisfaction with HCV care and reported cultural discrimination (See Appendix 2), whereby those who reported less satisfaction with their HCV care also reported greater perceived discrimination on the basis of Aboriginality. A smaller but nonetheless significant relationship existed between general and HCV-related discrimination and satisfaction with HCV care. This also indicates that greater experiences of discrimination was associated with less satisfaction with HCV care. On a more positive note, resilience was correlated with satisfaction with HCV care and satisfaction with health status suggesting that those who showed greater satisfaction with healthcare and better reported health also had higher resilience scores. However, health satisfaction was negatively associated with stigma in relation to HCV disclosure in that those who felt more stigmatised when disclosing their HCV-positive status, also reported lower satisfaction with their health.

Finally, reported quality of life was negatively correlated with HCV discrimination, such that those who reported poorer quality of life also reported greater experiences of HCV-related discrimination. Gender and HCV discrimination and the HCV stigma in relation to disclosure items were negatively correlated suggesting that females reported greater HCV-related and disclosure-related stigma. Resilience was once again positively associated with quality of life, that is those who reported greater resilience also felt that they had a better quality of life.

The three stigma and discrimination scales addressing HCV related discrimination, general healthcare discrimination and HCV stigma in relation to disclosure were all correlated with each other, thereby indicating that participants generally reported greater stigma and discrimination in all of these areas. Interestingly, cultural discrimination was positively

associated with HCV discrimination and being in prison. Participants who reported greater perceived discrimination based on their HCV-positive status and who had been in prison were more likely to report experiences of cultural discrimination.

Similar to the pattern above, resilience was associated with HCV discrimination and experiences of stigma in relation to HCV disclosure in that those who felt they had greater resilience also experienced less reported stigma and discrimination in those domains. Age was positively associated with resilience, suggesting older participants reported more resilience. Interestingly, age was also negatively correlated with HCV discrimination and perceived stigma in relation to disclosure, suggesting younger participants reported more HCV stigma and discrimination.

3.1.13 Exposure to HCV health promotion in the last 12 months

One hundred and eighteen participants (58.1%) had seen or heard information about HCV in the community in the last 12 months, whereas 85 (41.9%) had not (see Table 18). Of the 118 who had had some exposure to HCV information, 100 (84.7%) had seen a poster with HCV information and 63 (53.4%) had seen articles in newspapers targeting the Aboriginal community.

Only 25 (12.3%) participants reported that they had been involved in HCV-related community events, whereas 177 (87.2%) had not. Of those who had been involved in an HCV-related community event, the most common type reported was a community workshop on HCV ($n = 15$, 60.0%).

Table 18: Exposure to HCV health promotion in the last 12 months

	<i>n (%)</i>
Seen or heard any information about HCV in community	Yes 118 (58.1)
	No 85 (41.9)
Of the respondents who had seen or heard any HCV information ($n = 118$)	
Seen or heard any of the following (more than one answer could be provided)	
Hepatitis C posters	100 (84.7)
Information on the radio	22 (18.6)
Articles in Aboriginal newspapers	63 (53.4)
None of the above	7 (5.9)
Of the total sample ($n = 203$)	
Involved in any hepatitis C community events	Yes 25 (12.3)
	No 177 (87.2)
Of the respondents who were involved in any events ($n = 25$)	
Involved in any of the following (more than one answer could be provided)	
Community workshop	15 (60.0)
A stall at a community event	6 (24.0)
Hepatitis C retreat	7 (28.0)
'Where's the shame, love your liver'	8 (32.0)
None of the above	6 (24.0)

3.1.14 Variables associated with exposure to HCV health promotion materials

Correlational analysis revealed that exposure to HCV health promotion materials and events was associated with some important outcome variables (See Appendix 2). Exposure to HCV health promotion was related to resilience and satisfaction with HCV care. Participants who had seen any HCV health promotion or had been involved in any HCV community events reported higher levels of resilience, and greater levels of satisfaction with their HCV care. On a very positive note, exposure to HCV health promotion was related to HCV knowledge in that those who had seen promotional materials on HCV were more likely to have higher HCV knowledge scores.

Equally important, exposure to HCV promotional materials was associated with HCV treatment intent. The variable, examining intention to go into treatment, was dichotomised into either 'intend to go into treatment in the next two years' ($n = 99$) or 'intend to go into treatment in two or more years' ($n = 35$) with participants who reported never wanting to go on treatment excluded from the correlation analysis. The analysis found that those exposed to HCV promotional materials were more likely to report an intention to undertake treatment within the next two years.

Finally, exposure to HCV promotion materials was significantly associated with gender and age, suggesting that females and older participants were more likely than males and younger participants to have seen or been involved in any HCV promotion.

3.1.15 Geographical analysis

For this report, data were categorised using the Rural, Remote and Metropolitan Area (RRMA) system designed and used by the Australian Department of Health and Aging (AIHW, 2004). This system is generally used to classify areas of medical practice within Australia. Using measures of population, and an index of remoteness, the RRMA system classifies according to usual place of residence as: 1) metropolitan zone (capital cities and other metropolitan centres), 2) rural zones (large rural centres, small rural centres and other rural areas), and 3) remote zones (remote centres and other remote areas). Due to the small size of the rural and remote zones, these were collapsed, giving a final classification of two regions: metropolitan (that is, metropolitan Sydney) ($n = 164$, 80.8%) and non-metropolitan ($n = 31$, 15.3%). Group differences were determined using chi-square test for categorical data and Spearman's rho for continuous data.

Metropolitan and non-metropolitan participants did not significantly differ in their gender or level of education. However, metropolitan participants did report being significantly older (39 years vs. 34 years, $t = 2.275$, $df = 187$, $p = .024$) and living significantly longer with HCV than non-metropolitan participants (10 years vs. 6 years, $t = 2.440$, $df = 191$, $p = 0.016$). There was no significant difference between metropolitan and non-metropolitan participants in regards to receiving a referral to a specialist, treatment intention, currently or ever being on HCV treatment, or main place for HCV care. Metropolitan participants, however, were significantly more likely to have seen or been involved in any HCV health promotion (91.3%) than non-metropolitan participants (38.7%) ($\chi^2 = 5.471$, $df = 1$, $p = 0.019$). Additionally, there was no significant correlation between HCV knowledge, satisfaction with HCV care, HCV discrimination, HCV disclosure-related stigma, general healthcare discrimination, or cultural discrimination and geographical location.

3.2 Living with hepatitis C, decisions about care, and experience of treatment among Aboriginal people in NSW

A total of 38 survey respondents participated in an in-depth interview. Around a third ($n = 15$) of interview participants were female, with one interviewee identifying as transgender. The mean age of interview participants was 40 years. Eleven participants had experience of HCV treatment, and one participant was about to start treatment. Analysis was conducted by examining two groups of participants, where relevant: those who had undertaken HCV treatment and those who had not.

3.2.1 Hepatitis C stigma

As has been established in the literature from many countries and settings, the stigma associated with HCV is a defining characteristic of the experience of living with this infection (Treloar & Rhodes, 2009). This was replicated in this sample, both among those who had and had not experienced HCV treatment.

The social experience of living with HCV was apparent in a number of areas of people's lives such as decisions about and experiences of disclosing their HCV-positive status to family and community and health workers, at diagnosis, when seeking care or support, and when participants discussed their perception of HCV.

In relation to disclosure of HCV status, a range of experiences was recounted. Some participants had disclosed their HCV-positive status to family and to health services, and received support from both. Indeed, a small number of participants (in contrast to others presented below) resisted the notion that HCV was anything to keep 'secret'. They were very pragmatic in their disclosure to family and felt that there was little negative judgement about HCV as there was little awareness of HCV in the community.

Family, friends and I tell people that I got it so they know. Why keep it a secret? If you got it, you got it. (#19, unknown age, male, not on treatment)

So what sort of people have you told that you had hep C?

Friends and colleague.

And how did you disclose that, like did it just come up in conversation?

No I just came straight up with it.

And how was it received?

Quite well.

Quite well, so there was no bad reaction to it?

None at all, I didn't get 'oh I am completely shocked or anything'.

And what about your family and friends, how did you disclose your hep C to them and how did they react?

I just told them that I had hep C and that I told them that if there is any blood to make sure they handle me... so to speak, just to be aware that it is a blood virus. (#26, 45, male, completed treatment)

Some participants had been selective in disclosure (informing some family members but not others), or had received differing levels of support and acceptance from family. Others

recounted stories of support and acceptance coming over time, particularly as information about HCV was introduced into the family. However, the majority of participants reported limiting their disclosure ("feel like it's like a secret I'm meant to keep like, you know, from most people", #17, early 30s, male, not on treatment) to avoid what they feared would be a negative reaction. Indeed, some participants recounted initial or ongoing negative reactions from those they had told. Imbued within these accounts were notions of shame associated with having HCV, both for the person living with HCV and their family. We have included a large number of quotes here to give voice to the experience of these participants and to indicate the range of experiences, and the change in these, for some, over time.

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. (#24, 44, female, currently on treatment)

No, not my family no, I just, I don't know, I think to myself that they might look at me like different you know, so they might think, ah yes, he's got hep C, keep away from us. (#22, late 30s, male, not on treatment)

And have you disclosed your hep C status to family, friends or colleagues?

I did, and that was very difficult.

In what way?

They weren't educated either so they looked at it along the lines of ...they treated me as if I had HIV and I knew that they were petrified when a baby came into the family, they were petrified of me, you could just see it.

How did that make you feel?

Very uncomfortable, and I used to have my own cupboard at my mother's house. She didn't talk about it but she always made sure she gave me the same coffee mug and stuff like that (Laughs uncomfortably). (#15, late 40s, female, completed treatment)

With my family, my mum especially, you know, she didn't want me touching her or anything, but later she was supportive and accepting me after that. (#16, late 30s, female, not on treatment)

I think they found out ... I think they found out and I just agreed—like I just, you know, like I confessed. I think they seen something of mine or overheard a conversation, yeah. And I was very embarrassed but, yeah.

Were you supported by your family, friends or healthcare services?

Yeah, yeah, eventually ... yeah. Took, took them a while to accept it and some just won't have anything to do with ya. (#4, late 20s, female, not on treatment)

Not in a big way. I'll try not to share the bong with them even though you know you can't catch it through the bong, so people are more aware of that stuff, but not at the beginning you know, or even sharing a beer bottle with someone, people didn't even want to do that, so yeah, there's a lot more info, I suppose, now. (#13, late 30s, female, not on treatment)

You are viewed like a grot, you know, like everyone thinks you're grotty, that's why I don't like telling anyone and that, you know, because then they get like the wrong idea, you know, like you said, the blood to blood contact but most people don't know that, they just get like you know, if they know about it they're like off you sort of thing, they keep their distance and that and that makes you real ashamed, you know? ...

Well, I feel sort of ashamed about it but that's because of that stigma and that, that people put with it and that. Sort of, you don't wanna tell no one. Yeah. (#20, early 20s, male, not on treatment)

You know, we do, we get treated like a leper. All I can tell you is like if you are skinny and junkified, talk about junkie, they treat you like shit but if you look like a healthy, nice working man, you get treated better. It all depends on how you look. We live in a society of looks and how he looks and all that, you know? (#18, mid 30s, male, not on treatment)

Participants here also noted the association between negative reactions to HCV disclosure and a lack of information. The lack of information about HCV in Aboriginal communities and in health services will be discussed below.

Two participants drew strong associations between the stigma associated with HCV and racism, and experiences of colonialism. While only two participants were explicit in drawing these links, we cannot discount that other participants perceived the same links, but did not comment on the issue. Participant #14 felt a societal expectation that Aboriginal people would have stigmatised conditions, such as HCV. Participant #18, while speaking of embarrassment and shame associated with HCV, linked the appearance of HCV in Aboriginal communities with invasion and colonisation.

I think I would have to say that um, the automatic racist attitude that you know you'll come up against, you know, like, I expect you to have these things, you are black. Very negative things. (#14, late 50s, female, not on treatment)

It's just that when you find out you have got it they treat you like some type of leper. So you have got to always hide it, so if you go to the doctors and you get anything that says hep C on it, I always hide that and make sure it's in a safe part of me drawer, so anything to do with my hep C is in that safe. And just it's a shame, it brings shame on my family you know. Well that's what it feels like anyway ... I just feel embarrassed and that I shouldn't have this, you know this disease wouldn't be here if these assholes didn't invade our land in the first place. (#18, mid 30s, male, not on treatment)

3.2.2 Perceived challenges in HCV: information and education

As noted above, lack of information about HCV was perceived by some participants as a major challenge in managing their relationships with family and community. Participants reflected on their own low levels of knowledge, confusion about the protective effects of hepatitis B immunisation, missed opportunities in which services could have provided information, and also reflected on an overall low 'health literacy' around HCV.

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 jail, 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. It's a perception that if you've had a Hep shot that you not going to get hep C but they do nothing for hep C. (#3, late 40s, male, currently on treatment)

The challenges I guess, my other family members not being educated and having the correct information about the virus. I guess they could be going through what I went through with the other family members—that they could contract the virus from that person. (#15, late 40s, female, completed treatment)

I think the knowledge needs to go straight through the GP because if somebody is positive, I feel that over the years they have failed me, to educate me and not give me

the correct information ... Because I left that virus for years in my body and it was doing damage, every day that I had that, it had been doing damage to me. (#15, late 40s, female, completed treatment)

I think that basically we need more information because like a lot of people living with hep C they are misinformed like you try and tell them about treatment and they say like, oh no, I don't want to not be able to have sex, or I don't want all my hair will fall out. So there are symptoms that can happen but they don't happen to everyone, so there is a lot of negative information that is circulated in the community that stops people from participating in treatment. (#12, late 20s, male, completed treatment)

While some participants noted barriers to providing information to people at risk of, or living with HCV (such as priorities associated with drug dependence), others provided suggestions. One participant noted that attending courses could be linked with debt relief from State Debt Recovery in NSW, and noted that this would be an incentive for people with low incomes to attend such education programs.

Other participants noted additional barriers to making progress on HCV, including concerns about high levels of alcohol dependence among Aboriginal people.

Oh alcohol, that's the devil, that's the worst thing that the white men did to us, you know, our ancestors, is introduce them to alcohol. (#16, late 30s, female, not on treatment)

3.2.3 Diagnosis experience

The majority of all participants recalled very little information being provided at diagnosis, either about HCV treatment or about lifestyle modifications to support liver health. Even in instances where written information was provided, this was difficult for some participants to access and understand when further opportunities to discuss this information were not available.

Did they talk to you about limiting alcohol and safe injecting practices and all that as well?

Yes, they just gave me information to go off and read it myself ... So no one actually talked, all they gave me was a kit to take home with me.

And did you feel comfortable in reading that kit?

Oh no, well I haven't really read it, no, I get more from you know, sitting down and speaking to someone, verbally and stuff like that. Yes and you know I have got issues with my eyesight and whatever so ... Yeah, so people, they need to take that into account as well ... a hep C nurse and the hep C nurse may need to explain stuff to him orally. And there are people with literacy problems ... like just giving that information to me as a lay person and sending me to read it doesn't versus someone who knows it and works in it and knows the effect that it has on the body and the liver. (#7, mid 40s, male, not on treatment)

So when you were in jail and they told you, did they tell you, did they give you any information about treatment and lifestyle changes and things like that?

No, they just give me like a pamphlet kind of.

That's all, just a pamphlet?

Yeah.

But they didn't talk to you about treatment and all that though?

No, no, no, they just told me I had it and that; basically told me to go. (#21, mid 20s, male, not on treatment)

In addition to lack of information provided, participants reported a range of emotional responses to diagnosis such as shock, worry, denial, believing they were going to die straight away, and feeling depressed. In some cases, these reactions were associated with the lack of information provided, misinformation (particular associations of HCV with HIV and AIDS), participants feeling they did not know how to manage HCV, or feeling dismissed by their health workers. One participant reported dealing with HCV in a 'blasé' manner.

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, yeah, I just took it as it come, yeah, you know. (#13, late 30s, female, not on treatment)

I was a bit shocked you know cos they didn't give me a, hey are you feeling alright, just oh you've got hep C, here's your result, see you later, more or less, you know? (#22, late 30s, male, not on treatment)

Not very good. You think you are going to die straight away, or not very long ... Because that's the vibe around it you know—you are like the walking dead, like you have got AIDS you know? (#18, mid 30s, male, not on treatment)

3.2.4 Decisions about care and treatment

The material above has both shown that the participants received little information about HCV at diagnosis and that they were not exposed to information about HCV in other ways (via other people, community events or health services). Hence, decisions to engage with care and treatment are based on low levels of understanding of the natural history of HCV, and strong emotional responses to HCV for some, which may act as both barriers and motivators to engaging in care.

Some participants noted that they had, or had tried to, make changes to their lifestyle to promote liver health. In particular, some participants noted limiting intake of 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. (#26, 45, male, completed treatment)

As has been noted in samples of people living with HCV in Australia and elsewhere, the chance of success and side effects of current HCV treatment were cited as a barrier by many people who were aware of HCV treatment. Participants had heard that the treatment was 'gruesome', and noted a degree of preparation (in terms of family and life situation) which would be required before contemplating treatment, particularly around work. Even for someone 'seriously thinking about' treatment, the side effects of the medication were perceived as a barrier.

From what I have heard .. it's a bit of a gruesome one. It makes you pretty crook ... Well if it's going to make me crooker I don't know how I'd go, I'd probably just let it slide or, something like that. I'd just have to check it out when the time comes. Not sure how I would cope, just one at a time or something like that. (#8, 30, male, not on treatment)

I just don't want to be working at the time, you know, if I am real crook, I don't want to be real crook while I am working at the same time. (#20, early 20s, male, not on treatment)

I know that makes you sick so I didn't, I want to get rid of it but I'm not going on it if it makes you sick. (#22, late 30s, male, not on treatment)

The negative stories about HCV treatment were also reported by participants who had decided to undertake treatment: "I have seen my girlfriend do it and as I said it sent her a bit crazy you know, like she was a needle user as well, that's the only thing. And I was a little bit reluctant to do it" (#24, 44, female, currently on treatment). However, a number of other influences on decisions to have treatment were noted, relating to individual motivations to live longer and healthier, having convenient access to treatment (in prison or in services for people who use drugs), having a long-term engagement and familiarity with a service, and knowing others who had become very ill or died from HCV-related liver disease.

And [HCV is] rife around here so I know a lot of people have died from cirrhosis and I have not got much going on with my liver at the moment but I want to go on it so I can bust this hepatitis as fast as possible ... 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. (#25, demographic information removed to protect anonymity)

3.2.5 Choices about health services for HCV care

Aboriginal people in this sample accessed a range of health services including ACCHS, general practitioners and sexual health clinics. However, a minority of participants indicated that they did not attend any services for HCV care.

The choice of health service was associated with convenience, particularly for those who chose mainstream services. Participants who chose to attend ACCHS for HCV care noted the importance of feeling comfortable and welcome in these services. Most participants indicated that they were satisfied with the HCV care they were currently attending. However, one participant described a judgemental response from his health workers following HCV diagnosis:

A particular clinic, they deal with gay people and that ... And I don't like going there because once they find you have got hep C they are very judgmental. (#11, early 40s, transgender, not on treatment)

This was in contrast to comments made by a participant attending an ACCHS for HCV care:

They are supportive, they don't give me a hard time...yeah there's no change in how they treat me or whatever. (#6, late 20s, male, not on treatment)

Participants were asked what mainstream health services could do to support Aboriginal people with HCV. A range of responses was received relating to issues around racial discrimination, shame, trust between Aboriginal people and health services, and provision of more information.

Just treat us like white people, treat us on an equal level. (#11, early 40s, transgender, not on treatment)

Trying to give us a chance you know. We get ourselves, are in such a state sometimes you know what I mean, and we don't know where or who to trust. (#18, mid 30s, male, not on treatment)

Talk about it more really, like, have more flyers up, things in a medical centre and all that stuff, when they go there so they don't have to be ashamed and that and they can talk to the doctors about it. (#23, late 30s, male, not on treatment)

Yeah, give them more information. Sit them down and explain to them what they can do and how they can make it better. (#22, late 30s, male, not on treatment)

One participant related a story that tied together issues of shame, stigma, trust in health systems, isolation, lack of support and decisions about HCV care. This participant expressed deep mistrust of health services and health professionals, stemming from an earlier incident in which a doctor had discussed the participant's HCV-positive status in front of family members during a consultation for another health condition. Although this incident had occurred a number of years earlier, the participant was still ostracised by his family, refused to tell any other people (including health workers) about his HCV-positive status, and acknowledged that this mistrust and deep feelings of shame associated with HCV were barriers to engaging in HCV care. With low literacy, other sources of support and information (such as information resources) were not available to this participant.

The doctor came in while I was sitting there and was talking about treatments, that he couldn't give me that treatment because I am hep C you know, in front of them ... I have lost my family members ... [my family] looked at me like I don't mean anything to them. They walked straight out and they never came back. I feel isolated from them, like.....and it made me think suicidal thoughts because (very emotional, talking and crying) I have got noand I just feel like it was a life sentence, that, for me ... I don't talk to no one about it ... There are doctors and nurses at the clinic but I don't trust them after what that doctor done. (#31, 33, male, not on treatment)

Despite describing these barriers to trusting and engaging with health services and experiencing deep despair and loss, this participant had found his way to an HCV specialist (via a service for people who use drugs) to seek information about how to live well with HCV.

I want to learn to live healthy, like I want to know foods I can eat with hepatitis ... because I know drinking, like I don't ... anymore, no alcohol. (#31, 33, male, not on treatment)

3.2.6 Treatment experiences

Nine participants who had received treatment were interviewed as well as one participant who was very soon to start treatment. These participants recounted similar experiences to those people who had not had treatment in relation to low levels of information provided to them at diagnosis, or subsequent to diagnosis. Hence, participants who had received treatment either sought information themselves, or engaged with treatment services in processes that were not linked to initial diagnosis. Participant #15 noted she had never received the message that she could 'get rid of HCV'; that she did not have to live with it.

And I just didn't know, I didn't know how important it was to – I didn't have to live with the virus, that's the difference, nobody told me I didn't have to. (#15, late 40s, female, completed treatment)

In contrast, one participant with a relatively recent diagnosis was referred to a hospital-based treatment clinic within months. However, this participant, who had a strong and negative reaction to diagnosis (feeling 'shattered' and 'dirty'), felt that even a few months was too long to wait, and that an earlier appointment would be preferable to provide detailed information and to ameliorate negative reactions to diagnosis.

Well I reckon they should put you in to see a specialist straight away instead of leaving you for months, feeling crap, they should make you see a specialist straight away and it could calm everything down. (#24, 44, female, currently on treatment)

A variety of treatment models were accessed by participants. For example, some participants chose to attend a liver clinic which operated once per fortnight at their ACCHS. Other participants were treated in prison and some at tertiary hospital liver clinics. Typically, all participants were satisfied with the care and treatment they had received. For those attending tertiary hospital services, there was little interaction with their primary care doctors as they perceived all of their needs to have been addressed within the hospital clinic.

[The AMS] keep in contact and see how I am going and what the AMS could actually do with [the hospital] ... which ended up being pretty much nothing because [the hospital] up here pretty much handle the whole process of the treatment. They are always here to support me in any regards, the AMS, if I needed, help me to the [hospital] or returning from [the hospital] or anything else like that they were quite happy to get me over there and I didn't need their help but it was put out there. (#26, 45, male, completed treatment)

Another participant (#38) noted the central role that the AMS played in assisting her to initiate and maintain HCV treatment. This woman noted that weekly visits by an ACCHS staff member assisted her to adhere to and complete treatment.

We started talking [with ACCHS staff member] about it and it was all positive and um she said "well look you have got to have all the support around you to, I'm not sure how it is going to pan out, you have got to be stable and all that" so I had to get a house and I had a 6 month old baby when I started the treatment and I, at the AMS, my drug and alcohol counsellor came in to see me once or twice a week which was really good, to help me through it.

So do you think that the worker from the AMS coming over and seeing you every couple, like a couple of times a week was, how was it?

Yes, it was good because she used to come over every Wednesday and that's when I used to go and get my tablets and my shots.

Do you think that you would have been able to make it to your appointments without her coming and getting you?

Um I would have at the start and then it probably would have just dropped off, yeah, you know like, I would like put it off for next week and you know so they would have to take me off it because I wouldn't have kept up with the schedule. (#38, 39, female, completed treatment)

One participant, who lived in a regional area, actively decided to bypass her GP to engage with specialist services as she perceived GPs to have little information about HCV.

It was the only service here in at the time—it probably still is—that provides treatment for hep C, so to me they were the specialists. The GPs, well the ones that I went to, did not seem to have the information, so I went straight to the specialists. (#15, late 40s, female, completed treatment)

A further model of care that was strongly supported had incorporated a peer support worker within an HCV clinic offered at an ACCHS. The ACCHS environment was important to this participant because of its convenience, familiarity, welcoming, caring and safe environment in comparison with the hospital environment.

It's all done there at the AMS yeah so it's close, it's really nice and convenient, nice atmosphere, people there care, people I know, it's a place I'd rather do it instead of you know a clinical environment like a hospital you know ... Well I reckon they should do it more in their community where they feel safe, like I know that other communities do take on Aboriginal Medical Services, but Aboriginal Medical Service is a place

where you know like the people feel comfortable you know, it's your community. (#25, demographic information removed to protect anonymity)

The second element of this treatment model emphasised by the same participant was the peer worker. The peer worker was described as a credible, positive and helpful influence on the participant's decision to undertake treatment and to focus on aspects of his health to promote liver health, such as diet.

Well he's been through this, he's been through it. You know, he had HCV and he's completed the program so I take a lot of information off him because he knows and he is really enthusiastic about it and he wants other people to realize that it does work and as I said he rings me up and if he sees me on the street he asks me how I am going, he says are you eating your breakfast, lunch and dinner, the doctor is going to be there, the nurse, this and this time and all that so he won't let me go so he basically forces me to go. (#25, demographic information removed to protect anonymity)

The prison environment was described as facilitating care and treatment in a number of ways such as promoting HCV awareness via drug and alcohol courses. In relation to treatment, the stability and organised routines of the prison environment facilitated both accessing treatment and ensuring participants could 'commit' to treatment.

I done it in the prison environment, everything was there for me and that, you know what I mean, like I was called up once a day, get my tablets, once a week get an injection and it was all there at hand for me. (#27, 40, male, completed treatment)

Participants experienced variable treatment responses with a number of participations not achieving a sustained viral response (or 'cure'). Participants described 'some pretty bad stages' of treatment, and all received support from a range of services including psychologists, the liver clinic and the ACCHS.

And then there are the misconceptions about treatment. People go like no, no, I can't do that, it is too hard, so and so said that it is too hard—and it is hard—but with support and if you do what's recommended by the health professionals like um the people looking after me at the hospital when I was having treatment, and you just do the recommended suggested things and you get through it, do you know what I mean. You don't have to do it alone. (#15, late 40s, female, completed treatment)

Participant #30 expressed the most negative thoughts about a subsequent attempt at treatment. Despite reporting significant HCV symptoms, this participant indicated that she would refuse to have interferon-based treatment again because of the side-effects experienced in her first treatment.

Over the course of the treatment it made me quite sick and I don't think I would like to go through that again ... If I knew it was going to make me this sick, I would not have had it. It was not apparent that it was going to make me that crook, because it seems like, it feels like having cancer ... I would have avoided [having treatment].

I wouldn't have cared if I had hep C ... Yesterday my liver, there was so much pain I started crying and doubling over in pain, I just thought, is there any other way apart from having the interferon, I can get rid of this cos I don't want to have to go through that interferon thing again. (#30, 51, female, completed treatment)

The initial course of treatment did not result in a cure for participant #3. He reported that being in contact with the CSRH research team had 'kick-started' his engagement for a second round of treatment. Each participant recommended that others with HCV 'get the facts' about treatment:

I would just recommend that they get the facts, talk to other people that have been on it and pick the right time. it's not something you can go and do tomorrow. I know for me I had to prepare. I went and got all the information and then made a decision that

I will do treatment, but that I needed to wait until the time was right, so when I knew I was becoming a 2 day a week worker instead of full time, I thought now is the time to go on treatment. I could never have done it if I worked full time ... So it took me a year from the time I investigated until I was ready to do it. So I'd tell people to prepare their life and by doing that it gives you the ability to complete treatment, because some people would go on it and then throw the towel in and go, no it is too hard, you know ... I built my whole life around treatment—so, you know what I mean, it came first and everything else came second. (#15, late 40s, female, completed treatment)

3.2.7 Examining the experiences of participants who expressed low interest in HCV treatment

To supplement the information already canvassed in interviews with Aboriginal people living with HCV, we specifically sought additional participants who had indicated in response to survey questions that they had low interest in treatment. Transcripts of previous clients who expressed the same attitude to treatment were also re-analysed. Interview data from eight participants was analysed in this section. This included two participants who had spontaneously cleared the HCV infection (and one who reported no injection since that time), one person who had developed liver cancer, and one who had been told she was ineligible for treatment because of mental health issues.

Previously, the report indicated low levels of information, lack of HCV-related symptoms, concern about stigma, concern about treatment side effects and witnessing others become unwell as characteristics of participants' decisions about engaging with HCV treatment, both positively and negatively. These themes were reiterated in additional interviews focusing on those who expressed low interest in undertaking HCV treatment.

Well basically no because it is still not affecting me other than what I know about it now, you know, because it hasn't affected me, because it doesn't worry me, it hasn't really phased me but lately I have seen some people you know who I know quite well who have had it for a long time and are very, very sick, dying you know and it sort of made me think about you know doing the Interferon (#33, 55, female, not on treatment)

However, as participant #33 notes below, having lived with HCV for a long time draws attention to the variable nature of the infection in terms of the impact on an individual's health. This variable impact may allow people to believe that there is no need for them to engage with HCV care, or treatment, or that it is difficult to know 'when to get help'.

Oh yes, there is lots of myths you know. And then there are some people who are so sick and die from it and what not and there are people who have died from it and then you see people like me who have had it since the '80's and have had no effect at all, you know, that I am aware of. Yeah so you just don't know what to believe with it. I know other people who are really, really sick with it and it is just unbelievable that the same things affects people differently or there is different strands of it you know. (#33, 55, female, not on treatment)

Concern about treatment side effects, combined with low levels of support for people who may undertake treatment, was also reiterated in this sub-sample. Although understanding that more efficacious and tolerable treatment was on the horizon was expressed by some participants, one participant had since developed liver cancer. This participant indicated that not feeling unwell and concerns about treatment side effects were the main issues in decisions about HCV treatment. However, although informed about future treatment possibilities, this participant reported not receiving information from a health professional about the adverse impact of drinking alcohol on HCV progress, and reported high levels of alcohol use. Being able to capture experiences, such as this participant's, could add to messages promoting engagement with HCV care (including the need to monitor liver disease and the impact of alcohol and other lifestyle factors).

Concerns about stigma were embedded in both historical and contemporary experiences and enmeshed with Aboriginal identity. Participant #32 (now in her 40s) discussed being placed in an isolation room when she had her children in hospital. She also described her family 'alienating' her when she sought to engage with her nieces and nephews. This participant noted the fear of stigma as a major barrier to seeking HCV care and treatment. A further participant noted that she observed people who would "almost rather die than tell you they've got it ... they feel ashamed to be black, let alone feel ashamed for having hepatitis" (#32, 40, female, not on treatment).

Other physical and mental health comorbidities had resulted in some participants ruling themselves out for HCV treatment either because of medication contra-indications or the demands of coping with other conditions.

A number of experiences had changed participants' attitudes towards HCV treatment within the period of time that they were engaged with the research. For example, participant #33 indicated that she had witnessed, 'just in the last couple of weeks', a friend become unwell as a result of HCV and that this had led to her enquiring about HCV treatment to explore "what I can do about myself before I end up like my friend". A small number of participants (in this sub-sample and in the larger sample) reported they had not spoken to anyone else about HCV, and that this engagement had resulted in them considering further engaging with HCV care.

I mean you'd be the only one that I have really spoken to about it and that's only with the surveys really. (#34, 29, male, not on treatment)

These data indicate that attitudes towards treatment can be affected within short timeframes and with limited intervention when conducted in supportive, non-judgemental and culturally appropriate interactions.

3.2.8 Hepatitis C campaigns

3.2.8.1 Participants who had been treated

Two participants linked being 'surrounded by information' to their decisions to undertake treatment. Participant #12 stated that realising help was available (via information campaigns) was the catalyst for him to seek treatment. Participant #15 (late 40s, female, completed treatment) worked in an organisation in the BBV area, and being close to information in this way encouraged her to find out more about HCV treatment.

Definitely, that's when I started thinking about doing treatment when I realized that there was all the help out there. (#12, late 20s, male, completed treatment)

Only one participant indicated attendance at a 'Where's the shame, love your liver' workshop. This participant (#12) spoke very positively about the event and supported future such events to both involve a broad cross-section of community members and address misinformation about HCV.

Yeah it was good, they tried to involve the whole community and they had everyone from school kids and at the local high school right through to elders within the community and health workers and you know it was good, it had a really good, it was a really positive, positive couple of days in the community, it was good.

It's a good way of putting the message across hey?

Yeah, with music, its one we all share, you know.

That's right. And what do you think needs to happen to encourage other people living with hep C to find out more about it?

Um, I think that basically we need more information because like a lot of people living with hep C they are misinformed like you try and tell them about treatment and they say like, oh no, I don't want to not be able to have sex, or I don't want all my hair will fall out. So there are symptoms that can happen but they don't happen to everyone, so there is a lot of negative information that is circulated in the community that stops people from participating in treatment. (#12, late 20s, male, completed treatment)

3.2.8.2 Participants who had not been treated

Compared with participants who had decided to undertake treatment, there was a marked lower recall of community hepatitis campaigns with some participants indicating they had seen no such campaigns. The most commonly referred to form of information was pamphlets. Only one participant identified that they had heard of 'Where's the shame, love your liver', but indicated that they had not participated. A minority of participants linked exposure to information with a cue to action regarding HCV care.

Yeah, it just makes you more aware of it. it makes you more determined to do something about it you know. The more times you see it the more times you – like sometimes you see a photo or whatever and then it makes you determined to do something about it. Well, that's me anyway. (#10, late 30s, gender unknown, not on treatment)

Ah, it made me think about it yeah, like getting it checked up and that, because it said you need to get checked up and that. (#20, early 20s male, not on treatment)

3.3 Key stakeholder interviews

3.3.1 Overview

The investment from NSW Health (via NPA-IH funding) was structured to involve the establishment of Access Coordinator positions. Seven Coordinator positions were recruited including one who was positioned within an ACCHS. These positions were filled at varying times within the investment period (giving the Coordinators varying times in which to work towards the goals) and some Coordinators left the position prior to the end of the investment period. These positions were not re-filled. Coordinators were not able to be recruited to two positions, including Justice Health and one ACCHS position. In LHDs where funds for Coordinator positions were not fully expended, other arrangements were made to use this investment. For example, a workforce development program for ACCHS staff was developed for one LHD area, and in another, surplus funds were invested in producing a model of care document. This makes analysis of patterns across the various LHDs challenging.

3.3.2 Access Coordinators

Seven people who had held Coordinator positions were interviewed. To prevent identification of any individual participants, no further information about these individuals is provided. This is especially important given the very different contexts in which the Coordinators were working, the diversity of activities undertaken, and the somewhat polarised experiences reported by these participants.

The experience of Coordinators differed according to a range of factors, specifically geography (metropolitan versus non-metropolitan; larger area versus small area to cover), organisational positioning and location (within HARP/LHD structures versus within ACCHS), level of resourcing (for example, whether the coordinator was provided with a car, laptop, mobile phone), length of time within the Coordinator role (one of the 'foundation' group

versus someone appointed later in the project), prior experience specifically within the HCV sector, and length of time living or working within the local communities. This makes a thematic approach to data analysis difficult as the story of each coordinator is unique. Nevertheless, some noteworthy patterns did emerge within the data.

3.3.2.1 General perceptions of the coordinator role

It appeared that the Coordinators who had previously worked in the HCV sector, were well known in their communities and who commenced in their Coordinator positions at the beginning of the project relayed more positive experiences. One Coordinator felt that if the appointed person was unfamiliar with HCV, or with the local community, it would set up projects to 'fail' in some areas.

I think it would have been hard for people that haven't been in this kind of a background or haven't had a lot of history in health. For people who aren't familiar with their local areas. (#20)

Coordinators were positive about the mix of work involved in their role, particularly the opportunities to remain in contact with the community.

What do you enjoy about your role?

I think it's because it crosses all levels.... We are still able to touch grass roots, so we've got local, regional and state wide connections. (#20)

I think it was on a good track, these positions like half and half, strategic and operational. Because you can't teach people if you are not prepared to model it for yourself, how it looks and that's what I found the most that you know if I was the one that had to organize training and all that, I would be part of the people that would present co-present together and what it would look like for an Aboriginal health worker, how they would do it so that modelling is very important you know to plant the seed maybe for others to maybe think oh well maybe I can't do a lot, but even if I just do a little bit of advocacy or if I learn the procedures to do a good referral. (#24)

3.3.2.2 Shame, stigma and discrimination associated with hepatitis C

The shame, stigma and discrimination associated with HCV were noted by Coordinators as a formidable barrier when working with communities and with some health agencies. Indeed, one participant noted that the title of the Coordinator position, including the word 'hepatitis C' was a barrier in itself.

One of the other barriers I found was just actually our title even though it was a great title to have, as soon as I mentioned hep C, people started to run, they were like out the door so I kept trying to come up with some initiative ways to try and say my title without trying to, their faces going like – you're dealing with hep C, this is what we are dealing with. Once I got over that then I could bring out hep C stuff and they were OK with that. (#3)

It's a shame and there's a stigma around the drug use and they do live on the fringes of the community. (#25)

Issues that face Aboriginal people with hep C is that there is a lot of shame about it and the people who inject drugs, they've got their own little community and they don't necessarily want everyone else in the Aboriginal community to know about this problem that they have. (#27)

3.3.2.3 'Where's the shame, love your liver' Campaign

Overall, this aspect of coordinators' activities was described very positively. The Coordinators appreciated being able to work with communities and in a way that facilitated an open discussion of HCV, noting previously raised issues about HCV-related shame, stigma and discrimination.

As a whole, well hopefully you know, the benefit to the community is that hep C is out in the open and is nothing to be ashamed of and that kids can talk about it and that families can talk about it openly, and that takes away a lot of that stigma, you know, they're a drug user or they went to jail or whatever, if it is all out in the open and everyone discusses it, it is not such a big issue then. (#25)

3.3.2.4 Experiences within the workplaces

A number of the Coordinators raised concerns about the capacity of the services that they were placed within to effectively manage Aboriginal workers. These Coordinators felt that more was required to help their workplaces understand how to appropriately support Aboriginal workers. This included being aware of the overlap that many Aboriginal workers experience between their professional and personal lives, the need to maintain 'kinship integrity', and particularly, the importance of showing respect for an Aboriginal worker's expertise in engaging with the community. Further, the importance of feeling isolated when being a single Aboriginal worker in a mainstream team was noted with the accompanying lack of opportunity for 'cultural feedback'.

When you have Aboriginal people within a workforce, doesn't matter whether it's mainstream or whether it is an Aboriginal community controlled, for me as an Aboriginal person you know I not only have professional integrity that I need comply with in terms of my job, but the other really important thing is my kinship and my community integrity and they are things that I have to integrate within my professional and sometimes that community and that kinship integrity sometimes overlap with the professional. (#18)

I think that it is common with recruiting Aboriginal people because ... sometimes you have got a mainstream team there may only be one Aboriginal person within that team you know and then you've got no cultural feedback from another Aboriginal member within the team or you know an opportunity to debrief as you go outside the team, whereas if you are recruiting one alone it makes it harder for an Aboriginal person to be, lots of people adjust to it but it is so much easier culturally to have you know a team of 1, 2, 3 or more within a generalized team ... If you have got a manager that is well supportive of Aboriginal work and understand how they work, how the community, understand how they engage the community, then you can have more success with those programs and those workers. (#25)

They don't understand that we are the experts in our community and we know how to engage our community but they don't give us the respect to or the autonomy to go and do that, they've just got to control every aspect of it and not have that, not give us the same professional courtesy that we know how to do our role. (#25)

3.3.2.5 Timeframe and sustainability

While participants appreciated the overall structure of the NPA-IH program, and the complementary nature of the various aspects, the goals to be achieved within the project timeframe were perceived as unrealistic. Participants noted that they had achieved some significant gains in their area, but that further time and resources would be needed to consolidate these achievements in terms of the goals of 'systems change' due to the complexity of organisations and structures involved in this project and their varying and competing priorities. Further, some participants noted resistance from Aboriginal communities regarding the timeframe and lack of sustained resourcing.

What concerns me more than ever is that we will get to quite a high point and then they'll drop off, the Coordinators won't be there to keep that drive going and I don't know how, will it go away, or will the momentum keep going through some other avenue? (#3)

A lot of them again said, you know what happens after your position finishes, but there was no answer for this, you know we couldn't say look, we wish we could go on. But it was getting stronger, stronger and the community was building confidence in approaching us. (#3)

Trying to meet the requirements of the funding agreement within that two, two and a half, three year period I think is really unrealistic. We were referred to as change agents but I didn't feel like we were change agents, I think that we were more facilitators and a part of that facilitation was trying to work across those three levels of stakeholders and trying to not only identify where the gaps were but also trying to find how we can address those gaps. And I think that, in the 2 years that I have been in this position we've only begun to scratch the surface and I think you know if we were given another 3 years to work on this project I think we could see some more realistic outcomes and I think that what we have achieved thus far. (#18)

And then all of a sudden the positions are gone, it's just another band aid position; chuck Aboriginal project workers in, fix that and then go away, there's no really permanent positions at the end of it, you know, use and abuse Aboriginal workers to get what you need, mainstream can fix it up, we don't need the Aboriginal workers anymore but they're the ones that do all the ground work, we're the ones that engage the community, we're the ones that bring the community in. (#25)

I love this job and what I try to do with it ... I was worried that why couldn't these positions be maintained you know, I would have loved to have stayed on and had this as my permanent core business work because ... No one could take it on to the extent that it was meant to be taken on to maintain rapport and support, support for the clients because they have got their own core business ... If anything could come out of this interview my recommendation is that the hep C positions should be maintained, even if it is not at this level, if it is at an operational ... I reckon that that would be the best recommendation I could make because it's a big job, it's a job that – we have a lot of unknown hep C in our community and we need someone to keep a focus on it, you know because we have got all those stats and everything to back us up of why you know like another high incarceration rate, people going in and out of jail, and there are all those high risk behaviours that happen from jail, it is then brought home into the community you know, behaviours continue or they might have already had those behaviours before they went to jail and they might just do those behaviours a lot more with risk entailed you know so there is a lot of stuff that I reckon points to warrant these positions. (#24)

3.3.2.6 Re-orienting health services and systems change

The need to re-orient health systems to better engage Aboriginal people with HCV was recognized by Coordinators, and varying degrees of achievement were expressed in this regard. Issues raised included the need for models of care for Aboriginal people which are 'client-focused' and require clinical services to 'think outside of the square of the hospital' to be inclusive of primary care. The barriers experienced by one Coordinator in attempts to negotiate alternate models of care (beyond the traditional liver clinic) led to comments such as: "the same health system that employed me was my worst enemy" (27). This participant suggested further support of Coordinators' activities was needed, including the advocacy of "senior management of local health districts, from the Chief Executive down to the gastroenterologists" (#27).

One participant noted that the development of a clinical care model by the Agency for Clinical Innovation during the period of the project would have facilitated the work of the Coordinators with ACCHS. It would also have raised the importance of engaging Aboriginal clients with liver clinic care. Coordinators recognised the many and various other demands on the capacity of ACCHS impacted these organisations consideration of whether to further incorporate a focus on HCV care. However, the efforts of one Coordinator in developing HCV specific relationships were thwarted by other capacity issues in local ACCHS as some ACCHS were not functioning at some points during the investment period.

One participant spoke of what they felt was a troubling shift in the priorities of the Ministry of Health. This participant was worried this shift in priorities might erode the work done by the Coordinators to raise the priority and profile of HCV. To illustrate how this change in priorities might be affecting the perception of HCV as compared with HIV and STIs, the coordinator employed the following analogy of a bus.

And if you liken it to a bus or whatever you call it, you know you have got HIV and STIs sitting right up front on the bus and somewhere way down the back pushed right in the corner you have got hep C. (#18)

One final achievement to be noted at the systems level was the development and implementation of a clinical audit of services. The Coordinator developed this as a collaborative process in which the Coordinator was involved in addressing the recommendations made as part of the audit process.

Well with the structural changes as I said you know we rolled out a cultural audit so we were getting people to look at how their services were currently run and then you know we would come back with a set of recommendations and suggest maybe ways that they could improve their access to Aboriginal people in their services. But they weren't just dumped with that, we would, myself and [another] worker ... we would form part of the steering working group to implement some of those recommendations. (Identifier removed to protect confidentiality)

3.3.3 Managers and supporters of Access Coordinators

Six workers from five in LHDs were interviewed. These workers were directly involved in establishing the Coordinator positions and, in various ways, managing or supporting these positions. The experiences of these participants were also varied though issues relating to internal LHD structure, resources and processes were important to the roll-out of all Access Coordinators positions. The participants also expressed varying opinions about the degree of success of the programs with some LHDs recruiting and retaining Coordinator

positions for the majority of the funded period while other LHDs were unable to fill or retain the position to completion of the project. Some LHD participants were able to describe a list of achievements from this investment; others noted that the outcomes were 'minimal' or that 'nothing' was achieved.

3.3.3.1 Establishing the role and local input

An issue that was mentioned across the interviews was the limited time involved in setting up the coordinator positions and the imposition of a mandated focus to their work. Participants felt that while they were unable to decline the offer of such investment, a longer time frame, local consultation and an ability to tailor the position to the needs of the local area could have resulted in a more effective program. To this end, one participant noted that seeing how other areas were able to negotiate the use of funds when Coordinators were not recruited, it would have been beneficial to delay recruitment to allow for such a negotiation and tailoring of the program in order to better meet local needs.

In the first instance the jobs were given fairly, pretty in a mandate form, requirement from the Minister of Health and they were very strict around, very strategic and capacity-building in nature. (#14)

But I mean there was never the option to consider doing that like the money was tied to a wage and a position and we understood that that was something that had been secured and you know, I have enormous kind of respect for the fact that people in the Ministry managed to pull together the submission for funding. My understanding is that it was in a really short period of time and there was no consultation about it like they just kind of had to do it and secure it. But I think the way it played out in our area to some extent reflects that process. I mean, it wasn't particularly what we needed you know and it didn't actually work very well for us in practice. (#22)

I kind of wish I didn't recruit straight away with that mandate from the ministry to do so, and just kind of lagged along and had the opportunity to negotiate what did we want to spend it on. (#15)

I think the way the money got given to them, they didn't have much of a choice in how they rolled this out so it was you know a decision got made because they got money and they hadn't made a decision with what to do with it on a very quick turnaround. I think had there been a lot more lead in time, that that could have been thought through and it would have been better had there been scope for each area to say this is the model that would suit us better. I think everybody has very, there's limitations, there's different capacity to roll things out. So yeah look, ideally you can't just say this is the model and this is the model that has to be applied across the board because they are all different. (#21)

And the consultation process was very hurried and rushed ... I don't know that the consultation process by the ministry was thorough enough to see what sort of program the actual community wanted. (#16)

3.3.3.2 Local structures

The issue of locally-oriented versus a state-wide and consistent approach emerged as a strong theme in each of the interviews. In some LHDs, the Access Coordinators were recruited to an area which already had a high level of Aboriginal staff members, and as a result, it was difficult to find a place or a fit for the Coordinator position.

It was not like they came into a vacuum where there was nobody working in that space, there were already workers, so there were already workers you know, so there were issues around demarcation of work, relationships between the hep C Coordinator and the other Aboriginal staff was a little bit tricky because of that. It

didn't come out of our own local planning and needs identification – we were told, these are the positions, this is the model and of course you know we accepted it because it was an additional resource but it wasn't in relation to our identified needs and I am not sure it is the way we would have gone had we had the option of spending that money in a different way. (#22)

Another LHD was able to conduct an analysis of existing initiatives, workforce capacity and areas of unmet needs. Because of the geographical spread of the area, there was an opportunity to locate the Access Coordinator in an area that was not as well served by staff and services than other parts of that LHD.

The internal structure and arrangements within LHDs were also of importance. Some LHD participants also oversaw clinical HCV services which provided direct access for Coordinators to liver clinics while in other LHDs, the liver clinics were managed by a different organisational structure. In LHDs where there was already Aboriginal Sexual Health Workers, the Coordinator positions were implemented at a higher pay scale, but their duties may have been seen as complementary to existing staff, creating potential difficulties between workers. Other LHDs had capacity to provide Coordinators with resources beyond what would usually have been supplied to such workers such as their own car. While this provided the Coordinator with autonomy and capacity, it was not able to be replicated in other LHDs, even where the physical distances between target services were great. Internal resources such as a strong management and support structure were described as important by some LHDs, but not able to be implemented in others.

So we had program management support, we had day to day management support and then we also had this cultural mentorship so in the event that we could try cover the bases. (#17)

3.3.3.3 Workplace challenges

Echoing the comments of Access Coordinator participants, these interviewees also focused on the importance of producing the appropriate working arrangements for Aboriginal staff. To be provided with a job description with little or no local input was described as challenging. Some participants spent a long time doing ground work for the position in meeting and consulting with local Aboriginal organisations and key support units. Some LHDs embarked on more than one round of recruitment before being satisfied with the candidate recruited. Another LHD considered racial discrimination within clinical settings too much of a risk to place the Coordinator position in such a setting and therefore reoriented this role. While this structural change may have resulted in a more culturally safe working environment, it added complexity and challenges to the goal of making changes in clinical settings.

To put a solo worker in a clinical setting, a solo Aboriginal worker in a clinical setting was kind of culturally unsafe. They wouldn't have any sort of voice and they may actively be discriminated. Because there's intrinsic systematic racism in health, that's unfortunate but that is what there is. So therefore the position stayed out in community settings, health promotion settings, population health settings. So there was that added trick of being able to work with clinicians and sort of have an impact on clinicians when you are not actually sitting in their settings. (#14)

Participants also discussed the mix of strategic and operational aspects of the Coordinators' role. Some participants felt this was a difficult balance of skills to find in one worker and further, echoing again comments from some of the Coordinators, believed that the skills of their recruited workers were better focused in other directions. The notion that Coordinators, many of whom may have come from clinical, health education or community development positions, would have the requisite skills or capacity to move into roles

requiring them to drive systems change was perceived as something that Coordinators found 'hard to come to terms with'.

And I think that it has been an absolute waste to have an Aboriginal nurse with great skills and knowledge and medical expertise in hep C, in a totally strategic role. (#14)

[While acknowledge the 'high functioning' skills of the coordinator in some aspects of the role]: What we need is, there was a large bit missing for us, is someone getting around to the communities, the identified communities, from the surveillance data to really say: look, you know, treatment has changed a whole lot, we've got really good success rates, you know if you don't know, sure most of you ... if you haven't it's a really good thing to have because it will prevent liver disease in the future, especially if you are hep C positive, you know, that component we really missed out. (#15)

3.3.3.4 Goals of the program, reorienting services and systems change

The participants were, of course, aware of the main goal of this investment: to increase access to HCV care and treatment for Aboriginal people. The data from these participants focused mostly on efforts to increase the number of people taking up HCV treatment. Issues relating to care (education, appropriate testing, and lifestyle changes) were not devoted as much attention. However, some participants described that this program could only result in an overall marginal increase in numbers of Aboriginal people in HCV treatment, especially as clinicians began 'warehousing' patients to wait for more efficacious treatments, and also as a result of treatment waiting lists overall. In this environment of limited clinical capacity, participants described that only a certain number and a certain type of patients would be admitted to treatment. In this case, revision of overall project goals and KPIs was necessary to focus on outcomes that were both meaningful to HCV care and achievable.

Anybody marginalist, you know, if you are poor, if you are drug using, if we've got an illness or if you don't understand the system, it's hard to process all that stuff with it magnified within Aboriginal health so and we kind of knew that, we kind of had conversations with the Ministry to say this sort of stuff is not achievable so right from the beginning we followed the view that we would frame the success of the project using different criteria and the kind of things that we talk about didn't clearly have a measure but it was about connectedness, relationships. What we wanted to do was to try figure out if our area health service was able to develop good, effective partnerships with Aboriginal health organizations and what that relationship meant and how we might look at it, so that is what we focused on. We focused on issues around health literacy and capacity within communities, so we looked at viral hepatitis and we looked at broadening out the scope of the project so not just, our worker wasn't just working within a treatment sphere, we broadened that out to a community health promotions. (#17)

In terms of systems change, two participants noted that the structural barriers to Access Coordinators being able to influence systems were insurmountable. These participants described Coordinators as lacking the credibility and authority to change clinical systems in a 'very dinosaury' system:

So there was no actual direction on what they want and so some workers worked reasonably well when other workers, there were too many barriers in front of them especially around clinics and nurses, that's what they are trying to change, they are trying to change the way the clinical staff do business but it is too hard ... It is extremely hard for a worker to make change to a, you know a nurse, a practitioner or a nurse specialist, because they don't have the authority and they don't have

the credentials to do it ... brought up a lot of politics. Well a lot of the times it's like fighting systems, you know, if they are too rigid in their systems then a lot of times their workers and Access Coordinators are fighting systems instead of getting out there and doing the job. (#16)

You don't get to earn the right to be treated as a senior or as an agent of change, particularly in relation to Aboriginal health, without having a helluva lot of street cred and acknowledgement on the ground ... They had to get in there and magically whistle up change within the system that would lead to sustainable change ... I think that the 'agents of change' brief was unrealistic and based on a superficial and inadequate understanding of how change is achieved in health systems (#39)

A positive impact on systems, which was noted by one participant, described an outcome of this project as the agreement of each liver clinic in the area to preserve a number of treatment spots for Aboriginal people. In effect, the participant described the approach to treatment as 'striking while the iron is hot' for Aboriginal people and facilitating initiation of treatment for them, even if the clinic was operating at capacity. Further, one LHD was preparing to incorporate aspects of the coordinator role into the work of ongoing Aboriginal Sexual Health Workers and other workers, such as ongoing liaison with ACCHS:

[The other worker] has to have the mandate to stay in touch with Aboriginal Medical Services, it's the key contact for the AMS' and we found that that is pivotal as well because there is just one clear communication and a trust and a rapport, and cos they know her, they'll be like: so look we've got this guy can you come when you are next out at our Outreach, can you come into the AMS, you know, we know he is going to be here, for his diabetes check, but we want you to see him and have a chat to him, and it happens more and more once you have one identified person. (#15)

Participants made a range of suggestions for alternative ways of addressing the goal of improving care and treatment for Aboriginal people with HCV. Among the suggestions was to generate demand from the community to create responses in the hospital system.

Look, I think we would have worked with agencies and GP's, not necessarily with our own system I think, and made the movement come from the communities rather than try and change the health service clinical systems. The demand was put on them rather than on us asking them to change cos I think if you get GPs, community members, community agencies, individuals wanting care, then you are going to get some sort of reaction from the system. (#14)

So maybe we could have benefited more if we'd have had more workers on the ground that actually spread the word about hepatitis C at a higher volume, rather than trying to change the clinical side of it ... Well I think we would have had more people more aware of hepatitis C and then probably more aware of where they could go to get treatment for hepatitis C and then probably we would have had more people accessing clinics, and Aboriginal Services. (#16)

Another participant suggested that a treatment support officer could have been employed in the second half of the 4 year period of investment to capitalise on an intense period of building relationships between services.

You can only develop so many partnerships and referral pathways and get NGOs and Aboriginal services orientated in so long, if that makes sense ... But, retrospectively it would have been better ... to have someone come in and do an intense 18 months or you know, 12 months to 18 months of really rigorous partnership building, mapping and identifying what partnerships need to be made, what would benefit the community, whether it be partnerships with transport or

housing or partnerships with Aboriginal medical services and then a further 18 months then, providing some kind of more patient support linkage... we need something like a treatment support officer Someone who is always case coordinator, treatment coordinator. So, trying to coordinate what their needs are and all the barriers in getting treatment completed or right through on treatment or even from assessment to treatment, it would reduce all those barriers. (#15)

The notion of reaching a 'plateau' in the achievements of the Coordinator position was noted by a second participant, who suggested that the position would need to change if it was extended for another period to incorporate additional work with the Aboriginal population, and also to maintain and build on what was achieved in the initial period.

3.3.4 LHD HCV clinical staff

Ten participants from six LHDs were introduced. These participants held clinical and senior leadership roles within tertiary HCV treatment clinics. Perspectives of health workers were generally shaped by the local context in which they operated, and the relative connection to the local Aboriginal community or ACCHS they had in place prior to the investment period. However, some participants took a more systemic view of efforts to improve the health and health systems relating to HCV by referring to the complex issues underlying health inequities, the dogmatic approach of western medical knowledge and systems, and the importance of trust as an underlying resource to effective healthcare delivery:

Despite the fact that we have spent billions of dollars we still don't have a handle on how best to fix the gap between white people's life expectancy and the Indigenous people's life expectancy ... but the West does believe our approach is the only valid and if you don't like it then there is something wrong with you, rather than saying, hang on, why don't you see it as best, let's talk about it. And of course Indigenous people like to talk, they'll talk for a long time before they actually trust you.... and money alone just won't fix it, putting in another nice building; it's not fixable because the problems are trust and acceptability of the way people deal with it. (#26)

I think there are so many issues with the Indigenous population and it's hard to actually just put that down to one particular feature or fact. It starts everything from social disengagement to you know the group that you are targeting. Are you going to target the teenagers are you targeting people that are middle aged with hep C? If you are targeting people who are middle aged with hepatitis C, their biggest problem is that they are dying from diabetes, kidney failure and heart attacks. So you have to have strategies based on how much money you have and what you want to tackle ... what can I do usefully with this money and f you then have this business that you are going to have equity across the state and you are going to five \$2000 bit for 15 areas, it just doesn't solve anything (#41)

Health workers' experience of efforts to improve HCV care and treatment were mixed and grounded in their previous experiences of service delivery and cultural awareness training,. These experiences resulted in health workers being open and positive about future engagement with Aboriginal health programs and others having had 'detrimental and negative experiences' and remained 'confused and desperate' in a "continuing search for that thing that is going to give us the insight to all things Aboriginal" (#23).

Issues of resourcing and stability of staffing were raised as important barriers to engaging Aboriginal communities. Some health workers noted frustration with the ACCHS in the region, describing a process of continuing change in the CEO role, or that priorities for ACCHS attention were 'personality driven' which prevented one participant progressing connection with the service.

In converse, some health workers recognised the impact of staffing stability within LHDs as affecting efforts to engage Aboriginal communities. When budget or staffing resources were restricted, LHD clinics contracted their services to focus on clinical work. In this situation, activities which promoted the 'visibility' of LHD clinical staff (and hence the visibility of HCV among Aboriginal services and communities) were reduced. However, in this situation, an important focus was to maintain the 'trust' of Aboriginal workers in the clinical service. This highlights the everyday pressures on, and limitations of, HCV clinics in comparison to the greater resources offered within clinical trial contexts. In the context of long waiting times for HCV clinic appointments, one participant noted a 20% 'did not attend' rate for initial and subsequent clinic appointments. In contrast, this participant remarked on the relative success of clinical trials in engaging Aboriginal people with HCV.

Out of those Indigenous patients, five have gone on to clinical trials ... and three have only gone through the normal system. So the clinical trials, they get a lot more support so I don't know if that's the person has rung them and talked to them more regularly or whatever when she's been chasing them to get on to the study... it might have been because [the clinical trial coordinator] is more flexible with clinic times because [there isn't] the restriction of the [regular] clinic (#40)

While this group of health workers typically also discussed the stigma associated with HCV for Aboriginal people, one participant felt that issues of stigma and social isolation were issues for all people living with HCV. One non-Aboriginal participant believed that notions of 'shame' have been overplayed and positioned as a barrier to open and non-judgemental engagement about HCV:

The more I hear that word thrown around I look to see who is saying it and it's people who aren't working particularly hard with the Indigenous people, they are sitting in offices and thinking about how it must be and coming up with the terminology ... sure there is, but then we all have things we're ashamed of and if we just deal with it comfortably and say look it doesn't matter where you got it or how you got it ultimately you've got it and let's get on with stopping you getting more consequences from it. (#26)

The practical barriers to HCV care and treatment as it is currently delivered was noted by health workers. One worker referred to experience in another country in which pre-test counselling had been condensed to a shorter process; antibody testing was done by oral swab; and PCR testing was done by finger prick blood test (rather than venous blood draw). These modifications were seen as enabling greater numbers of people to engage with HCV testing in ways that lessen barriers (related to time and blood draws). On a related point, one participant noted that some people attend an HCV hospital clinic having had no pre- or post-test counselling in a GP setting, and very little preparation regarding what to expect of the HCV clinic process.

So what happens is they haven't been well primed. They get a letter to the liver clinic, they think that are just going to come and get some medication, walk out the door and get treated. And of course no, that's not going to happen. What happens is we say "no, we got to send you to the psychologist, we got to check your Fibroscan, we got to check a liver ultra sound to make sure everything is, blood tests, what your genotype is, what your viral load is, so it is a lot more involved ... there is a misconception and GPs just writing them a letter, whether you know how they expect the treatment is and what their expectation is, may be completely different to how it is actually going to be (#40)

In addition, the assessment and preparation for treatment processes were described as containing a number of 'hurdles' each of which could result in clients being lost to

the process. One participant added the issues of 'patient motivation' and Aboriginal culture more generally to the discussion of low engagement in HCV care. It is important to note that hurdles to HCV care could emanate from health worker attitudes and misunderstandings which shape interpretations of Aboriginal people's choices about healthcare in relation to culture, rather than informed by understandings of social disadvantage and the disconnect between western health systems and a holistic approach to health important to Aboriginal people (National Aboriginal Community Controlled Health Organisation, 2005).

And that can take a long time and people can drift away you know in that process, but there are some hurdles to overcome and you lose a few at each hurdle.

So what other hurdles do you reckon are the main ones up there?

Transport ... Ah, the first hurdle is the stigma and confidentiality concerns. The second one is competing health priorities for some of those people, you know like hep C can be way down the list if... Housing, family and other chronic co morbidities ... yeah and getting food on the table and for people with prison issues then clearly that is much more of a priority you know. (#32)

I would say the major issue is around patient motivation. They make their appointments but then they just don't show up ... I think it's a whole range of factors ... I have been told that sometimes it's just cultural, that that's the way Aboriginals are, that they are poor at attending their meetings and appointments and so forth. I think that a lot of their lives are consumed with other problems as you suggest—their alcohol, social welfare, mental illness and drug use. So I think it is multi-factorial ... Overall though it's very disappointing because I feel we could do some good work in helping these people but if they don't come through my doors I am very limited with what I can do. (#38)

Besides other priorities for clients in relation to life issues, participants also noted physical health comorbidities as leading to delays in uptake of treatment. Further, one participant noted that the focus of HCV services should be on HCV assessment, and indeed a broader liver health agenda for Aboriginal communities, to draw upon advances in technology and to reduce stigma around liver care.

So you know we are in that stage where maybe we are not treating all that many people anyway, but certainly we have now got a bigger number of people waiting to be treated, because quite often they have got so many comorbidities, and are sorting out their comorbidities ... Well the thing is that we are in a very changing landscape, ok, so I don't think the focus needs to be so much on treatment anyway, the focus needs to be on assessing liver disease and triaging people in terms of what they need as far as treatment goes. But the priority is getting people to understand what their liver disease, what their liver health, taking the Fibroscan out there a lot more, getting people screened ... So I think the priority is to get the message out there: we've got really good tools now, you just need to come to the clinic, we can tell you how much liver disease you have got, we can tell you if you really need to start thinking about the treatment right now or whether you can wait but the important thing is to come and get assessed and come and find out if you have actually got hepatitis C because ... we have had quite a few, a handful of people who have been told they, at the clinic especially, who have been told they have hepatitis C and they don't actually have it because nobody has done any further testing, you know somebody did the antibody test and told them they have hepatitis C ... We just wouldn't focus on hepatitis C for one thing at all, we would just focus on liver disease generally because we think that the Aboriginal population is probably at risk for a whole range of liver diseases, there's so much diabetes and hepatitis B ... invite people to come in to a clinic to do a blood test and do a Fibroscan and you know

talk to them about if they have got any risk factors, and if they have got risk factors for hepatitis C, then you do hepatitis C testing and hepatitis B testing ... know just go down this pathway of talking more about liver health rather than just focusing on hepatitis C and you know, just getting the message out there how important your liver is. You know I just think that there is so much stigma with hepatitis C, change the message to liver health and for lots of reasons, Aboriginal people could have liver disease. But at the same time you know get the message out there that there is something that can be done so it is worthwhile coming for the assessment, that there is treatments for hepatitis C, there is treatments for hepatitis B, that you have got, that there is treatments for all types of liver disease. (#32)

3.3.5 Staff of Aboriginal Community Controlled Health Services

Results from interviews with six participants are described, including three services (four participants) in areas in which an Access Coordinator had been recruited, and two services (two participants) in an area with no Access Coordinator. Participants included health workers from varying specialities as well as employees working in executive or management positions.

None of the participants described having sufficient awareness or experience of the NSW Health investment to be able to comment in any detail. Indeed, one participant expressed frustration at being invited to comment on a program (in this evaluation) for which there was little perceived oversight or involvement of the ACCHS.

nobody followed up to see if it was delivered and nobody followed up except from now to make sure what was the outcome of it ... It is very frustrating because weand now we are getting questions asked to us about how do we feel about it and what was the outcome of it, what was the delivery of it (#10).

Some participants were aware of the 'Where's the shame, love your liver' activities (as well as other community development activities such as Body Armour and Chopped Liver), some were aware of the Coordinator positions, and some were aware of various staff development programs in HCV. One Sydney-based participant commented that the effect of the Coordinator position may be somewhat diluted in metropolitan areas compared with rural settings where there are fewer services to connect with and also fewer care pathways. This participant also noted that the positioning of Coordinators within LHDs would create barriers in connecting with the community and community-controlled sector.

I think in a smaller community it might be able to come to grips with getting healthcare providers together from you know your local hospital, your local AMS, maybe your local GPs and that can be manageable in a smaller setting. But it seems to me in Sydney, you've just got so many health providers, so many different pathways and different programs to network in with that creating those kinds of connections is a mammoth task and can't just be put down to a relatively powerless worker who has been put into a unit in the area health service ... obviously you can't put someone in a hospital setting and believe, expect them to be responsible for every Aboriginal person with hepatitis C in the entire wider community ... but their connections in our setting hasn't been strong. ... but you know just one isolated Aboriginal worker who is not at all connected to the community or the community controlled sector isn't really in a very powerful position (#36)

Providing HCV care in the ACCHS setting was described as influenced by a number of factors which echo previous results, including stigma (fear of the 'institutionalised racism' in the hospital setting, and HCV being a 'scar on their life'), confidentiality concerns (especially in small, rural and isolated communities), difficulties attracting and retaining staff (either as ACCHS workers or in a visiting capacity), comorbidities, social and material disadvantages within Aboriginal communities, distance and transport issues, lack of

community awareness of HCV, as well as organisational issues relating to the demands of the hospital-based HCV treatment regime (which were not able to be devolved to the ACCHS setting such as pharmacy and psychological support). Some participants noted that a 'liver health' component had been introduced to community health days, but that these activities were less well attended than those aimed at other health conditions such as heart disease, diabetes and asthma. Further, the lack of a clinical workforce for HCV in ACCHS was also noted as impeding the development of HCV care in this setting. One participant emphasised the issue in relation to skill mix. For example, sexual health workers were described as very important in terms of social and practical support for those preparing for and undertaking HCV treatment, but these workers were not able to provide the clinical support required.

3.3.6 Stakeholders and other Aboriginal health workers

Interviews were conducted with 11 participants who worked in the HCV area. These participants included Aboriginal and non-Aboriginal people, working in Aboriginal organisations and in Aboriginal-designated positions with mainstream organisations. To protect confidentiality, no further information is provided.

The issues raised by these participants typically reflected similar themes reported by previous participants such as shame and stigma associated with HCV. Overall, their knowledge of the Access Coordinators program was limited, and data presented here will focus on issues related to understanding barriers and enablers to care and treatment of Aboriginal HCV.

In terms of the Access Coordinator program, a few specific comments were made which echoed issues raised previously regarding consultation, sustainability issues and the potential of these positions to achieve change at the systems level:

I think it could have been done a little slower, so there was more consultation with the communities and workers ... and I think it's a problem that, after four years of funding dries up, if there's no one funded to continue it, it will drop off. (#8)

Look [the Access Coordinators] don't have the power to make any changes. All they can do is consult, talk, try to liaise and negotiate, and say "this is where I can see this and gaps", you know recommend "this is where I think you should be doing" ... they can't force that, they can write it up in their report and say "There's a gap here, there's a gap there, I've spoken to this person", it's really up to that area they are working in, because they've got no power to make any change. No influence. I think that some of those positions, this is my personal opinion, some of those positions have really had battle. And others have been very welcomed and respected and because of that, I think there's going to be some changes, but then there are others that have got the attitude more or less "Don't think you are just going to come in here and teach us how to suck eggs, because we've been doing this for a long time" And I've heard those comments. (#1)

3.3.6.1 Barriers to HCV treatment

There were differences of opinion relating to barriers to engaging with HCV treatment which were linked to service availability. In regional areas, or those otherwise not well serviced for people who inject drugs, issues such as knowledge about treatment and its availability, as well as practical issues such as transport to services in other areas were noted.

In a highly serviced area, issues around assisting clients to overcome the last 'hurdle' and commit to treatment were described as related to the long and arduous nature of treatment. This barrier was especially difficult to negotiate when HCV was not seen as a priority in everyday life, and clients did not perceive any negative effects of infection for themselves or others with HCV. The unfortunate growing numbers of HCV-related deaths was described as potentially influencing clients' views of the seriousness of HCV.

Well the problem is that there is not people dropping from hep C around them right now and so it's serious in terms of a lifelong situation however considering that the people appear living from day to day, one day doesn't seem much in the scheme of 20 years that it may take to have an effect on your body. And so although there is an understanding that it is serious, it's something that is put on the back burner as in as not being a top priority. [when treatment is easily available...] A lot of our clients understand that they can get treatment from us but it's like the final hurdle to actually be committed to doing it ... Well more willingness to take treatment and yeah it goes to seeing it as a priority or seeing it as relevant as to what they are doing each day. You know, if they don't feel sick, if they are not feeling sick from it or whatever then it's not seen as a priority in the scheme of day to day living. (#30)

I mean we've had a death just recently of one of our clients of hep C, but he is our first death as such from hep C itself and I suppose since they are making it real would be making it relevant so that it is something important and yeah it does affect you long term sort of thing but it is important to get treated. (#30)

In under-serviced areas, the distance to a clinic and reliance on public transport can make access to care and treatment unfeasible. In this instance, one participant called for the establishment of outreach clinics to smaller areas to avoid placing insurmountable burdens on people with HCV, particularly while people are on HCV treatment (hence minimising drop-out from treatment).

Yeah like for the big check-ups probably monthly I think it is or every six weeks, they had to go to [a large town] and then there is follow up. Of course he was my client so I said look I'll transport you because you know it would cost him and his wife a train ticket to get down there, and for them you know being on the dole or pension, it would cost them a fair bit. But the train would leave here at 8:30 and get home at 6 o'clock at night ... Yeah and his appointment might be at 12, he'll be out of there by 12:30 and then he has to walk around for 5 or 6 hours you know. But I said look I am happy to take you down ... and that's like because of their sickness too you know, they get tired and there's nowhere to lay down sort of stuff, that was the thing with this fellow. You know, outreach, outreach clinics to the smaller areas ... You know they put a lot of money into, a lot of government funding into other programs with outreach where I think if they had outreach for hep C, it would make a big difference and a lot of people would stay on their treatment like this bloke used to miss some of his appointments because he didn't want to get on the train ... it's a big day, they've got to save up for it and then they just get to the stage where they say no I'm not going. (#28)

3.3.6.2 Financial incentives for treatment

One participant noted the possibilities of proposing financial incentives to encourage people to consider HCV treatment. The participant drew on knowledge of the hepatitis B vaccination incentive trials, and an understanding of the importance of financial incentives to motivate clients as well as most people (Topp et al., 2013).

I would actually love to see a project aimed around you know people who will consistently follow up on their hep C treatment over a 3 month or 6 month or even a 12 month period, if there was financial incentive ... And I honestly 100% believe that that's the bottom line of what will actually motivate the clients that I deal with because you know we have tried other things with ...access to treatment is not a problem, you know knowledge about treatment isn't a problem or anything like that and so the final barrier of getting somebody to wanting to actually engage in treatment is what I see as the issue and 'what's in it for me' is the bottom line and is what a lot of our clients are motivated by and financial benefit is one of those things so I think really it does benefit people... Well that's it you know and because they are an injecting drug user, I think that for us to suddenly moralize or something is a bit wrong sort of thing, well I shouldn't say, hypocritical ... It motivates me then why shouldn't it motivate other people and so forth. (#30)

3.3.6.3 Importance of prison as an access point for treatment

The opportunities presented in the prison environment for access to HCV treatment was noted by a number of participants. However, the reach and coverage of HCV treatment programs in prison was perceived as 'patchy'.

I actually see prison as an ideal opportunity if the person is willing to actually engage in treatment because you know they are in a stable environment and can have ongoing treatment ... And from what I have heard, some of the prisons are quite good at it and some not so but I think there should be more of a check off list of standardization that if anyone engaging in the justice system should be actually engaged around hep C and whether or not they want treatment. (#30)

3.3.6.4 The 'story' of HCV treatment, peer education and positive speakers

As people in prison witness others experiencing the side effects of treatment, this could negatively contribute to the 'horror story' which prevails in perceptions of treatment as being very difficult.

Yeah I think in gaol a lot of people who have seen people that have been treated on Interferon and stuff like that, they've just gone, no, that's not for me, so when they've seen people get treated for hepatitis C and they've seen the side effects they've gone no, there's no way they are going to touch it. (#29)

To counter such negative perceptions of HCV treatment, participants highlighted the importance of positive speaker programs and peer education.

I think we need more positive speakers.... I don't necessarily think that they'd have to be Aboriginal as such. It would be wonderful if they were sort of thing however yeah people who are willing to speak to Aboriginal people about hep C you know how they got up from doing sex work or injecting drug use sort of thing, just people like that would still be appropriate in any case but if they were Aboriginal it would be even better ... I just find peer-based education and stuff does really work, in a non-confrontational way. (#30)

I think if we really are going to address the issue, we do need to continue projects like the access coordinators and I guess the peer work I think is one of the best ways as well to get out into those communities. I really think it needs that peer. Like I said, I think it's very different when it's an equal talking to you, rather than an outside person coming and giving you information when it's just your friend or someone you

see regularly sharing that information to you, it's really a different way of learning and hearing that information that people take it in. (#2)

I think having someone to be able to speak up and not be shamed and say "Ay, I've had it and I used to have this lifestyle and I don't ...I no longer have. Been through treatment, it was a bit rough but it was OK", that stuff catches on. (#1)

3.3.6.5 The burden of HCV-related stigma

Reflecting what has been raised by other groups of participants, the impact of stigma and shame associated with HCV was similarly raised by participants in this group. The layering of stigma—being Aboriginal, being a drug user, and having HCV—was noted with participants suggesting that some people struggled merely to be 'treated as a human being'. One participant noted that barriers to seeking care because of stigma would apply in some cases to decisions about attending an ACCHS.

I think even AMS's, even alcoholics will say that they don't like going to the AMS, you know even though they are black people there are still classes in the black population, you've got these levels of your black people that work, your black that are clean you know what I mean and then you have got like gumis who drink every day and whatnot and then you've got what people call junkies and gumis, the classes within the black. (#29)

Look it's a big issue for the whole community and I guess it's especially an issue amongst Aboriginal intravenous drug users, because like I said, there is an extra stigma and discrimination for them to accessing services, especially in Aboriginal specific services. (#2)

Look at any country in the world where there's low socio economic disadvantage, you are going to have much higher rates of blood borne viruses like hep C, you are going to have higher rate of injecting drug use. So it's about linking it back to these people are part of systems fucked over and this is a result of it sometimes. You know? Yeah. They say disadvantage and all that other stuff leads to this, but when it you know, we put our own mob down when it's lead to this and we know that that's going to be the end result. You know like, not that we don't have a choice but we know that a lot of people aren't going to be able to cope with what's been happening and the cycle over many years here, this is the end result. And then we reject them because of it. We are further socially isolating them and treat them like they're worthless, but if you can change that mind set of community and say "Hey these are part of our mob, these could be your brother or sister or cousin or aunty or uncle, they might have made some mistakes" they are looking at the incarceration rates and the level of hep C in prisons and how over incarcerated are we? You know like we've got to stand by you know and support when people are down, don't kick them in the guts when they're down and out. They are already down and out, we don't need to kick them in the guts. (#1)

This participant also linked stigma around HCV (as at the 'dirty end of health'), and resulting silence around HCV, with its lower priority as a result of the self-determining organisation of ACCHS Boards and the overwhelming burdens that ACCHS struggle to meet as a result of other chronic health conditions.

It can be difficult depending on who you get I guess on the Board. You got to remember not everyone on the Board comes from Health background, they are community representatives and they know what the needs are of their community

and stuff, but they might not know too much about some things that are kept silent like hep C. They may not know a lot around things of home immunization and drug reforms and all that stuff. They are tougher about the war on drugs and the [inaudible] increase in drug behaviour. So you know, they may not have that education in that area. And so it can be hard to work in ...like you know the dirty end of health, sexual health and hepatitis. Dirty end health. They may not be an issue for them when they are focusing on mostly on chronic conditions. You know like the diabetes and all the other heart and stuff or children stuff. (#1)

In the following excerpt, the participant links the attitude and conduct of health workers to requirements for additional support for people seeking care, and ultimately to barriers to attending HCV care in tertiary services.

Some of the nurses that actually work in that area help these people with their treatment or if you are on another program, alcohol and drugs or something like that some of the nurses treat them like second class citizens you know, treat them, well they just talk to them like they are talking to a doctor or something like that you know and these blokes are like I don't know what you are talking about half the time ... I was just acting more like a support person to have that sort of, well with that same bloke, they didn't like his partner being in because she spoke up for him and they must have just thought that she was causing trouble ... She didn't want to go because it would upset her husband because she'd be asked to leave or she wouldn't be allowed in, so it was just easy for me to go and some of the stuff, when this nurse was talking to him, he would look at me and I'd just have to tell him in plain English instead of all this other stuff that she was going on about, and I don't think she even realized or didn't want to realize, she just kept talking in her ... Well he used to hate it you know when he had to go and he would make sure and say 'can you make sure you are there' ... and I used to move my days and that around, make sure to go there with him, just give that support you know. But I think if they had more hep C workers or hep C nurses, that were Aboriginal or understood the Aboriginal or any sort of, the people that are working with hep C that I have seen aren't very educated people you know and just to take that extra 10 minutes to explain it properly instead of oh I have got another appointment in 5 minutes this is how it is going to happen, see you later ... and it just puts the fellows off you know and he said to me he said: I'd rather go without treatment you know. (#28)

4 Discussion

There are a number of elements arising from the data collected in this study to discuss and from which to draw recommendations for future programs supporting care and treatment of Aboriginal people with HCV. This section has been organised to represent lessons learnt from the lived experience of HCV (drawing upon surveys and interviews with Aboriginal people), and lessons learnt from the program of investment (drawing mostly on interviews with Aboriginal and non-Aboriginal health workers and stakeholders).

4.1 Understanding the experiences of Aboriginal people with HCV (using survey and interview data from Aboriginal people and health workers)

Two hundred and three participants completed the survey. This sample is remarkable in a number of ways, particularly regarding the measures of relative social disadvantage. Approximately 60% of participants had completed some high school or less, approximately 90% indicated government assistance as the main source of income, and approximately 80% had ever been in prison.

In comparison with national statistics, our sample is broadly reflective of some socio-demographic characteristics of older Aboriginal people. For example, 7% of our sample reported that they had either completed Year 12 education or had attended university. This is the same proportion reported among Indigenous people aged 55 years and above in national statistics, but significantly lower than Year 12 completion rates among young Indigenous people (in 2008 data, 30% of those aged 25–34 years completed

Year 12 education) (AIHW, 2011). However, this sample reported much higher rates of reliance on government benefits than the national Indigenous population (with employment rates across age groups between 40–60%) (AIHW, 2011).

With this understanding of the sample completing the survey, there are a number of positive findings to note related to knowledge of, and engagement with, HCV care. The results from the survey indicate comparable rates of engagement with care and HCV treatment in relation to measures of treatment intention, receipt of referral to specialist, and uptake of HCV treatment when compared with samples which have not specifically recruited Aboriginal people living with HCV. While these results indicate comparable rates of engagement with HCV care between Aboriginal and non-Aboriginal samples, it is important to note that Aboriginal people experience a proportionally higher prevalence of HCV. Hence, these results should not be interpreted as the 'best that can be achieved'.

Uptake of HCV treatment: Approximately 16.7% of this survey sample had received treatment (6 participants reported currently being on treatment, 28 participants reported previous treatment, Table 9). The 2012 data from the NSP Survey in NSW shows that, among those self-reporting as HCV-positive, 87% indicated that they had not had HCV treatment (or did not answer the question) with 7 people (1.9%) currently on treatment (Iversen & Maher, 2013). It is also important to note that this result is not related to sampling, as few survey participants were recruited from liver clinics.

HCV Treatment intention: Of those who had not had treatment, 55% indicated that they intended to have treatment within the next two years (Table 9). Among a NSW sample of treatment-naïve people self-reporting as HCV-positive recruited from the Medically Supervised Injecting Centre

and four inner Sydney OST clinics, this figure was 45% (Treloar, Hull, Dore, & Grebely, 2012). Further, a sample taken of people living with HCV (who were treatment naïve) across NSW reported approximately one-third intending to have treatment in the next two years (Treloar et al., 2011).

Receipt of referral to specialist: In this sample, 41% had received a referral to a specialist and of those people, 55% had seen a specialist about HCV (Table 9). In a previous study of a NSW sample self-reporting to be HCV-positive, 46% had received a referral to a specialist and 48% of these reported having seen a specialist (Grebely et al., 2011).

HCV knowledge: The knowledge score reported by this sample was a mean of 11.4 (of 16 questions) (Table 11). In a sample recruited from the Medically Supervised Injecting Centre and four inner Sydney OST clinics, mean knowledge was 6.5 (of 12 questions) (Treloar et al., 2012). In the current study, 55% indicated the correct answer to the question 'Does HCV always cause symptoms?' In the study conducted across NSW (Treloar et al., 2011), only 33% provided a correct response to this item. In a study comparing knowledge of Aboriginal and non-Aboriginal clients of NSW pharmacies participating in the Fitpack scheme, there were mixed results in knowledge with Aboriginal participants having comparable knowledge on some items, but fewer Aboriginal participants providing correct answers in relation to risk of sharing ancillary equipment (72% vs 88%), and that treatment does not always cure HCV (47% vs 68%) (Paquette et al., 2012). These results, however, do indicate significant gaps in knowledge of this sample, which may in turn impact engagement with HCV care.

HCV care: 79% of this sample had seen a GP or other health worker specifically for HCV within the last year (indeed, 63% reported this within the last six months) (Table 10).

Changes to lifestyle: The majority of participants reported making some change to their lifestyle since HCV diagnosis (with most common responses indicating reducing/cutting out alcohol (66%), increasing exercise (53%), change to diet (52%), reducing/cutting out illicit drug use (50%), and accessing information about HCV (46%)). Only 8% of the sample indicated that they had made no changes (Table 10).

In choosing where to attend for HCV care, the ACCHS and a GP not within an ACHHS were each reported by approximately 20% of the survey sample (Table 6). Most participants reported feeling satisfied with the HCV care they received (Table 8). However, two-fifths of the survey participants reported having been diagnosed for more than 10 years (Table 1) and although approximately half reported being satisfied that the diagnosis experience was conducted in a culturally sensitive and appropriate way, only a third of participants reported receiving pre-test and post-test counselling (Table 5). Two-fifths of the participants reported that their diagnosis test was provided as part of a routine test (Table 4). Previous qualitative research reports negative experiences of post-test counselling (including information distribution and referral) in settings such as methadone clinics and prisons (Temple-Smith, Gifford, & Stoove, 2004). Given the importance of diagnosis to connect people with information, care and treatment (Treloar et al., 2010), the roles of other services (particularly drug and alcohol services, and prisons) in providing diagnoses need careful examination, particularly due to the likelihood of a positive HCV result occurring in these settings (Temple-Smith et al., 2004).

Our data in relation to stigma and discrimination reflect previous findings from national data for Australian Indigenous populations (AIHW, 2011), research among people who inject drugs (Ahern, Stuber, & Galea, 2007) and who live with HCV (Golden, Conroy, O'Dwyer, Golden, & Hardouine, 2006), and research findings in general populations (Scambler, 2006). In our data, lower HCV knowledge was associated with greater perceived discrimination on the basis of culture, and relationships were found between measures of satisfaction with care and quality of life, and measures of stigma and discrimination

in various contexts. Adding to this pattern of results is the association between higher measures of resilience and higher satisfaction with healthcare. These results reflect those found in the national Indigenous population. People who had experienced discrimination were more likely to report lower levels of trust in a range of social services, including healthcare (AIHW, 2011). The issue of trust in services forms a core theme in interview data and will be discussed in more detail below.

In responses from survey participants, it is noted that exposure to HCV education is positively associated with engagement with treatment. This highlights the need for expanded and ongoing work to provide education to Aboriginal people living with HCV.

Finally, further contextual information from this survey should be used in developing any future care and treatment models. Despite concerns about HCV discrimination (Table 15), and concerns about judgement and HCV-related stigma described by interview participants, most survey participants expressed a strong connection to the Aboriginal community, and far less connection to any sense of HCV community (Table 2). Hence, issues of cultural appropriateness and safety remain integral to any HCV care plans.

Although there were some dissenting voices, the core issue of HCV stigma dominated the experience of many interview participants. In some participants' experiences, HCV-related stigma was further compounded by perceptions of racism. Extreme reactions to diagnosis (such as feeling 'shattered' and 'dirty') and very limited or no disclosure of HCV-positive status were present within these data. These data also reflect the discussion of 'shame' (a word commonly used by interview participants) raised in a previous report (McNally & Latham, 2009). Participants explained they had little knowledge about HCV when diagnosed and that little information was available in Aboriginal communities to support them in living with the virus. Although some participants reported that relationships with family had improved with time and information, others reported that their HCV-positive status was secret or they were isolated from family.

The experience of diagnosis was described as lacking detailed or appropriate information, as reflected in the survey data. Poor diagnoses experiences have similarly been reported in studies which did not target Aboriginal people (Hopwood & Treloar, 2004; Temple-Smith et al., 2004; Treloar et al., 2010). The provision of referrals to community-based services would provide a low threshold access point at diagnosis and for continuing access.

However, existing community services (such as Hepatitis NSW and NUAA) would need to be sufficiently resourced to receive such referrals, and respond to them in culturally appropriate and safe ways. Being able to access such an organisation (and access anonymously) to augment HCV care would allow people to navigate (or bypass) concerns expressed by some participants about being identified as someone living with HCV at health services.

Beyond diagnosis, attention is required to the delivery of information and education to Aboriginal people living with HCV. Given the lower education rates and other indicators of socio-economic disadvantage and marginalisation, additional strategies, services and support may be required to ensure that information is provided in an accessible and culturally sensitive manner at diagnosis and at other times. For example, additional strategies suggested by these data include presentation of information for those with low literacy in conversation through audio-visual means (such as DVD, drama or music), peer-delivered information, and reinforcement of information via existing contact with services (such as prisons). While there was a noted instance of information about HCV being provided in drug and alcohol courses within prisons, the impact of such courses has not had optimal effect or reach, given the overwhelming proportion of the survey sample who had been in prison and the remaining deficits in knowledge (both expressed in interview and reported in the survey data). Indigenous people typically receive shorter sentences than non-Indigenous people (National Indigenous Drug and Alcohol Committee, 2012).

Hence, the format and provision of prison-based education should be tailored to those with short sentences.

It is also important to draw attention to the issue of health worker attitudes and the assumptions underpinning the operation of HCV clinical systems. Aboriginal healthcare is organised around concepts of holistic health (Couzos & Murray, 2007) while the western medical system is clinically organised with few services integrating across systems or diseases (Kodner & Spreeuwenberg, 2002). Previous research has shown the importance of unpacking assumptions underlying health professionals' understandings of cultural differences to better respond to the needs and priorities of Aboriginal people (Newman et al., 2013). It may be that ongoing work is required to support HCV clinical staff in understanding the issues important to Aboriginal people in making decisions about health and healthcare. The findings from this project would contribute to such discussions. For example, the majority of survey participants reported making changes to lifestyle (such as cutting down alcohol consumption) while also reporting not being provided with health promotion information.

Since implementation of this project, a separate project has been conducted within a Sydney LHD focusing on community engagement, awareness of HCV, and promotion of HCV care and treatment. The Deadly Liver Mob has been implemented by a Needle and Syringe Program (NSP) in western Sydney in partnership with the LHD sexual health service. Led by Aboriginal staff (of both the NSP and sexual health service), this project promoted specific days in which a range of services and activities focused on liver health were available at the local NSP. Clients are incentivised to attend and to refer others to the service. Reports from program managers indicate that over 130 people have been tested for HCV, as well as referrals made to a range of health and human services. These types of programs contribute to both providing information to the broader Aboriginal community (working to reduce the burden of shame and stigma associated with HCV), and providing culturally appropriate information to people at risk of and living with HCV in ways that do not reinforce HCV stigma. Indeed, participants in the health worker interviews suggested similar types of approaches including the use of Fibroscan technology to augment other clinical tools.

Participants in this sample made a range of decisions about where to access HCV care and treatment. As shown in the survey data, both ACCHS and non-ACCFS GPs were used by this sample. For some, convenience of setting was the most important element of their decision. Other participants, specifically those who chose ACCHS services, perceived these services as more welcoming and safer than mainstream services. In relation to access to HCV treatment, some participants felt well-cared for in conventional tertiary treatment settings. Other participants appreciated and looked for other models of care, particularly HCV services which were co-located with other services (especially those services targeting people who inject drugs), and services they trusted and felt 'safe' within. A new model, involving an Aboriginal peer worker as part of a hospital outreach to an ACCHS, was very positively endorsed by the participant who had experience with this model. Other HCV care and treatment programs incorporating peer workers have also evaluated positively both in Australia and elsewhere (Crawford & Bath, 2013). Broader programs, using notions of 'patient navigators' have been developed specifically for minority populations experiencing marginalisation and disadvantage, and are being trialled in Aboriginal health systems for other health conditions to promote community health literacy and engagement with treatment (Garvey et al., 2011; Treloar et al., 2014). Since the development and implementation of 'patient navigators' there have been several studies

that have investigated the efficacy of navigation interventions, predominantly around breast cancer. Overall, patient navigation has been found to improve many aspects of disease care including screening rates, adherence to follow-up visits, initiation of treatment, and stability or improvements in quality of life (Robinson-White, Conroy, Slavish, & Rosenzweig, 2010; Wells et al., 2008; Burhansstipanov et al., 1998).

The findings from the survey demonstrated that large proportions of participants had sought information, had regular HCV care, and had made changes to their lifestyle to support liver health. The interview data similarly showed very strong motivations among participants to take steps to promote their health and resilience in seeking information and care despite significant concerns about confidentiality, and fear of the shame associated with HCV. These positive results should be viewed against the stark background of reported marginalisation (with 80% of survey respondents having ever been in prison) and social disadvantage (most on government support, and most with only some high school education).

The interview data explored the issues that were important to participants' choices about engagement with care and treatment. Research in other populations of people living with HCV shows a range of influences, particularly concerns about treatment efficacy and side effects (McNally et al., 2006), and different perspectives of these barriers among those who are less engaged with treatment (with barriers to treatment relating to perceptions of a lack of HCV symptoms, and other priorities in life), and those who are engaged with HCV care (wanting to live longer and take on family responsibilities) (Treloar, Rance, Dore, & Grebely, 2014). These general themes were reflected in the interview data. The similarities between concerns and experiences of Aboriginal people and other populations living with HCV do not suggest that services and strategies to engage these populations should also be the same. Our understanding of the health and social experiences of Aboriginal people should shape our responses. Although expressed barriers to HCV treatment may be similar, Aboriginal people live in a context of ongoing disparity in health outcomes, and overall greater disadvantage and marginalisation compared with non-Aboriginal people (AIHW, 2011). While experience of disadvantage has its own impact on decisions and capacity to engage with treatment (Marmot, 2003), the level of distrust in health systems may be magnified for a group of people who are criminalised because of injecting drug use, stigmatised on the basis of infection, and have experienced historical and contemporary racial discrimination in health and other systems. Our findings from the survey and interview data attest to these complex relationships.

Given the perception of HCV treatment as 'gruesome' and the resistance of treatment on the basis that it will make people unwell, Aboriginal people may choose not to engage with HCV care (or treatment) if they perceive that it offers no value. This requires investment to change the discourse around HCV treatments providing a more balanced discourse of the treatment experience by dissemination of successful treatment stories (Treloar et al., 2014). Further, promotion of non-invasive techniques such as Fibroscan, which provides individualised and immediate feedback on liver health, could be incorporated into generalised well-person checks given the other benefits the assessment of liver health may have for Aboriginal people.

The variety of choices made, and preferences expressed by participants, points to the need for ongoing development of innovative models to provide appropriate choices for clients to meet their needs and preferences. Innovative models of care will be discussed below.

4.2 Learning from the 4-year program of investment: Interviews with health professionals

This set of interviews focused on the implementation of the NSW Health investment in improving the care of Aboriginal people with HCV, with a particular focus on the establishment of a 4-year program of Access Coordinator positions.

As noted above, there were different experiences in each LHD in relation to recruitment, retention and activities undertaken by Access Coordinators. Indeed, some LHDs were not able to recruit Access Coordinator positions, or had periods of time in which the position was not filled. One LHD has continued the Access Coordinator position after the completion of the four year program, with an expanded remit.

These interviews aimed to examine the structural and organisational issues affecting the activities and impacts of the Coordinator positions, particularly examining relevant LHD and ACCHS structures. It became apparent, however, that issues internal to the work context in which the Coordinator positions were housed were perceived as having more impact on the implementation and achievements of the Coordinator positions than issues between various health systems. Although the issues may vary across the positions involved, a common set of concerns related to the cultural safety of the workplace, the nature of the role, the background and skill mix or the type of person recruited, and the lack of local input into the development of the Coordinator role.

There was a difference of opinion between the Access Coordinators and the Manager participants regarding the legacy of the investment. The Coordinators strongly voiced the need for an ongoing program of work. The Manager participants, however, called for a modified program of work which built on the achievements of the first period. Further, there was some notion that focus on community education and development (rather than primarily with services) was required to generate a shift in the responsiveness of health systems.

Despite these critical perspectives, most Coordinators and Managers commented positively on some aspects of the program, particularly the 'Where's the shame, love your liver' community development activities. The endorsement of 'Where's the shame, love your liver' as a means to raise community awareness of HCV was almost universal. Additional benefits from such programs could be considered, such as using these activities for ongoing programs with community, and as a means to build relationships between HCV services and ACCHS.

The participants involved in HCV clinical care reported little impact of the Access Coordinator program on their activities. In regional areas this was related to distance; with some HCV services being located at a significant distance to the Coordinator position. Other participants felt they had experienced no change in demand in relation to the attendance of Aboriginal people at their service.

One tangible achievement within HCV clinical services was the agreement in one LHD to prioritise access of Aboriginal people to HCV treatment, thereby removing any waiting time to begin treatment (after usual assessment and preparation), noting that clients may be lost to the treatment pathway if referred to a waiting list. A second achievement was the development of a cultural audit process, which supported clinical services to examine and address issues within their organisation that may be perceived as barriers to Aboriginal people accessing the service.

Engagement with ACCHS was described as difficult by a small number of LHD participants. This related to varying issues, but particularly to the already full health agenda for Aboriginal people and services, and in some areas, disruption to ACCHS operations. The lower profile of HCV, associated stigma, the differing backgrounds of ACCHS Board members combined with a lack of specific HCV funding may contribute to HCV not being seen as a priority for ACCHS action. The notion of 'health literacy' within ACCHS Boards has been raised in another area of emerging concern, namely cancer, with recommendations of ongoing cancer information campaigns at community grass-root levels, as well as with ACCHS workers and Board members, and in turn, with cancer specific services regarding specific issues for Aboriginal communities and ACCHS (Treloar et al., 2013).

The notion of trust was raised in various ways in these data. Participants living with HCV noted the importance of being able to access care in familiar, safe and trustworthy settings. An extreme instance of breakdown in trust was recorded and resulted from inappropriate disclosure of HCV-positive status to family members by a health worker. Health professionals spoke about the importance of building liaison, trust and partnership between their (typically mainstream) service, ACCHS and the Aboriginal community. However, these roles are sometimes ones that are sacrificed when budget savings are required. While prioritising the pressing need for clinical services in Aboriginal health, the important work of building partnership at all levels cannot be underestimated (Gilson, 2003; Meyer, Ward, Coveney, & Rogers, 2008; Rowe & Calnan, 2006), especially for minority populations and those experiencing disadvantage and marginalisation (Shelton et al., 2010; Ward & Coates, 2006). As suggested in interviews with health workers, the structural support of a model of HCV care for Aboriginal people would be useful for a number of purposes, including assisting LHD workers in understanding the ways in which HCV is managed in ACCHS. Such a model was developed in the course of this project. The data would suggest that work to develop trust and partnership between services is an important element in implementing such a model of care. Other important areas include : incorporation of HCV (or more broadly, liver health) in chronic disease programs; a focus on community education about HCV; incorporation of HCV care and treatment activities in services where Aboriginal people with HCV are identified (prisons, services for people who inject drugs); other models of care such as supported by a peer worker, a treatment support officer, patient navigator programs, or trials of group models of care as suggested previously (McNally & Latham, 2009). It could be suggested that the advances in technology (in relation to Fibroscan and improvements in treatment) could support a new program of investment which prioritises engaging Aboriginal people in liver assessment; building on community campaigns such as 'Where's the shame, love your liver', which contribute to greater awareness and reduction in stigma; as well as peer-led campaigns which focus on changing the discourse around HCV (assessment is worthwhile and treatments are improving). This type of investment would need to include ongoing programs of health workforce development and training.

Finally, the importance of the corrections system must be noted. The rate of imprisonment of survey participants of close to 80% is an overwhelming finding. While gains have been made in models of HCV treatment in NSW prisons (Boonwaat, Haber, Levy, & Lloyd, 2010), the opportunities missed for promoting better understanding of HCV among prisoners must be examined. It is a significant failing of this overall project that no Access Coordinator position could be filled in Justice Health.

4.3 Limitations

This program of investment was complex with many complementary activities. It is difficult to capture this complexity in a series of participant interviews which occurred at one time in its history. However, given the delays encountered in gaining approval to access LHD and ACCHS agencies, it was not possible to conduct interviews at more than one point in time (as was the initial intentions of this project). The data present participants' experiences of the program typically within its last year of funding.

This report has only limited information from the perspective of those working within ACCHS. A number of ACCHS declined offers to participate in this research, mainly because of capacity issues. The relative priority given to this project in relation to participating in the evaluation may also be reflective of the comments made by participants of the relatively low impact this project had on the ACCHS sector, including that funding was not directed to ACCHS.

The third aim of this project suggested that recommendations should be provided during the research for changes to the role or operation of the Access Coordinators. The research process was unable to meet this aim. The significant delays incurred as a result of LHD restructure of research ethics and governance processes significantly delayed data collection involving LHD sites where most of the Access Coordinators were based. The ongoing processes around LHD research ethics and governance will require significant additional time in future projects to ensure that LHD timeframes can be accommodated (Vajdic et al., 2012).

4.4 Concluding remarks

It could be stated that the profile of HCV care and treatment provided by the data indicates that there is good access to and provision of services for Aboriginal people in NSW. Results comparable to other studies were shown in relation to HCV knowledge, changes to lifestyle to promote liver health, intention to have treatment, referral to specialists, attendance at specialists and uptake of treatment. However, the health impacts of HCV for Aboriginal people, as for all other health conditions, will produce a greater burden on individuals, communities and health services as a result of overall poorer health and social disadvantage and marginalisation. There is a possibility for disparities in HCV care to emerge in the future as advances in care and treatment develop. With the advent of interferon free treatments in the next 5 years (Grebely & Tyndall, 2011), there exists the possibility that disparities between Aboriginal and non-Aboriginal people become entrenched in HCV care and treatment delivery. The data provide clear and specific recommendations to support the continued improvement of the care and treatment of Aboriginal people with HCV in line with other populations affected by HCV.

5 Recommendations

- Raise the health literacy of Aboriginal communities in relation to HCV in order to lessen the burden of stigma and discrimination felt by people diagnosed with HCV
- Consider replication of innovative HCV engagement programs (such as ‘Where’s the shame, love your liver’ and the Deadly Liver Mob) in other areas and/or in an ongoing program of activity, ensuring that key principles of local consultation and modification to local context are embedded
- Continue efforts to build relationships and partnerships between mainstream and Aboriginal health services—that is, workers and systems need to be seen as professional, discreet, credible and culturally safe
- Develop an ongoing program of HCV training for staff of ACCHS, or support the ongoing inclusion of HCV modules in other programs (such as programs offered by the Aboriginal Health College or in induction modules)
- Improve the quality of diagnosis via the provision of information in culturally appropriate ways and according to need (such as literacy support)
- Provide referral information for Aboriginal people living with HCV, and at diagnosis, to community organisations (such as Hepatitis NSW and NUAA) to provide anonymous access to information and support
- Promote HCV care and treatment in places where Aboriginal people access services including ACCHS and general practice, noting the over-representation of Aboriginal people in NSPs, drug treatment services and prison. Issues to emphasise include the importance of being tested properly, ease of liver health scan (via Fibroscan, where available), actions that can be taken to better live with HCV, the changing nature of treatments and post-release referral pathways between prisoner health services and ACCHS, or other primary care services
- Support clinicians in high prevalence services to be aware of their important role in raising awareness and recommending care/treatment
- Consider the inclusion of HCV in chronic illness plans, well-person checks and other ways that existing health structures (both ACCHS and mainstream services) can be used to embed HCV care for Aboriginal people in health systems
- Consider building a network of peer workers in the HCV area as there is a growing body of evidence of the added benefits that peer workers bring for marginalised populations
- Develop models of a ‘treatment support officer’ role or patient navigator to manage practical and logistical issues regarding testing, treatment assessment and preparation, as well as management during and after treatment, including peer workers within such models
- Emphasise the importance of the local context and consultation process in development of new models of care, or implementation of new positions
- Consider trials of incentivised participation in HCV programs (for example, education programs which relate to the State Debt Recovery program, or assessment, or treatment programs) including the development of ethical and culturally safe protocols to support such trials
- Consider the opportunities arising in NSW with the roll-out of activity-based funding protocols such as opportunities to maintain designated positions in HCV treatment programs for Aboriginal people
- (Given the stigma associated with HCV) consider the development of referral and care pathways that minimise the number of times an Aboriginal person with HCV is required to ‘tell their story’ to a new clinician or at a new service

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Appendix 1: Cronbach Alpha for all scales

	α
HCV care satisfaction scale	.919
General health symptoms	.912
HCV stigma and discrimination scale	.916
HCV disclosure scale	.886
Cultural stigma and discrimination scale	.921
Healthcare discrimination scale	.890
Resilience scale	.915

Appendix 2: Correlation Matrix

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.
1. Seen or heard any health promotion ¹	1															
2. Plan to go on treatment in the future ¹	.167*	1														
3. HCV knowledge ²	.297***	.076	1													
4. HCV discrimination ²	-.053	.070	.069	1												
5. Stigma in relation to disclosure ²	.008	.048	.105	.726***	1											
6. Cultural discrimination ²	-.049	-.081	-.152*	.163*	.125	1										
7. General healthcare discrimination ²	-.049	.104	.079	-.370***	.210**	-.120	1									
8. Resilience ²	.142*	-.026	.079	-.279***	-.252***	-.021	-.060	1								
9. Satisfaction with HCV care ²	.181*	.001	.043	-.170*	-.117	-.294***	-.211**	.230***	1							
10. Quality of life ²	-.105	-.116	-.061	-.176*	-.097	-.032	-.138	.248***	.045	1						
11. Health satisfaction ²	-.046	-.111	-.081	-.135	-.149*	.016	-.031	.286***	.105	.629***	1					
12. General symptoms ²	.091	-.079	.053	.192**	.173*	.122	.068	-.194**	.029	-.316***	-.341***	1				
13. Aboriginal community ¹	.044	-.094	-.018	.038	-.023	.083	.035	.044	.119	-.079	-.091	.115	1			
14. Gender ¹	.229***	-.145	.093	-.186**	-.189**	-.103	-.042	.026	.215**	-.081	-.018	.145*	.186**	1		
15. Age ¹	.158*	.061	.119	-.187**	-.215**	.061	-.107	.235***	.075	.063	.003	.031	.066	.074	1	
16. Ever been in prison ¹	-.033	-.077	-.227***	.082	.055	.192**	.022	-.049	-.137	-.038	.023	-.050	.098	-.112	.029	1

1 Spearman's rho

2 Pearson's

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

***Correlation is significant at the 0.001 level (2-tailed).